The culture of teenage and young adult cancer care in England: A multiple-case study across four networks of care

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Abstract

Background

It has long been recognised that young people have unique needs which differ from those of children or adults. Yet within healthcare, they have spent years without being recognised as a speciality within their own right. Teenage and young adult cancer networks in the United Kingdom have however evolved over the past twenty years. Services have been shaped by national guidance, released in 2005, and with much input from the charitable sector. These services in England are structured around complex networks, with secondary and tertiary care delivered in either a specialist Principal Treatment Centre, or within an associated 'designated' or 'shared care' hospital.

Aims

The aim of this research was to look closely at these services, to specifically examine the culture of care for young people receiving cancer care in England. The current economic climate of the National Health Service (NHS) presents an ongoing challenge for specialist health services to demonstrate their value and cost-effectiveness: teenage and young adult cancer care being one of these specialist services. Evidence to underpin specialist health services is crucial to make a difference and sustain change.

Methods

Adopting a case study approach through a critical realist lens, this multiple-case study was conducted across four teenage and young adult cancer networks in England. A conceptual framework consisting of three core concepts of culture was used to guide study design, conduct and reporting. A qualitative, multi-method approach was used across 24 NHS hospitals, and included: semi-structured interviews with healthcare professionals (n=41), and young people (n=29); participant observation, walking tours and shadowing techniques. Thematic analysis was used to identify themes between, within and across the four cases; deconstructing and reconstructing the components of the culture of care that emerged thereby enabling synthesis and contextualisation of data.

Findings

The findings of this study are presented in three parts, framed around the three core concepts of culture: the dynamic contexts of the culture; the visible processes and less visible values which underpin the culture; and the way culture was learned and shared. In terms of the context of care, the impact of the physical environment on young people's experiences of socialising and accessing peer support were highlighted. There were key features of the culture which were clear and visible. Underpinning these features were three values at the core of delivering young person-centred care: recognising individuality, empowering and promoting normality for young people. To develop a culture which embraces and promotes these core values, it was found to be particularly important to have effective communication and leadership, healthcare professionals with the right attitude, and a sufficient number of young people using a service.

Conclusion and recommendations

The importance of the core values that underpin care, and the need for education, effective leadership and multi-disciplinary team working, should all be recognised and prioritised when developing and evaluating interventions that contribute to the delivery of care to this unique patient group. Care delivered in an environment which promotes normality through facilitating socialisation with peers is optimal for the creation of a culture of care which is holistic and young person-centred. The findings of this study provide qualitative evidence of care delivery. This data will be further considered alongside the quantitative data generated in other workstreams of the BRIGHTLIGHT programme of research. However, taken alone, these findings provide evidence to assist all healthcare professionals and services to grow and nurture a culture of care that meets the unique needs of young people with cancer, and to improve their experiences of care; and further progress healthcare organisations towards a future where specialist, holistic care is accessible for all young people.

Acknowledgements

There are many people to thank who have supported and sustained me throughout this process. I would like to offer my heartfelt thanks to my two Supervisors, Professor Faith Gibson and Dr Rachel Taylor. Their guidance, patience and support has assisted me to navigate the daunting terrain of doctoral research; reigning in my focus whilst always enabling and encouraging me to grow.

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Part A

Young people have unique health and social care needs. Current trends are moving towards a welcome change, where young people are cared for in an age-appropriate environment with a distinct philosophy of care. What these environments look like and how care is delivered, from the perspectives of those who deliver care to young people and those receiving care, is the focus of this study. This first part of the thesis will set the scene, explaining why the research was undertaken, what it aimed to achieve, and how it was conducted.

This young lady was the winner of the BRIGHTLIGHT photography competition, 2016. Her photograph displays a series of images taken across her cancer timeline: portraying a powerful image of a young person's cancer experience from a young person's perspective.
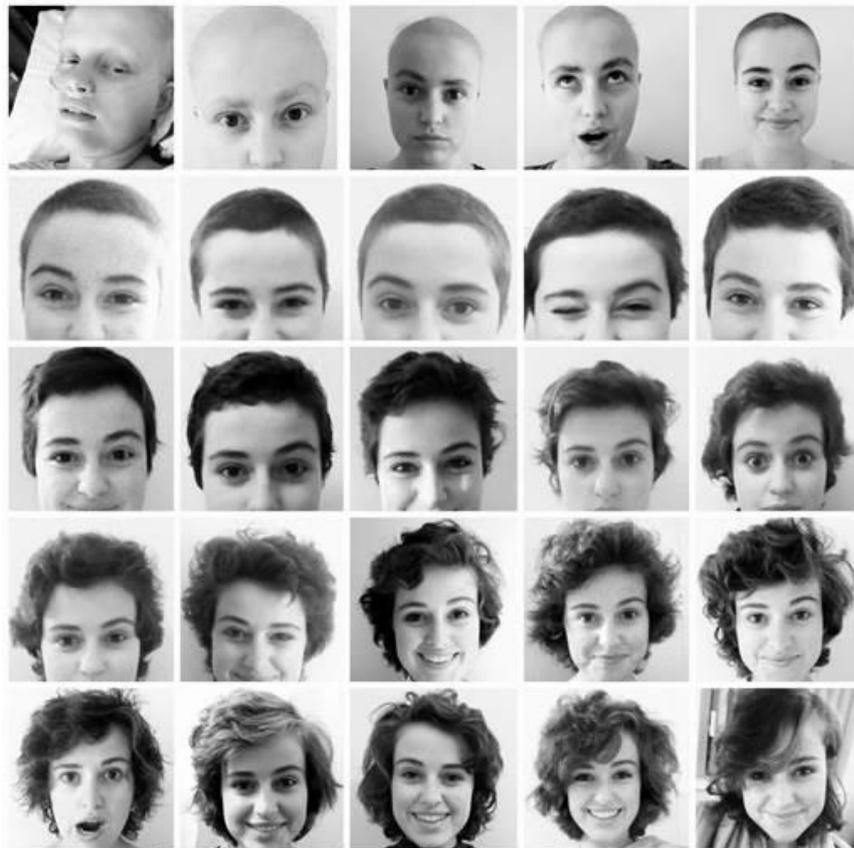
Reproduced with permission: Olivia Buckland.

Chapter 1

Setting the scene: Clinical context

1.1 Research question

This research explores the care experiences of young people with cancer, aged 13 to 24, across a range of settings where they are cared for. It also explores the experiences and views of the healthcare professionals delivering care to young people across these different settings. The aim of this research was to produce primary data about the culture of care for young people with cancer in England. The current economic climate of the National Health Service (NHS) presents an ongoing challenge for specialist health services to demonstrate their value and cost-effectiveness: teenage and young adult cancer being one of these specialist services. Evidence to underpin specialist health services is therefore crucial to make a difference. This first chapter will set out the clinical context of the thesis, describing what is currently known and understood about young people with cancer, the current service structure, and the healthcare professionals delivering care. The context will be further presented in Chapter 2, where culture will be expounded. This will provide the conceptual context of the study and show how cultural definitions, concepts and theory can be used to explore the care experiences of young people with cancer and the healthcare professionals caring for them.

1.2 Young people with cancer

It has long been recognised that young people have unique needs which differ from those of children or older adults, first formally identified in United Kingdom (UK) health policy in the Platt Report (Ministry of Health, 1959). Yet too often, policy describes children and young people as a single population and frequently older teenagers or young adults can become lost within adult health services (Stevens, 2006; Royal College of Physicians (RCP), 2015). In the UK in 2013, it was reported that 800,000 teenagers were living with asthma, one in seven aged 11-15 had a long-term condition or disability, and diabetes affected 29,000 of those under 18 years (Association of Young People's Health (AYPH), 2015). It is statistics like these that reinforced the work of Viner and Barker (2005) in exposing the heightening health needs of teenagers. These statistics do not include young adults, which in the UK is considered to include those up to 24 years, and is aligned with evidence that shows that brain development continues into early adulthood (Dumontheil, 2016). In

other countries such as those in North America, young adulthood is deemed to extend far beyond this (Barosh *et al.* 2015), encompassing those up to 39 years (Barr *et al.* 2016). Changes in the socioeconomics of society has meant that today's young people take longer to reach 'adult' milestones (e.g. owning their own home) and what was commonplace to achieve by the age of 20 is now often not reached until 30 or beyond (Morgan, 2011; Vespa, 2017).

Young people with cancer are a further subset of this generation, with health needs that are unique when compared to other young people accessing health services, for example young people with long-term conditions such as diabetes or cystic fibrosis; as cancer is a life-threatening disease which is, in most cases, *treated,* as opposed to a life-limiting disease which is *controlled.* Since the 1990's, young people with cancer in the UK have increasingly been seen as a speciality within their own right (Carr *et al.* 2013). An average of 198 young people (aged 16 to 24) are diagnosed with cancer every month (BRIGHTLIGHT, 2017). While this is low when compared to the older adult population (aged 40 and upwards), cancer is responsible for 11% of deaths in teenager and young adults and is the second highest cause of mortality after accident-related deaths (Whelan and Fern, 2008).

1.2.1 Young people with cancer: unique issues

Young people are caught between two distinct phases of life: childhood and adulthood (Fern *et al.* 2013). The adolescent years are a time of vast physical, psychological and social change, and although traumatic and life-changing at any age, a cancer diagnosis during these vulnerable years has the potential to disrupt a young person's pathway into adulthood (Whiteson, 2003; Marris *et al.* 2011; Zebrack, 2011). Figure 1.1 summarises the multi-faceted issues that young people with a cancer diagnosis face and the effect on their family and those who care for them.

Young people
Medical: A range of cancer types (child, adolescent and adult cancers) often requiring complex management. Due to this being a period of rapid growth and body change, cancer in this age group is often not found until later than for either children or older adults, which can make it harder to treat.
Psychosocial: At a time of insecurity and self-questioning, confidence and perspectives of self-image can be both emotionally and physically affected by cancer treatment.
Relationships: Sexual function, drive and fertility are all often affected by cancer treatment which can break down relationships and discourage future partners. Young people may have to face losing their fertility completely.
Peers: Relationships with peers can be damaged by cancer treatment. Young people are often isolated at a time when trying to identify with and seek acceptance from peers.
Financial: A financially independent young person may need to turn back to their family for financial support. Young people and families can face huge debts due to lost earnings, travel and accommodation expenses whilst going through extended periods of cancer treatment.
Family: Disruption of family life and increased dependence on family at a time when young people are moving towards establishing their independence.
Employment/education: Interruption and lost opportunities in education or employment at a time when a young person is planning their future.

Figure 1.1. The unique issues affecting young people going through cancer and cancer treatment (Whiteson, 2003; Marris et al. 2011; Taylor et al. 2013).

1.2.2 Young people with cancer: unique cancer types

Tumour distribution in young people is also unique, and different to that of child and adult populations (Whelan and Fern, 2008). Young people straddle three categories of cancer types: those that occur in childhood, those that occur in adulthood and cancers which are more unique to teenagers and young adults (Whelan and Fern, 2008), therefore a wider range of cancers prevail when compared to the population as a whole (Figure 1.2). In addition to a wide tumour distribution, there is variation of the common tumour types in young people *within* this age range. Younger teenagers (aged 13 to 19) more commonly experience childhood cancers, e.g. leukaemia, whereas older teenagers and young adults (aged 20 to 24) experience more 'adult' cancers, e.g. carcinomas. While all cancer types can and do occur

across the age spectrum, there is a distinctive change in common tumours as young people mature from adolescence to young adulthood (Figure 1.3).
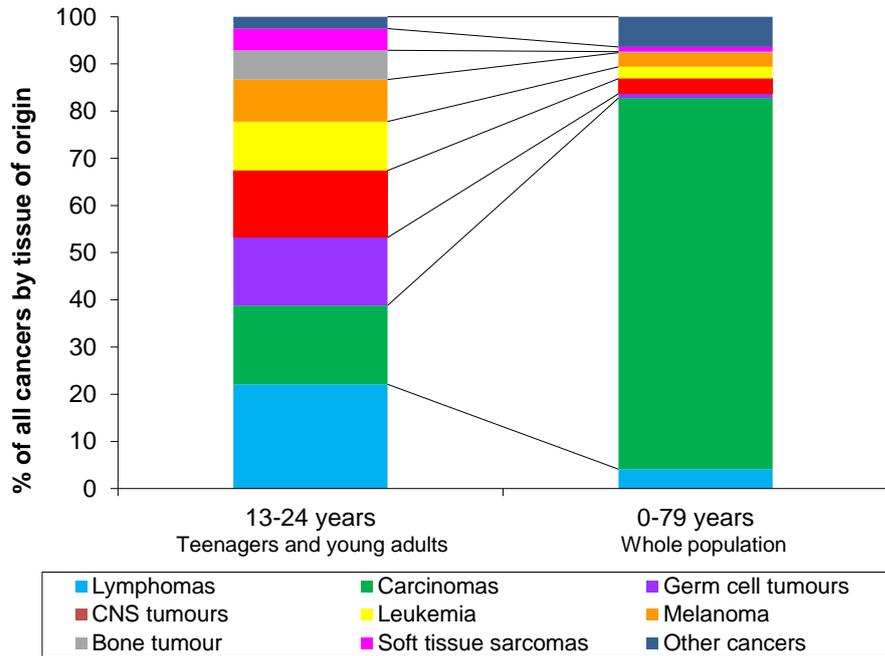
Figure 1.2. The distribution of tumour types in young people is unique and not replicated in other age groups (adapted with permission from authors) (Whelan and Fern, 2008).
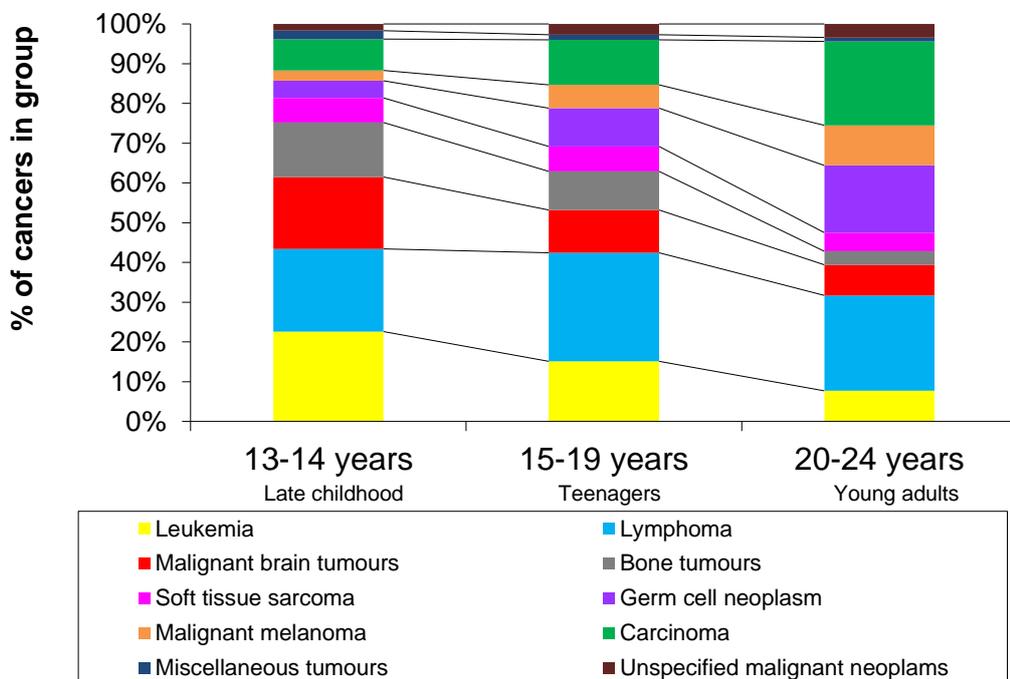
Figure 1.3. The distribution of tumour types alters within the teenage and young adult population: tumours seen in younger patients differ from young people who are approaching adulthood (adapted with permission from authors) (Whelan and Fern, 2008).

Caring for young people with a large range of cancer types, alongside the difficulties of treating rapidly developing bodies experiencing puberty, creates an array of challenges for clinical teams (Smith *et al.* 2016). The rigid structure of child and adult cancer services has meant that ensuring young people receive correct and timely referrals, necessary medical expertise, best treatment protocols and care pathways has been described as a particular challenge (Whelan and Fern, 2008).

1.3 History of young people's cancer care

To further assist the reader in understanding the context of this research, the historical context of young people's cancer services will be presented: where services have emerged from, how they have developed and where they are headed. Firstly, the wider, global perspective will be presented, before narrowing the focus to look specifically at the history of teenage and young adult cancer services in England.

1.3.1 The International perspective

The various ways that the international teenage and young adult cancer community has grown in size and structure, and with evolving aspirations, resembles the journey of young adulthood itself. There have been several highlights for teenage and young adult cancer care internationally over the last decade. There is an increasing evidence-base, with journals dedicated to the specialty, and a notable, widening of the age range to include young adults aged up to 39 in North America (Barr *et al.* 2016). The UK was the frontrunner in establishing services for young people with cancer, with the development of the first dedicated unit in London in 1990 (Carr *et al.* 2013). Later in the 1990s, in North America, numerous working groups and task forces were developed following publication of the first report which acknowledged the unmet needs of this population (Bleyer, 1996).

In 2007, the Australian Adolescent and Young Adult Cancer Reference Group was formed and services received government funding, co-ordinated by consumer support group CanTeen (Osborn *et al.* 2013). Further funding was released by the Australian Government in 2013 and now five geographically-spread cancer services provide care for young people across the whole of Australia (Barr *et al.* 2016).

In mainland Europe, teenage and young adult oncology was not nationally well-recognised until 2010 (Barr *et al.* 2016). The European Network for Cancer Research in Children and Adolescents (ENCCA) was a five-year project, which

ended in 2015, comprised of 11 countries whose work facilitated equitable standards of care and access to treatment across Europe (Saloustros *et al.* 2017). Over the course of the five years, ENCCA founded multiple steering structures, and contributed considerably to the creation of a more effective and cohesive network of child and adolescent research in Europe (ENCCA, 2016). Moreover, it facilitated the critical mass of expertise and interest for conducting new and long-term research which was both appropriate and young-person centred (ENCCA, 2016).

In the United States (US), further advances took place with the formation of a partnership between the US National Cancer Institute (NCI) and 'Livestrong' to create a Progress Review Group for teenage and young adult cancer in 2005. This group scrutinised and explored the issues that impact the care of the 70,000 new young people diagnosed with cancer each year in the US and published their findings (Shaw *et al.* 2015). The challenges of creating a model of care that catered for all young people in a country as vast as the US have been recognised (Shaw *et al.* 2015). A priority of the Progress Review Group was to understand the poor improvements in cancer survival in the teenage and young adult age group, when compared to children or older adults over the last 20-30 years. Significant progress has been made to combat the disparity in survival rates and the work of the Progress Review Group remains ongoing (Ferrari and Barr, 2017).

In Canada, an operational task force held two international summits that steered a succession of recommendations to develop the field which were similar to those of the Progress Review Group in the US (Fernandez *et al.* 2011). In terms of formal training, a one-year post-graduate diploma in teenage and young adult oncology was developed (Barr *et al.* 2016). Similarly, a series of post-graduate modules in teenage and young adult cancer care are now delivered in the UK, through partnership with the charity Teenage Cancer Trust (Coventry University, 2017).

The lack of developmental progress in teenage and young adult cancer services in less economically developed countries is noteworthy (Barr *et al.* 2016). In an attempt to increase international awareness and recognition of the unique needs of young people with cancer, five key charities worked together to set up the 'International Charter of Rights for Young People with Cancer' (Rajani *et al.* 2011). This is a world-wide, web-based campaign to improve support and access to services for young people with cancer. The main message behind the campaign is: *"access to quality cancer care is a right, not a privilege"* (Rajani *et al.* 2011, p50).

This charter was produced to advocate for change globally, however there is evidence demonstrating it is largely unknown by both young people and professionals in Europe (Jones *et al.* 2017; Pini *et al.* 2017). It is likely, therefore, that it is even less familiar to those in lower-and-middle income countries. In recently published research into the European perspectives of teenage and young adult cancer services, views about the International Charter were surveyed. More than 85% of patients (n=301) and 95% of healthcare professionals (n=106) agreed with the content of the Charter (Jones *et al.* 2017; Pini *et al.* 2017). These data validated the suitability and acceptability of the Charter statements among both patients and professionals. It would, however, be of greater value internationally if it was promoted and global awareness increased (Jones *et al.* 2017; Pini *et al.* 2017). The Charter's statements can hold no influence over policy, and therefore practice, if it remains poorly shared and discussed. Achieving the recommendations laid out in the International Charter will require effort, resource and enthusiasm of the entire teenage and young adult cancer community, in addition to the Government and charitable organisations that fund and resource these services (Rajani *et al.* 2011).

It is generally accepted that a world-leading configuration of cancer care for young people currently exists in the UK (Carr *et al.* 2013), with similar models now starting to be implemented in other countries (Shaw *et al.* 2015). The momentum that has built over the last two decades must continue, despite the challenges, if we are to develop equitable, age-appropriate cancer services for young people on a global scale. If we are to advocate for specialist services for teenagers and young adults with cancer, more evidence is required to demonstrate benefit to patients. Moreover, research to investigate the cost benefits of specialist services is required; this is critical in low-and-middle income countries where the cost of healthcare is paramount. Other countries would be wise to draw on the learnings of the UK; the successes and challenges that have occurred during the development of services over the last three decades. However, the landscape of services from country to country is different, the context for the UK is important to understand by first exploring the history, before critically exploring the current models of care.

1.3.2 The landscape of services in England

Specialised teenage and young adult cancer services in the UK have evolved over the past thirty years, with much input from the charity Teenage Cancer Trust (Whiteson, 2003; Carr *et al.* 2013). In the 1960s, the model of children's cancer care emerged and is now fully established (Whelan, 2003), and adult services were

reconfigured in 2001 into cancer networks, resulting in improvements in both patient experience and outcomes with their implementation (Macmillan Cancer Support, 2012). It has taken longer for a model of cancer care for young people to be developed; a visual overview of the highlights of the history of teenage and young adult cancer services in the UK are presented in Figure 1.4.

The original seed of teenage and young adult cancer services was planted in London in 1987, with the work of a group of forward-thinking practitioners in the field who formed the first charity to address the health needs of young people (Bleyer, 2011), the precursor to the now eminent national charity 'Teenage Cancer Trust' (Selby & Bailey, 1996; Bleyer, 2011). The first teenage cancer ward opened in London, the Middlesex Hospital, in 1990 (Carr *et al.* 2013).

Awareness continued to grow in the UK and in May 1994, the first International Conference on Teenage and Young Adult Cancer Medicine was held in England, and following this a seminal text was published, 'Cancer and the Adolescent' (Selby & Bailey, 1996). A key document, the '*Policy framework for commissioning cancer services*,' which was promptly abbreviated to the '*Calman-Hine report*,' was written to direct cancer service development nationally and acknowledged the special medical and psycho-social care requirements of adolescents (Department of Health (DoH), 1995). The points raised in the Calman-Hine report reinforced the views and vision of the founders of Teenage Cancer Trust (Whiteson, 2003).

The Calman-Hine report impacted cancer services for all age groups in the UK (Haward, 2006), advocating a person-centred approach to cancer treatment. However, there were issues with the implementation of the policy that have lessened its effect, meaning that variations in service delivery and quality continue to exist (Haward, 2006).

HISTORY OF TYA CANCER CARE IN THE UK

KEY HIGHLIGHTS

2011
BRIGHTLIGHT study received funding, JAYAO launched

2014
NICE released updated service standards

2016
1st Global Adolescent and Young Adult Cancer Congress

2010
The International Charter of Rights for TYA with Cancer

2005
NICE released 'IOG', NCRI TYA CSG formed

2004
Formation of TYAC

2008
Feasibility work for BRIGHTLIGHT study began

2002
1st UK Patient Conference: 'Find your sense of tumour'

1996
1st text book: 'Cancer and the Adolescent'

1995
Calman Hine Report

1990
1st TYA ward opened, Teenage Cancer Trust founded

1994
1st International Conference for TYA Cancer Medicine

TYAC: A professional group 'Teenagers and Young Adults with Cancer'; NCRI: National Cancer Research Institute; CSG: Clinical Studies Group; JAYAO: Journal of Adolescent and Young Adult Oncology; NICE: National Institute of Health and Care Excellence; IOG: Improving Outcomes Guidance

Figure 1.4. Historical highlights of the evolution of teenage and young adult cancer services in the UK.

Throughout the late 1990's the movement and interest in young people's cancer care continued and a further seven specialised units were funded by the third sector and opened across the country from 1990 to 2005 (Teenage Cancer Trust, 2018). Service model variation and inequity remained a central problem for cancer services for all ages (Haward, 2006), and despite the opening of more teenage cancer units, national co-ordination of health services for young people with cancer was lacking (Whelan, 2003).

In 2004 a group of healthcare professionals came together from across the UK to form 'TYAC' (Teenagers and Young Adults with Cancer). The aim of TYAC was to be the unified voice of professionals working with young cancer patients (TYAC, 2017). In 2005, a second group of professionals and patient representatives formed the 'National Cancer Research Institute (NCRI) Teenage and Young Adult Clinical Studies Group', who were and still are key in driving research to improve outcomes through first-class research (NCRI, 2012). At a similar time, the National Cancer Research Network was established and set out to improve recruitment to clinical trials for patients of all ages in the UK, which was achieved in adults but not as yet witnessed in young people (Barr *et al.* 2017).

The release of the National Institute for Health and Care Excellence (NICE) 'Improving Outcomes Guidance' (IOG) for children and young people with cancer in 2005 was a significant landmark on the landscape of UK teenage and young adult cancer service development. This document provided essential detail about secondary care services, such as clinical organisation, facilities, and diagnostic and therapeutic modalities (NICE, 2005a); primary care and community services were not the focus of these guidelines. Almost a decade later in 2014, NICE released an updated set of service standards for secondary care. It documented the standards for quality care provision of all cancer types, separating young patients into 0-15 years and 16-24 years (NICE, 2014a). This document was released in line with the NHS Outcomes Framework 2014-2015 (DoH, 2012). A corresponding theme between these two documents was *"ensuring that people have a positive experience of care"* (NICE, 2014a, p. 8). They stated that providers and commissioners of services should refer to the NICE quality standards when planning gold-standard services (NICE, 2014a).

While these policies and guidelines were integral to guiding and shaping teenage and young adult cancer services in England, the recommendations were originally based on limited empirical evidence. The evidence review, which underpinned the

IOG (NICE, 2005b) is a collation of evidence on child and adult cancer services, some of which was assessed to be of fair to poor quality. For example, the IOG evidence review (NICE, 2005b) reported the evidence for the optimum treatment setting for children and young people with cancer. They reviewed:

> 1 non-randomised controlled trial of poor quality;
> 1 systematic review of good quality;
> 1 retrospective cohort study of fair to poor quality;
> 3 reviews, 2 of good quality; 1 of fair quality;
> 6 historical case series, 2 of good quality; 4 of fair quality;
> 1 guidance of fair quality;
> 1 dissertation/evidence review of fair quality;
> 1 expert opinion of fair quality.
> (NICE, 2005b)

Among the range of evidence described above, NICE (2005b) identified: seven studies within children's cancer; six in adult cancer; and only two were evidence specific to teenagers and young adults: one of which was specific to one cancer type and one was a single-site thesis of a specific region in England. It therefore seems reasonable and fair to suggest that the recommendations presented in the IOG were founded on no high-quality evidence specific to the population that they were representing.

The surveillance report later released by NICE (2014b) identified a lack of new evidence to support the changing or updating of the current guidelines for the configuration and delivery of young people's cancer care. The surveillance report emphasised the importance of the BRIGHTLIGHT study. BRIGHTLIGHT is a collection of research projects designed to together answer the overarching research question: "*Do specialist services for teenagers and young adults with cancer add value?*" (www.brightlightstudy.com). The BRIGHTLIGHT study was cited as essential evidence towards updating the service guidelines for teenage and young adult cancer services:

> *"Through the surveillance review of the children and young people with cancer service guidance and subsequent consultation with stakeholders, no new evidence which may potentially change the direction of guidance recommendations was identified. However ongoing studies, such as the BRIGHTLIGHT study may impact on the guidance in the future therefore the guideline should remain on the active surveillance list until the results of this study are published."* (NICE, 2014b, p.4)

This highlighted the impetus of the BRIGHTLIGHT study findings; long-awaited in the teenage and young adult cancer community (Carr *et al.* 2013). The research reported in this thesis is an essential part of the overarching programme of BRIGHTLIGHT research, which will be described in detail in section 1.5.

In 2015 the Independent Cancer Taskforce report highlighted several areas for improvement in cancer services for teenagers and young adults (The Independent Cancer Taskforce, 2015), two of which included:

1. Ensuring that 'gaps' between child and adult cancer services are rectified and transitional care is provided.
2. Establishing clear criteria for designation/de-designation of hospitals caring for this age group.

As a result of this, NHS England committed to focusing on these key priority areas, in addition to recommendations regarding the inclusion of teenagers and young adults in clinical trials (The Independent Cancer Taskforce, 2015). As a result, a National Service Review is currently being undertaken, which is being driven by a group of expert professionals on behalf of NHS England (Hough, 2018). The aims of the review are to improve both patient experience and outcomes, and to guarantee equitable quality and access of cancer care for all teenagers and young adults (Hough, 2018). It is pertinent to note that the National Service Review does not comment on the environment and culture of care for this group.

1.4 Health services for young people

Despite the evolution and development of cancer services for young people in England, as shown across the history timeline, variation has remained regarding where young people with cancer receive their care (Kennedy, 2010). This is not just the case for cancer, all young people have been described to be *'on the margins of medical care'* (RCP, 2015). Inflexible services, poor communication, insufficient education for health professionals, and patchy and variable guideline implementation were reasons previously highlighted as to why young people's health needs have remained unmet (RCP, 2015). Viner (2001) presented sufficient numbers of young people accessed hospitals in the UK to merit provision of dedicated health services. Viner also recommended that 'other facilities' should be provided where it was not possible to provide a dedicated ward for young people (Viner, 2001). However, it could be argued that where funding and resources are limited, the needs of particular groups of young people with additional and ongoing

health needs should be prioritised. Due to extended and frequent hospitalisation, young people with complex long-term illness, disability or a cancer diagnosis have needs that extend beyond the medical issues that would commonly face a healthy adolescent in hospital; such as difficulties building social networks, altered relationships with family and friends, and interruptions to their education/careers (Sawyer *et al.* 2007).

Despite a strong focus in the NHS to advocate for person-centred care (Health Education England, 2017) and to improve cohesion and transition between health services (Seale, 2016), services are pragmatically split to serve specific populations: neonates, children, adults, and the elderly. Increasingly, young people are becoming a population with specific health services to meet their needs. As already described, the cancer specialty pioneered the development of dedicated services for young people in the UK (RCP, 2015). A more detailed description of current cancer services for young people with cancer in the UK is presented to provide further essential context to this case study.

1.4.1 Where are young people with cancer treated?

A multitude of national Government guidelines and reports have clearly indicated that, in terms of secondary and tertiary care, good practice demands adolescents to be cared for on separate wards to both children and adults, and have recognised that young people have different needs in the hospital setting; for example, they require a different style of communication and information provision to children and older adults (Ministry of Health, 1959; Royal College of Paediatrics and Child Health, 2003; Healthcare Play Specialist Education Trust (HPSET), 2015; PHE, NHS England and DoH, 2017). Despite Government recommendations advocating 'young person friendly' health services (PHE, NHS England and DoH, 2017), many young people in the UK are still cared for on adult wards (Dean and Black, 2015) or in children's services (Jones *et al.* 2017) (Figure 1.5). Yet it has been consistently suggested that it is 'inappropriate' to deliver care to young people in either child or adult environments of care (Kelly *et al.* 2004; Steinbeck and Brodie, 2006) or in settings not equipped to meet their needs (McDonagh and Viner, 2006).

Prior to the release and implementation of the IOG (NICE, 2005a), a study was conducted to ascertain where teenagers and young adults with cancer were cared for (O'Hara *et al.* 2012). This was the first evidence to describe places of care prior to the implementation of the NICE guidelines (NICE, 2005a). O'Hara *et al.* (2012)

highlighted that 52% of young people received some inpatient care within a hospital, that became known as a Principal Treatment Centre, and a larger proportion were aged 15 to 18 years in comparison to 19 to 24 years. In 2013, a similar report was released which presented the notifications of teenagers and young adults aged 15 to 24 years to Principal Treatment Centres (O'Hara *et al.* 2013). These reports cannot be directly compared as the first report included only patients recorded as inpatients, whereas the second report is broader and encompasses patients in all settings. However, the two reports documented similar findings in terms of where young people with cancer were cared for, providing the same message about young people's variable access to age-appropriate cancer care.
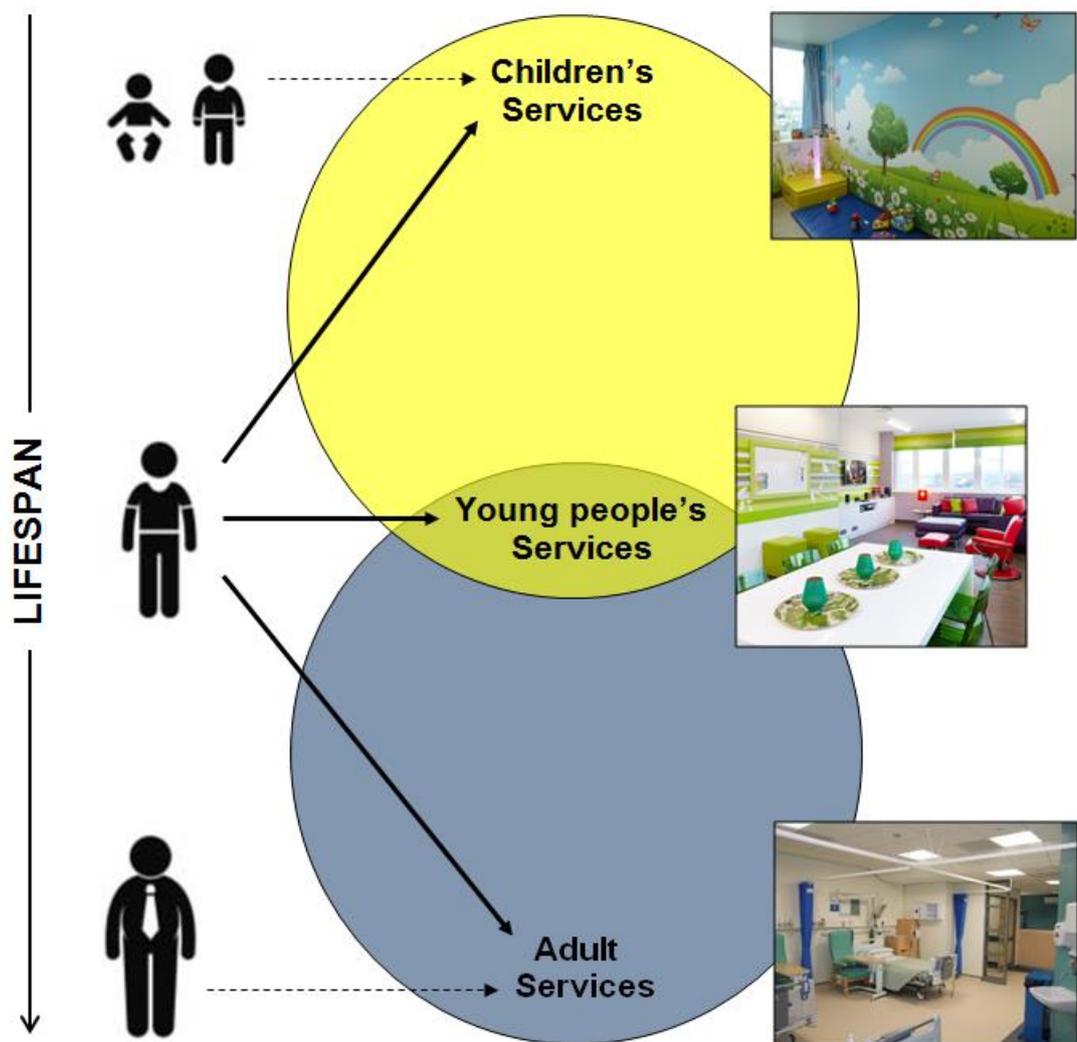
Figure 1.5. An illustration of the three types of health service where young people with cancer may be cared for (Images: Nottingham University Hospitals NHS Trust, 2017).

1.4.2 Cancer services for young people

Place of care was a key focus within the IOG (NICE, 2005a), which stated that young people should be cared for in an *"age-appropriate environment"* and have access to *"age-appropriate facilities"* (NICE, 2005a, p. 110). Similarly, the 'Blueprint of Care' for young people with cancer provided valuable recommendations, proposed by experts in the speciality, outlining the features of specialist services for this patient group (Smith *et al.* 2016). However, specialist services could not be mandated without sufficient evidence to underpin them and this led to the process of designation. Designation is where cancer services for young people in England are structured in networks of care, with a central Principal Treatment Centre as a 'hub' of expertise. Hospitals with adult cancer services surrounding the Principal Treatment Centre could apply to be 'designated' to provide cancer care to young people aged 19 to 24. The designation of these hospitals was decided by the Children and Young People's Co-ordinating Group for each network of care. The designation process was not covered in the service specification (NHS Commissioning Board, 2013) therefore all hospitals which provided specialised cancer services could request to be designated to care for young people. The current service model for young people with cancer in England consists of 13 teenage and young adult networks of care: within each network there is a Principal Treatment Centre (Figure 1.6) and varying numbers of associated designated hospitals.

Figure 1.6. Map of the location of the 13 teenage and young adult cancer networks in England. Each network of care surrounds a central 'hub' of specialist expertise at a Principal Treatment Centre: (1) Cambridge; (2) Bristol; (3) Oxford; (4) Liverpool; (5) Newcastle; (6) East Midlands; (7) Birmingham; (8) Southampton; (9) Leeds; (10) Manchester; (11) South Thames; (12) North Thames; (13) Sheffield.

The Principal Treatment Centres provide treatment expertise across the range of cancers common in young people, supported by a dedicated teenage and young adult multidisciplinary team to meet the psychosocial needs of this population, within an environment that is tailored to the developmental and social needs of young people (Carr *et al.* 2013; Smith *et al.* 2016). It is recommended that children and young people up to 18 years of age receive their cancer treatment at a Principal Treatment Centre (NICE, 2005a; NICE 2014a), although for most patients it will be possible and necessary for some parts of their care to be provided by their local hospital in a 'shared care' arrangement (NICE, 2005a). Shared care is seen frequently in children's cancer care, however is not well established for teenagers and young adults. Supportive care such as management of nausea and administration of blood products can be delivered in children's shared care service depending on the local policy agreed between hospitals (NHS Commissioning Board, 2013).

Paediatric Oncology Shared Care Units are part of a general children's hospital ward, with authorisation to provide certain aspects of supportive care for children and teenagers with cancer, such as administration of blood products or uncomplicated chemotherapy regimens. Paediatric Oncology Shared Care Units accept young people up to age 16, sometimes age 18, enabling some of their care to be delivered closer to home and thus reducing travel time to the Principal Treatment Centre. Currently adult cancer services will not provide shared care to enable older teenagers and young adults to receive care in this way (NICE, 2005). This is an example of the variation in context for young people's cancer care, and is something that is addressed in the forthcoming review of teenage and young adult cancer services (Hough, 2018).

Children's community nursing and palliative care teams are able to provide some cancer care at home for young people up to 16 years, however children's community nursing services are not available across the whole of England (NICE, 2005a). This means that some young people receive community care from district nurses, who may not have all of the knowledge and skills required to meet a young person's needs. The upper age limit accepted for treatment in children's services and the lower age limit for admission to adult services was previously highlighted as an important issue (Hollis and Morgan, 2001). Young people aged 17 can still fall awkwardly in between child and adult care, particularly in terms of access to clinical trials (Hay *et al.* 2016).

Additionally, as already mentioned, within each network providing secondary and tertiary care, there are specific district general hospitals allocated to provide care to young people aged 19 to 24, termed designated hospitals. While those aged 19 to 24 can have their treatment in a Principal Treatment Centre, they can also choose to be cared for in the adult service at their most local designated hospital (NICE, 2014). Adult district nursing teams can provide these patients with some elements of their care at home (NHS England, 2014). The recommendations are that young people who chose to receive their care at a designated hospital will have their diagnosis notified to the teenage and young adult multi-disciplinary team in the Principal Treatment Centre of that network. Subsequently, the *"sharing of responsibility for patient management"* between the tumour site-specific clinical team at the designated hospital and the teenage and young adult experts at the Principal Treatment Centre is recommended (NHS Commissioning Board, 2013, p.6).

Young people at designated hospitals should have *"unhindered access"* to the support of the wider multi-disciplinary team via outreach work performed by the specialist professionals from the Principal Treatment Centre, e.g. young people's social workers (NICE, 2005a, p.110). A template was created to assist teenage and young adult designated hospitals to prepare their service for peer review: peer review is an assessment of the strengths, areas for development and overall effectiveness of the hospital's services (National Cancer Action Team, 2010). However, despite having a template to prepare, of the 76 designated hospitals listed that were included in the peer review 2012-2013, 20 performed very poorly and achieved less than or equal to 50% compliance of the designated hospital peer review standards (National Peer Review Programme, 2013). There were no consequences from the review and these hospitals have remained designated for teenagers and young adults, despite lacking many elements of a young-adult friendly cancer service (National Cancer Action Team, 2010).

Within each network there are also hospitals that are not allocated to provide care to teenagers and young adults with cancer, termed non-designated hospitals. Evidence indicates a portion of young people are still cared for in non-designated hospitals without access to the age-specific expertise of the teenage and young adult multidisciplinary team at the Principal Treatment Centre (O'Hara *et al.* 2013), despite this conflicting with the national recommendations (NICE, 2005a). This means that there are young people who will not have any access to age-appropriate young-people's care throughout their entire cancer timeline (O'Hara *et al.* 2013).

In summary, there is a chronological age issue as the word 'teenage' suggests it applies to those aged 13 to 19, however this has not been applied consistently. There are a variety of services where a young person could receive their cancer care, dependent on their disease, age, location and availability of services (NHS England, 2015) (Figure 1.7).
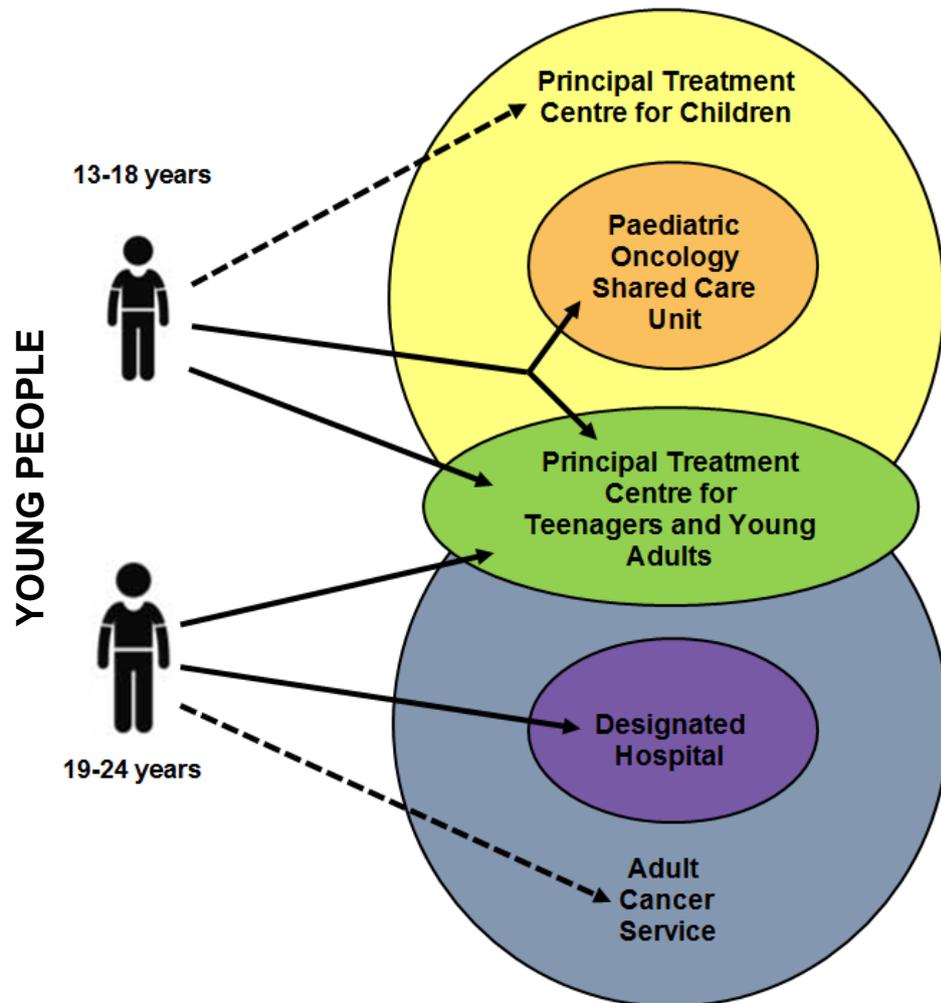
Figure 1.7. The range of places where a young person with cancer may receive their care, dependent on whether they are 13-18 years old or 19-24 years old. Young people may receive access to specialist teenage and young adult cancer care (highlighted by the solid arrows), but young people may still be cared for in either child or adult cancer services (highlighted by the dashed arrows).

Specialist environments of care are provided for young people at the Principal Treatment Centres, and a small but growing number of the designated hospitals, which are predominantly funded by Teenage Cancer Trust. Teenage Cancer Trust is a charitable organisation in the UK that is dedicated to improving the lives and outcomes of young people with cancer (Teenage Cancer Trust, 2017). They design and equip specialist units within NHS hospitals, in addition to funding specialist staff,

education and research (Teenage Cancer Trust, 2017). To date, there are Teenage Cancer Trust funded facilities in 28 hospitals across the UK, however this has been driven by passion and strong beliefs as opposed to a robust evidence in support of specialist services (NICE, 2014b). Each teenage and young adult cancer network is led by a regional Teenage and Young Adult Cancer Network Co-ordinating Group. The key role of this group is to work collaboratively with other care providers, support designation of services and to employ network-wide policy and procedure (National Cancer Action Team, 2011; NHS England, 2013).

To ensure all young people have expert input into decisions made about their treatment and care, regardless of where a young person decides to be cared for, all newly diagnosed patients aged between 16 and 24 years should be discussed in the teenage and young adult cancer multidisciplinary team meeting in the Principal Treatment Centre: *"Young people (aged 16-24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer-site-specific and a teenage and young adult multidisciplinary team"* (NICE, 2014, p.12). However, since the release of the NICE IOG in 2005, there has remained widespread variation in adherence and implementation of this recommendation (O'Hara *et al.* 2013), and therefore variation in access to dedicated teenage and young adult cancer services (Carr *et al.* 2013; Jones *et al.* 2017). The widespread variation in implementation of the IOG recommendations for services was a result of several factors: the age/maturity of services; differences in the size and geography of networks; differing numbers and configurations of hospitals within the networks; and historic traditions, views and practices causing resistance to change or implementation of new service structures (O'Hara *et al.* 2013).

The National Cancer Peer Review Programme produced a best practice specification for teenage and young adult cancer services (National Cancer Action Team, 2011), which listed measures to assist management and organisation of these services, coinciding with the aim of the Coalition Government: *"to deliver health outcomes that are among the best in the world"* (National Cancer Action Team, 2011, p.6). These guidelines were a specification produced to facilitate quality checks and commissioning of cancer services. The key concern was that all services provided are appropriate and of high quality at each level of care: specialist cancer centres, smaller cancer units and local services. The '2013/2014 NHS standard contract for cancer: Teenagers and Young Adults' (NHS England, 2013) stated that the 2011 service specification did not encompass the commissioning of

designated hospitals for young people. This therefore presented some explanation for why there was a difference in the quality of facilities and support available for young people between different services and settings (NHS England, 2013).

Khan *et al.* (2013) evaluated how the provision of young people's specialist cancer care in England had progressed. They used the most robust data source available at the time, the 'Teenage and Young Adults with Cancer' notification database, to extract patient referral data. Figures showed that 63% (aged 15 to 18 years) and 34% (aged 19 to 24 years) of patients diagnosed in 2009-2010 were referred to a specialist teenage and young adult multi-disciplinary team. This indicated an unacceptable percentage of young people were being missed at these early stages of the care pathway. Research has highlighted that a protracted pathway to diagnosis is an ongoing issue for teenage and young adults, and services should focus on improving patient involvement in decisions about their care (Furness *et al.* 2017). Furthermore, Furness *et al.* (2017) suggested that patients perceived their care positively in Principal Treatment Centres and recommended for future research to determine the impact of the variety of cancer services in which young people are cared for in the UK.

There is a general lack of research evaluating how well these teenage and young adult cancer care networks operate and therefore it is currently unknown whether this is the optimal model of care delivery for this patient population. The centralisation of children's cancer services led to well-documented improvements in survival rates, and it was hoped that this could be replicated for the teenage and young adult patient population (Lewis and Morgan, 2007). Research into the views of the healthcare professionals who co-ordinate and contribute to running these networks would be beneficial to improve the quality of cancer services that are provided, across all care settings. Furthermore, it is advocated that services should enable an integrated approach, with the young person's choice as paramount (NICE, 2005; NICE, 2014). The current service review could have implications for how and where this age group of cancer patients are cared for (Hough, 2018). Irrespective of the content of this review, young people will still require specialist care, and therefore a larger evidence-base is required to understand the view and experiences of young people and professionals receiving and delivering these services.

1.4.3 The development of the teenage and young adult workforce

Alongside the development of specialised services, the teenage and young adult cancer workforce has also emerged as a discrete speciality as specifications recommended a collaboration of expert professionals, known as a teenage and young adult multi-disciplinary team (NICE, 2005a; NHS Commissioning Board, 2013). Providing healthcare for this age group requires acknowledgement of a young person's developmental transition from child to adult (Arnett, 2000), in addition to meeting the clinical and holistic needs of a cancer patient (Zebrack *et al.* 2007). The IOG (NICE, 2005a) made recommendations for appropriate healthcare professionals to create a teenage and young adult cancer multidisciplinary team, with the aim of adding value through supporting treatment planning with the tumour site-specific multidisciplinary teams, in addition to providing psychosocial support (NHS Commissioning Board, 2013). These recommendations echoed those that were being developed in North America during this period (Shaw *et al.* 2015). Workforce planning within the NHS requires not only the appropriate number of staff to care for patients, but also staff with the appropriate skills, behaviours, attitudes and values (Cable and Pettitt, 2018).

While suggestions were made as to the core membership of the multi-disciplinary team, at this time there was limited evidence recommending competence, education or training requirements for this group of professionals (Taylor *et al.* 2016). In the UK, the development of nurses with expertise in caring for young people with cancer has happened organically, meeting the psychosocial and physical needs of young people on a daily basis (Smith and Olsen, 2018). An additional and unique member of the teenage and young adult multi-disciplinary team at the Principal Treatment Centres is 'youth support co-ordinators' or 'youth workers' (Morgan *et al.* 2016). Anecdotes and experience have shown these roles as pivotal as a source of support, distraction from difficult scenarios, and assistance in engaging young people with their peers (Morgan *et al.* 2016; Martins *et al.* 2017). However, the results of a formal evaluation of the youth support co-ordinator role are yet to be released (Cable, 2018).

Until recently, much of this development of the skills and knowledge required to care for young people with cancer has been through experiential learning (Smith and Olsen, 2018) as opposed to being evidence-based. The 'Delphi survey' within the BRIGHTLIGHT programme of research (more detail on BRIGHTLIGHT in Section 1.5) explored the competencies of the workforce caring for young people with

cancer. Initial work described the favourable characteristics of healthcare professionals caring for this population (Gibson *et al.* 2012). This work formed the basis of a survey which retrieved responses from an expert international panel, and provided a framework of competencies and attributes of this particular professional group which was hoped to assist workforce planning, shape education and training programmes (Taylor *et al.* 2016).

The findings of the BRIGHTLIGHT Delphi survey encompassed four core competency domains: communication, attitude, knowledge and skills (Taylor *et al.* 2016b). These findings will be valuable as services are further developed, to describe, plan and justify the composition of the specialist teenage and young adult multi-disciplinary team (Taylor *et al.* 2016b). Further to this, it would be of value to understand the impact of these professional competencies on the culture of care, as they will naturally influence how care is delivered to young people. A large part of studying the culture of care therefore is exploring the communication, knowledge, skills and attitudes of the healthcare professionals delivering care.

Guidance on the delivery of care to young people with cancer has noted the challenges of providing education for professionals who work with this group:

"Due to the broad range of healthcare professionals who come into contact with this patient group, their education and training needs will inevitably differ… service managers therefore need to acknowledge the levels of knowledge required across the whole of the healthcare team." (Cable, 2016, p. 53).

The difference in education needs of professionals described above by Cable (2016) indicated a need for increased evidence around the knowledge required by all professionals, in all care settings who care for young people with cancer. While there has been work looking at the competencies of professionals who provide specialist care for teenagers and young adults with cancer (Taylor *et al.* 2016b), this work was established by experts working within specialist teenage and young adult cancer care settings, and did not include the views of professionals based in other non-specialist care environments. More evidence surrounding the development of knowledge on caring for young people in non-specialist care settings could assist in shaping the education and training of a wide range of professionals who work with this unique patient population.

1.4.4 The challenges of providing care to young people with cancer

There is an alternative, opposing perspective to the positive aspects presented so far, of being cared for/providing care in teenage and young adult cancer settings. Although under-researched, there is potential for care in these environments to present emotional challenges to both young people and their families, and to healthcare professionals.

An environment in which young people are surrounded by peers with cancer, although facilitating friendships and peer support, inevitably also brings loss (Marshall *et al.* 2016). In a narrative inquiry of young people and their families' experiences of hospitalisation in Australia, 'confronting illness and death' was a key theme that emerged (Barling *et al.* 2014). Young people are faced with losing friends, companions and facing unexpected bereavement, when considered together, they serve as a reminder of the reality of their own illness and mortality (Barling *et al.* 2014). Following the death of friends, it has been recognised that young people often communicate about their grief using social media (Mackland and Wright, 2018). This would be the same for young people in both children's and adult care settings, indeed Barling *et al.* (2014) reported that particularly in adult cancer services in Australia, hospitals are associated with death and suffering. Young people are thus facing the possibility of death at an earlier stage in their lives. It has been suggested that without appropriate bereavement support, young people are at greater risk of having issues with their emotional and mental health, and there is need to develop a formal bereavement support services for this population (Mackland and Wright, 2018). There is a further need to explore this aspect of caring for young people with cancer and the impact of the different environments of care have on young people's need and experiences of bereavement and bereavement support.

Additionally, there are challenges for healthcare professionals: supporting the needs of young people with cancer and their families is emotionally demanding (Marshall *et al.* 2016). For healthcare professionals, although not researched within teenage and young adult cancer care specifically, there is evidence to show the challenges that face those working regularly with cancer patients (Cohen *et al.* 2010). While all professionals working with this group are vulnerable to work-related challenges and stress, research has shown that nurses in particular are persistently exposed to stressors (Borteyrou *et al.* 2013). However, while regular exposure to death and suffering has been associated with emotional distress for healthcare professionals,

workload and relationships with colleagues were ranked more highly as causes of emotional distress in an oncology nurses (Raingruber and Wolf, 2015). The emotional burden of caring for very unwell cancer patients, with the stress of consistent exposure to death and dying, may impact on retention of caring staff in this specialism (Borteyrou *et al.* 2013). This however it is only one factor to consider among other organisational workplace stressors (Borteyrou *et al.* 2013). It is imperative that there is psychosocial support available to healthcare professionals (Marshall *et al.* 2016) as it is known to reduce some of the emotional burden experienced by those working closely with this patient group.

1.4.5 The ongoing call for 'young-people-friendly' health services

Young people's cancer services have been recognised as a 'gold standard' for young people's healthcare in the UK (RCP, 2015). Originally published in 2005, and with subsequent refreshed editions, the 'You're Welcome' quality criteria described the standards for measuring whether a health service is 'young person friendly' in England (DoH, 2005; DoH, 2007; DoH, 2011; Public Health England (PHE), NHS England and DoH, 2017). These quality descriptors were the first of their kind and can be applied to all young people's health services (Hargreaves, 2011). The criteria reported were of value to clinicians, service managers and developers, and leaders of health organisations to improve the services offered to young people. They have been endorsed by the World Health Organisation (WHO) (McDonagh *et al.* 2013) and were generated alongside clinical practice, with evidence of strategies to enhance young people's health outcomes and experiences (Public Health England, NHS England and the Department of Health, 2017). It might be questioned as to why the original 'You're Welcome' criteria were not used to guide the development of teenage and young adult cancer services.

Despite world-wide initiatives such as *Adolescent Friendly Health Services: An Agenda for Change* (WHO, 2002), an international review of young people friendly health services identified a paucity of evidence to support dedicated young people's health services, with so few being formally evaluated (Tylee *et al.* 2007). The Association of Young People's Health (AYPH) emphasised the importance of robust evidence evaluating health services for this age group and that young people's ideas and issues regarding health matters should be listened to and acted upon just as readily as other age groups. This is a core principle of the BRIGHTLIGHT study and of the work presented in this doctoral thesis.

1.5 The BRIGHTLIGHT programme of research

To provide further context for this doctoral research, it is essential to place this case study within the overarching programme of research: BRIGHTLIGHT. BRIGHTLIGHT is a national programme of research evaluating teenage and young adult cancer services (National Institute for Health Research Programme Grant for Applied Research: RP-PG-1209-10013). The overall aim of BRIGHTLIGHT is to establish whether specialist cancer services, as outlined in the IOG (NICE, 2005a), are associated with better outcomes both during and post-treatment when compared to other services where young people are cared for. This multiple-case study formed the qualitative component of the wider research programme. The aim was to gather the personal perspectives of young people and professionals, thus collecting rich data exploring environments and experiences of care in a multitude of care settings.

1.5.1 A call for more evidence

A succession of projects took place as part of this programme of research, focussed on exploring the added value of specialist care and services for young people with cancer (Figure 1.8). BRIGHTLIGHT is specifically evaluating the delivery of cancer services in secondary and tertiary care according to the IOG; this does not include guidance on primary care services for teenagers and young adults with cancer. While there are existing guidelines for teenage and young adult cancer services (NICE, 2005; National Cancer Action Team, 2011; NHS England, 2014; Smith *et al.* 2016), a lack of robust, comprehensive empirical evidence has been noted (NICE, 2014b). The development of updated service recommendations for teenagers and young adult cancer services was suspended; awaiting the results of the BRIGHTLIGHT Study to assist in informing these services (NICE, 2014b). This case study was one component of the BRIGHTLIGHT study.
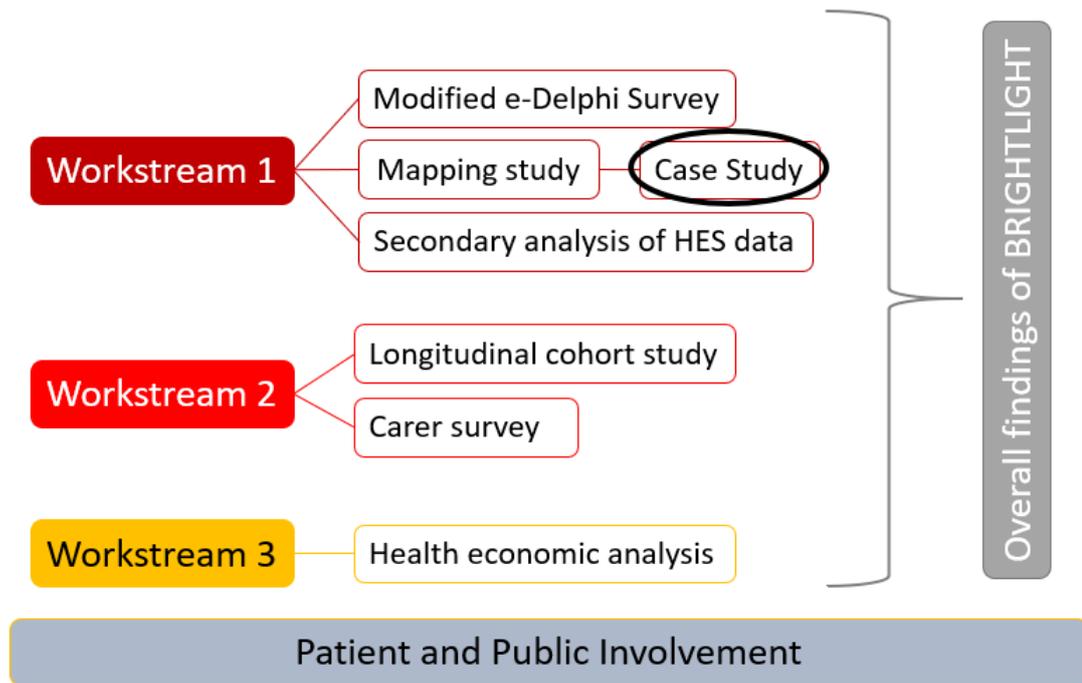
Figure 1.8. A schema of the workstreams and studies encompassed in the BRIGHTLIGHT programme of research. The case study presented in this thesis is indicated in the black circle.

Prior work, all published, included exploring young people and professional's priorities for a teenage and young adult specialist cancer unit (Taylor *et al.* 2011); the competence of healthcare professionals delivering care (Gibson *et al.* 2012); a feasibility study which conceptualised young people's experience of cancer (Fern *et al.* 2013; Taylor *et al.* 2013); and a study which mapped teenage and young adult cancer services in England (Vindrola-Padros *et al.* 2016). As part of this initial work, Vindrola-Padros *et al.* (2016) reported broad, overarching components of specialist teenage and young adult care, which influenced the placement of the BRIGHTLIGHT case study in the overall programme. The case study was designed with the purpose "*to refine the main components of care, to identify what age-appropriate care means*" (Vindrola-Padros *et al.* 2016, p. 365).

1.5.2 Mapping Study

The 'Mapping Study' (Vindrola-Padros *et al.* 2016) was an essential precursor to this case study, as it was conducted to inform the selection of the sites. In this section the aim, methods and outcome of the Mapping Study are reported to evidence how decisions were made, and how and why the four networks of care were selected for this case study.

In 2012-2013, a study titled *"Mapping Teenage and Young Adult Cancer Services in England: the BRIGHTLIGHT Directory of Care"* was conducted in 11 of the 13 specialist Principal Treatment Centres in England (the research team were unable to gain access to the remaining two Principal Treatment Centres). The overall aim of the Mapping Study was to identify the key components of young people's cancer care to be explored further in more depth. It provided an overview of the organisation of care across England at that time, and of the unique clinical configurations and socio-geographical contexts of the Principal Treatment Centres.

A collaborative method involved observation at the Principal Treatment Centres, semi-structured interviews with healthcare professionals, young people and their family members. Young people were asked to take photographs of important aspects of their Principal Treatment Centre and use these images to construct a 'map' of their care. Young people were then interviewed and a deeper understanding of the content of the map was obtained. Family members and healthcare professionals were asked to participate in a focus group or interview on their use of the Principal Treatment Centre environment. Furthermore, the researcher carried out observations in each unit and undertook documentary analysis to collate details about each service, including number of referrals, available facilities, staffing and support services.

Each Principal Treatment Centre had a unique history, structure, environment, and patient population that shaped care delivery. Overall, young people and their families denoted satisfaction with their care, and indicated that the facilities and staff were the most helpful aspects (Figure 1.9). Young people indicated that access to age-appropriate, fun activities with other young people were essential. Moreover, the findings from staff members were important as they reported multi-disciplinary team meetings and certain outreach models as helpful aspects of their work. They also highlighted the challenges of working in a teenage and young adult service, such as the lack of a wider recognition of the importance of the specialist service and staff shortages.
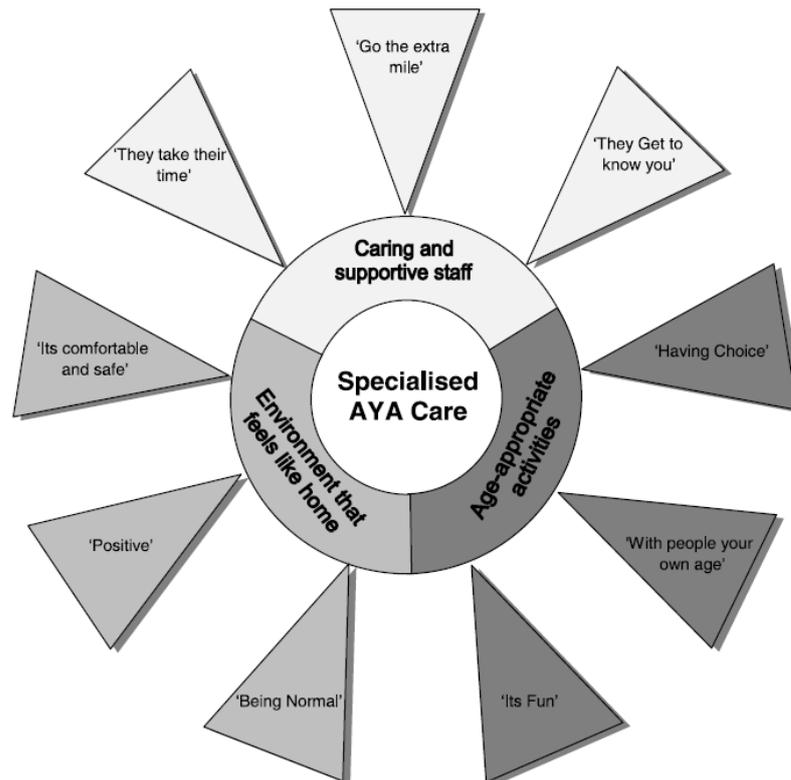
Figure 1.9. The main components of teenage and young adult cancer care provided at Principal Treatment Centres (Vindrola-Padros et al. 2016). (AYA: Adolescent and Young Adult)

The findings of the Mapping Study laid a foundation for this multiple-case study and the full report and published manuscript reporting this study are detailed in the appendix (Appendices 1 and 2 respectively).

1.5.3 Case study site selection

The site selection involved an expert panel to assist in the decision-making process. The expert panel were country-wide and consisted of expert professionals working as: clinical oncologists and clinical nurses in the field; professors in cancer medicine, young people's cancer care and health care evaluation; researchers working in psychology, epidemiology and health economics. Each member of the expert panel received a pack of information resources for each network containing: a summary of primary/secondary data about the history, size, services and structure of the network; a network map; and a local ethical approval timeline for the Principal Treatment Centre. Using this information, the expert panel were asked to select four sites based on the following defining features:

1. Patient population
2. Geographical coverage
3. Teenage and young adult services available
4. Distribution of specialist teenage and young adult services across different age groups:
   a. Are all 13-24-year olds treated in the same facility or with the same team?
   b. Are 13-24 years divided among paediatric, teenage and young adult, and adult services?
5. Arrangement of shared care
6. Size of the service (number of patients, number of healthcare professionals, represented disciplines)
7. History of the service (amount of time since teenage and young adult services were established/opened)

The selected sites represented diversity in history, structure, size and geography of Principal Treatment Centres and their associated networks of care; and thus, represented the diversity in teenage and young adult cancer care in England. The members of the expert panel were given two weeks to look at the information and send completed assessment forms with their selection back to the BRIGHTLIGHT research team (Appendix 3). Using the assessments provided by the expert panel, the research team listed the top four selected sites, which were contacted. All four networks agreed to participate in the research, and therefore the process of obtaining ethical approvals began, detailed more in Chapter 4.

1.6 Motivation for conducting the research

The research questions were both driven by the BRIGHTLIGHT programme of research and also from my own clinical practice as a nurse. Working previously at University College London Hospitals in the young people's cancer service, I cared for many teenagers and young adults who were going through cancer treatment. Young people often shared their experiences of being in their local hospital, either initially when they first became unwell and were diagnosed, or throughout for shared care. A mixture of emotions and experiences were described, and these were often negative. It became a point of interest to understand how young people who received all of their care outside of a specialist teenage and young adult setting perceived their care. Additionally, a comparison of the care provided in specialist centres as opposed to other settings would allow a greater understanding of what

makes teenage and young adult cancer care different. I therefore commenced this research into the culture of cancer care across multiple care settings.

1.7 Structure of the thesis

The structure of this thesis, alongside a description of each chapter is presented in Table 1.1, and can be used to assist in the navigation of this thesis.

Table 1.1. The structure of the thesis and a description of the purpose of each chapter.

	Chapter title	Purpose of chapter
Part A: sets the scene of this thesis, explaining why the research was undertaken, what it aimed to achieve, and how it was carried out.		
1	Setting the scene: clinical context	This introductory chapter has set the scene of the thesis, describing what is currently known and understood about young people with cancer and the current service structure and delivery.
2	Setting the scene: theoretical context	Outlines the concept of culture guiding the research, providing the conceptual context of the study and how definitions and theories of culture can be used to explore the care experiences of young people with cancer and those providing their care.
3	Narrative review of the culture of teenage and young adult cancer care in the UK	Presents a narrative review of the literature on the culture of teenage and young adult cancer care in the UK, specifically including research which sits under the domains of culture underlined in Chapter 2.
4	Methodology, methods, setting and sample	Chapter 4 describes, critiques and justifies the methodology and methods used in this research. It also describes the research setting and sample.
Part B: presents what this exploration found about the culture of care for young people with cancer and presents the implications of these findings for practice, policy and future research		
5	*Culture takes place within a context: the* physical and social environments of care	
6	*Culture consists of both 'above the surface' processes and 'below the surface' values:* communication and core values	The second part of the thesis is presents the findings in three chapters, corresponding with the three core concepts of culture that guided the research. These included the presentation of the components that contributed to the culture of teenage and young adult cancer care, both the more visible 'above the surface' and less visible 'below the surface' components, in addition to how culture of care was learned, shared and perpetuated.
7	*Culture is something that is learned, shared and perpetuated: the* development of healthcare professional holistic competence and the culture of care	

Table 1.1. The structure of the thesis and a description of the purpose of each chapter (cont.).

	Chapter title	Purpose of chapter
8	Discussion	This chapter will discuss the implications of the study findings in relation to previous literature and the current context of healthcare services for young people.
9	Conclusions and recommendations	A conclusion of the thesis findings, along with the recommendations and implications of this research on healthcare policy, practice and considerations for future research is presented in this chapter.
	Epilogue	This will conclude the narrative with a personal reflection of the research experience and the researcher's professional development through the process.

1.8 Conclusion

The evolution and current provision of dedicated teenage and young adult cancer services for young people have been presented in this chapter. It is important to recognise that health services in the UK are falling further into economic crisis; and therefore, the provision of expensive services that care for relatively small patient numbers will be a low priority. Accordingly, we need robust evidence to make the recommendations in national policies and guidelines a permanent feature within the NHS and to make services accessible for all young people. Research to explore the culture of care and the experiences of young people with cancer in a variety of care settings will allow us to understand the best models of care to support young people through their cancer and beyond. This case study aims to provide new knowledge regarding how we deliver cancer care to young people in England.

Chapter 2

Setting the scene: Conceptual context

2.1 Introduction

This chapter presents the concept of culture and how culture can be used to explore and understand young people's experiences of cancer care. It can also be used to understand healthcare professional's perceptions of caring for young people with cancer. Cultural definitions and theory is applied to the research questions and explored critically as a concept to assist an understanding of the delivery of cancer care to teenagers and young adults.

The overarching focus of this study was to consider the culture of teenage and young adult cancer care in England. As highlighted in Chapter one, this is a population of young people in England who are cared for within a variety of care settings, located across a number of hospitals within the NHS. It is therefore valuable to explore NHS and UK healthcare culture as this will help to further contextualise this study and its findings.

2.2 Research paradigm

Prior to conducting any research, it is important to consider the appropriate research paradigm: the approach to the research, including recognition of the researcher's philosophical position, which will guide the study methodology, application of theory and thus the generation of knowledge (Denzin and Lincoln, 2011). Qualitative enquiry employs a wide variety of methods which are sensitive and flexible to the complex social world being studied (Mason, 2002). This case study employed critical realism; a research paradigm associated with Roy Bhaskar (Bhaskar, 1978). Critical realism is the combined theory and practice of science, social science, and explanatory critique; with a strong emphasis on the influence of the researcher's ontological position (Bhaskar, 1978). Based upon the main features of critical realism (Bhaskar, 1978; Easton, 2010; Archer *et al.* 2016), this section will outline how the research paradigm connects with the concept of culture.

Critical realism is a moderately new philosophical view, proposing a profound alternative to the positivist and interpretivist paradigms (McEvoy and Richards, 2006). Critical realist ontology is a practical estimation of life events, presenting a pragmatic research methodology, which enables researchers to convey the nature

and causes of social processes, to facilitate theory development and influence change (Easton, 2010). Critical realists assume that there is a real world out there, yet there is no way that such an assumption can ever be proved or disproved (Easton, 2010), and because all measurement is open to failure, triangulation using multiple methods will allow us to gain a greater grasp on reality (Sayer, 2000). 'Critical' implies a need for attention to detail, precision, rigour and consistency (Crossan, 2003), which must be applied to all qualitative research to ensure credibility. Recognising that our presence as researchers influences what we are trying to study is essential (Easton, 2010); being reflective, transparent and honest throughout the conduct of a study counteracts issues relating to the unavoidable researcher influence.

Critical realism defends the need to study any situation, irrespective of the size of the population or sample being studied, providing the aim is to explore and understand things as they exist (Easton, 2010). The key difference of this epistemology to a positivist paradigm is the view that observation is fallible: critical realists are critical of the assumption that we can know reality with certainty (Trochim, 2006). Bhaskar (1978) suggested that the context of an action ('real' reality) and the scene in which the action occurs ('actual' reality), form two of the three proclaimed levels of reality (Bhaskar, 1978). The third level ('empirical' reality) is where actions are observable and can be linked to observed outcomes (Bhaskar, 1978): it is this level that is open to observational error, therefore post-positivists stress the importance of bringing together multiple measures and observations when studying a phenomenon (Trochim, 2006).

The aim of this research was to explore the culture of care through a variety of qualitative methods brought together in a collective case study. Through consideration of its components, the critical realist paradigm aligned with both the researcher and the methodology:

> i) The culture of teenage and young adult care can neither be proved nor
> disproved, rather it can be explored in the way that it exists.
> ii) Use and triangulation of multiple methods can reduce observational error
> and allow a greater grasp on the reality of the culture of care.
> iii) The influence of the researcher presence can be noted and reflected on,
> with the use of an aware, open and honest approach to data collection,
> interpretation and analysis.

This research was founded upon the ontological position that the delivery of cancer care to young people is a reality that exists, based within a historical and cultural context, and can be observed and explored through a critical lens. The development of specialist services to deliver care to teenagers and young adults with cancer was based upon knowledge drawn from child and adult cancer care (NICE 2005b), as opposed to evidence specific to the care of this age group. This critical realist paradigm guided every aspect of this research, including the contribution to new knowledge about the culture of young people's cancer care. The concept of organisational culture will now be considered, and a critical realist lens applied to assist in understanding the layers and concepts of culture.

2.3 Culture

In the past, culture has been described as an indefinable and fluid concept (Jahoda, 2012) and as such, there has been no agreement as to a single definition of culture (Harris, 2001). At least 150 definitions of culture have been identified (Kao *et al.* 2004); anthropological literature contains many notions and definitions of culture yet there remains no concrete agreement about its meaning (Smircich, 1983; Harris, 2001). Original literature on culture is comprised of over 160 definitions (Jahoda, 2012); many of which provide essential contributions which underpin more recent cultural literature.

Despite the lack of agreement as to a single definition of culture, there is an overarching agreement that culture "*represents the blueprint of human living*" (Kao *et al.* 2004, p. 271). One of the most widely known definitions for organisational culture is *"the way we do things around here"* (Lundy & Cowling, 1996, p.61). Most anthropologists would accept a definition of culture which describes a shared collection of values, rules, concepts and behavioural norms which enable the operation of a society or social group (Hudelson, 2004). These descriptions of culture were important to consider when studying the culture of teenage and young adult cancer care. One could interpret that if societal culture represents *"the blueprint of human living"* (Kao *et al.* 2004, p. 271), then the culture within a health setting represents 'the blueprint of care.' This however is an over-simplification of culture, and misses the detail of its component parts (Kao *et al.* 2004).

In response to the complexity of the concept, culture has been presented as a model by several authors (Herman, 1970; Hall, 1976; Schein, 1984; Hofstede, 1991; Cunningham and Kempling, 2009). Models can be useful for those evaluating or

studying an organisation as they can help us to view a culture and its component parts more clearly; thus, providing a framework through which we can better discern and understand how an organisation does function. Four broad perspectives of organisational culture are described below, followed by a presentation of key models that influenced this study.

2.3.1 Organisational culture

Anthropological perspectives of a societal or group culture were influential in how culture is viewed today in other contexts, and have been applied to how culture is viewed in organisations (Davies *et al.* 2000). At a similar time to the social science movement towards understanding culture in the 1970's and 1980's, organisational and industrial researchers began to study collective meaning systems and organisational approaches to culture and cultural change (Weber and Dacin, 2011).

There are two broad schools of thought regarding organisational culture: i) culture is an attribute of an organisation, and ii) culture is a metaphor for an organisation (Smircich, 1983; Scott *et al.* 2003; Jung *et al.* 2009). In more detail:

i)   *Culture is an attribute of an organisation:* culture has been described as an attribute which can be controlled or manipulated by those working in that organisation (Davies *et al.* 2000) and which influences the development and reinforcement of employee beliefs (Smircich, 1983; Langfield-Smith, 1995). Davies *et al.* (2000) suggested that "*organisational culture emerges from that which is shared between colleagues in an organisation, including shared beliefs, attitudes, values and norms of behaviour*" (p.112).

ii)   *Culture is a metaphor for an organisation*: this emerged from a relativist perspective in which social interaction forms the culture, in simple terms the organisation 'is' the culture (Scott *et al.* 2003). An organisation's culture expresses the social ideals, beliefs and values shared by that organisation, as opposed to guiding them (Siehl and Martin, 1981). Use of specialised language, traditions, rituals and behaviours are 'tools' which symbolise the beliefs and values of that culture (Smircich, 1983).

Scott *et al.* (2003) suggested that viewing culture as either an attribute or metaphor can have implications for healthcare research and policy. However, critical realism enables understanding of the nature and causes of social processes (Easton, 2010).

In this case study, studying the social processes and structures as attributes of the culture of care in the organisations visited enabled an understanding of their *contribution* to the culture to be described. This study was conducted to generate evidence and recommendations for policy, practice and future research in teenage and young adult cancer care. Viewing culture as a series of observable social processes and structures, facilitated the generation of discernible and measurable recommendations: whether culture is described as what the organisation 'is' or 'has' is irrelevant. It is more important, in terms of making recommendations for policy and practice from our findings about culture, to acknowledge whether culture is static or dynamic in nature.

2.3.2 Static versus dynamic culture

Culture can be viewed as either static or dynamic (Braithwaite *et al.* 2005). A positivist stance is that culture is static and concrete in nature (Kao *et al.* 2004). A static approach to culture means it has concrete qualities, forming a template for social behaviours, i.e. *the* common behaviour standards set by a *social* group (Cialdini and Trost, 1998). Similarly, Kao and colleagues (2004) described the static view as a *"system of rules"* (p. 271) which can be predicted and measured. A weakness of this definition is that it fails to indicate how culture can be controlled or changed. The independent existence of culture proposed in the static perspective suggests that culture is self-determined and self-governed and therefore incapable of influencing the behaviour of those within it (Kao *et al.* 2004).

Other authors have argued that culture should be viewed from a dynamic perspective. Lenburg and colleagues (1995) proposed that culture is dynamic and adaptive in response to the environment, which changes continuously. It includes a system of concepts embodied in symbols taught from one generation to another (Lenburg *et al.* 1995). Alternatively, Kitayama (2002) presented a system view to explain the dynamic nature of culture. The system view proposes that an individual's thought processes shaped their behaviour, prompting them to conform to the practices and norms of those they are surrounded by. This highlighted that the configuration of these processes and behaviours will shift depending on the group, making the culture dynamic (Erez and Gati, 2004).

A strength of the dynamic approach to culture is its application to research where context is important to the culture. When studying culture in healthcare services, the emphasis on culture being adaptive in response to the environment is of particular

importance (Spector, 2000), as processes, structures and environments are constantly changing and evolving, particularly within the NHS (Latney, 2016). Conceptualising culture to include the environmental influence is pertinent to research where context plays a role (Bowling, 2002; Sobo, 2009), such as in this multiple-case study. Furthermore, the recognition that a culture can change as an organisation changes and evolves, can be aligned with a critical realist view. In an exploration of a reality as it currently exists (empirical reality) we can only view that moment in time (Sayer, 2000), it is therefore not possible to predict how a culture was before or how it will be in the future. However, through a critical lens, learnings can be taken from the social processes and structures observed and applied.

This view is not only in keeping with the research paradigm, but has been described to be more aligned to the views of those who have researched organisational culture in UK healthcare (Davies *et al.* 2000), where culture has been discussed as a changeable attribute of the NHS (Department of Health, 2015). An organisation's culture is the learned and shared knowledge and behaviour of the people within, underpinned by their norms, values and beliefs (Sobo and Loustaunau, 2010). Those within a culture strive to share and enforce a set of cultural norms, and these may shift and evolve over time as a result of both internal and external changes to that cultural setting (Sobo and Loustaunau, 2010).

Knowledge about a culture can "*be changed or adapted by its users to fit new conditions"* (Sobo and Loustaunau, 2010, p.2) and this infers the importance of cultural knowledge to influence policy and practice in healthcare. In the NHS, culture is seen to emerge as a summation of several components of an organisation (Davies *et al*. 2000), and while not always predictable and controllable, this does mean that there are situations and variables which can be studied and shared to generate new knowledge and change practice. The components which come together to form a culture are often presented as layers or levels of organisational culture.

2.3.3 Models of organisational culture

Edgar Schein, a social psychologist, has been influential in the organisational culture literature. In the 1980's Schein recognised the necessity to define a concept as complex as culture, particularly due to the increasing popularity of its study in this era. Schein (2010) presented this definition of culture:

"[Organisational culture] is a pattern of shared basic assumptions learned by a group as it solved its problems of external adaptation and internal integration…" (Schein, 2010, p.18)

Schein (1984, 1992, 2010) presented a synthesised, tripartite view in his model of culture (Braithwaite *et al.* 2005), and created clear boundaries between the layers. This subdivision of culture into three layered segments enables them to be studied more closely (Hogan and Coote, 2014); this provides a useful model to facilitate the study of organisational culture in healthcare (Figure 2.1). Schein suggested that a culture is grounded in the pattern of underlying assumptions of those within it: to understand what is happening at a shallower, surface level of a culture, one must explore and interpret the basic underlying assumptions (Schein, 2010). Underlying assumptions are typically unconscious in nature; however, these can have great impact upon the other two more superficial levels of organisational culture: espoused values and artefacts. Moreover, Schein suggested that there is interaction and interplay between the three levels of an organisation's culture (Schein, 2010).
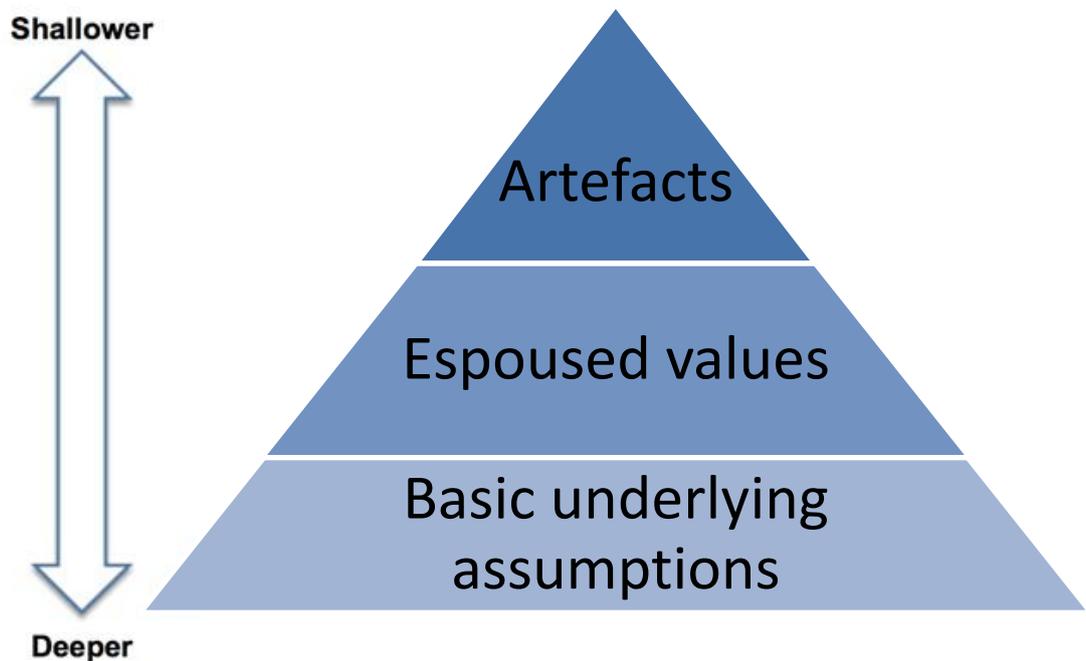
Figure 2.1. The three levels of organisational culture (Schein, 2010).

Alongside the model, Schein (2010) described a 'chain reaction' process: within a culture, underlying basic assumptions become espoused values that will eventually lead to visible, learned behaviour. Positive or negative responses resulting from this

behaviour will alter the values of the group accordingly, thus this value over time becomes taken for granted. This value becomes less and less visible as it is embedded within the culture, eventually becoming an underlying assumption. Schein has also described his model in relation to the visibility of the concepts: the shallowest level encompasses the visible artefacts, and at the deepest level there are the less visible underlying assumptions of a group (Schein, 1992).

Schein advocated a multi-level analysis of organisations using this model (Schein, 2010). This approach to studying culture provides a helpful initial structure for assessing healthcare organisations, yet there are practical challenges with studying such hidden and complex concepts such as shared beliefs and values of colleagues in an organisation. Erez and Gati (2004) interrogated various models of culture and concluded that the majority focussed on either visible, external cultural factors or the values of a culture, just below the surface. They found that few studies scrutinised the deepest, most internal level of culture. One could surmise that this paucity in research is due to the challenge of researching and observing culture at this deepest level. Hudelson (2004) recognised the difficulty of this task and recommended the use of a range of methods, of which ethnography was identified as suited to the study of the deeper values and motivations of an organisation's culture.

Schein (2010) described how it was *"not really possible to describe an entire culture… [it is possible to] begin to identify some of the deep elements"* (p.35). It is therefore essential that this is considered when interpreting collected data: using a critical realist research paradigm marries with this. The notion that all observation is open to error and therefore research captures an empirical reality which may be a snapshot of some of the 'deep elements' of culture. A critical realist epistemology which supports data triangulation through combining multiple data collection methods therefore allows us to gain a greater grasp on the reality of these challenging concepts of culture (Sayer, 2000; Sobo and Loustaunau, 2010).

A strength of Schein's model is that it provides a valuable conceptual framework for analysing processes that drive improvement and innovation within an organisation (Hogan and Coote, 2014). There is a dearth of published, empirical research testing Schein's model. Hogan and Coote (2014) recognised this and applied the model in a study examining the working practices of law firms in Australia. Semi-structured interviews with the organisational directors of six law firms were conducted, and from these findings a scale was developed to measure organisational performance

against Schein's model. This measure was used in a postal survey with a range of stakeholders working in the six organisations, to assess performance in relation to culture.

The results showed that Hogan and Coote (2014) were in support of the concepts and relationships presented in Schein's model; they described Schein's model as a valuable tool to assist in understanding the behaviours which were crucial to the performance of organisations within the law industry (Hogan and Coote, 2014). Hogan and Coote (2014) found similar relationships between the artefacts, norms and values of a culture as those hypothesised by Schein (2010). Their work highlighted the indirect process from deep-seated cultural values to the organisation's outcomes and performance. Moreover, they found that organisational values offered a broad foundation to behaviour, whereas norms could more specifically guide expected behaviours within an organisation. Hogan and Coote (2014) demonstrated the value of the model in measuring and understanding organisational effectiveness within the law industry, however it is important that we recognise the limited applicability of this work to the healthcare settings.

One particular limitation of Hogan and Coote's (2014) work was the participant sample: although large, the sample was 78% male, which reflected the demographics of those working in the law industry. This does not however reflect the demographic working within in the NHS; recently reported as 77% female (NHS Digital, 2017). A culture which is predominantly male is likely to function differently to an organisation where the majority of members are female (Alvesson and Billing, 1992). There are likely to be gender-role differences in the organisational concepts of values, norms and behaviours (Alvesson and Billing, 1992), such as altruism being suggested as a female-typed behaviour (Kidder, 2002). Moreover, a culture focussed around 'clients' as opposed to 'patients' has a different focus and is a further fundamental difference, which lessens the applicability of Hogan and Coote's study (2014) to healthcare settings. The term 'client' depicts payment and suggests a culture of customer service, whereas 'patient' indicates a vocation with caring interactions. However, while there is limited primary research testing Schein's model, healthcare literature has referred to the multiple components of the model (Davies *et al.* 2000). Cultural models which segregate distinct levels of culture have been regarded as both useful and valuable in healthcare organisations (Scott *et al.* 2003; Jung *et al.* 2009).

Examining a health organisation using cultural levels allows differentiation between the range of elements that contribute to the system functioning: the visible artefacts and structures, and the attitudes, values and assumptions of employees (Jung *et al*. 2009; Davies and Mannion, 2013). Davies and Mannion (2013, p.2) documented:

> "Culture operates at three levels:
>
> Level 1: artefacts – The most visible manifestations of culture, including the physical layout of services, established processes of care, staff rotas and reporting arrangements, dress codes, rituals, reward structures, and ceremonies. This would include, for example, normal working patterns, the agenda and processes of board meetings, and the arrangements for handling patient complaints and staff concerns.
>
> Level 2: beliefs and values – Used to justify particular behaviours, provide a rationale for choosing between alternate courses of action and distinguish "right" from wrong. Examples include respect for patient autonomy and dignity and the prevailing views on current individual and collective performance.
>
> Level 3: assumptions – The unspoken, largely unconscious, expectations and presuppositions that underpin day to day work. For example, assumptions about the nature of the caring role, the knowledge and perspectives of patients and relatives, and the relative role and power of doctors, nurses and managers."

This description of the levels of culture is useful to demonstrate the use of the model in relation to healthcare services (Davies and Mannion, 2013). Hudelson (2004) advocated identifying and exploring these levels individually, for example identifying the basic assumptions or shared values of a specific professional group. Moreover, Hudelson (2004) suggested that this could provide insight into the existence of professional subcultures which could be affecting the socio-behavioural dynamics of an organisation's culture.

Other models that help to examine 'culture' do exist. Similar to the multi-level model presented by Schein (2010), an iceberg model has been described to depict both culture in general (Hall, 1976) and organisational culture (Herman, 1970; Cunningham and Kempling, 2009). There are inconsistencies in the anthropological, social science and organisational research literature as to the exact derivation of the iceberg model; in the 1970's it emerged within the anthropological and

organisational research literature simultaneously. In anthropology, Hall's (1976) ideas about culture were presented in his seminal text 'Beyond Culture', and provided rich inquiry into covert culture and the way culture conditions us to perceive the world. These concepts underpinned an iceberg model of culture (Hall, 1976) (Figure 2.2). At a similar time, a social psychologist used an iceberg model to depict organisational culture (Herman, 1970) (Figure 2.3).
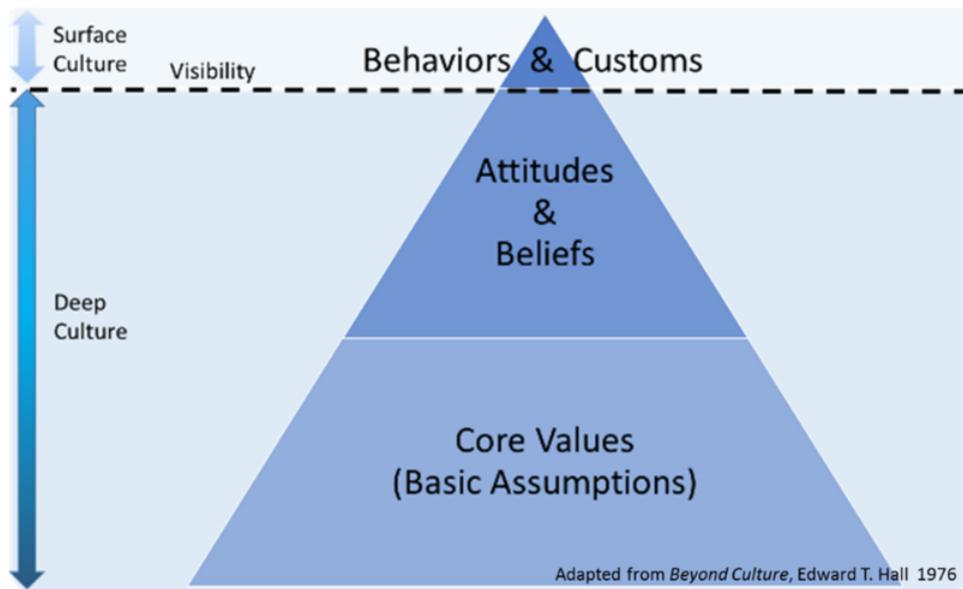
Figure 2.2. Hall's (1976) iceberg model of culture.
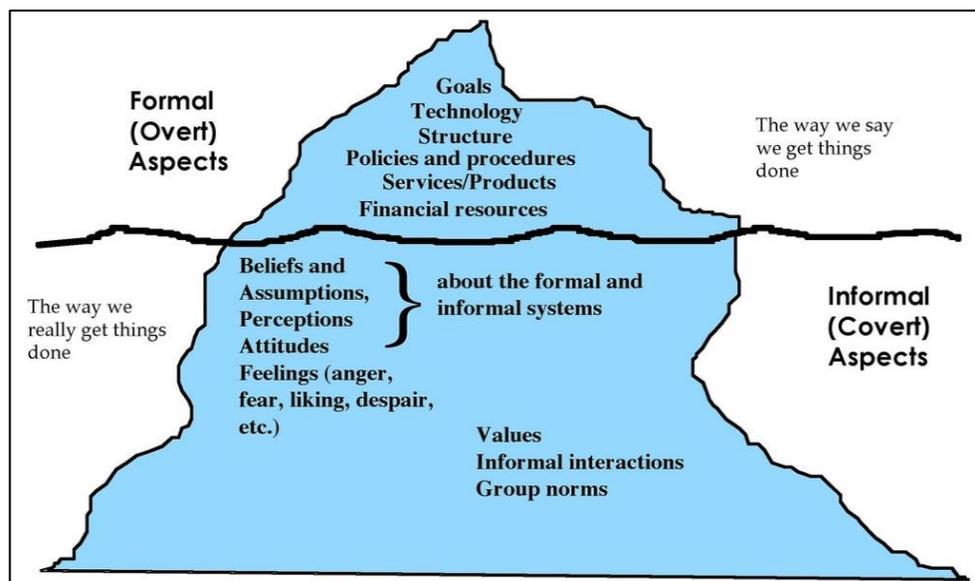
Figure 2.3. Herman's (1970) iceberg model of organisational culture.

The iceberg model divides culture into two overarching levels: i) visible, overt elements which exist 'above the surface' and ii) less visible, deeper elements of a culture hidden 'below the surface' (Hall, 1976). This is represented by the two portions of the iceberg above and below the water. The most hidden third level, the deepest part of the iceberg, represents the values, norms, beliefs and assumptions of those who belong to a culture (Hall, 1976).

Herman's (1970) model suggested that the mass under the water, i.e. the components of the hidden culture, were alike across all organisations (Cunningham and Kempling, 2009). However, Cunningham and Kempling (2009) found that the strength and size of the hidden 'deep' culture varied considerably across the organisations they studied within the public sector: some public services displayed strong cultural values and attitudes, governed by and engrained by long-standing employees. The behaviour and norms of the service were therefore rooted in well-established assumptions, values and attitudes of a particular group (Cunningham and Kempling, 2009). The notion of an iceberg as a model has been used within contemporary literature looking at the culture of businesses and organisations (Hofstede, 1991; Rick, 2014). A strength of the iceberg model is that it encompasses a wide range of social processes and emphasised the multi-faceted construction of culture within an organisation (Weber and Dacin, 2011). This approach to studying organisations has encouraged a more widespread research agenda where models of culture have widened and opened up the multiple ways of looking at an organisation and its component parts (Weber and Dacin, 2011). Moreover, a model such as the iceberg, can assist a researcher in selecting their methodology and epistemology, through which they can unwrap the complexity of a particular culture (Hudelson, 2004; Weber and Dacin, 2011).

The iceberg models (Herman, 1970; Hall, 1976) and Schein's model (2010) both present culture as multi-level. The fundamental principles behind all of the models are the same, and can be applied when studying culture within an organisation: three levels which illustrate the visible and invisible elements of a culture. In a setting such as a hospital, it could be that awareness often extends only to what is visible: the obvious structures and objective processes that can be easily monitored and manipulated. However, it has been recognised that the appreciation of the deeper levels of culture is valuable, drawing attention towards the unseen beliefs, values and assumptions that can drive a health organisation (Davies *et al.* 2000). It

has been suggested that these aspects of an organisation's culture may be more challenging to endorse or change (Davies *et al.* 2000).

The iceberg model is adaptable to its context of application (Rick, 2014; Language and Culture Worldwide, 2015) and therefore can be applied to the exploration of culture within the specific context of this case study. There are other existing models related specifically to corporate culture, however these did not relate to the healthcare context of this case study, for example Hofstede's 'Multi-Focus Model on Organisational Culture' (2017). This was a model to assist organisations to measure effectiveness and create strategies to enhance performance, however this was created as a strategic tool to measure to performance in an organisation, as opposed to facilitate the exploration of a culture (Hofstede, 2017). Existing literature has shown that we are yet to determine the components which create the culture of caring for teenage and young adults, across all of the settings in which young people with cancer are cared for. The performance of an organisation cannot be measured against cultural aspects that are not yet defined or understood, therefore it was more appropriate for this exploratory study to be guided by core concepts of culture as opposed to a measurement tool.

Organisational literature within healthcare has explored the concept of culture within health organisations and communities (Davies *et al.* 2000, Scott *et al.* 2003, Kao *et al.* 2004, Sobo and Loustaunau, 2010). It has been stated that *"effective and humane healthcare demands that we all learn more about culture – what it is, how it functions, and its relevance for our interactions and their outcomes"* (Sobo and Loustaunau, 2010, p.1). Moreover, the importance of the culture of organisations within health and social care settings is a current NHS priority (Department of Health, 2015; King's Fund, 2017). Central to exploring young people's experiences is understanding the culture of the health services in which they are cared for, it is therefore necessary to look specifically at culture within the context of healthcare.

2.4 Culture in healthcare

Cultural paradigms in health and nursing have been influenced by anthropological perspectives (Kao *et al.* 2004). Understanding the social and behavioural dynamics of a health system are fundamental to understanding health culture (Braithwaite *et al.* 2005). Scott *et al.* (2003) undertook a review of literature looking at culture and cultural change programmes in healthcare organisations. They found little agreement over the exact meaning of healthcare culture and opposing claims

whether organisational cultures can be effectively shaped by external forces or variables (Scott *et al.* 2003). In the UK, investigation into service quality, such as the Francis Report (The Stationery Office, 2013), increased media publicity around health services resulting in quality of services and care to be a priority within policy (Jung *et al.* 2009; Davies and Mannion, 2013).

Culture in large healthcare organisations has been described as a 'mosaic' that is rarely uniform (Davies and Mannion, 2013). How culture works in terms of health is more important than us reaching a clear-cut definition (Kao *et al.* 2004). Kao *et al.* (2004) explored how culture was studied in the fields of anthropology and nursing. To amalgamate several definitions from nursing, Kao *et al.* (2004) conceded that *"culture includes a system of concepts embodied in symbols taught from one generation to another"* (p.271) Additionally, Kao *et al.* (2004) recognised the contribution of the environment towards a culture and identified that culture responds and adapts to its environment, which constantly shifts, and that people's behaviour is structured by their interactions with the environment. This mirrored Hall's (1976) view that when studying humankind: *"it is impossible to separate the individual from the environment in which he functions"* (p.100). Establishing therefore an understanding of the environmental context of young people's cancer care was integral to the conduct of this case study. It was important to understand how and whether culture changed depending on the environmental context of care.

Current healthcare services have multiple settings, e.g. clinics, hospitals, rehabilitation units, day centres, primary health centres and patient homes. These numerous environments of care add complexity to the system for both providers and users, therefore understanding this complexity is essential to improving care quality (Latney, 2016). Additionally, increasing this complexity yet further, health services consist of various structures, processes, inputs, outputs and outcomes (Bowling, 2002). Health services research therefore, is partially comprised of analysis of these 'tangible' components of an organisation (Sobo, 2009; Bowling, 2002). These components are represented in the external, visible layer of the iceberg model of organisational culture (Herman, 1970; Hall, 1976). Conversely, workplace culture has been described as being 'invisible', only becoming visible through the processes, conversations and relationships that exist within it (Egener *et al.* 2017). Such aspects of culture are recognised as harder to research (Bowling, 2002), and it has been suggested that the gathering of rich, qualitative data through interviews

and observations is important to obtain insight into the values and attitudes of healthcare professionals (Callen *et al.* 2009).

There have been empirical studies examining these components of organisational culture in relation to organisational performance in healthcare (Jacobs *et al.* 2013); organisational culture and health outcomes (Braithwaite *et al.* 2016); and staff wellbeing and patient experience (Maben, 2013). Yet there is a lack of research however which links the 'less visible' aspects of culture in specific healthcare contexts to the experience and perspectives of those within it: a systematic review of the literature advocated for more rigorous research to be conducted linking the effect of healthcare organisational culture directly to patients (Braithwaite *et al.* 2016). Within clinical environments, a positive culture has been described to be empowering for healthcare professionals, moreover it can affect the way in which patients are cared for (Egener *et al.* 2017); and for this reason, it is essential it is understood and explored.

In health services, it is accepted that culture is connected to organisational effectiveness (Scott *et al.* 2003; Kings Fund, 2017). Recently, the King's Fund (2018) reported six characteristics of a 'healthy culture', as a tool to assist health organisations within the NHS to assess their culture. A weakness of the work was a lack of clarity regarding the methodology and research process. The King's Fund (2018) presented this work as a collection of online reports, articles and blogs, as part of a series of smaller projects which were collated. An example of one of the reports that fed into this was 'Exploring CQC's (Care Quality Commission) well-led domain: How can boards ensure a positive organisational culture?' (King's Fund, 2014). This was a practical guide, which drew on examples of good leadership, to assist hospital boards in creating a culture that was well-led (King's Fund, 2014).

The importance of leadership in the creation of a culture within health services was recognised in other work by the King's Fund (2018), as part of six characteristics of a healthy culture:

1. Inspiring vision and values;
2. Goals and performance;
3. Support and compassion;
4. Learning and innovation;
5. Effective teamwork;
6. Collective leadership.

The concepts presented by the King's Fund (2018) around a healthy culture are of value when studying culture in health services and are corroborated by their overlap with the existing literature presented earlier in this chapter. The term culture has been used to signify the shared experiences and perspectives that form around a place or phenomenon, descending from the first-hand experiences of those relating to that place or phenomenon (Kelly, 2008). This case study research drew on the first-hand experiences of patients and professionals to explore the shared experiences and perspectives of care. The six characteristics of a healthy culture (King's Fund, 2017) assisted the researcher to understand the key concepts to consider interpreting the first-hand experiences of those either receiving or providing young people's cancer care.

Marshall *et al.* (2002) undertook a qualitative case study which explored the importance of culture in relation to clinical governance in primary care services. Fifty senior managers took part in semi-structured interviews. Among the responses in these fifty interviews, no clear definition of culture was suggested. Nonetheless, the concepts of the right mind-set, beliefs, norms and values all emerged in the interviews, corresponding with existing definitions and theories about culture. In line with the characteristics of a healthy culture advocated by the King's Fund (2018), Marshall *et al.* (2002) discovered the concept of 'team climate' as important to organisational culture and emphasised multi-professional team work. Marshall *et al.'s* (2002) study only interviewed senior managers and therefore failed to capture the voices and perspectives of other members of the organisations, which could have given an incomplete or skewed picture of the culture of those organisations. Marshall *et al.* (2002) highlighted the importance of including a wide range of voices and experiences when researching a culture to gain a comprehensive and multi-faceted perspective.

2.5 Summary

This chapter has highlighted that there are a variety of approaches to defining culture. The literature has demonstrated the complex, multi-faceted and multi-level nature of culture; making it not easy to define, explain or research. Through consolidating the definitions, concepts, models and critical thought presented in this chapter, three core concepts about culture were applied and resulted in the conceptual framework which guided the conduct of this case study:

1. Culture takes place within a context, and is therefore dynamic and changeable (Lenburg *et al.* 1995; Kitayama, 2002; Erez and Gati, 2004).
2. Culture consists of both visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).
3. Culture is something that is learned, shared and perpetuated through effective teamwork and leadership (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; King's Fund, 2017).

There is no identifiable model of culture that has been validated and tested within the health organisation research field. Thus, these three core concepts about culture shaped the approach to researching culture used in this multiple-case study. In particular, this exploration of the culture of young people's cancer care was conducted using a multi-layered lens: what is above the surface and below the surface. The notion, presented in the iceberg model, of looking 'above the surface' and 'below the surface' was used to develop, frame and present the research findings. Additionally, the three core concepts summarising culture guided the narrative review of the literature, which forms the content of the next chapter.

Chapter 3

Narrative literature review of the culture of teenage and young adult cancer care in the UK

3.1 Introduction

This chapter reviews what is already understood and documented in the literature about the culture of teenage and young adult cancer care in the UK; specifically, in relation to the core elements of organisational culture which were presented in Chapter 2. The network structure of secondary and tertiary teenage and young adult cancer care in England was detailed in Chapter 1; this illustrated the complexity of services, comprised of numerous environments of care, and understanding this complexity was essential to understanding the culture and quality of care (Latney, 2016).

Within teenage and young adult cancer care settings there are various structures, processes, inputs, outputs and outcomes and health services research seeks to understand these components of an organisation (Sobo, 2009; Bowling, 2014). However, it is too simplistic to assert that multiple health organisations would have a homogenous culture, although some cultural characteristics may be shared (Callen *et al.* 2009). The aim therefore of this narrative review was to explore existing research to understand the known cultural characteristics specific to delivering care to this population, across the variety of settings in which they may receive care. The conceptual framework, which consisted of three core concepts of organisational culture presented in Chapter 2 guided this narrative review, and informed the review query and search strategy used. These were:

1. Culture takes place within a context and environment, and is therefore dynamic and changeable (Kitayama, 2002; Erez and Gati, 2004; Sobo, 2009).
2. Culture consists of both visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 1992; Rick, 2014).

3. Culture is shared and transmitted through learning and teamwork (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; King's Fund, 2017).

A systematic approach was used to search for primary research on the topic. A narrative review method was employed (Ferrari, 2015). This is a method for identifying and summarising existing published research, highlighting new areas not addressed in current evidence. The synthesis of the review findings is presented and encompasses the overarching themes related to the culture of teenage and young adult cancer care.

3.2 Methods

The aim of this review was to identify what patient and professional experience tells us about the culture of teenage and young adult cancer care in the UK. It was important to acknowledge that the culture of care would impact on patient and professional experience. Patient experience has been defined as *"the sum of all interactions, shaped by an organisation's culture that influence patient perceptions across the continuum of care"* (Wolf *et al.* 2017, p. 5). Literature reporting patient and professional experience were therefore sought; embodying significant and relevant detail about the culture and delivery of care which were important to this review. A systematic approach was taken to facilitate fair interpretation and translation of existing published research (Ferrari, 2015).

3.2.1 Search strategy

The Cochrane Library was searched initially to establish the absence of a pre-existing review of this topic. Five key online literature databases were searched, covering the fields of nursing, medicine, allied health and social science literature: CINAHL Complete (Cumulative Index to Nursing and Allied Health Literature), Child Development and Adolescent Studies, MEDLINE, PsycINFO and ASSIA (Applied Social Science Index and Abstracts).

The research question was deconstructed into components, and synonyms were ascertained for each word. The following terms were used to conduct the literature search: "cancer" and "adolescent" (and all appropriate synonyms) combined with "culture of care". Following this, "cancer" and "adolescent" (and all appropriate synonyms) were combined with words extracted from the three core learnings about culture (presented in Chapter 2) ("goals", "processes", "structures", "knowledge",

"behaviours", "values", "norms", "basic assumptions", "teaching", "learning", "teamwork", "context", "environment").

Studies were eligible for inclusion in the review if they fulfilled the following inclusion criteria:

1. Published from 1995 to October 2017 [1995: when the first UK Government report (DoH, 1995) recommending health services address the unique needs of young people was published].
2. Based in the UK/Ireland [due to the global variance in the delivery of health services (WHO, 2018a)].
3. Empirical research.
4. Research which included young people with cancer aged 13 to 24 years [to correspond with the widest accepted age range for the teenage and young adult cancer population in UK/Ireland (Ferrari *et al.*, 2016)].

Studies were excluded if:

1. Non-UK/Ireland studies.
2. Policy, service guidance, grey literature, opinion pieces, discussion papers, editorials.
3. Studies without extractable findings specific to young people's cancer care [i.e. dominant focus on child or adult cancer care].
4. Studies focussed on a single specific treatment, service intervention or small subgroup of the population, e.g. provision of a specific fertility service.

Titles and abstracts of papers were screened and to enhance the electronic searches, reference lists were manually searched for additional relevant papers. Full text articles of potentially relevant studies were obtained and information from each study was extracted into an Excel database to ensure similar characteristics of each study were being compared (Centre for Reviews and Dissemination, 2009).

3.2.2 Quality assessment

The dominant yield of the search were qualitative empirical studies (n=13), alongside a small number of studies which used surveys/questionnaires to collect quantitative descriptive data (n=6). Qualitative empirical studies were critiqued using the CASP (Critical Appraisal Skills Programme (CASP), 2017) qualitative checklist tool. For the six papers which used surveys/questionnaires, a 10 question 'Critical

Appraisal of a Survey' tool was used to guide quality assessment (Centre for Evidence-based Management (CEBMA), 2017).

Both 'tools' assisted the quality assessment process of the methods and reporting of the studies identified in the search to determine their suitability for inclusion in the review. Studies were classed as 'Level 1', 'Level 2' or 'Level 3' based on their percentage of fulfilment of the listed items of the critical assessment criteria applied (CASP, 2017; CEBMA, 2014): 'Level 1' was the best quality evidence at ≥80% of criteria fulfilled; 'Level 2' was 50-79% and 'Level 3' was <50% of criteria fulfilled.

3.2.3 Synthesis strategy

Thematic synthesis was employed to allow a structured and systematic approach to the organisation, analysis and synthesis of the literature (Green *et al.* 2001; Dixon-Woods *et al.* 2005). Moreover, thematic synthesis enabled both qualitative and survey data to be brought together coherently (Snilstveit *et al.* 2012), suiting the literature yield of this review. Included papers were printed and read in their entirety; notes and annotations of key messages about the care experiences and care culture were made. The literature was coded to identify the emergent themes, and an Excel spreadsheet corresponding to these themes was used to assist synthesis across papers, and to clarify and organise the information extracted from the literature (Green *et al.* 2001).

3.3 Results

3.3.1 Search outcome

A total of 1366 studies were identified. Duplicates were removed, titles and abstracts were screened, and reference lists were searched manually for identification of any missing and potentially relevant studies. A total of 18 studies (19 papers) were included in the review (Figure 3.1), illustrated according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses, also known as the 'PRISMA' guidelines (Shamseer *et al.* 2015). Two of the included papers (Mulhall *et al.* 2004; Kelly *et al.* 2004) reported on the same study; these were both included in the review as they reported different aspects of the study findings and both related to the culture of care.

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┌─────────────────────────────────────┐
│ Records identified through database  │
│ searching and pre-identified through │
│ prior knowledge                      │
│ n = 1366                             │
└─────────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────────┐
│ Exclude after title review and       │
│ duplicates removed                    │
│ n = 1315                             │
└─────────────────────────────────────┘
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              n = 51
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┌─────────────────────────────────────┐
│ Exclude after abstract review        │
│ n = 19                               │
└─────────────────────────────────────┘
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              n = 32
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┌────────────┐   ┌──────────────────┐   ┌──────────────────────────────┐
│ Records    │   │ Full articles    │   │ Reasons for exclusion        │
│ identified │──▶│ reviewed for     │──▶│ • Not empirical research = 3 │
│ through    │   │ eligibility      │   │ • Non-UK research = 2        │
│ hand-      │   │ n = 34           │   │ • Emphasis not on 13-24      │
│ searching  │   │                  │   │   years = 3                  │
│ reference  │   └──────────────────┘   │ • No focus related to the    │
│ lists      │          │               │   culture of care = 7        │
│ n = 2      │          ▼               └──────────────────────────────┘
└────────────┘   ┌──────────────────┐
                 │ Papers included  │
                 │ in review        │
                 │ n = 19           │
                 └──────────────────┘
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Figure 3.1. Flow chart of search strategy and outcome.

3.3.2 Study details and quality

The 18 included studies (19 publications) were published from 2003 to 2017. An overview of the aims, design, quality and themes identified in the studies included in the review are summarised in Table 3.1. Five studies used surveys/questionnaires, 15 used a variety of qualitative methods, and one study used both quantitative and qualitative methods. Populations studied included young people only (n=7), young people and parents (n=2), young people and healthcare professionals (n=3), young people, parents and healthcare professionals (n=3), healthcare professionals only (n=2) and one study reported from the perspective of the 'whole service' (Table 3.1). These studies represented the perceptions of 843 young people, 50 parents and 168 healthcare professionals (ranging from 10-271 per study).

The majority of the published research identified was of high to moderate quality (Levels 1 and 2 respectively), with only two studies rated as low quality (Level 3). The two studies rated poorer in quality, using a service evaluation style (Level 3)

were both included as they offered unique insights which were regarded as important to this review: both reported on distinct aspects of young people's cancer care, including education mentoring (Pini, 2009), and the implementation of new nursing processes and their effect on the workforce (Knott *et al.* 2013). The themes that were identified in each paper are listed to highlight their prevalence and strength (Table 3.1).

Table 3.1. Overview of the aims, design and quality of the studies included in the review.

Author and year	Study aim	Sample	Location	Design/methods	Themes identified	Quality assessment[1]
Wilkinson, 2003	To assess the views and attitudes of young people with cancer, parents, healthy peers and professionals involved in treating them.	Young people (aged 15-20 years) (n=14)	One major cancer centre	Qualitative data collected using focus groups and patient interviews.	Environment; peer support; medical expertise; young-person centred and holistic care.	Level 2
Kelly et al. 2004 & Mulhall et al. 2004 (One study, reported in 2 papers)	To describe the culture of a specialist adolescent cancer unit. The study sought to explore the experiences of those being cared for/working on the unit.	Young people (aged 13-20 years) (n=10) Parents (n=10) Healthcare professionals (range of roles) (n=14)	One adolescent cancer unit of an inner city hospital	Ethnographic approach using in-depth interviews with patients, parents and professionals, and non-participant observation on the cancer unit.	Environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1
Mitchell et al. 2006	To discover the perspectives of parents, children and young people about the psychological and social support they received at different stages of their cancer diagnosis and treatment.	Young people (aged 13-19 years) (n= 75). Parents (n=82)	Seven UK treatment centres representing a range of northern/southern, ethnic, urban/rural contexts for data collection.	Postal survey sent out by the seven participating treatment centres.	Environment; peer support; professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 2
Smith et al. 2007	To engage with a large group of young people to explore their experience of services and aspects of services they wanted to see change.	Young people (aged 14-24 years, over 50% had received their care on a children's ward) (n=271)	The 3rd "Find Your Sense of Tumour" conference, 2004	Multiple choice questions were asked in a series of short sessions throughout the conference, answered via an electronic handset.	Peer support; professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 2

Table 3.1. Overview of the aims, design and quality of the studies included in the review (continued).

Author and year	Study aim	Sample	Location	Design/methods	Themes identified	Quality assessment[1]
Grinyer, 2009	To compare and contrast the issues raised about their experiences, from both young people diagnosed with cancer and parents of young people with cancer.	Young people (n=30) Parents (an existing qualitative data which included narrative parental accounts) (n=28)	Young people were interviewed on a specialist, age-specific ward (n=12), a non-specialist ward (n=12) and for others place of care was not stated (n=4)	Comparative analysis, using a narrative correspondence method, using two qualitative, narrative data sets.	Environment; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 2
Morgan, 2009	To explore the experiences of young people who were shown their cancer samples through a microscope to assist their understanding of their illness and treatment.	Young people (aged 13-24 years) (n=27)	One Principal Treatment Centre in the north of England.	Questionnaires were completed by consented participants at three time points before and after they viewed their cancer samples about the experience and its impact.	Young-person centred and holistic care; communication, information delivery and patient choice.	Level 2
Pini, 2009	An evaluation of education mentoring for young people with cancer.	Young people (n=29) Healthcare professionals (n=10)	A teenage and young adult Principal Treatment Centre in one hospital teaching trust	Postal questionnaire was sent to 75 teenage and young adult patients and 10 staff members	Professional roles, attitudes and team working; communication, information delivery and patient choice.	Level 3
Gibson et al. 2010	To distinguish the experiences of children and young people, particularly in regards to communication, across a wide range of ages using innovative methods.	Young people (aged 13-19 years) (n=11)	Three Principal Treatment Centres in the UK	Qualitative methods consisting of peer interviews, group discussion, and a written task. Individual interviews were undertaken both in hospital and at home.	Environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1

Table 3.1. Overview of the aims, design and quality of the studies included in the review (continued).

Author and year	Study aim	Sample	Location	Design/methods	Themes identified	Quality assessment[1]
Taylor et al. 2011	To identify and compare the key components of a specialist teenage and young adult cancer unit from the perspectives of young people and professionals.	Young people (n=75) Healthcare professionals (n=22)	Workshops were held across two locations in England, and the national patient conference was held in England also.	Three workshops were held, one with young people and two with healthcare professionals. Electronic survey with young people at an annual patient conference.	Environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1
Gibson et al. 2012	To scope and define the preferred competencies of professionals involved in teenage and young adult cancer care.	Young people (n=22) Healthcare professionals (range of roles)(n=80)	Central, non-NHS locations, with professionals joining from 10 hospitals across England.	Two workshops with healthcare professionals, one education day with professionals, using interactive methods: two ranking exercises, and a group discussion.	Professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1
Fern et al. 2013	To reflect on a conceptual model of the cancer experience for young people, providing greater insight to young people's experience of cancer and the care they received.	Young people (aged 13-25 years) (n=11)	England (recruited online)	Qualitative study based on participatory methods, using semi-structured peer-to-peer interviews	Environment; peer support; professional roles, attitudes and team working; communication, information delivery and patient choice.	Level 1
Knott et al. 2013	To evaluate the methods used to introduce a self-monitoring process for young people's cancer treatment in a teenage and young adult cancer ward.	The service as a whole	A cancer service for teenagers and young adults (13-24 years) in the UK	Critical reflection was used to evaluate the implementation of the self-monitoring proves, to facilitate learning, leadership and practice development.	Professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 3

Table 3.1. Overview of the aims, design and quality of the studies included in the review (continued).

Author and year	Study aim	Sample	Location	Design/methods	Themes identified	Quality assessment[1]
Coyne et al. 2014	To discover to what extent children's participation in shared decision making is supported and promoted in practice and its influence.	Young people (aged 13-16 years) (n=8)	A paediatric haematology-oncology inpatient unit and day care unit in a children's hospital in Ireland	Audio-recorded, open-ended, flexible individual interviews, structured around six topic areas related to shared decision making.	Medical expertise; communication, information delivery and patient choice.	Level 1
Darby et al. 2014	To identify the spiritual and religious needs of young people with cancer and to explore the implications for enhancing patient care.	Young people (aged 11-16 years) (n=9) Parents (n=7) Healthcare professionals (n=8)	One oncology department at a large children's hospital	Phenomenological study, using semi-structured interviews with young people and separate interviews with their parents. Additionally, focus groups were conducted with professionals from the ward.	Environment; peer support; professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 2
Taylor et al. 2016a	To elicit young people's views about accessing and participating in cancer research.	Young people (aged 18-25 years) (n=230)	Workshop held at a non-clinical office facility and survey was conducted at a patient conference.	Participatory, qualitative methods were employed at a workshop, which involved creative methods. A subsequent survey was conducted.	Professional roles, attitudes and team working; communication, information delivery and patient choice.	Level 1
Vindrola-Padros et al. 2016	To identify the key components of teenage and young adult cancer care and services in England.	Young people (aged 13-24 years) (n=21) Parents (n=15) Healthcare professionals (range of roles) (n=34)	11 Principal Treatment Centres in England	Qualitative methods, including semi-structured, open ended interviews, collection of documentation, and non-participant observation.	Environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1

Table 3.1. Overview of the aims, design and quality of the studies included in the review (continued).

Author and year	Study aim	Sample	Location	Design/methods	Themes identified	Quality assessment[1]
Day et al. 2017	To investigate healthcare professional views of involving adolescents with leukaemia in decision-making about their treatment.	Health professionals (multi-disciplinary teenage and young adult haematology team) (n= 89)	One inner-city UK tertiary referral centre	Semi-structured interviews, informal conversations, and observations of multi-disciplinary team meetings	Professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 2
Pugh et al. 2017	To explore the awareness of lifestyle advice and views of healthcare professionals working with young people with cancer on the delivery of information about lifestyle to patients.	Health professionals (n= 114)	UK-wide (recruited via online mechanisms including promotion through charitable organisations)	Anonymous online survey	Peer support; professional roles, attitudes and team working; young-person centred and holistic care; communication, information delivery and patient choice.	Level 1

[1] Scored as a percentage fulfilling the 10 items of the critical assessment tool criteria (CASP and/or CEBMA): Level 1=>80%; Level 2= 50-79%; Level 3= <50%.

Principal Treatment Centre: Principal Treatment Centre; UK: United Kingdom

3.4 Assimilation of study results

The analysis of the 19 papers revealed six overarching themes: 1) environment; 2) peer support; 3) professional roles, attitudes and team working; 4) medical expertise; 5) young-person centred and holistic care; 6) communication, information delivery and patient choice. The themes identified in each of the included papers were listed in Table 3.1.

3.4.1 Environment

Ten studies highlighted the importance of the environment. The environment contributed considerably to the culture of care, with specialist environments for young people providing a dynamic, positive, friendly and relaxed atmosphere (Kelly *et al.* 2004; Mulhall *et al.* 2004; Vindrola-Padros *et al.* 2016). The provision of dedicated physical space has been found to be a core element of specialist care for young people with cancer (Taylor *et al.* 2011). Distracting activities were highly valued and central to providing an age-appropriate environment of care (Gibson *et al.* 2010; Fern *et al.* 2013; Darby *et al.* 2014; Vindrola-Padros *et al.* 2016), making a culture where having fun was important (Vindrola-Padros *et al.* 2016). In particular, essential elements of the environment were: music (Mulhall *et al.* 2004); the Internet (Vindrola-Padros *et al.* 2016); and additional spaces for young people to spend time when they were in the hospital, such as the kitchen and activity room (Gibson *et al.* 2010; Mitchell *et al.* 2006; Taylor *et al.* 2011). An essential element of the ward was to have provisions in place to facilitate family and friends to stay overnight on the ward with the young person (Taylor *et al.* 2011).

Described were specialist environments for young people, with dedicated social space bring young people together (Gibson *et al.* 2010; Taylor *et al.* 2011) and give a sense of community and connectedness (Kelly *et al.* 2004; Mulhall *et al.* 2004, Darby *et al.* 2014). Moreover, this has been linked with providing young people with a sense of normality (Grinyer, 2009; Vindrola-Padros *et al.* 2016), which was also shown to positively influence young people's well-being (Darby *et al.* 2014). Both adult and child-centred care environments were not deemed to be 'age-appropriate' for young people (Smith *et al.* 2007; Grinyer, 2009), and young people who experienced treatment on a children's ward felt the environment did not meet their needs (Mitchell *et al.* 2006).

Achieving the 'perfect' physical environment for young people was not without its challenges. The perspectives of healthcare professionals, young people and their families may be different; what families viewed as a close-knit and intimate environment, healthcare professionals felt to be cramped (Mulhall *et al.* 2004). It was challenging to provide décor, space and facilities that suited all young people's needs and preferences across this age spectrum, spanning from early teens to young adulthood (Fern *et al.* 2013)

Authors reported tension between young people's desire for privacy and the enforcement of treatment-related isolation (Gibson *et al.* 2010; Darby *et al.* 2014). Although young people wanted privacy, extended periods of enforced isolation led to loneliness (Darby *et al.* 2014). It was noted that privacy needs change in line with a young person's state of illness (Mulhall *et al.* 2004). It was important to young people that the environment was easily accessible to their family and friends (Wilkinson, 2003). It has been acknowledged that shared care environments were important for young people and their families, reducing the distances travelled for treatment and providing valuable opportunity for young people to continue their education (Wilkinson, 2003).

3.4.2 Peer support

Twelve studies suggested that young people benefited from contact with other young people throughout their cancer treatment. Young people wanted to be around other young people who were of the same age as them (Wilkinson, 2003; Smith *et al.* 2007) and who understood what they were going through (Kelly *et al.* 2004; Mulhall *et al.* 2004; Knott *et al.* 2013). Moreover, connecting with young people living beyond cancer was reported as a helpful experience for young people (Taylor *et al.* 2011; Fern *et al.* 2013).

Young people did not just talk about receiving peer support; the act of providing support to other young people was described as pleasurable (Darby *et al.* 2014). Furthermore, it was important that young people could still access and maintain their existing friendships (Wilkinson, 2003; Mitchell *et al.* 2006; Gibson *et al.* 2010). Professionals were described to have an important role to play within this process, promoting peer connections and social interactions between young people (Vindrola-Padros *et al.* 2016; Pugh *et al.* 2017).

3.4.3 Professional roles, attitudes and team working

The roles, attitudes and approach of professionals looking after young people were pivotal to the culture of care, reported in fifteen studies, and research showed they established the tone and atmosphere of a service (Kelly *et al.* 2004; Mulhall *et al.* 2004; Taylor *et al.* 2011). Staff attitude was an important part of the tone (Smith *et al.* 2007; Gibson *et al.* 2012), described on dedicated adolescent cancer units to be relaxed and friendly, yet professional (Kelly *et al.* 2004; Mulhall *et al.* 2004). Young people wanted to be looked after by healthcare professionals who were kind, supportive and good listeners (Gibson *et al.* 2012; Vindrola-Padros *et al.* 2016). The manner and tone set by professionals was shown to have a powerful impact on the overall culture and philosophy of care on a ward (Kelly *et al.* 2004; Taylor *et al.* 2011; Knott *et al.* 2013).

The literature discussed a range of professional roles caring for young people, which together contributed to meeting the specialist needs of this age group (Mitchell *et al.* 2006; Darby *et al.* 2014; Vindrola-Padros *et al.* 2016). Nurses were described as vital in enabling young people to be given choice regarding their care (Smith *et al.* 2007; Coyne *et al.* 2014). Young people felt they had varying relationships with different members of the multi-disciplinary team. They expressed that they felt more trust towards clinically trained professionals to discuss treatment-related decisions such as clinical research (Taylor *et al.* 2016a), and felt more comfortable discussing other types of non-clinical research with social workers and youth support workers. This confirmed that young people perceived their relationship with different healthcare professionals in distinct ways, advocating a multi-disciplinary, inter-professional and holistic approach to caring for young people (Pini, 2009; Knott *et al.* 2013; Day *et al.* 2017; Pugh *et al.* 2017).

Team working was an integral aspect of the culture of caring for young people with cancer (Kelly *et al.* 2004; Mulhall *et al.* 2004; Pini, 2009; Knott *et al.* 2013; Vindrola-Padros *et al.* 2016). A team approach where there was a mutual sense of support among professionals which positively impacted care delivery (Mulhall *et al.* 2004; Vindrola-Padros *et al.* 2016). In addition to fulfilling their specific roles, professionals also needed time for reflection and for professional development (Knott *et al.* 2013). Moreover, ongoing learning and professional development was not only at an individual level, but shared and embedded as part of a dedicated team philosophy and culture (Mulhall *et al.* 2004; Knott *et al.* 2013). Team culture was firmly rooted in historical processes and philosophies of working; which needed to be firmly

challenged if system, service or culture changes were to be implemented (Knott *et al.* 2013).

3.4.4 Young person-centred and holistic care

The importance of healthcare professionals understanding of how to work specifically with young people and to care for their individual needs was identified in fifteen studies. Central to the delivery of care for young people was the building of trust through supportive, open and honest communication (Kelly *et al.* 2004; Mulhall *et al.* 2004; Mitchell *et al.* 2006; Morgan, 2009; Gibson *et al.* 2010; Gibson *et al.* 2012; Day *et al.* 2017; Pugh *et al.* 2017). Young people wanted healthcare professionals who they could confide in (Gibson *et al.* 2010) and reported wanting their holistic and psychosocial care to be as high-quality as their medical care (Grinyer, 2009; Fern *et al.* 2013). Psychosocial care has also been recognised as a priority by healthcare professionals caring for young people (Taylor *et al.* 2011).

Young people wanted healthcare professionals looking after them to take their time to build rapport and relationships with them (Gibson *et al.* 2012; Knott *et al.* 2013; Vindrola-Padros *et al.* 2016). Having a passion to work with young people was reported as a favourable attitude of healthcare professionals caring for young people (Gibson *et al.* 2012). They wanted a young-person-centric approach to communicating with healthcare professionals about their care (Gibson *et al.* 2010), similarly the more well-known models of person-centred care (Gibson *et al.* 2010; Vindrola-Padros *et al.* 2016) and person-centred care (Gibson *et al.* 2012; Knott *et al.* 2013) have been advocated with this patient group.

Healthcare professionals needed to encourage young people's participation in distracting activities, advocated to alleviate some of the boredom experienced during hospitalisation (Smith *et al.* 2007). Moreover, the provision of specialist roles, such as a 'Learning Mentor,' offered an alternative perspective of a young person going through cancer treatment (Pini, 2009). Such professionals reinforced the importance of young people's continued engagement with school or higher education (Wilkinson, 2003; Pini, 2009), and assisted education of other members of the MDT about such holistic issues (Pini, 2009).

Restricted time was a barrier to professionals providing young-person centred care, and professionals desired more time to connect with patients and families (Darby *et al.* 2014). When time was invested in this, it was recognised and valued by young people and their families (Vindrola-Padros *et al.* 2016).

3.4.5 Medical expertise

In addition to the passion and knowledge to work with this specific population, ten studies found having medical expertise for dealing with the treatments and clinical issues common to this patient group as a key part of care. Specialist teenage cancer units have been deemed 'centres of expertise' in treating cancers common in young people (Wilkinson, 2003; Grinyer, 2009; Taylor *et al.* 2011). Clinical expertise has been acknowledged to be of high importance to patients and their parents (Mulhall *et al.* 2004; Gibson *et al.* 2010; Gibson *et al.* 2012), building young people's trust in those caring for them (Coyne *et al.* 2014). Young people perceived the treatment delivered in a specialist teenage cancer ward to be of the highest level available, where professionals have a shared recognition of how to best provide care to young people (Wilkinson, 2003; Kelly *et al.* 2004; Mulhall *et al.* 2004; Vindrola-Padros *et al.* 2016).

Linked to this, young people have frequently shared poor experiences of their journey to diagnosis and experiences of receiving their diagnosis (Wilkinson, 2003; Smith *et al.* 2007; Fern *et al.* 2013). Poor experiences of care at this stage can have a profound impact on young people's early experiences of a complex health system (Fern *et al.* 2013), and has been shown to lead to resentment towards healthcare professionals involved in the diagnostic stages of their care (Wilkinson, 2003). However, if medical processes, care and related information were delivered effectively and appropriately during the early diagnostic phase, this created a level of trust in the expertise of a young person's healthcare team (Fern *et al.* 2013).

3.4.6 Communication, information delivery and patient choice

Communication, information delivery and patient choice were themes identified in eighteen of the included studies. Professionals caring for young people with cancer were seen to be an educator (Darby *et al.* 2014), providing young people and their families with information. Timing and delivery of information was found to be an important aspect of caring for young people (Grinyer, 2009; Fern *et al.* 2013), as was the accuracy of the information (Mulhall *et al.* 2004). Part of the culture of caring for young people was a belief in empowerment through partnership working (Gibson *et al.* 2012; Knott *et al.* 2013; Darby *et al.* 2014). Young people embraced opportunities to learn more about their disease, and many were eager for information (Morgan, 2009). Provision of accurate and timely information assisted the involvement of young people in decisions about their care and treatment

(Grinyer, 2009; Coyne *et al.* 2014). This led to the empowerment of young people and therefore linked to the notion of young person-centred care (Gibson *et al.* 2012). Young people aged 12-18 years indicated that they wanted to be involved in choices about their care but not have sole responsibility (Coyne *et al.* 2014).

Young people's information needs differed due to several factors. Their needs varied across the cancer timeline, requiring different information at each stage of treatment (Fern *et al.* 2013). Professionals expressed that information about lifestyle and staying healthy would be best provided for young people who are on treatment (Pugh *et al.* 2017). Furthermore, young people's information needs could also differ with age (Fern *et al.* 2013; Coyne *et al.* 2014) and personality (Morgan, 2009). For this reason, information provision was recommended to be tailored to suit young people on an individual basis (Morgan, 2009).

The level of information provided and involvement in decision-making has also been found to vary according to the young person's state of illness (Morgan, 2009; Gibson *et al.* 2010; Fern *et al.* 2013). Professionals, parents and carers have been reported to display sensitivity towards the fluctuations in young people's wellness/illness state (Morgan, 2009; Gibson *et al.* 2012; Coyne *et al.* 2014). While sensitivity to a young person's needs within their state of wellness/illness can be viewed as a positive approach, it may also be a barrier to involving young people in their care. Research has described how professionals can feel compelled to 'protect' young people when they felt particularly unwell, viewing them as vulnerable, and thus creating a barrier to empowering young people to be involved in their care (Knott *et al.* 2013; Taylor *et al.* 2016a; Pugh *et al.* 2017). Nonetheless, it has been suggested that when acutely unwell, young people were less likely to want to be involved in shared decision-making and would choose to depend more on their parents or carers (Coyne *et al.* 2014).

Similarly, the perception that patients are vulnerable was suggested to be a barrier to nurses recruiting young people into clinical research (Taylor *et al.* 2016a). One study reported a matriarchal attitude of the nursing staff, where nurses were reluctant to support patients to self-care and nurses considered specialised and age-appropriate care to include the provision of all technical aspects of care for patients and families (Knott *et al.* 2013). Sensitivity to patients and families has been suggested as the best approach to deal with the individual anxieties and vulnerabilities of young people and their families (Grinyer, 2009). This aligns with a young-person centred and individualised approach to delivering care.

It has been recognised that there is poor provision of certain types of information for young people with cancer including: information specifically around fertility (Mitchell *et al.* 2006); lifestyle choice (Fern *et al.* 2013; Pugh *et al.* 2017); information for young people's siblings (Mitchell *et al.* 2006; Smith *et al.* 2007); friends, and schools (Smith *et al.* 2007). Young people have described experiences where they felt that information delivery was inappropriate, focussed more towards either adults or children (Wilkinson, 2003; Mitchell *et al.* 2006; Smith *et al.* 2007). Young people wanted information to be provided in a variety of formats (Pugh *et al.* 2017) and for more information to be available in an audio-visual format (Mitchell *et al.* 2006).

Linked to keeping young people well-informed about their care was involving young people in decisions about their care and providing patients with choice where possible (Morgan, 2009; Coyne *et al.* 2014). Morgan (2009) recognised that when young people were denied choice they exhibited decreased self-esteem, and nurses have been suggested to be vital facilitators and advocates to enable young people to make their own choices (Coyne *et al.* 2014). Young people wanted to feel empowered to make decisions about their care, including whether they wanted to participate in research, and felt it was their right to know what their research options were (Taylor *et al.* 2016a).

3.5 Discussion

This narrative review has identified and synthesised existing primary research, presenting what patient and professional experience has conveyed about the culture of teenage and young adult cancer care in the UK. Existing literature has primarily focussed on specialist teenage and young adult cancer settings where young people were the prime focus of the service. There are still significant numbers of young people without access to, or who choose not to access, specialist services. They therefore receive their care at either a local hospital, in a children's service, or in adult cancer centres (Birch *et al.* 2014). While the six themes presented in this review have conveyed important learning about caring for young people with cancer, it is essential that future research investigates the culture of care delivered to young people across all services and environments within the networks of care. This would provide a more comprehensive, accurate, and nation-wide depiction of the culture of care for young people with cancer in the UK.

Both professional team working and communication were key components of care identified in this review. As described in Chapter 1, teenage and young adult cancer

secondary and tertiary care is organised into networks, where treatment and care are co-ordinated by professionals working in or across multiple settings. It is therefore not only important to understand care delivery across a variety of environments (child, adult and specialist teenage services), but it would be beneficial to understand mechanisms and experiences of communication and team working within and across the teenage cancer care networks. As presented at the beginning of this chapter, culture is shared and transmitted through learning and teamwork. Moreover, professionals' roles and attitudes were identified as contributing towards young people's experiences of care; these elements differed depending on where and by whom a young person received their care.

At a time of financial hardship, the current climate of the NHS may not be conducive to providing specialist care to meet the needs of teenagers and young adults, since this constitutes a very small cohort of the wider cancer patient population (Cancer Research UK, 2017). Nonetheless, research which explores the current culture of caring for this population across different places and settings can help to build a picture of current patient experiences of care. Through exploration of what happens both 'above' and 'below the surface' in terms of providing cancer care to young people, a model or framework for how and where care is best delivered could be generated. It is the responsibility of everyone caring for young cancer patients to help improve their care and provide young people with the best possible experiences of healthcare. Increased evidence underpinning care practices would be of great benefit to those working with teenage and young adults, as some professionals fail to acknowledge their unique needs (Gibson *et al.* 2012).

It must be recognised that the findings obtained from the papers included in this review have limitations. Some of the studies have methodological weaknesses, as reported through the quality assessment of the literature (Table 3.1) and eight were conducted in one place of care. The review purposefully included UK-based studies only, which increased the applicability of the review findings to this doctoral research (based in England, UK). However, this does limit the applicability of the findings to young people's cancer care settings in other countries; where health systems and services are structured and financed differently, or societal views and attitudes towards young people may also be different (WHO, 2018a).

Within the literature, it is generally acknowledged that there is a lack of knowledge surrounding the care experiences of young people with cancer, and the 19 papers included in the review aimed to expand on this evidence. Despite its limitations, the

findings synthesised and presented in this review have provided valuable insights into the key elements of the culture of care for this group, and have identified where the gaps in our current knowledge lie. O'Hara *et al.* (2012) presented that 52% of young people received at least some of their care within a specialist inpatient ward. As the current evidence is generated solely in these specialist settings, the experiences and perspectives outside these settings warrants further exploration.

3.6 Summary

The review has highlighted the core components of caring for young people with cancer; care which extends beyond clinical needs, and is holistic and tailored to the unique issues affecting young people receiving cancer care (refer back to Figure 1.1). In order to further understand the culture of teenage and young adult cancer care in the UK, research needs to widen the focus to include the experiences of young people in other services in which they are cared for, i.e. child and adult cancer care settings. Through a greater understanding of the cultural characteristics that enable optimal delivery of care to young people with cancer, we can provide health services with the knowledge that they will facilitate best care practices across all care settings. To fully explore the culture of teenage and young adult cancer care in the UK, research into the culture of care both *within* and *across* the teenage and young adult cancer networks is crucial. The following three research questions are yet to be answered, and therefore they will the focus of this primary research:

1. How does the context of each Principal Treatment Centre and its network shape young people's individual experience of care?

2. What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?

3. What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?

Having positioned this case study research within the existing literature, the following chapter will describe and justify the methods used and the methodological issues associated with the conduct of this research.

Chapter 4

Methodology, methods, setting and sample

4.1 Introduction

This chapter will outline the methodological approach taken and methods used to explore the culture of teenage and young adult cancer care in England. As previously mentioned, this research was underpinned by a critical realist paradigm. This chapter provides more detail about this epistemological stance. The rationale is described, in support of selecting a qualitative case study approach, and the sampling, recruitment, data collection and analysis procedures used are all addressed here. In addition, the importance of reflexivity and triangulation to promote research rigour throughout these procedures is highlighted. Finally, the ethical issues surrounding the conduct of the study are presented. This chapter focusses on the methods used and the methodological issues associated with the conduct of this research; all steps were guided by the 21 recommendations documented in the 'Standards for reporting qualitative research' (O'Brien *et al.* 2014). The use of these standards ensures visibility of the necessary steps that were taken to enhance the transparency of the conduct and reporting of this study.

4.2 Defining the question

As highlighted already, teenage and young adult cancer services in England are delivered within complex networks of care. Studies to date have investigated the delivery of care to young people in specific and specialist settings, and suggested that the core elements of caring for young people with cancer included: the right environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; communication, information delivery and patient choice. The premise of this study was to argue for a broader exploration into the culture of care, particularly the deeper aspects of 'culture' which lie 'below the surface', both *within* and *across* the teenage and young adult cancer networks. Investigating culture is however complex as both visible and less visible elements of culture must be examined, as depicted in the presentation of models of culture in Chapter 2. In order to undertake this exploration, the methodological approach and techniques used were guided by the following three research questions:

1. How does the context of each Principal Treatment Centre and its network shape young people's individual experience of care?

2. What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?

3. What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?

4.3 Ontology and epistemology

Ontology and epistemology are two vital considerations within research (Denzin and Lincoln, 2005). It is important for a researcher to understand their beliefs about and relationship with the known (ontology), as these beliefs shape how the researcher views the world, behaves in it and thus how they go about studying it (epistemology) (Denzin and Lincoln, 2005). This is determined by the research paradigm, a concept which was first introduced in Chapter 2. This doctoral research was founded on the key ontological assumption that there are shared processes, structures, values, norms and basic assumptions which construct the culture of caring for young people with cancer. Moreover, this culture cannot be proven or disproven, it can only be explored in the way that it exists. These ontological assumptions were fundamental to the research and impacted upon all aspects, including, how the research was planned and organised, the methodology used and the knowledge produced (Creswell and Poth, 2018).

Realism has been recognised for over two decades as a research paradigm which presents a unified approach to the biological, psychological and social nature of nursing research; bridging both the social and natural sciences together (Wainwright, 1997). Critical realism is a moderately new philosophical view, proposing a profound alternative to the positivist and interpretivist paradigms (McEvoy and Richards, 2006). Critical realist ontology is a practical estimation of life events, presenting a pragmatic research methodology, which enables researchers to convey the nature and cause of social processes, to facilitate theory development and influence change (Easton, 2010). The 'critical' element acknowledges a need for attention to detail, precision, rigour and consistency (Crossan, 2003); these must be applied to all qualitative research to ensure credibility. The use of a 'critical' eye and mind throughout the design and conduct of this doctoral work was considered to be an essential aspect of the critical realist paradigm; deemed essential to enhance the precision and rigour of the study.

There is a lack of research drawing upon a critical realist perspective to investigate health care structures and practices (McEvoy and Richards, 2006). Some case study researchers have written from a positivist viewpoint, assuming predictability from their case study and allowing causal explanations and generalisations to be made (Easton, 2010). However, a post-positivist 'realist' viewpoint, in which the presence of unobservable phenomena is accepted, can also be used to assist our understanding of observable phenomena (Crossan, 2003). This is useful in the study of culture, a phenomenon where both the visible and less visible components coexist (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).

In line with this exploratory approach, critical realism defends the need to study any situation irrespective of the numbers of units of analysis involved, providing the aim is to explore and understand things as they exist (Easton, 2010). This differs significantly from a positivist perspective, in which personal preconceptions need to be put aside to allow identification of objective data based on empirical findings (McEvoy and Richards, 2006). Moreover, it has been argued that a positivist paradigm does not support in-depth investigation of human behaviour and interactions (Crossan, 2003). Positivism therefore was not an appropriate paradigm for this doctoral study, where the aim was not to discern causality or to gather objective data about care delivery, rather it was to explore the culture of care holistically through observing and understanding the experiences and interactions of patients and professionals: situations where reality was not rigid nor indeed measurable (Crossan, 2003).

The benefit of conceptualising in this way emphasises three fundamental questions, as stated by Easton (2010):

1.   What are the entities that define our research field?
2.   What are their relationships?
3.   What are their powers and liabilities?

These three fundamental questions, provided a clear path to explore the research questions through the lens of critical realism. The connection between these questions, how they assisted the researcher to investigate the visible and invisible entities of culture, as well as how culture was shared within different and changing contexts, are presented in Table 4.1. As described previously, the concept of culture is complex and broad, therefore it was challenging to ensure that data collection and

interpretation focussed on answering the research questions: Easton's (2010) work was particularly helpful here.

Table 4.1. Linking Easton's (2010) three fundamental questions, the study research questions and the three core concepts of culture which formed the conceptual framework.

Easton (2010)	Study research questions	Conceptual framework: three core concepts of culture
What are the entities that define our research field?	How does the context of each PTC and its network shape young people's individual experience of care?	Culture takes place within a context, and is therefore dynamic and changeable (Lenburg *et al.* 1995; Kitayama, 2002; Erez and Gati, 2004). Culture consists of both visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).
What are their relationships?	What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?	Culture is shared and transmitted through learning and teamwork (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; The King's Fund, 2018).
What are their powers and liabilities?	What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?	Encompasses all three of the core concepts of culture.

4.4 Methodology

It has been suggested that few authors of case studies offer a defence of their choice of the case method on formal epistemological grounds (Easton, 2010). There was, in this study, clear congruence of case study methodology with the epistemological position of the researcher. While case studies can be situated within a positivist paradigm, this research was founded on the epistemological proposition that the organisational culture of cancer care delivery was not measurable, rather any exploration would need to be around the way the culture of care existed and

was experienced (Easton, 2010). Thus, a qualitative methodology was required to enable exploration in this way (Silverman, 2016).

Case study methodology evolved throughout the 20th century as a way of creating an understanding of the interconnected facets of a phenomenon rather than viewing it as multiple disconnected elements (Thomas, 2011). The service structures of young people's cancer care in England has a complex arrangement and young people are cared for in a range of settings. It was therefore essential that the study methodology enabled the collection of multiple perspectives, and the exploration of a range of experiences, in order to capture any variation of cancer care in these different contexts. Case studies seek to investigate phenomena within a context or series of contexts ('collective' or 'multiple-case' studies), and it is a methodology that is uniquely suitable when studying complex settings where several interrelating variables exist (Stake, 1995; Yin, 2014). Central to studying a culture is understanding the context, and the importance of the environment of care was highlighted as a key theme impacting care delivery to young people (Chapter 3): all factors that supported the use of a case study.

Case studies can be descriptive, exploratory or explanatory (Yin, 2014). This case study took both a descriptive and exploratory approach, seeking to describe the phenomenon of teenage and young adult cancer care in its real-life context, and to identify research questions to guide future research (Yin, 2014). The two leading proponents of the case study methodology are Yin (2009, 2014) and Stake (1995, 2005) and in this case study elements of both these approaches were used.

Yin (2014) and Stake (2005) offer distinctly different approaches to case study methodology (Bolbin *et al.* 2013): their differences have been examined by Yazan (2015). Drawing on the work of Yazan (2015), a justification for the combined use of these two approaches in this exploration of the culture of young people's cancer care is presented in Table 4.2, and illustrates how a blended approach incorporating both these two perspectives was used.

Table 4.2. A comparison of Stake's and Yin's case study approaches (adapted from Yazan (2015, p.148)).

Element of approach to consider	Stake (1995, 2005)	Yin (2009, 2014)	Case study on the culture of care
Ontology: what is the nature of reality?	Reality is subjective and subjectivity is central to understanding. The nature of the phenomena in question should be studied holistically and requires looking at a multitude of contexts.	Reality is objective, measurable and predictable. Causal explanations can be developed and different strategies are employed to achieve this.	The holistic and complex nature of the culture of teenage and young adult cancer care requires looking at care delivery in a multitude of contexts, exploring how this directly affects the experiences and interactions of patients and professionals. This required exploration as opposed to an objective approach.
Philosophical view	Constructivist	Positivist	Critical realist It has been suggested that a critical realist approach can encompass elements of both constructivism and positivism (Perry *et al.* 1998).
Epistemology: What is the relationship between the researcher and the researched?	The researcher spends an extended period 'in the field' with an aim to develop an understanding of the phenomena being explored as time goes on. The researcher may have an insider role or view however any insider bias is accepted.	The researcher is detached from the phenomena being studied. Interview data is expected to be supported with other evidence and there is an aim to control for researcher bias. Yin does acknowledge that biased views will impact case study findings.	The researcher aimed to develop an iterative and increasing level of understanding of the phenomena being explored throughout the course of data collection. It was acknowledged that there was the potential for researcher bias due to having an insider role, and it was planned that this would be addressed through reflection throughout the process.
Definition of case study	It is the *"study of the particularity and complexity of a single case, coming to understand its activity within important circumstances"* (2005, p. xi).	It is the study of *"a contemporary phenomenon within its real life context, especially when the boundaries between a phenomenon and context are not clear and the researcher has little control over the phenomenon and context"* (2009, p.13).	This case study sought to explore the overarching case of the culture of teenage and young adult cancer care in England, through a process of exploring the delivery, experiences and perspectives of care in multiple care contexts.

Table 4.2. A comparison of Stake's and Yin's case study approaches (adapted from Yazan (2015, p.148)) (cont.).

Element of approach to consider	Stake (1995, 2005)	Yin (2009, 2014)	Case study on the culture of care
Case study research design	*Intrinsic:* focus is on understanding one particular case but does not test or develop new or existing theories. *Instrumental:* investigates an issue or refines a theory. The exploration may be of a typical or atypical case. *Collective:* the extensive study of multiple instrumental cases to increase understanding, with potential to develop theoretical explanations in a wider context.	*Single-case embedded:* study of one case with several units of analysis. *Single-case holistic:* study of one case as a whole. *Multiple-case holistic:* several cases studied as a whole. *Multiple-case, embedded:* study of several cases with multiple units of analysis within each case.	A multiple-case, embedded design was developed with the expectation that studying four networks of teenage and young adult cancer care would provide insights into the culture of teenage and young adult cancer care in England. The study of a range of cases collectively was used to obtain an understanding of the overall topic being explored rather than the individual cases.
Data collection	Data collected is qualitative, and uses observation, interview and document analysis.	Data collected can be quantitative and qualitative, using a variety of data collection methods: archival records; documentation; participant observation; direct observation; interviews; physical artefacts.	This qualitative case study research used a range of these tools: including observation, shadowing and interviews.
Data analysis	Analysis is comprised of giving meaning to a researcher's initial impressions in additional to the final summation of findings.	Comprised of examination, categorisation and tabulation: combining both quantitative and qualitative findings to address the study questions.	Data analysis was the process of making sense of the data collected. The researcher set out to reduce and interpret what was collected with rigour, transparency and reflectivity. The aim was to address the research questions posed at the beginning of the study.

4.4.1 Multiple-case study

Both single case studies and multiple-case studies have been acknowledged as variants within the case study methodology (Yin, 2014). When a study encompasses more than a single case, a multiple-case study is required (Gustafsson, 2017). Multiple-case studies enable the researcher to study several cases to illuminate similarities and differences between the cases (Stake, 2005; Baxter & Jack, 2008) and across the cases (Yin, 2014). The terminology 'collective case study' (Stake, 2005) and 'multiple-case study' (Yin, 2014) are used to describe the collection of data from a number of cases to understand a particular phenomenon (Gustafsson, 2017). The nature of exploring four networks of care indicated the suitability of a multiple-case study approach, which allowed for a collective use of methods already used within young people's cancer care to be incorporated (Kelly *et al.* 2004; Grinyer, 2009; Fern *et al.* 2013; Vindrola-Padros *et al.* 2016): for example, observational methods and semi-structured interviews.

However, it has not always been accepted as a credible methodology and has received criticism due to a lack of explicit guidance on its conduct (Yin, 2009). Yin (2009) has acknowledged that there are criticisms. Working with both Yin and Stake is thought to counteract some of these criticisms. For example, it has been suggested that a novice researcher undertaking a qualitative case study would benefit from following the guidelines provided by Stake (2005), in particular the use of data triangulation to provide 'data validation' and to reduce the risk of misrepresentation of data (Yazan, 2015). Moreover, use of a reflective approach where all data gathering, analysis and interpretation processes are documented with rigour and transparency is considered an essential part of conducting a qualitative case study if findings are to be considered accurate and valid (Thomas, 2011; Yazan, 2015).

A potential weakness of case study research is that it may not be appropriate to contribute to a larger debate and that findings lack generalisability (Stake, 2005; Yazan, 2015). Findings may have minimal obvious benefit, be unpredictable or insular (Stake, 1995). It has been argued that these issues can be avoided by careful selection of the case/s to be studied, through clear definition of the 'case', and through using a research design which considers the potential of the research to contribute on a larger scale at the outset (Stake, 2005). Selection and

investigation of several cases widens the window of exploration and therefore the scale of the contribution, creating stronger and more reliable evidence (Baxter & Jack, 2008): "*We recognise a larger population of hypothetical cases and a small population of accessible ones*" (Denzin and Lincoln, 2005, p. 455). Even in larger case studies, the sample is normally too small to excuse haphazard sampling, therefore purposive sampling is often used to enhance quality of output and validity of the findings (Denzin and Lincoln, 2005).

One overriding advantage of using a multiple-case design is the foundation of a greater breadth of empirical evidence, and therefore the creation of more convincing theoretical explanations (Gustafsson, 2017). In this multiple-case study, data about the context, structures, processes, perspectives and experiences in a series of hospitals were gathered, which enabled the presentation of the 'empirical reality' of young people's cancer care. The combination of experience and contextual data collected in each of the cases enabled theoretical propositions about the culture of care to be developed from the findings.

The multiplicity of definitions, approaches and variety of perspectives can provide challenges for researchers when designing case studies (Yazan, 2015). Juxtaposition of the two main case study approaches (Table 4.2) provided opportunity to select and combine the research techniques from the two approaches to best serve and support the purpose and aims of this study (Yazan, 2015). These more practical elements of designing a case study was however underpinned by a thorough understanding of the relationship between the researcher's epistemology, the case study approach used and subsequent research-related decisions (Yazan, 2015).

4.4.2 Critical realism and case study

Understanding the relationship between the epistemological orientation of a researcher and the approach to case study that they use, is essential (Yazan, 2015). Yin states that reality is objective, measurable and predictable (Yin, 2009). A purely objective, positivist stance would not have been appropriate to answer the research questions regarding the culture of cancer care. It has been argued that positivism does not enable the exploration of human beings and their behaviour (Crossan, 2003); both vital components to explore when studying culture. The overall case of teenage cancer care in England is, as has already been highlighted, broad and complex, with multiple perspectives and contexts of care that require comprehensive

exploration. Consequently, Yin's (2014) logical and structured approach to case study design and data analysis was employed, for example using tables as a framework for cross-case analysis with the emerging data (Yazan, 2015).

Acknowledgement of the researcher's personal ontology is also important, here this was aligned with a critical realist philosophy. It has been suggested that a critical realist approach can encompass elements of both constructivism (*Stake's approach*) and positivism (*Yin's approach*) (Perry *et al.* 1998), and thus could be deemed the perfect research paradigm where a blend of Stake and Yin's critical realism has been advocated and used in qualitative case study (Christie *et al.* 2000; Easton 2010). A constructivist approach to case study involves investigation of the beliefs of individual respondents in the case being studied (Krauss, 2005), whereas a critical realist undertaking case study aims to discover the observable and non-observable structures, processes and interactions (Christie *et al.* 2000): this aligned perfectly with the depictions of culture, suggesting it has observable and non-observable components (Herman, 1970; Hall, 1976; Schein, 2010). The case study approach used in this doctoral study predominantly used Stake's (2005) approach, but benefitted from the 'tools' that Yin (2014) offers to assist in the process of undertaking case study research.

Stake's (2005) view regarding a collective case study such as this, is that the interest is not on the individual cases themselves as in a single case study, rather the focus shifts to the phenomenon which the overall case study is exploring. In the case of this doctoral study, this was the culture of care and was regarded as the sum of the individual experiences, perspectives and observations (the individual units of analysis). Case study offered the potential of a rich data set, including different perspectives, reported in such a way that the reader is *"able to smell human breath and hear the sound of voices… nothing is lost in their refraction"* (Thomas, 2011, p. 7). The case study approach also allowed an investigation of complex, contemporary phenomena within real life contexts (Baxter and Jack, 2008; Yin, 2014). It allowed the researcher to work in close collaboration with participants to facilitate them to share their experiences; illustrating perspectives of reality which in turn assists the researcher to interpret and understand the participant's actions (Baxter and Jack, 2008).

Following careful consideration of all the possible methodologies, qualitative case study was determined to be the most appropriate research methodology to answer the questions and maintain congruence between research aims, ontology and

epistemology. In terms of data collection, case study methodology uses detailed, in-depth data collection processes and incorporates multiple data sources to form a bound case (Creswell and Poth, 2018). Stake (2005) and Yin (2009) generally agree on the reliance of multiple sources of data. Data can be collected by methods such as interviews, documentary analysis and observations; and can result in a detailed case description of the phenomena being studied (Willgens *et al.* 2016). This approach aligns with the critical realist research paradigm, where the triangulation of multiple methods will allow a researcher to obtain a greater grasp of reality (Sayer, 2000). Thus, the triangulation of multiple data sources provided comprehensive insights to understand the overall case, to get 'below the surface', and to discover the empirical reality of the culture of teenage and young adult cancer care in England.

4.5 Methods

An advantage of using case study methodology is that triangulation of multiple data sources can be used (Thomas, 2011), assisting the exploration of the phenomena being studied: in this case, to understand the empirical reality of the culture of teenage and young adult cancer care in England. This multiple-case study employed a range of data collection techniques, including: semi-structured interviews with young people; semi-structured interviews, tours and shadowing with healthcare professionals; and participant observation. Walking interviews and photography with young people were two further techniques that were piloted early on in the study.

4.5.1 Semi-structured interviews: method and procedure

The main data collection technique used was semi-structured interviews, a method which has been successfully employed with both young cancer patients and with healthcare professionals (Kelly *et al.* 2004; Grinyer, 2009; Vindrola-Padros *et al.* 2016; Kenten *et al.* 2017; Marshall *et al.* 2018). DiCicco-Bloom and Crabtree (2006) suggest that qualitative research interviews contribute to a conceptual and theoretical body of knowledge, centred around the meanings of the interviewee's life experiences. The experiences of young people receiving care and healthcare professionals providing care were fundamental to exploring the culture of care, and in particular the research question: *what are the perceptions of care of young people and professionals in each PTC and its network?*

Interviews can vary in structure, ranging from structured interviews where the questions are fixed, to entirely unstructured, where only the initial overarching topic for discussion is established (Fielding and Thomas, 2008). The interviews in this multiple-case study were semi-structured which allowed for some flexibility in the questions asked and gave the participants freedom to express their own perspective, thus presenting the researcher with new insights (Payne, 2007). Using a semi-structured format allowed the conversation to be steered by the participant, whilst still being guided by the researcher's topic guides; these differed for the healthcare professional and young person interviews (Appendices 4 and 5 respectively).

The iterative nature of the qualitative research process, in which data collection and early stage reflection and analysis run in parallel, can lead to changes and additions to the interview guide as researchers discover more about the topic (DiCicco-Bloom and Crabtree, 2006). While this approach was considered, the researcher had concerns about whether this would reduce the replicability of the interviews and therefore impede the process of comparing and synthesising the data collected across the different sites, therefore the same topic guides were used with all healthcare professionals and all young people who participated. The findings from the narrative literature review and the exploration into the definitions and models of culture shaped the development of the interview topic guides. Both topic guides were reviewed in advance. The healthcare professional guide was reviewed by experts in the field, the core members of the BRIGHTLIGHT research team. The guide for young people was reviewed by the Young Advisory Panel (YAP). The YAP, a group of young patient representatives, was created to guide and influence BRIGHTLIGHT's strategy and to support the conduct of the study, to ensure the research results provide patient benefit. This was of value to BRIGHTLIGHT as it enabled the involvement and voice of young people themselves to be present in all aspects of the research process.

The interviews were all conducted between October 2014 to December 2015. Interviews were held in a quiet area of the participant's choice, thus ensuring the participant's comfort with the interview environment and empower them during the interview interaction (Elwood and Martin, 2000). More specifically, interviews were undertaken in: clinic rooms; offices; ward 'quiet rooms'; ward social areas; and around patient's bed spaces or in side-rooms. With permission, the interviews were digitally recorded and transcribed by an independent transcription company, and

following this, the accuracy of transcription was checked against the digital recordings through initial reading by the researcher. This provided a necessary opportunity for immersion into the data for the first time (Fielding and Thomas, 2008). The transcriber had signed a confidentiality agreement, and all transcripts were anonymised upon receipt by the researcher. Following each interview reflective field notes were recorded. There were two exceptions to this, when healthcare professionals denied permission to digitally record the conversation, therefore notes were hand written throughout the interview, and these were expanded and additional details about the conversation were added immediately after the interview. This was not ideal as the retrospective hand writing of notes relied on the researcher's memory, providing potential for bias (Van Maanen, 2011), and possibly may have been influenced by the researcher's own biases (Hamo, 2004). Further challenges and ethical considerations regarding the conduct of interviews with young people are discussed in sections 4.5 and 4.6.

4.5.2 Tours

With healthcare professionals, tours were a method of providing the researcher with information about the environment of care, using the same concepts as the walking interview technique. Tours were provided by healthcare professionals in all of the hospital units and wards visited by the researcher, in some cases they were digitally recorded as part of a walking interview. In the majority of cases, the tour was conducted separately prior to a static, semi-structured interview, and provided a valuable opportunity for rapport building, informal conversations and familiarisation of the environment of care being visited.

4.5.3 Walking interviews

Anthropologists and ethnographers have used 'walking alongside' participants as a form of observation, to study the subject in motion, and to experience and understand everyday practices (Jones *et al.* 2008; Clark and Emmel, 2010). These 'walking and talking' methods have emerged across the social sciences as an ideal technique for exploring individual's relationships with an environment (Jones *et al.* 2008). The walking or 'go along' interview can encourage identification of resources that may be overlooked when using traditional interview styles (Jones *et al.* 2008; Garcia *et al.* 2012). Walking interview methods have been used to encourage young people to think about how they conceptualise and view their physical environment (Clark and Emmel, 2010). Clark and Emmel (2010) have described several benefits

of the walking interview method over the traditional sit-down interview; these were influential in the researcher's decision to use walking interviews as a method:

- Gives participants greater control over the interview;
- The participant can show, rather than describe, the physical spaces to the interviewer;
- Placing experiences into their special context can assist the participant to verbalise their thoughts to the interviewer;
- The researcher viewing physical environments can help to build the researcher's understanding of the topic being discussed;
- The environment walked through can elicit thoughts and stimulate discussion, perhaps on abstract yet informative topics that may not have presented without visual prompting.

The walking interview uses the physical surroundings as a 'walking probe.' Exploring a place that is significant to the participant causes the surroundings to prompt rich discussion, often with little input required from the researcher (De Leon and Cohen, 2005). A further unique benefit of walking interviews is that they can empower the interviewee and provide opportunity for rapport building (Carpiano, 2009). An approach considered to be particularly important when interviewing young people and can help manage power imbalances (Christian *et al.* 2010). Walking interviews can also provide a closeness between the researcher and participant due to the shared engagement of body and space (Ross *et al.* 2009).

As the walking interview method *"has great potential to shed light on how participants use and understand different spaces"* (Jones *et al.* 2008, p. 8), it had potential to be successful with both the young people and healthcare professionals. There was the potential to bring another dimension to the interview format and to assist the discussion of their experiences in relation to the physical environments of care.

4.5.4 Pilot of using walking interviews

The walking interview was a novel technique within healthcare research, therefore the method was piloted with one young participant and one healthcare professional. On both occasions the interviews were successful: the researcher asked participants for verbal feedback, which was positive towards the experience. It was for this reason that during the research design phase that the walking interviews were considered an appropriate method of data collection.

There were however challenges that emerged during data collection which mirrored challenges that have been previously identified by Jones *et al.* (2009). They discovered that not all participants felt comfortable showing the researcher around an environment, with some participants expressing that they would feel self-conscious. Furthermore, within healthcare environments, there were issues around maintaining confidentiality during conversations with healthcare professionals in particular. It was however concluded that this method was not appropriate for all participants, therefore a flexible approach to the interviews was adopted where either a walking, static or combined approach was chosen by the participant, and adapted according to their needs and the surroundings where necessary.

4.5.5 Use of photography with young people

In addition to the option to walk and talk, young people had the opportunity to take photographs of 'helpful' and 'unhelpful' elements of their environment of care before they were interviewed to guide the discussion of their experience of care. Instructions for taking the photographs were provided both verbally and in writing to young people (Appendix 6), indicating that they were not permitted to capture people's faces in their photographs.

Photography in qualitative research is used as a way of attempting to understand the world through the participant's eyes (Thomson, 2008; Paulus *et al.* 2014). 'Photo-elicitation' or 'photo-interviewing' is a method where the researcher uses the images taken to stimulate and assist discussion with the participant (Paulus *et al.* 2014). Alternatively, photography can be a data collection technique, providing visual insight into a participant's experience (Holm, 2014). Photography and similar creative methods have been used successfully with children and young people both as a data collection technique (Coad, 2007) and as a tool to assist and elicit conversation (Holm, 2014; Byrne *et al.* 2016; Vindrola-Padros *et al.* 2016). Permission was granted in all sites where local ethical approval was sought for photographs to be taken. In cases where young people showed an interest, they were given an additional information sheet about the use of photography.

A critical and reflexive attitude is required to distinguish the limitations, disadvantages and the reasons for using creative methods with young people (Punch, 2002), therefore the use of photography was completely optional: it was not a popular choice with young people. In the majority of interviews, the use of photography was rejected. The option to take photographs was provided to young

people, either from their bed or while walking around their care environment. Some young people expressed that they did not feel well enough to walk around, some were attached to too many wires or tubes which made moving awkward, and others were simply not interested in taking photographs. This highlights the importance of having a flexible and individualised approach to conducting research with young people (Punch, 2002).

Following the pilot of using photography, in which young people generally lacked interest, the method was not pursued as a form of data collection. If young people did choose this option, any photographs collected during the interviews were used in a 'photo-elicitation' style to stimulate and assist in discussions with the participant (Harper, 2002). Consistent with this approach, any photographs taken were not included in the data analysis. This was a methodological decision, taken due to the lack of uptake of this method of data collection.

4.5.6 Shadowing

Sociological and anthropological research has championed a range of observation-oriented methods, with the term shadowing associated with a variety of ethnographic approaches (McDonald, 2005; Brixey *et al.* 2008; Gill *et al.* 2014). Shadowing is a method whereby the researcher closely follows an individual over an extended period of time to study their actions (McDonald, 2005; Quinlan, 2008). McDonald (2005) explored the contribution of shadowing as a technique to understand perspectives or roles, record behaviour, and generate experiential learning. Shadowing was therefore incorporated as a data collection method due to the potential to illuminate the perspectives of the range of healthcare professionals, and how their roles and behaviours contributed to the culture of care.

Shadowing can harvest valuable, first-hand data from targetted individuals that are key to understanding the phenomena under examination (McDonald, 2005). There can be flexibility in the length of time a researcher spends shadowing participants. Quinlan (2008) suggested that shadowing can be conducted for periods ranging from an hour up to a whole month, either on consecutive days or intermittently. In this doctoral study, shadowing was conducted in short periods, which totalled a maximum of four hours with one healthcare professional. This was considered sufficient to provide insight into their role, without causing undue intrusion on busy work routines.

Shadowing allowed the researcher to move with participants (Czarniawska, 2007). It was a useful technique to use when observing professionals, whose roles encompassd dynamic and changing routines, tasks and locations. Shadowing counteracted the issues of lacking space and time when observing certain individuals, which can be a barrier during non-participant observation or more static styles of ethnography (Czarniawska, 2007).

Writing field notes throughout the period of shadowing was the ideal method of documenting observations (McDonald, 2005). However, during the shadowing carried out in this study it was frequently inappropriate or impractical to write notes in real time. There was often a lot of walking between locations, such as offices, clinics and wards, in addition to observation of both personal and professional interactions with colleagues and patients. It was therefore deemed more practical for short field notes to be written at opportune moments as an aide-mémoire to the researcher, and these were expanded into detailed field notes immediately following the period of shadowing. This mobile and fluid approach to documentation reflects the mobility and fluidity of this method of data collection (Czarniawska, 2007). During each period of shadowing, healthcare professionals were asked insightful questions at appropriate moments to assist the researcher to understand what was being observed. Questioning was useful to clarify the intentions, purpose and priorities of what was observed or spoken (McDonald, 2005).

One limitation of shadowing highlighted by Mintzberg (1970) and Czarniawska (2007) was the exclusion of specific, confidential discussions or activities. This occurred on several occasions during data collection period, for example during a clinic appointment where the researcher was asked to step outside during sensitive discussions with patients. While this was not ideal, it was not detrimental to the quality nor richness of the data collected about the overall culture of care through shadowing, and importantly it facilitated the comfort of participants at all times (Czarniawska, 2007). A summary of the advantages and disadvantages of shadowing is presented (Table 4.3).

Table 4.3. Summary of the advantages and disadvantages of shadowing (adapted from Czarniawska, 2007, p. 58)

Advantages	Disadvantages
- Mobility: a way of doing research that mirrors the mobility of life/the work setting - A unique opportunity for self observation	- Requires constant attention - Frequently presents the researcher with ethical decisions - Can be psycho-socially uncomfortable or inappropriate at times (perhaps leading to exclusion of the researcher in some situations)

4.5.7 Participant observation

Ethnography is *"the study of both explicit and tacit cultural knowledge"* (Spradley, 1980, p. 8). Ethnographers seek to understand cultural phenomena, comprehend both obvious and inferred cultural knowledge, through observing behaviour and interactions of those within a particular culture (Spradley, 1980); placing these in wider contexts, such as government policies (Denzin and Lincoln, 2005). This multiple-case study explored the phenomena of the culture of care across teenage and young adult cancer networks and therefore incorporation of observation techniques was considered important to assist this exploration.

Participant observation involves immersion within a situation, setting or space, which enables the researcher to develop relationships with the people within that setting or space (DeWalt and DeWalt, 2011); collecting observational data adds breadth to research. Tedlock (2000) proposed that it can help to answer contextual questions that cannot be answered through interviews alone. The special features of the approach are well-suited to the study of complex societies or situations, such as the study of culture and cultural practices (DeWalt and DeWalt, 2011). Exploration including looking at the interconnections and linkages between locations as well as those that are local is considered to be important in a multiple-case study (Yin, 2014); thus using participant observation in a range of settings was in concordance with the cross-case approach taken in this study.

Observations can be covert or overt, structured or unstructured, and participant or non-participant (DeWalt and DeWalt, 2011). In this case study, all observations were overt to absolve potential ethical dilemmas of observing in clinical environments. While a framework was used to assist in structuring observation field notes and used to guide the collection of observation data (section 4.5.8), observations were

predominantly unstructured to create a greater scope for identifying unexpected events, objects and behaviours. A particular danger of using a structured approach is that relevant data can be overlooked, therefore it was decided that a naturalistic approach, using a flexible, unconfined and participatory observation approach, would be better suited to the exploratory nature of this study.

The advantage of case study findings from several locations enabled the gathering of a multitude and range of participant perspectives: likened to pieces of a puzzle that are placed together to build a complete image (Nadai and Maeder, 2005). A period of three months was spent within each sub-case (network of care). Throughout this time, periods of participant observation took place within all of the Principal Treatment Centres visited in each network, as well as number of the other hospitals in the four networks of care (more detail on this is provided in section 4.6). The researcher made initial contact with each of the hospitals visited to arrange a suitable time to be present in the clinical areas, and worked closely with the relevant professionals, most commonly nurses, to arrange where and how to spend periods of observation.

A variety of events were observed and recorded over the course of data collection. Those observed were: healthcare professionals caring for young people, including the whole range of the multi-disciplinary team; and other professionals within the hospitals e.g. porters; patients, parents, siblings, extended family and friends. Places targeted for observation were clinical spaces where young people are cared for, both inpatient and outpatient/day case, social spaces for patients, and other areas around the hospital such as corridors and the hospital canteen. The types of events observed included clinical interactions with patients, interactions between professionals and patient-to-patient interactions. Additionally, interactions between and with family and friends were observed. Consultant clinics, multi-disciplinary team meetings, network-wide meetings, ward handovers, cancer tumour site-specific meetings, and social events for young people both within hospital and off-site were also observed.

4.5.8 Field notes

The use of field notes in this case study allowed contextual information to be recorded. They contained information about the structures and processes of care observed during the tours, shadowing and participant observation. Moreover, behaviour and interactions that occurred were also documented, which added depth

to the observational data and assisted the researcher to collect data on the less visible aspects of the culture of care ('below the surface').

Field notes can vary in format, for example a structured description of what has happened (Spradley, 1980); a chronological log of what is happening in the setting (Patton, 2002); or a descriptive account and reflection of what was observed (Emerson *et al.* 1995). The main drawback of field notes is the potential for low reliability since the circumstances of the events observed cannot be repeated, and therefore cannot be validated by another researcher (Hamo, 2004). In a multiple-case study where it was possible to observe similar, comparable events in different locations, the use of a structured, systematic and repeatable approach to the recording of field notes was therefore appropriate (Van Maanen, 2011). Spradley's (1980) framework enabled a systematic approach to the documentation of field notes:

1. SPACE - layout of the physical setting; rooms, outdoor spaces, etc.;
2. ACTORS - relevant details of the people involved;
3. ACTIVITIES - the various activities of the actors;
4. OBJECTS - physical elements: furniture etc.;
5. ACTS - specific individual actions;
6. EVENTS - particular occasions, e.g. meetings;
7. TIME - the sequence of events;
8. GOALS - what actors are attempting to accomplish;
9. FEELINGS - emotions in particular contexts.

This framework was advantageous as it triggered the researcher to include detailed contextual information when writing field notes, such as staff members present in meetings or clinical areas. Moreover, the framework encouraged the researcher to keep a record of personal reflections on the data and the collection processes. A process that will be explored more in 4.6 where research rigour is addressed.

4.6 Setting

The overall case was cancer care for teenagers and young adults in England, and four networks of care for teenagers and young adults with cancer were the sub-cases, selected by an expert panel as a result of the findings in the 'Mapping study' (Vindrola-Padros *et al.* 2016) (Chapter 1). The networks of care included multiple nested cases: the inpatient and outpatient teenage and young adult cancer services at the Principal Treatment Centre; the inpatient and outpatient cancer services at associated designated hospitals; children's cancer services caring for young people

at paediatric oncology shared care units; and other related services where young people with cancer were receiving care.

4.6.1 The overall case, sub-cases and nested cases

It is essential to clearly define the study setting and to identify the specific 'case' being explored (Thomas, 2011). Denzin and Lincoln (2005) describe a case as a bounded system, where the case is studied in its social, physical, economic or historical context, and bound by time and place, because this is essential to understanding the case. Similarly, Merriam (1998) describes a case as *"a thing, a single entity, a unit around which there are boundaries"* (p.27); it can be an organisation, a person, a group, a policy or a programme. In this multiple-case study, the bounded system of teenage and young adult cancer care was distinct and definable and presented the overall case to be studied.

The case was comprised of several embedded sub-cases (Yin, 2014), chosen so as to grasp the differing contexts of the culture of care; this study was conducted in four different networks of care. The sub-cases were also bound by organisational, place, physical and social characteristics, the description of which were unique to that network. The networks further comprised several hospitals, providing the nested cases of the study (Yin, 2014). It has been suggested that choosing distinct cases with variation between them can illuminate differences in structures and processes (Miles and Huberman, 1994); these being some of the key components of culture that required exploration in this study. It is from within these nested cases that the young people and professionals were sampled and thus collectively provided the units of analysis for the study. This structure is illustrated in Figure 4.1.
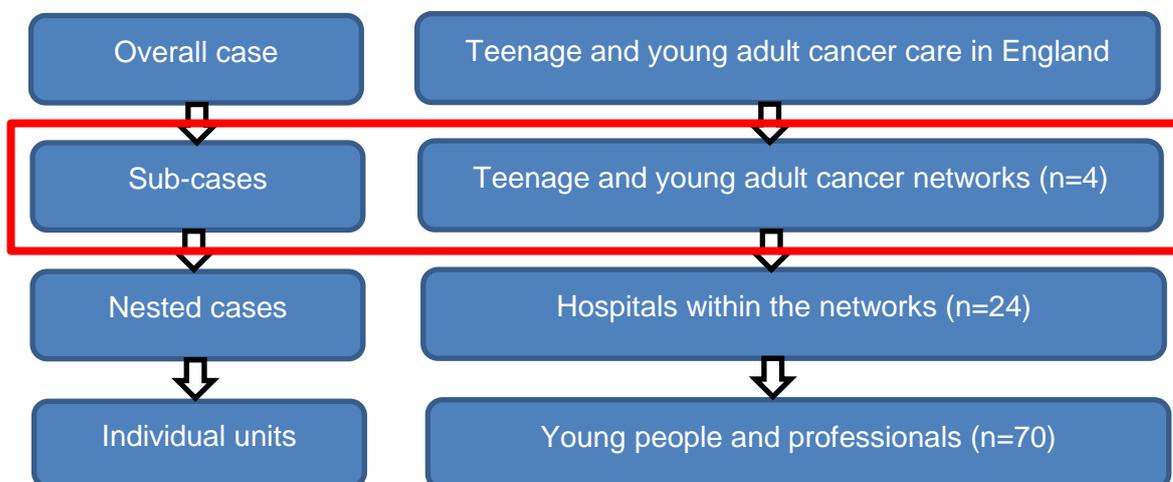
Figure 4.1. The components of this multiple-case study, highlighting the sub-cases within the multiple-case study design.

4.6.2 Setting: sub-cases

The four sub-cases (highlighted by the red box in Figure 4.1) were selected to represent the diversity in geographical coverage, shared management arrangements, patient population, size, history, availability and distribution of specialist teenage and young adult services (Table 4.4).

Table 4.4. The characteristics of the sub-cases of this multiple-case study: the four networks of teenage and young adult cancer care.

Network characteristics*	Sub-cases			
	Network 1	Network 2	Network 3	Network 4
Data collection period	October 2014 – December 2014	January 2015- March 2015	May 2015 – July 2015	September 2015 – December 2015
Geographical coverage	Large	Medium	Very large	Medium
Size of the service	Large	Medium	Large	Medium
History of the service	Well-established service	Less-established service	Well-established service	New ward but well established service
TYA services available at Principal Treatment Centre	Specialist services for inpatients and outpatients which are co-located	Three specialist wards split over three hospitals	Two specialist wards split over two hospitals	One specialist ward in one hospital
Arrangement of designation/ shared care for patients	Large numbers of designated and shared care hospitals, close together	Small numbers of designated and shared care hospitals, well spread out	Large numbers of designated and shared care hospitals, well spread out	Medium numbers of shared care and designated hospitals, well spread out

*Characteristics based on the selection criteria used by the Executive team in the BRIGHTLIGHT Mapping study. Data displayed is purposely vague to ensure the hospitals are non-identifiable.
TYA: Teenage and young adult.

4.6.3 Setting: nested cases

Local approvals were obtained from 14 Research and Development ('R&D') departments, which covered 17 of the hospitals visited, to allow the recruitment of patients (not provided as appendices to ensure the hospitals remain non-identifiable). An additional seven hospital sites were visited in which healthcare professionals were recruited to the study (Health Research Authority (HRA)

approval process for conducting research with professionals was not in place at the time of study): this totalled 24 nested case sites (Figure 4.2).

Overall case	Teenage and young adult cancer care in England
⇩	⇩
Sub-cases	Teenage and young adult cancer networks (n=4)
⇩	⇩
Nested cases	Hospitals within the networks (n=24)
⇩	⇩
Individual units	Young people and professionals (n=70)
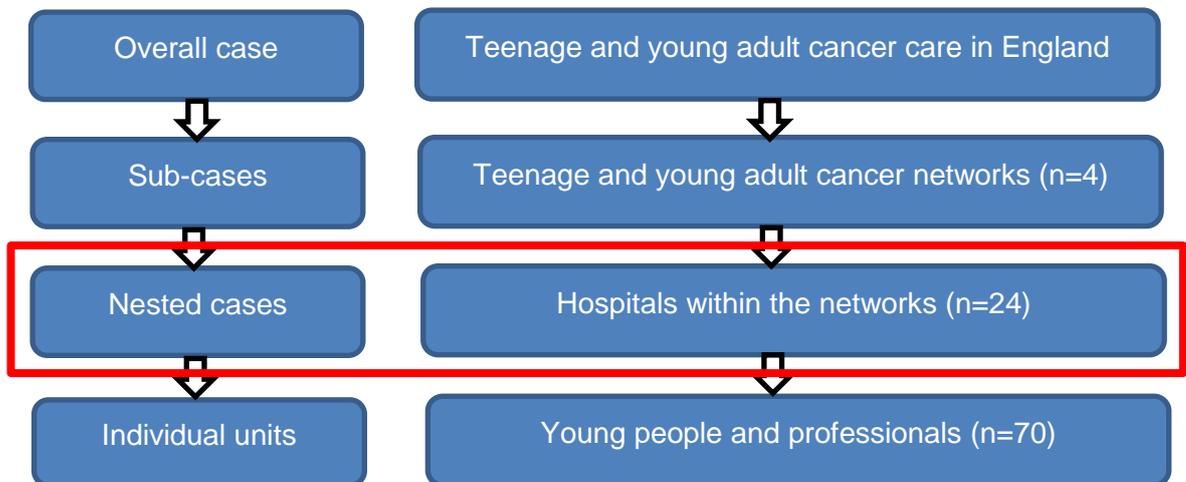
Figure 4.2. Highlighting the nested cases within this multiple-case study.

Young people receiving cancer care (aged 13 to 24 years) and health professionals delivering cancer care to this population were the combined population for this study. These two groups formed the units of analysis within each nested case. Observations, including tours and shadowing, were also used to collect data. The number of hospitals visited (nested cases) within each network of care (subcase), and the type and amount of data collected within each of these, is presented in Tables 4.5a, 4.5b, 4.5c and 4.5d.

Table 4.5a. Summary of the numbers of hospitals visited in the first network of care (subcase 1), data collection methods used, and hours of observation/participants involved.

	Hospitals in which data were collected	Data collection method	Hours (h)/ participants (n)
Subcase 1	1	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=1 n=1 n=0
	2	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=16 n=7 n=4
	3	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=1 n=0 n=1
	4	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=0
	5	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=1 n=1 n=0
	6	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=6 n=1 n=1
	7	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=0
	8	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=3 n=1 n=0
Totals	**8**	**Tours/shadowing/participant observation** **Semi-structured interviews with HCPs** **Semi-structured interviews with young people**	**h=32** **n=13** **n=6**

Table 4.5b. Summary of the numbers of hospitals visited in the first network of care (subcase 2), data collection methods used, and hours of observation/participants involved.

	Hospitals in which data were collected	Data collection method	Hours (h)/ participants (n)
Subcase 2	1	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=16 n=3 n=4
	2	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=6 n=2 n=4
	3	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=4 n=1 n=0
	4	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=3 n=1 n=1
	5	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=0
	6	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=0
Totals	**6**	**Tours/shadowing/participant observation** **Semi-structured interviews with HCPs** **Semi-structured interviews with young people**	**h=33** **n=9** **n=9**

Table 4.5c. Summary of the numbers of hospitals visited in the first network of care (subcase 3), data collection methods used, and hours of observation/participants involved.

	Hospitals in which data were collected	Data collection method	Hours (h)/ participants (n)
Subcase 3	1	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=12 n=4 n=3
	2	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=8 n=2 n=3
	3	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=3 n=1 n=0

Table 4.5c. Summary of the numbers of hospitals visited in the first network of care (subcase 3), data collection methods used, and hours of observation/participants involved (cont.).

	Hospitals in which data were collected	Data collection method	Hours (h)/ participants (n)
	4	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=0
	5	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=1 n=2
	6	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=4 n=1 n=1
Totals	**6**	**Tours/shadowing/participant observation** **Semi-structured interviews with HCPs** **Semi-structured interviews with young people**	**h=31** **n=10** **n=9**

Table 4.5d. Summary of the numbers of hospitals visited in the first network of care (subcase 4), data collection methods used, and hours of observation/participants involved.

	Hospitals in which data were collected	Data collection method	Hours (h)/ participants (n)
Subcase 4	1	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=18 n=5 n=4
	2	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=3 n=1 n=0
	3	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=4 n=1 n=1
	4	Tours/shadowing/participant observation Semi-structured interviews with HCPs Semi-structured interviews with young people	h=2 n=2 n=0
Totals	**4**	**Tours/shadowing/participant observation** **Semi-structured interviews with HCPs** **Semi-structured interviews with young people**	**h=27** **n=9** **n=5**

4.7 Sample

Recruitment of young people was attempted in all nested cases in which local R&D approvals were obtained. All young people who participated were given the choice to choose a pseudonym to ensure anonymity, some of whom were not interested in doing so, and therefore they were assigned a pseudonym by the researcher. These have been used throughout the thesis. All healthcare professionals were given an anonymous identification number. A summary of the characteristics of all young people and healthcare professionals who participated in semi-structured interviews in the study is provided (Table 4.6).

Table 4.6. Summary of the characteristics of the study interview participants.

	Healthcare Professionals n (%)	Young People n (%)
Total	41	29
Gender Male Female	 2 (5) 39 (95)	 10 (34) 19 (66)
Age Median age [range] 13-15 16-18 19-24	 NC NC NC NC	 19 [13-24] 6 (21) 8 (27) 15 (52)
Main treatment centre/place of work Principal Treatment Centre Designated Hospital Paediatric Oncology Shared Care Unit	 23 (56) 14 (34) 4 (10)	 22 (76) 7 (24) 0 (0)

NC: Not collected.

4.7.1 Sampling and recruitment of healthcare professionals

Sampling in qualitative inquiry can be a contentious issue, with overlapping of terminology such as 'selective', 'purposeful' and 'theoretical' sampling techniques (Coyne, 1997). Sampling must be congruent with the aims of the research (Palinkas *et al.* 2015): 'purposeful' sampling is where participants are targeted and selected if deemed to be information-rich data sources to answer the research questions proposed (Patton, 2002). This is a particularly effective strategy when time and resources are limited (Patton, 2002). Purposeful sampling was appropriate to identify illustrative units of analysis in this multiple-case study to assist exploration of the phenomena (the culture of teenage and young adult cancer care). Purposeful and targeted strategies emphasised sample variation and breadth and thus enabled investigation of differences and commonalities in perspectives and experiences (Palinkas *et al.* 2015) central to the research questions that underpinned this study.

Due to the practicalities of undertaking this study, where entry to each site occurred sequentially, an element of inductive sampling was also accomodated in the design. This is where subsequent samples were based on previous analysis, with an aim to identify illustrative cases to enable targeted exploration of particular emerging findings about the culture of care (Morse, 2000).

Healthcare professionals were targeted purposefully to reflect the scope of the teenage and young adult multidisciplinary team. The target sample was ten healthcare professionals in each sub-case, with a range of clinical, support and allied health roles, from hospitals across each of the networks of care. In each network, contact was made with the lead nurse and/or clinician for teenager and young adult cancer care and they were recruited to the study. Additionally, the key lead professional was used as a point of contact and guidance to assist in identifying other healthcare professionals to be interviewed and/or shadowed, with the expressed aim of representing the diversity of the multi-disciplinary team. The researcher used the first days in the Principal Treatment Centre to observe the daily dynamic of the service and to become familiar with the surroundings. This time was also used to establish relationships with professionals on the wards and units, who were potential participants in the study. A variety of team meetings and handovers were attended to further forge relationships and to provide opportunities to discuss the study with a range of professionals caring for young people, including clinicians, nurses, social and youth support workers, and other allied healthcare professionals.

For those professionals who agreed to participate in an interview, the time and meeting place was arranged, written information about the study was shared (Appendix 7), and written consent was obtained (Appendix 8). All potential participants were provided with an opportunity to ask questions about the study. The aim was to recruit 6-10 healthcare professionals from each of the four networks of care, reflecting the scope of the multidisciplinary team. A total of 41 healthcare professionals took part (Table 4.7): specifically, this included: ward based-nurses (9); clinical nurse specialists (8); nurse leaders/managers (9); non-nurse service managers (2); doctors (3); and 'others' included: youth support co-ordinators (4); social workers (3); psychologist (1); and education roles (2).

Table 4.7 Profile of the healthcare professional study participants and their method of participation.

	Identifier	Role	Place of work	Involvement
Network 1	HCP 1	Other	PTC	WIV & shadow
	HCP 2	Other	PTC	WIV
	HCP 3	Doctor	PTC	SSIV & shadow
	HCP 4	Nurse	PTC	WIV
	HCP 5	Nurse	PTC	WIV
	HCP 6	Nurse	PTC	WIV
	HCP 7	Other	PTC	SSIV
	HCP 8	Nurse	POSCU	WIV
	HCP 9	Nurse	DH	WIV
	HCP 10	Nurse	DH	SSIV
	HCP 11	Nurse	DH	SSIV & tour
	HCP 12	Nurse	POSCU	SSIV & tour
	HCP 13	Nurse	POSCU	SSIV & tour
Network 2	HCP 14	Nurse	PTC	SSIV
	HCP 15	Other	PTC	WIV & shadow
	HCP 16	Nurse	PTC	WIV & shadow
	HCP 17	Other	PTC	SSIV & shadow
	HCP 18	Nurse	DH	SSIV & tour
	HCP 19	Other	PTC	SSIV
	HCP 20	Doctor	PTC	SSIV
	HCP 21	Nurse	DH	WIV
	HCP 22	Nurse	DH	SSIV & tour
Network 3	HCP 23	Other	PTC	SSIV & shadow
	HCP 24	Nurse	PTC	SSIV & shadow
	HCP 25	Other	PTC	SSIV & shadow
	HCP 26	Allied Health Professional	PTC	SSIV
	HCP 27	Nurse	DH	SSIV
	HCP 28	Other	PTC	SSIV
	HCP 29	Nurse	DH	SSIV & tour
	HCP 30	Nurse	DH	SSIV & tour
	HCP 31	Nurse	PTC	SSIV
	HCP 32	Nurse	POSCU	WIV & shadow
Network 4	HCP 33	Nurse	PTC	SSIV
	HCP 34	Nurse	DH	SSIV & tour
	HCP 35	Nurse	DH	SSIV
	HCP 36	Doctor	DH	SSIV & tour
	HCP 37	Nurse	PTC	WIV & shadow
	HCP 38	Other	PTC	SSIV
	HCP 39	Other	PTC	SSIV
	HCP 40	Nurse	PTC	SSIV
	HCP 41	Nurse	DH	WIV & shadow

Abbreviations: PTC=Principal Treatment Centre, DH= Designated hospital, SSIV= semi-structured interview, WIV= walking interview, POSCU= Paediatric oncology shared care unit.

4.7.2 Sampling and recruitment of young people

Young people with cancer, aged 13 to 24 years, were recruited in the 17 hospitals in which local R&D approval was obtained. While sampling was planned to be purposeful, there were challenges with recruiting young people to the study, as

young people were not always feeling well enough to want to be approached to consider or indeed to take part in an interview. Convenience sampling was introduced, thus those who expressed an interest and feeling well enough to participate in an interview, were approached (Palinkas *et al.* 2015). In the hospitals with smaller numbers of teenage and young adult patients (the designated hospitals and paediatric oncology shared care units), recruitment of young people was also convenience in nature. The researcher utilised the lead nurses' knowledge of their patients to assist in identifying when patients would be present in the hospital to provide opportunity for introductions and to intitiate rapport building. This process was more straight-forward in the Principal Treatment Centres where there were greater numbers of teenagers and young adults to approach.

The target sample was six young people in each sub-case, therefore 24 young people across the overall case. Researcher access and approval processes were obtained for 17 hospitals across the four sub-cases which enabled the recruitment of young people who were receiving care in a variety of hospital settings. The inclusion and exclusion criteria for this study were:

Inclusion:
- Aged 13-24 years.
- Diagnosis of cancer.

Exclusion:
- Unable to speak English or communicate verbally; as the researcher was not able to speak any other languages.
- Unable to give informed consent/assent to take part in the study; as this was about young people sharing their perspectives and experiences of care, it was important that they understood what was involved and were participating of their own free will (HRA, 2018).
- Inpatient but on conditional leave from custodial care; as the young person would be shackled to a prison warder and would not be permitted to leave the area of care and the warder would be present when the young person was interviewed. This would not enable the young person to give an honest account of their care; and their experience would also be anomalous to the rest of the population.

The strategy was to obtain a sample of young people ranging in age, diagnosis, receiving care in a variety of environments, thus exploring the perspectives of a

range of young people in order to answer the research questions comprehensively (Patton, 2002; Denzin and Lincoln, 2005). The study aimed to recruit young people with different disease types, including:

1. Blood cancer: Leukaemia and lymphoma
2. Solid tumours: Sarcoma, Central Nervous System, Germ cell
3. Carcinoma

It was considered important to try and recruit young people across the range of tumour types because care pathways and settings are often determined and managed within tumour type, and this may have impacted on patient's experiences of care (Kenten *et al.* 2017). There were however, challenges with recruiting young people within all of the known disease types. The researcher selected convenience sampling to optimise recruitment in the various sites and as a result young people with the most common cancer types within teenage care settings (leukaemia, lymphoma, osteosarcoma) participated; those being the most prevalent in the specific care settings visited. The researcher less frequently identified young people with rarer diseases, such as brain tumours, or those more common in adults. While the researcher made several attempts to connect with Clinical Nurse Specialists to assist in recruitment of young people with some of these rarer diseases, for example, diseases of the central nervous system, a patient group who are often underrepresented in research, successful recruitment did not occur during the timeframe for data collection.

Similarly, for the recruitment of healthcare professionals, the researcher worked with the lead nurse and relevant healthcare professionals within each hospital to identify potential young people for the study. A process of rapport building with young people took place during the periods of participant observation on the wards and units. This assisted the recruitment process as it helped young people to establish trust in the researcher (Christian *et al.* 2010). A verbal discussion about the study alongside written information (Appendix 9) was given to young people and they were provided with time to consider the study and ask questions about it.

Once young people had agreed to participate, a time for an interview was arranged and prior to the interview they were provided with further opportunity to ask questions or to opt out should they wished to. Written consent was obtained before the interview (Appendix 10), and for those less than 16 years of age, written assent was obtained (Appendix 11) alongside written consent from their parent or guardian

(Appendix 12). Each young person was asked where they would like to have the interview: if they would either like to walk as they talked with the researcher or whether they would like to talk in a quiet place of their choosing. Furthermore, young people were asked if they would like to take photographs of the helpful and unhelpful elements of their environment before the interview.

A total of 29 young people participated in the study: 19 females and 10 males. Ages, ranged from 13 to 24 years, with a median age of 19. The majority of patients were cared for in a Principal Treatment Centre (n=22), and the remaining young people received their care in a designated hospital (n=7). While there were no interviews conducted with young people within a paediatric oncology shared care unit, several young people had received their care in both settings and therefore shared these experiences. The profile of the young people who participated is presented in Table 4.8.

Table 4.8. Profile of young people interviewed in the study.

	Pseudonym	Diagnosis	Main place of treament
Network 1	Hannah	Blood cancer	PTC (IP & DC) + POSCU
	Emily	Blood cancer	PTC (IP & DC)
	Lucy	Solid tumour	PTC (IP & AC)
	Jade	Blood cancer	PTC (DC) + POSCU
	Alena	Solid tumour	PTC & DSCH
	Connie	Solid tumour	DH (& YPU)
Network 2	Monica	Solid tumour	PTC (IP & RTX)
	Natalia	Solid tumour	PTC (IP & DC)
	Kye	Blood cancer	PTC (IP)
	Caroline	Blood cancer	PTC (IP & DC)
	Mia	Solid tumour	PTC (IP
	Julia	Blood cancer	PTC (DC)
	Liam	Solid tumour	PTC (IP & DC)
	Jack	Blood cancer	PTC (IP & DC)
	Rhianna	Solid tumour	DH (DC)
Network 3	Kelly	Blood cancer	PTC (IP & DC)
	Abdi	Blood cancer	PTC (IP & DC)
	Jason	Blood cancer	PTC (IP & DC)
	Anna	Solid tumour	PTC (IP) & DSCH
	Nina	Blood cancer	PTC (IP & DC)
	Molly	Blood cancer	PTC (IP)
	Terry	Blood cancer	PTC (IP & DC)
	Sasha	Blood cancer	DH (IP)
	Jake	Blood cancer	DH (DC)
	Callum	Solid tumour	POSCU (& local hospital)
Network 4	Nicole	Solid tumour	PTC (IP & DC)
	Jen	Blood cancer	PTC (IP & DC)
	Laura	Blood cancer	PTC & DH
	Simon	Blood cancer	DH (DC)
Abbreviations: PTC: Principal Treatment Centre; IP: Inpatient; DC: Day case; DH: Designated hospital; POSCU: Paediatric Oncology Shared Care Unit; RTX: Radiotherapy.			

4.8 Data analysis

Processes of analysing case study evidence have not been well-defined, and often rely on careful management and transparent presentation of the evidence, alongside the application of personal yet rigorous empirical thought (Yin, 2014). Yin (2014) recognised the contribution of a researcher's personal analysis style on the process, and similarly Stake (2005) suggested that researchers must find their own methods of analysis, through a process of trial, error and reflection.

Thematic analysis can be used to deconstruct, understand and interpret data surrounding the conceptualisation of a specific phenomenon (Joffe, 2012). Schmidt (2004) suggested that the first stage of analysis of all qualitative data should build foundational categories for analysis, embodying the analysis strategy for case study methodology proposed by Yin (2014): *"emergence of a case typology by working data from the ground up"* (p.137). Yin (2014) suggested that within this strategy, a useful exercise to begin this process is to 'play' with the data to search for patterns or concepts. This approach was considered, and this approach was drawn upon in the latter stages of analysis when data was viewed as 'the whole' in light of the conceptual context of this study relating to culture.

An alternative form of qualitative data analysis was considered and undertaken, which involved the development of a category matrix and placing data within categories (Miles and Huberman, 1994). Miles and Huberman (1994) present a staged approach of reducing, displaying, drawing conclusions and verifying data. These phases were used to guide the analysis procedure, with thematic analysis (Braun and Clarke, 2006) and cross-case synthesis (Yin, 2014) as the specific analysis techniques used within these phases. The dual approach of using thematic analysis and cross-case synthesis was considered the most appropriate and systematic method of analysing the volume of data collected (Figure 4.3). These techniques were applied to both the transcript data from the semi-structured and walking interviews, in addition to field note data that were collected in the tours, shadowing and periods of participant observation.
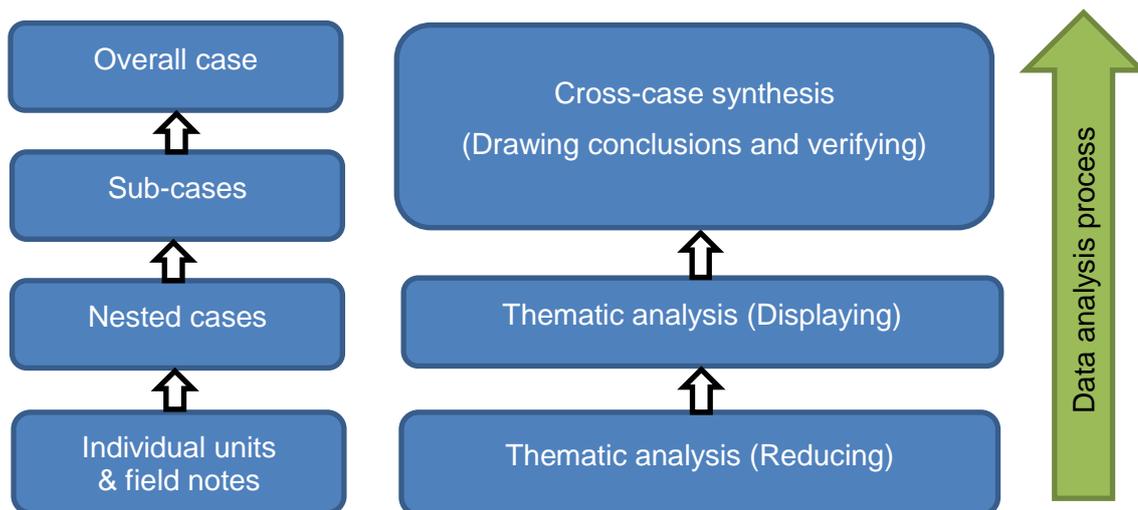
Figure 4.3. The steps taken in the data analysis process, with reference to the phases of qualitative data analysis presented by Miles and Huberman (1994).

4.8.1 Reducing

Thematic analysis is a flexible method of data analysis and is adaptable to different research paradigms and qualitative methodologies (Willig, 2013). It was therefore adaptable to the analysis of a large and complex multiple case-study data set. Interview and field note data were read through to gain a sense of both the individual units of analysis, nested cases and the subcases, as a means of familiarisation and comprehension of data (Baxter and Jack, 2008).

Attention was then focussed on the individual units of analysis and the reduction of the data. The first step, involved the generation of initial codes across all transcripts and field notes, which was conducted by hand on printed transcripts and field notes. Alongside memoing and note-taking on the transcripts, an initial process of grouping codes into early-stage themes and sub-themes was conducted through using colour-coding (Miles and Huberman, 1994). Appendix 13a presents an example of the process of this initial phase of data coding and theme generation.

Building descriptions and understanding the meaning behind what was observed was primarily approached through a process of reading, thinking and re-reading field notes (DeWalt and DeWalt, 2011). As with the transcripts, memoing and coding was used to reduce and organise the field notes to assist with the generation of key themes, and to find linkages between what was observed, and to what was said by participants in the interviews.

4.8.2 Displaying

Following the generation of the initial themes and sub-themes from the individual units of analysis, tables were used to combine the data from the nested cases, to present it as subcases. Data from young people and healthcare professionals remained separate at this stage, although a process of reflection of the data allowed overlaps and comparisons to naturally be drawn. Additionally, within these tables, descriptions and key excerpts from the field notes were arranged into the categorised themes (DeWalt and DeWalt, 2011). The phrases extracted from the data, and their reduction into the emerging themes, was presented in horizontal rows (Appendix 13b). At this stage, data were still being analysed as four separate sub-cases.

It is essential to reinforce that the process of displaying data was an important part of the analysis (Miles and Huberman, 1994), allowing clarification, synthesis, and generation of further themes from data at the nested case level through the steps of thematic analysis, searching for and reviewing themes (Braun and Clarke, 2006). At this stage, the individual units of analysis had been analysed independently and tabulated according to the themes that were arising. Each sub-case continued to be analysed independently.

4.8.3 Drawing conclusions and verifying

The tables displaying data analysed at the nested case level were printed and worked on by hand, allowing close viewing to aid recognition of associations between the themes and categories. This assisted the process of the identifying and drawing initial conclusions from the data (Miles and Huberman, 1994). The original themes and categories were further refined, and the researcher regularly returned to the raw data to assist this process.

The next phase of analysis required a progression from the empirical reality of the findings (Bhaskar, 1976) to the development of a conceptual understanding of the culture of care (Miles *et al.* 2014). Gerring (2007) stated that the conclusion from a case study is either illustrative or confirmable. The purpose of this case study was both descriptive and exploratory; generating findings which would culminate in an illustrative conclusion, and to inform recommendations for policy, practice and future research. It was important for the context of each sub-case to direct the development of the study conclusions (Baxter and Jack, 2008). Therefore, the researcher regularly returned to the raw field notes in this stage of 'drawing

conclusions'. This enabled re-immersion in what was observed and re-familiarisation with the rich, contextual data collected, to ensure it was not lost during this conclusive phase of the analysis (Phillippi and Lauderdale, 2018).

An additional analysis technique was drawn upon at this stage: a technique which is specific to multiple-case study research (Yin, 2014). Cross-case synthesis is a method of aggregating findings across a series of cases to look for commonalities and differences (Yin, 2014) (Appendix 14). This method was employed as the nature of this multiple-case study required analysis and understanding of not only what the individual units of analysis revealed about their nested cases (hospitals) and sub-cases (networks of care), but analysis which deconstructed and reconstructed the data to understand the overall case (culture of care in England) (Yin, 2014). The themes which had emerged from the collection of nested cases with each sub-case were mapped onto wall-mounted whiteboards. Associations, similarities and differences between the themes presented in the four sub-cases were then more easily identified. This cross-case analysis compared the perspectives and experiences of young people and healthcare professionals *across* the different settings in the networks thus enabling synthesis and contextualisation of data (Spenser *et al.* 2004).

This process of drawing conclusions involved analysing the interplay and exchange between data and prior theoretical underpinnings (Schmidt, 2004). From here, the common themes that were identified across the four sub-cases required consideration within the context of the cultural models; already presented in chapter 2. It was at this stage that the conceptual framework of culture was reviewed and considered to guide the analysis strategy:

1. Culture takes place within a context, and is therefore dynamic and changeable (Lenburg *et al.* 1995; Kitayama, 2002; Erez and Gati, 2004).
2. Culture consists of both visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).
3. Culture is shared and transmitted through learning and teamwork (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; King's Fund, 2017).

The themes generated in the previous phases were categorised at this stage according to their congruence with the conceptual framework of culture, and data were organised corresponding to this:

- Data related to the settings and environments of care;
- Data related to goals, processes, structures, knowledge, behaviours ('above the surface');
- Data related to values, norms and basic assumptions ('below the surface');
- Data related to the sharing and learning of the culture of care.

Identified passages and content from the individual units of analysis (interview transcripts, and discrete excerpts from the field notes) were extracted and allotted to their corresponding table and into the column displaying the appropriate theme within the spreadsheets (Schmidt, 2004). At this stage, data from all nested cases within each sub-case was kept in separate rows. The source of all extracted data was documented in the table to ensure the origin and context were easily traceable (Miles and Huberman, 1994). The prevalence and content of the categorised data were initially compared within each nested case and sub-case, which assisted the development and revelation of internal patterns in the data related to each of the themes (Miles and Huberman, 1994). Any further content that opposed the overarching themes was also documented in an additional column in the spreadsheet.

Brinkmann (2014) argued that through analysis data are broken down, shaped and reconstructed into different forms. This final stage of drawing conclusions from the data involved reconstructing data into a shareable form: into messages that were clear for the audience. With such a large and complex set of data, it was a challenge to distil the findings of the study in order to address the initial aim, purpose and questions proposed. The three research questions, combined with this notion of culture being comprised of components both 'above the surface' and 'below the surface' was used to guide abstract thinking about the analysis. The themes which were present across all sub-cases were related to the original research questions:

1. How does the context of each Principal Treatment Centre and its network shape young people's individual experience of care?
2. What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?

3. What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?

External patterning has been described as the final stage of data analysis, where themes are explored in connection to a pre-existing knowledge base generated in other research, policy or practice (Schmidt, 2004). It has been suggested that to fully understand research findings, they should be compared and contrasted to pre-existing data, to situate the new findings into the landscape of knowledge (Baxter and Jack, 2008). This has also been referred to as generating 'theoretical coherence' of data (Miles *et al.* 2014). It was appropriate therefore at this stage to draw upon the taxonomy produced from the findings of the BRIGHTLIGHT Mapping study (Vindrola-Padros *et al.* 2016) (Figure 4.4). This taxonomy was considered during the verification stage of data analysis (Miles and Huberman, 1994) with an aim to both validate the study findings, and to assist interpretation through connecting them with this pre-existing conceptualisation of teenage and young adult cancer care.
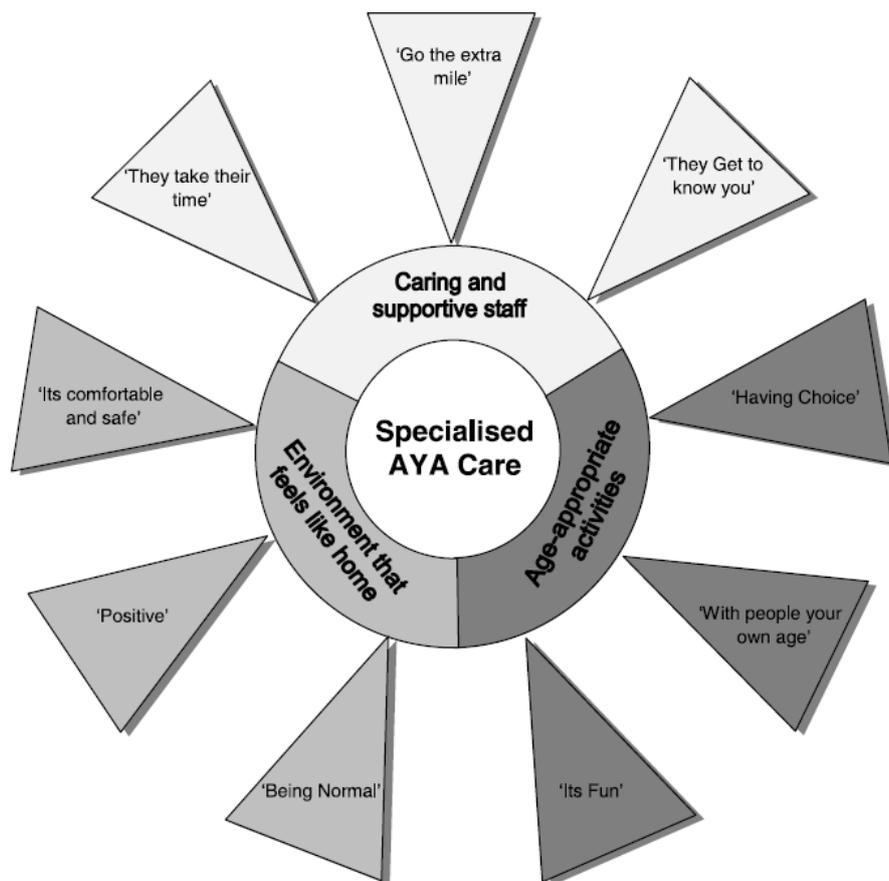
Figure 4.4. The main components of teenage and young adult cancer care (Vindrola-Padros et al. 2016).

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The epistemological position of the researcher is recognised to be influential in all stages of qualitative research, and is the key instrument in the process of data analysis (Braun and Clarke, 2006). To address this, the researcher was continuously aware of her epistemological stance and values as a nurse, and how these may have impacted data analysis, interpretation and therefore the development of the conclusions. This is explored in the following section.

4.9 Rigour

Rigour in qualitative research refers to the integrity of the conduct of the study and therefore the credibility of its findings (Noble and Smith, 2015). Rigour encompasses concepts such as validity, reliability and generalisability; terminology commonly associated with positivist research however redefined within qualitative paradigms (Golafshani, 2003). Lincoln and Guba (1985) suggested that the terms truth value, consistency and applicability are better suited to describe rigour in qualitative research; conversely, Patton (2002) argued that validity and reliability are core concepts to consider when designing and examining qualitative research. Seale (1999) suggested that 'trustworthiness' comprises the concepts of validity and reliability, and therefore the concept of trustworthiness will be discussed to examine the approach taking to ensuring rigour in this study.

Strategies can be used to heighten the trustworthiness of research (Noble and Smith, 2015). Meyrick (2006) provides a framework for practitioners to apply when designing and examining medical and health-related research, which can be used to aid assessment of qualitative rigour. This framework was applied to the conduct of this study (Figure 4.5). All study processes were conducted and documented with a transparent and systematic approach, important when producing quality qualitative research (Meyrick, 2006; Noble and Smith, 2015). An overview of all mechanisms which promoted trustworthiness and rigour throughout the duration of the study is presented (Figure 4.5), however two major components of trustworthiness worthy of discussing in more detail: triangulation and reflexivity.

4.9.1 Triangulation

Baxter and Jack (2008) stated that *"triangulation of data sources, data types or researchers is a primary strategy that can be used and would support the principle in case study research that the phenomena be viewed and explored from multiple perspectives"* (p.556).
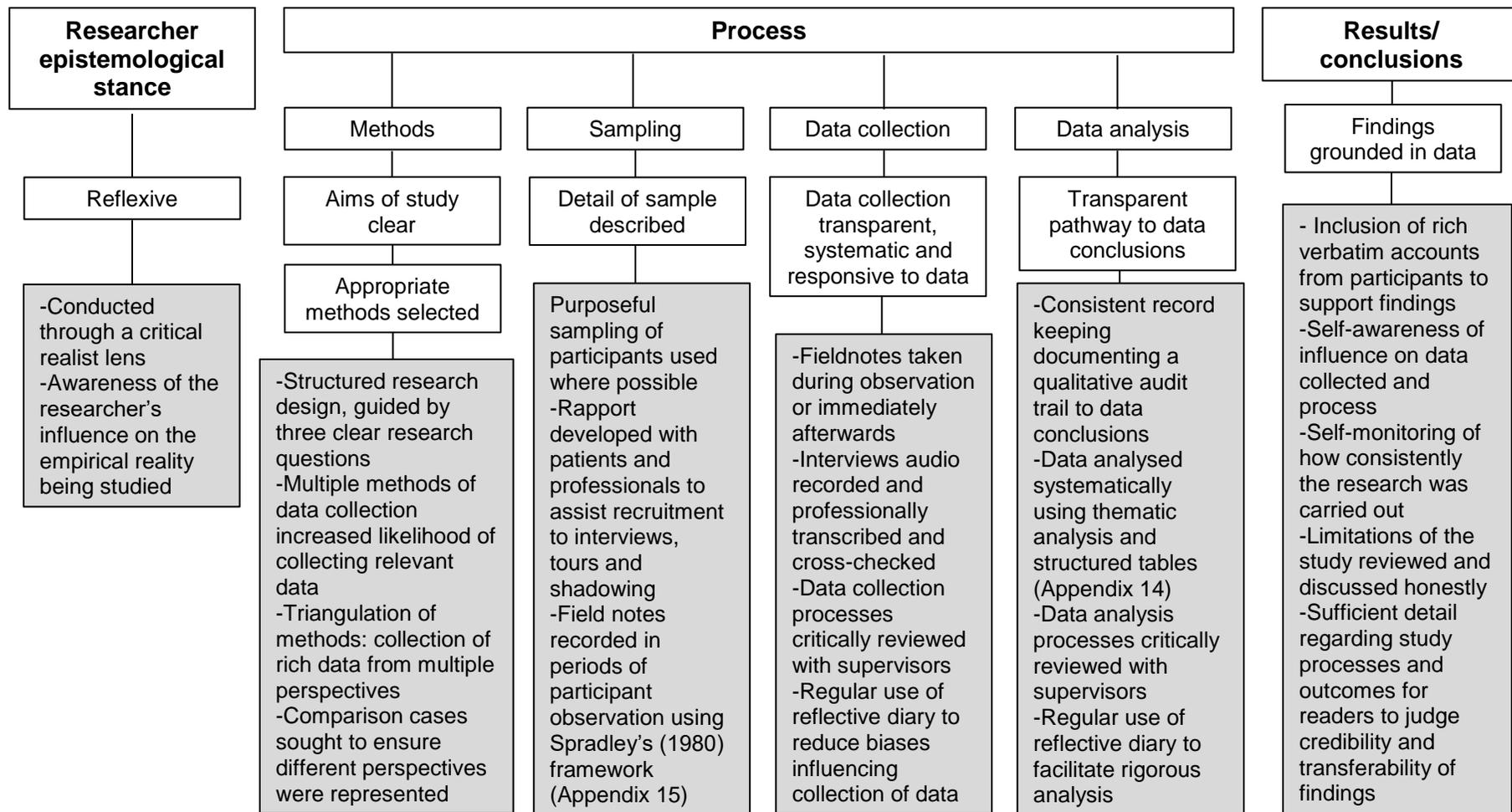
Figure 4.5. Application of a framework for assessing quality and rigour in qualitative research to this multiple-case study (adapted from Meyrick (2006) and Noble and Smith (2015).

Triangulation is viewed as advantageous because obtaining several combined perspectives is superior to obtaining one perspective (Thomas, 2011). Data triangulation exploits the use of different methods and perspectives to generate thorough and comprehensive conclusions (Noble and Smith, 2015); viewed as a key component of case study paradigm (Thomas, 2011). Triangulation of methods, samples and sources is important for 'external validation' of data (Noble and Smith, 2015), promoting the credibility and trustworthiness of research findings (Baxter and Jack, 2008). Moreover, it is important to note that the credibility of a case study is linked to the quality of data acquired from a range of data sources (Yin, 2014). In this multiple-case study, undergoing triangulation gave the researcher opportunity to identify and synthesise both parallels and variations across and within data sets (Lincoln and Guba, 1985; Yin, 2014); this was viewed as an important contribution to enhancing methodological rigour, trustworthiness and generalisability.

While the lack of generalisability of findings can be perceived as a weakness of case study research (Wikfeldt, 1993), through triangulating findings gathered across a multiple-case study it can be argued that the study findings have greater generalisability and transferability: as part of collective knowledge sharing among a specific healthcare cohort (Flyvbjerg, 2006). In this case, this involved sharing a collection of knowledge (triangulated from multiple sources) about the culture of cancer care for young people, among those who cared for them. While case study research cannot offer universal theories, it can offer context-dependent knowledge which can be of value to all who wish to learn about that phenomenon and the context in which it occurs (Flyvbjerg, 2006). The findings of this multiple-case study are transferable to a range of individuals working with young people with cancer; and while the relevance of the findings may vary, the study provides a contribution that will be valuable across the range of contexts in which it was conducted.

4.9.2 Reflexivity

Qualitative research requires a reflexivity and self-awareness, where the influence of the researcher on the processes of data collection and interpretation are recognised, as are their potential biases (Denzin and Lincoln, 2011). A researcher's professional and personal perspective must be made clear, as must the epistemological 'lens' through which the inquiry has been conducted (Greenhalgh, 2014). This doctoral study was conducted in a critical realist paradigm, where the presence of the researcher was recognised as influential on what was being studied (Easton, 2010).

A reflective, transparent and self-aware manner gave control over the unavoidable researcher influence and enhanced the rigour of the study (Easton, 2010).

Reflexivity has been recognised to show transparency of the researcher's feelings during the research process (Flood, 1999; Patton, 2002). The researcher employed a self-critical and self-aware stance and regularly considered the way her thoughts, experiences and emotions affected the data collected; whether it is done consciously or unconsciously, the researcher is the instrument of data collection therefore their impact is inevitable (Baillie, 2015). Following each period of observation, time was spent reflecting on how the researcher's presence impacted the participants, situations and consequently the data (Baillie, 2015). This was documented as part of the field notes in addition to writing a personal research diary. Regular supervision during fieldwork created further opportunity for reflection and discussion of any concerns or issues which arose during data collection.

At the time of data collection, the researcher was working as a Staff Nurse in one of the hospitals where data was collected. While this was an unintentional coincidence, it was important to recognise, prepare for and reflect on the impact of this through the course of this study. This is often called an 'insider' role and the issues that were unique to that role that could endanger the credibility, rigour and findings of a study (Allen, 2004). The term 'insider' is used when a researcher carries out a study with people, communities or organisations that they are already a part of (Asselin, 2003). There are advantages to being an 'insider': the researcher is known in the setting, has easy access to participants, understands the context of the setting, and research access into the organisation is likely to be granted without issue (Asselin, 2003).

As an insider in one hospital, the researcher had greater background knowledge and familiarity with the environment, staff and processes within that hospital; there was already a rapport with many of the staff. Thus there were some advantages that assisted the researcher in terms of familiarity. However, to reduce this perceived influence on the setting, a nursing uniform was not worn and a university identification badge was clearly displayed to encourage identification as a researcher, and not a nurse. In such circumstances, nursing research literature has described a conflict between familiarity and distance (Allen, 2004). In this multiple-case study of the culture of care the researcher had an 'insider' perspective in only one hospital of the 24 hospitals visited. This meant that while its possible influence should be highlighted for transparency, the considered disadvanges of the 'insider'

role would only have impacted data collection in one nested case, thus a small proportion of the overall data collected. Confidence in its minimal impact, was assured through early medtholodogical decisions taken, so for example data were collected using the same methods, procedures and approach in all the hospitals visited. As previously mentioned, in all hospitals visited rigour was maintained through triangulation and reflexivity throughout study conduct.

It is arguable that in the majority of the settings visited, and with the majority of interviewees, the researcher would have been viewed as an 'outsider'. Asselin (2003) emphasised that when a researcher is familiar with the research environment, objectively 'seeing' the setting may be harder and his or her past experiences, beliefs, expectations and emotions can prevent the necessary detachment required for objective and unbiased data collection. Alternatively, Allen (2004) suggested that whether a researcher is an 'insider' or 'outsider' is irrelevant providing they are aware of their own feelings, expectations and emotional responses when conducting fieldwork. Taking this view prepared the researcher to adopt a reflexive perspective to the whole research process, which facilitated a sensitivity to the ongoing impact of being both a nurse and a critical realist.

4.10 Ethics

This study was approved by (London – Central NHS Research Ethics Committee, Reference: 13/LO/1869) (Appendix 16 and 17). Approval at each hospital R&D department was co-ordinated through the NIHR Coordinated System for gaining NHS Permission and individual hospital approval was required from all the hospitals where young people were interviewed.

Reflecting on the experience of researchers who conducted the preceding study (Mapping Teenage and Young Adult Cancer Services in England: The BRIGHTLIGHT Directory of Care, REC reference: 12/EM/0316) and the BRIGHTLIGHT Cohort Study (REC reference: 11/LO/1718), variation in time to approve the study in each hospital R&D department was envisaged from the outset. The study accommodated this unpredictable timeline to a certain extent; early-stage data analysis was concurrent with data collection where possible and furthermore the data collection process was sequential. Fieldwork was undertaken in one hospital whilst ethical approvals in other hospitals were being processed.

Individual hospital approval processes were not undertaken in every hospital caring for young people with cancer in the four networks as this would not have been possible in the study time frame. Hospital R&D approvals were completed in 17 of the 24 hospitals visited, and therefore at the additional seven hospitals interviews were not conducted with patients; however other types of data were collected (tours, shadowing and interviews with healthcare professionals; and observation). R&D approvals were sought in all Principal Treatment Centres in the networks in addition to designated hospitals where the researcher had established timely and efficient communications with the appropriate professionals to instigate approval processes promptly. In two designated hospitals, R&D approval processes were begun however these were not completed before the fieldwork period ended and therefore recruitment was not possible in those hospitals. Significant delays in gaining local R&D approval in some of the hospitals lead to delayed entry into some hospitals and extended the overall period of data collection by three months.

Access was assured from the Lead Clinician and Lead Nurse caring for teenagers and young adults in each participating hospital following an introductory letter, and information was provided to all healthcare professionals involved in caring for teenagers and young adults in each service during the study set-up via written information and a presentation at each hospital multi-disciplinary team meeting. An honorary contract was not required at each site due to the researcher being an NHS employee (NIHR, 2015); instead an NHS to NHS letter of access was issued by the researcher's NHS employer (Appendix 18). The approving letter from the NHS REC was also submitted to the University Ethics Committee with the protocol for 'light touch review' and university ethical approval was confirmed (Appendix 19).

As a registered paediatric nurse, the researcher adhered to the requirements of her Code of Professional Conduct (Nursing and Midwifery Council, 2015), which documented nurses as responsible for their professional conduct and behaviour in all potential roles, including research. Specific issues around research with young people, informed consent, protecting confidentiality and balancing risk of harm with potential benefits were all thoroughly considered prior to commencing the study; these are discussed next.

4.10.1 Research with young people

The recommendations in the 'IOG' (NICE, 2005a) are for patients aged 16-24 years. The national evaluation of specialist teenage and young adult cancer services, the

BRIGHTLIGHT Cohort Study (presented in Chapter 1), also involved young people aged 13-15 years olds to reflect the established configuration of teenage and young adult services in England. In line with the Cohort study, young people aged 13-24 years were eligible in this study. It was felt important that young people less than 16 years had the opportunity to be involved in this case study, to gain the perspectives of younger teenagers regarding their experiences of care. The researcher sought the support of experienced children's healthcare professionals and researchers who understood and respected young people's rights to privacy and confidentiality. Assent was obtained from all those less than 16 years after gaining consent from their parents or guardians, which assisted young people to feel empowered to assess their willingness to participate independently. The appropriateness of the topics covered in the interview schedule was confirmed in the design phase of the study by young people in the BRIGHTLIGHT user involvement group, the 'YAP' (Young Advisory Panel), who have been involved in all aspects of BRIGHTLIGHT work, from inception through to dissemination (Taylor *et al.* 2018/9).

The general societal tradition of unequal power relations between children and the adult population is also present within research (Punch, 2002). This is an important consideration regarding the conduct of face-to-face interviews with young people and a developmentally appropriate approach must be employed (Christian *et al.* 2010). Several strategies were used in this study to restore potential power imbalances and to give young people control over their involvement in the research, these strategies were aligned with the suggestions of Kirk (2007): power relations, informed consent and confidentiality. The strategies for restoring power imbalances between young people and adults in research that were employed in this multiple-case study were (adapted from Kirk, 2007):

- Use of methods that allowed young people to feel part of the research process and which give them the maximum opportunity to provide their views;
- Being responsive to young people's own agendas;
- Checking on young people's willingness to participate throughout the interview, including being aware of non-verbal cues such as body language;
- Reaffirming with young people that they can decline participating or answering particular questions.

Throughout the research process, none of the young people who were included in the study requested to withdraw from their interview or asked for the researcher to

leave a clinical or social area during periods of observation. The researcher upheld sensitivity to young people's behaviour, body language and verbal cues throughout tours, interviews and periods of participant observation and if any young person wished to withdraw or wished the researcher was no longer present, then this would have been honoured. Use of existing data would have been requested at the young person's discretion. If the young person became distressed, immediate support would have been provided. The researcher's background as a nurse provided valuable familiarity and comfort, with the possibility of needing to support young people in distress, should the need arise (Allen, 2009).

Researchers have an ethical responsibility to be prepared to deal with potential negative emotions that young people may experience because of participation in a study (Kirk, 2007). Additionally, referral was in place to gain support from the most appropriate clinical person for that young person; part of the set-up at each hospital was the identification of a member of staff who could provide psychological support for study participants should it have been required.

4.10.2 Informed consent

There are three key issues associated with informed consent that are particularly pertinent in research with young people: the information provided about the study is fully understood, consent is voluntary, and the participant has the necessary capacity to consent (Kirk, 2007). Any research can be perceived as being burdensome for young people and their families when they are dealing with the day to day realities of cancer and its treatment. It is essential that the researchers were confident that the young person, and where relevant, the family, gave voluntary, informed consent to participate, and that this consent was an on-going process (Gibson and Twycross, 2007). Most young people were undergoing cancer treatment when they were approached to participate in the interviews. It was essential that both consent and assent was well-informed. To ensure young people understood what participation involved, all information sheets created for young people were written to a reading level suitable for those aged 13 onwards and written consent/assent was only sought when the researcher felt confident that the young person understood what involvement in the study entailed. The need to produce appropriately tailored information for young people has been recognised (Kirk, 2007). Separate information sheets were available for parents/carers and healthcare professionals. Written consent was obtained from young people older than 16 and from young people and their parents/guardian if they were younger

than 16. As the study involved young people sharing their experiences, the young person's willingness to participate was paramount.

Informed consent during observation and the notion of deception are discussed as problematic in observational research (Mulhall, 2003). During periods of participant observation, a fully overt and open approach was used which involved regular conversations with patients, families and staff about the aims and conduct of the research (Mulhall, 2003). A poster was displayed in the teenage and young adult wards and units in the Principal Treatment Centres where a large portion of the researcher's time was spent (Appendix 20). During periods of participant observation, there were no patient details taken and the purpose was to gain an understanding of the caring behaviours and interactions that occurred within the context, therefore written consent was not required from 'actors' within those observations (Spradley, 1980). The formal handovers, meetings and clinics were observed whilst a specific professional was being shadowed, therefore the professionals gave prior indication that a researcher would be present and verbal consent was obtained by all individuals.

4.10.3 Confidentiality and data protection

The eight principles of the Data Protection Act 1998, concordant with the more recently published 2018 Act, were adhered to in the conduct of this study (Data Protection Act, 2018). Only the minimum data necessary to fulfil the aims of the study was obtained; deleting all personal data as soon as possible; and retaining data in a safe and secure location (Data Protection Act, 2018). Data were initially stored on a University encrypted, password-protected laptop during the field work. Data were safely transferred for back-up via an NHS approved, password-protected USB stick to the NHS N3 network (secure encrypted Internet) based at the Clinical Trials Unit at University College London Hospital. This was onto a secure server that was also password protected. Data were later transferred by an NHS approved, password-protected USB stick to the transcriber for transcription. The transcriber was contracted under the principles of confidentiality and the secure handling of digital and transcribed materials.

Participant numbers were inserted into the transcripts upon receipt and any places or names in the transcripts were removed to ensure anonymity. The anonymised data were then stored on the NHS approved, password-protected USB stick, and was always handled on an encrypted laptop or a secure office computer at the

University or the Clinical Trials Unit. All paper data and consent forms were stored in a locked, fire-proof cabinet, in a room that required personal identification access within the Clinical Trials Unit. Confidentiality was maintained by ensuring no information identifying the young person or family was written in field notes or appeared in transcripts of interviews. Only the researcher and the transcriber had access to digital recordings of the interviews, and the recordings were deleted when the transcripts were confirmed as correct.

4.10.4 Balancing risks and potential benefits for participants

The potential benefits of this study are predominantly long-term, hoping to benefit future teenage and young adult cancer service users as opposed to directly affecting the participants in the study. Young people are usually keen to contribute to findings that will impact changes in service provision and respect for their rights (Fern *et al.* 2014). Patients may benefit from the opportunity to talk about their experiences and feel that their views are listened to (Taylor *et al.* 2016a). It was considered that this study would be of potential benefit to staff members within each hospital, providing an opportunity for professional development, to learn more about young people's services, and to be involved in a research study.

It was considered that participation in the study could have caused participants inconvenience and there was potential for some low-level discomfort due to the presence of the researcher in the clinical areas in particular. Observation has been reported to make those being observed feel uncomfortable, stressed or anxious (Patton, 2002; Mulhall, 2003). It has been argued that observational research will unavoidably compromise the privacy of those being observed therefore researchers need to be sensitive during the conduct and reporting when using observation or ethnography to ensure participants are protected (Denzin and Lincoln, 2005). During periods of participant observation, constant awareness and assessment of each situation occurred and the researcher left if it was felt her presence was unwanted or inappropriate. Prior to entering the field, it was determined that if anything contravening hospital policy or codes of professional conduct was observed, professional processes of incidence reporting would have been followed. This case did not arise during the fieldwork. A summary of the management of ethical issues in this multiple-case study is presented in Table 4.9.

Table 4.9. Summary of ethical issues considered in this doctoral study

Ethical issue	How it was managed
Research with young people	-Power imbalance restored by giving young people elements of control, e.g. location of semi-structured interview -Young people regularly reminded of their freedom to withdraw from the study at any stage -Researcher sensitive to her presence in clinical and social areas where young people were
Informed consent	-Written information for young people at suitable reading level (age 13 plus) -Written assent for those <16 years (alongside written parental consent) and written consent for all participants >16 years -Verbal consent obtained from those specifically being observed -Poster describing the researcher and the study overtly placed on the wards visited
Confidentiality and data protection	-Safe storage and transfer of all data on a password protected, encrypted lap top via an encrytped USB stick -All transcripts anonymised -Consent forms stored in a locked, fireproof cupboard in a secure office space
Balancing risks and potential benefits	-Risk to participants of the study minimal due to the exploratory and flexible approach to data collection -Psychological needs of participants considered at all times and researcher remained sensitive to this throughout data collection

4.11 Summary

This chapter has presented the epistemological position of the researcher and the rationale for using a qualitative, multiple-case study design. Methods, including sampling and recruitment, the data collection procedure, and data analysis process have been presented and discussed critically. This included descriptive details of the individual units of analysis and the four sub-cases studied in this doctoral study, setting the context for the findings presented in the following chapters. Finally, the role of reflexivity in maintaining rigour was explained and the ethical issues encountered during the research highlighted. This concludes Part A of this thesis, and in summary, it has presented how and why this research was conducted, what it aimed to achieve, and how it was carried out.

The second part of this thesis, Part B, is comprised of Chapters 5, 6 and 7: a presentation of the study findings in three separate chapters. These three chapters reflect findings which relate to the three core concepts of culture (see Chapter 2), bringing together data from all sources and settings to explore the culture of care for young people with cancer. A discussion will follow this, which encompasses

exploration of the implications of these findings in relation to previous literature. Finally, the conclusions of the study will be outlined, and the original contribution will be presented and discussed. Additionally, the implications of the study findings, and recommendations for policy, practice and future research will be posed. The thesis will close with an epilogue, documenting the researcher's reflections of this whole process.

Part B

In Part A of this thesis, both the clinical and theoretical contexts were presented, a review of the existing literature highlighted the current gaps in evidence, and the methodology and methods used to explore the research questions were explained. This has set the scene for what follows.

Part B presents the study findings in three chapters (Chapters 5, 6 & 7), corresponding to the three core concepts of culture that guided the research. The themes and subthemes explored in each of these chapters are presented in Tables 5.1, 5.2 and 5.3 respectively. These will include a presentation of the components that contributed to the culture of teenage and young adult cancer care, both the more visible 'above the surface' and less visible 'below the surface' components, in addition to how culture of care was learned, shared and perpetuated. A discussion follows (Chapter 8), which encompasses exploration of the implications of these findings in relation to previous literature. Finally, the conclusions of the study will be outlined, and the original contribution presented and discussed. The implications of the study findings, and recommendations for policy, practice and future research will be proposed (Chapter 9). The thesis will close with an epilogue, documenting the researcher's reflections of this whole process.

Table 5.1. An overview of the title, themes and sub-themes presented in Chapter 5.

Title:	**Culture takes place within a context: the physical and social environments of care**
Theme:	**Physical environment**
Sub-themes:	Factors which affected where young people were cared for: - Diagnosis - Personal circumstances - Geographical location - Age
	Important elements of the physical environment: - Aesthetics - Facilities & Internet - Social space - Flexibility - Bed spaces: bays and side rooms
	Contribution of the physical environment to the culture of care: - Atmosphere - Mood and behaviour

Table 5.1. An overview of the title, themes and sub-themes presented in Chapter 5 (cont.).

Theme:	Social environment
Sub-themes:	Important elements of the social environment: - Role of healthcare professionals - On-site and off-site activities - Social media - Access to peers
	Contribution of the social environment to the culture of care: - Peer support - Family support
Theme:	**The relationship between the physical and social environments**

Table 5.2. An overview of the title, themes and sub-themes presented in Chapter 6.

Title:	**Culture consists of both 'above the surface' processes and 'below the surface' values: communication and core values**
Theme:	**Communication**
Sub-themes:	Interpersonal communication: - Healthcare professional knowledge - Continuity of care - Flexibility and accessibility - Specific roles
	Intra-hospital communication: - Joined up working - Continuity of care - The role of the lead nurse
	Hospital-to-hospital communication: - Multi-disciplinary team meetings - Clarity in healthcare professional roles
Theme:	**Core values of teenage and young adult cancer care**
Sub-themes:	Recognising individuality
	Promoting normality
	Empowering young people

Table 5.3. An overview of the title, themes and sub-themes presented in Chapter 7.

Title:	**Culture is something that is learned, shared and perpetuated: the development of healthcare professional holistic competence and the culture of care**
Theme:	**Healthcare professional holistic competence**
Sub-themes:	Environment
	Experience continuum
	Enthusiasm
	Education
Theme:	**Perpetuation of the culture**
Sub-themes:	Young people
	Leadership
	Buy-in
	Time

This image of a cell was an artist's interpretation of the findings presented in Chapter 5. This, and other illustrations of a similar style, were used in the theatrical interpretation of the findings named the 'BRIGHTLIGHT study: There is a Light' and were displayed on the stage floor of all 11 performances of the show.
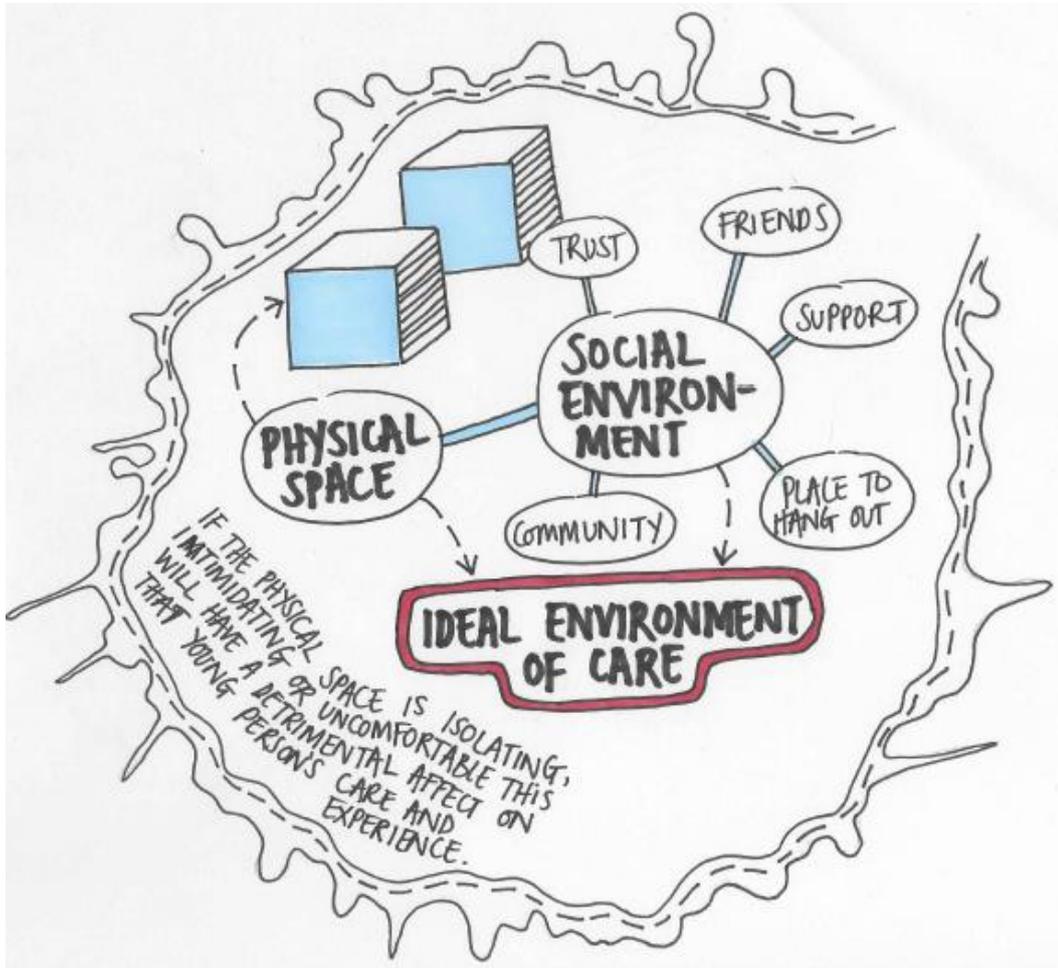
(Reproduced with permission: Jessica Loveday).

Chapter 5

Culture takes place within a context: the physical and social environments of care

5.1 Introduction

This chapter is the first of three; all three of which will present the study findings, segregated in accordance with the three core concepts of culture which comprised the conceptual framework, previously introduced in Chapter 2. This chapter will describe findings related to the first core concept of culture: *culture takes place within a context, and is therefore dynamic and changeable (Lenburg et al. 1995; Kitayama, 2002; Erez and Gati, 2004).* Presentation of the research findings begins with this context for this study, examined here is the contribution of the environment on the culture of care. This includes both the physical surroundings in which young people are treated in, as well as the social environment created through the people they are exposed to. Data revealed a further theme: the relationship between these two overarching themes, as the physical environment that had a key role in the creation of a social environment (Figure 5.1).
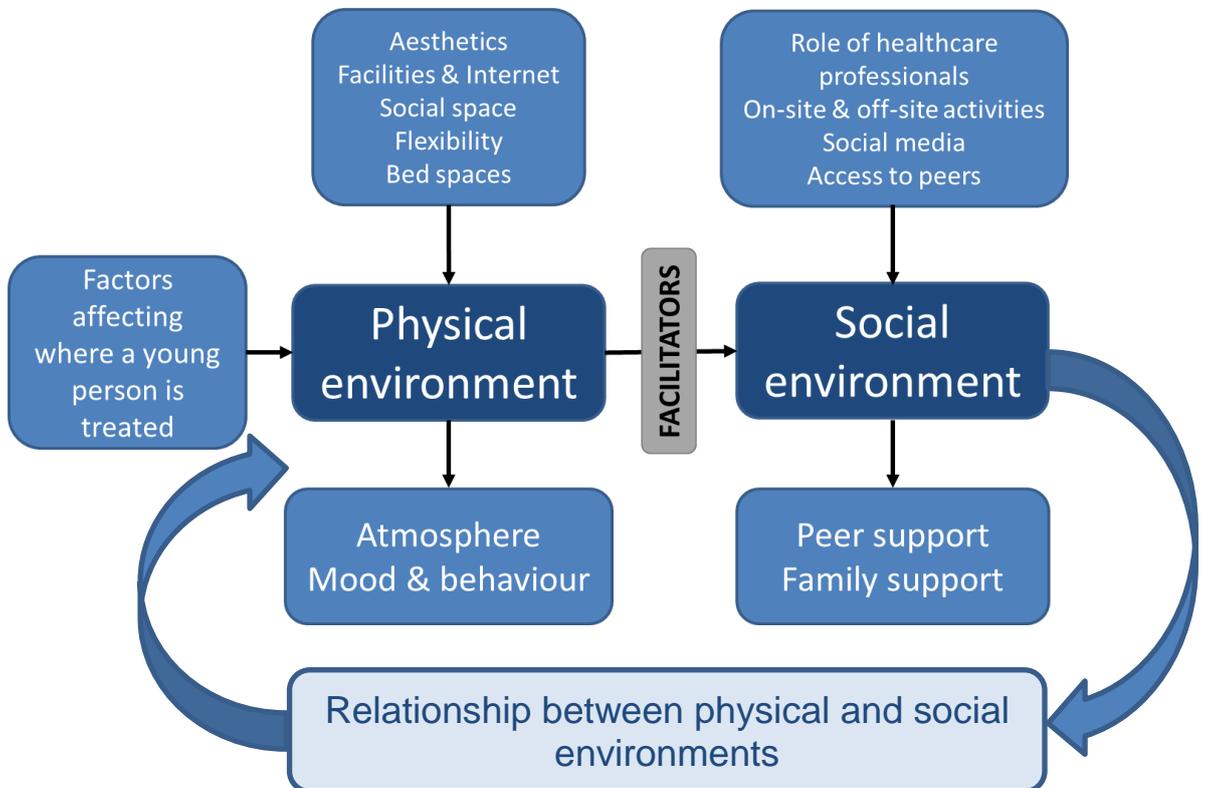
Figure 5.1. A thematic map illustrating study findings about the physical and social environments of care, their connections and relationships.

5.2 The physical environment

Three main sub-themes will be discussed: factors which affected where a young person was treated; important elements of the physical environment; and the contribution of the physical environment to the culture of care. Explored will be some of the visible 'above the surface' structures and processes of care, the features of the physical context in which young people's care takes place, and the combined impact on how care is experienced by young people: these themes are presented in Figure 5.2.
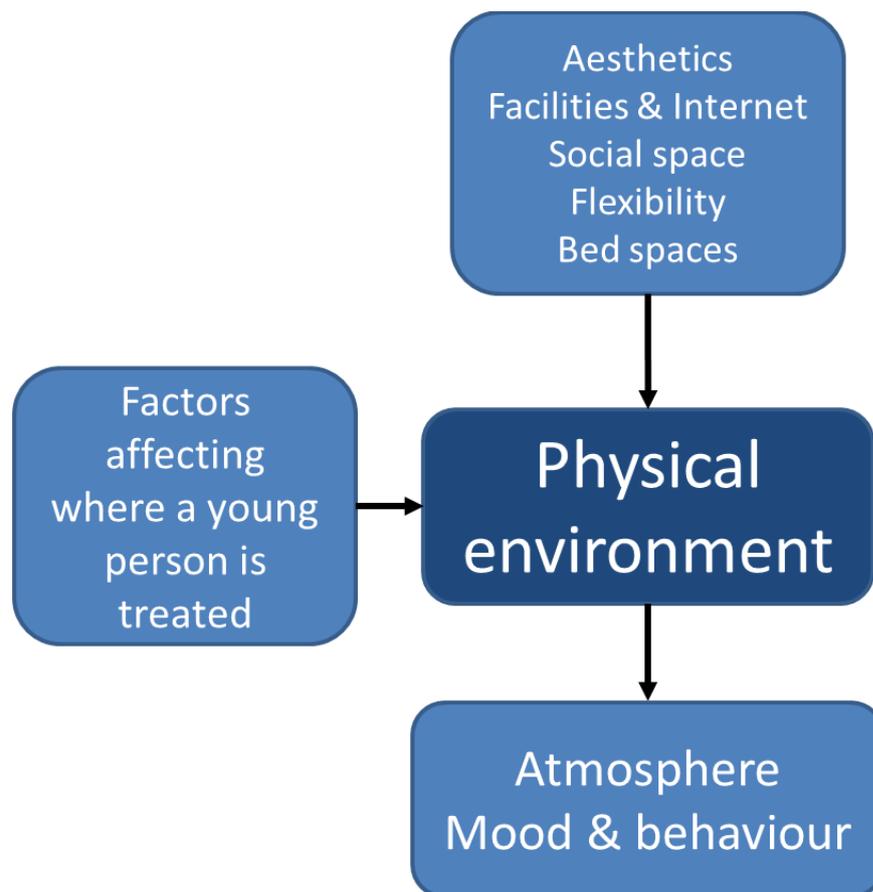
Figure 5.2. A thematic map illustrating study findings about the features and contributions of the physical environments of care.

5.2.1 Factors which affected where young people were cared for

Provision of choice about place of care was a theme which emerged particularly in the interviews with healthcare professionals and young people in the designated hospitals. Several sub-themes emerged from the interviews across all four networks

as factors that influenced the decision of where young people received their care: diagnosis; personal circumstances; geographical location; and age.

5.2.1.1 Diagnosis

The first determinant of where young people received their care was their diagnosis and associated treatment pathway. Young people presenting with a rarer diagnosis required a specialist medical team or surgeon, access to a specific clinical trial, or specialist treatment offered in particular hospital. For these reasons, young people with a rarer cancer diagnosis described not having a choice about where they received their care:

"I have to split my treatments between-, my big ones are here [designated hospital], so I have to travel down here and then my smaller ones I can have at the [Principal Treatment Centre], which is on the young person's unit… there was no alternative."
(Connie, 21, sub-case 2, designated hospital & Principal Treatment Centre)

As a consequence, there were young people who described travelling significant distances from their home to receive the specialist cancer care they required; highlighting the impact that a cancer diagnosis could have on place of care, where young people with a very rare cancer diagnosis may not have an option to choose where they receive their care.

A different experience was described by the majority of young people (aged 19-24 years) whom had more common cancer diagnoses, as they did have a choice. These young people discussed their reasons for making that choice, recognising that Principal Treatment Centres provided specialist care and access to specialist expertise for their disease:

"I was happy to come here [Principal Treatment Centre], because I had lymphoma. It's like a lymphoma centre here. They've got all the specialists… my Consultant is in charge of all the trials."
(Caroline, 21, sub-case 2, Principal Treatment Centre)

5.2.1.2 Personal circumstances

Young people described the impact of their personal circumstances on where they decided to have their cancer care. There were three aspects which informed their decision to be in a designated hospital: 1) closer to their home; 2) family, financial implications of the added travel; 3) education or work-related commitments.

Those who had a young family felt it would be easier for them to juggle the commitments of family life with travel to a hospital closer to their home. This was particularly convenient for patients who were cared for as outpatients, which

enabled them to spend less time away from home. Moreover, when young people required care as inpatients, it was easier for their family to visit them regularly if they were in a hospital closer to home:

"With me living in [city] as well, and because of having to live here, and the kids, and my partner, and family and everyone... like my family would have to come and visit me, split themselves between things."
(Sasha, 24, sub-case 3, designated hospital)

Young people described financial implications which contributed to where they chose to be cared for. In all care settings across all four networks of care young people mentioned that neither themselves nor their family received financial support to assist with the cost of frequent travel to and from the hospital. Moreover, healthcare professionals mentioned that the cost of travel was a common issue for a lot of young people and their families during their cancer treatment. Receiving their care in a designated hospital closer to their place of education or work was also described to be helpful by young people, particularly if they had their treatment in a day care or outpatient setting:

"…because I go to college in [city], it was just more convenient…I go to college in the morning on Tuesday, do my two lessons, then I have chemo in the afternoon. So it just fitted in a lot easier than having to travel to [Principal Treatment Centre]."
(Rhianna, 18, sub-case 2, designated hospital)

This view was also shared by healthcare professionals, as they recognised that work and education were factors influencing young people's decision to receive their care locally at a designated hospital:

"…we do tend to see the older age group who may be in employment or university, therefore I think a lot of the time they want to stay here [designated hospital] because it is easier travel-wise."
(HCP19, sub-case 2, designated hospital)

5.2.1.3 Geographical location

This sub-theme highlighted the geographic location of their home in relation to the different hospitals offering cancer care. As presented in the description of the sub-cases in Chapter 4, there was disparity and variation in where and what services were offered across the four networks. Despite variation in geographical size and service structure, in all four networks increased travel time was a key reason for young people deciding to have their care in a hospital closer to home. This was often due to convenience:

"It was just a matter of convenience. I live about a fifteen-minute drive away from here..."
(Jake, 20, sub-case 3, designated hospital)

"It was just more convenient…just fitted in a lot easier than having to travel to [Principal Treatment Centre]"
(Simon, 21, sub-case 4, designated hospital)

In the geographically largest network of care, with the greatest distances between the Principal Treatment Centre and its associated designated hospitals, the inconvenience of travelling to and from the hospital was discussed in the interviews with healthcare professionals. Linked to the convenience of travel was the notion of familiarity for young people. The majority of young people initially presented at their local designated hospital when they first became unwell, prior to beginning their cancer treatment. Young people described a sense of familiarity with their local hospital and the staff there, and a comfort in being cared for in an environment that was familiar to them. In some cases, young people built a relationship with their clinical team at the designated hospital through this early diagnostic period, and felt comfortable to receive their cancer care from a team that they already knew:

"I've been here a few times. I've met [Consultant] and I know [TYA Lead Nurse], and I met a few of the nurses on the ward before as well...I do think this is a very important part of it, I felt comfortable in my surroundings."
(Jake, 20, sub-case 3, designated hospital)

This was an early demonstration of the importance of patients feeling comfortable within their surroundings, influencing their experience of care.

5.2.1.4 Age

There was variation in segregation of patients within the hospitals. In some Principal Treatment Centres, the younger and older patients were divided (13-18 years and 19-24 years). Those patients on the boundaries between these age groups were given a choice as to whether they were cared for in the younger or older age group settings, providing their diagnosis permitted it:

"The model that we've got… I think it's good we've got a younger one and it's good we've got an older one because the difference is very clear… but it's also a bit of that tailor-made stuff for more individualised care… if it's a seventeen-year-old with colorectal cancer they'd be better here because all the doctors are here…
(HCP30, sub-case 3, Principal Treatment Centre)

Young people acknowledged the benefits of being treated with other young people, regardless of the age gaps between them. Differences in age amongst these groups of young people were deemed irrelevant as simply the fact that they were all young

people together, *"in the same boat"* (Lauren, 16, sub-case 4, Principal Treatment Centre), gave a sense of equality:

> *"…there's no kind of air or pretence or no 'I'm better than you because I'm older,'…there's a sense of equality just because of age..."*
> (Jason, 23, sub-case 3, Principal Treatment Centre)

Services specifically for young adult inpatients (19-24 years) were in some cases less equitable, with different 'bed protection' rules to the teenage ward (13-18 years). 'Bed protection' refers to the restrictions in place as to who has priority over certain hospital beds: young adults did not have exclusive use, nor priority, for using these beds and often they would be given to older adults if they were needed. This resulted in the 'young adult ward' being filled with adults of all ages, which caused young adult patients who were admitted to be placed in other less appropriate wards in the hospital where there were empty beds. Over the period of data collection, several young adult patients were admitted to various adult wards across the hospital, while much older adults remained as long-term patients on what was called the 'young adult' ward:

> *"It would never be filled with young adults. Ever. The beds aren't protected… If you say, yes, you're going to be in a young adult unit, and then there's just elderly care provision surrounding you. It's not the right message..."*
> (HCP7, sub-case 1, Principal Treatment Centre)

Concern was expressed by healthcare professionals working with the young adult patients that this needed to be addressed. The service claimed age-appropriate care for all young patients (13-24 years) however healthcare professionals questioned whether the care provided for young adults (19-24 years) was giving *"the right message"* as the beds were not protected for them.

5.2.2 Important elements of the physical environment

The décor, structure, function and facilities of a physical environment tailored specifically to the needs of young people were also highlighted as important. The sub-themes are presented alongside examples of descriptions and quotes from young people and healthcare professionals.

5.2.2.1 Aesthetics

Young people described the aesthetics of the environment that were important to them; which included wanting a colourful, bright and fun décor that was not too 'babyish', patronising and with no "*Peppa Pig*". Conversely, they wanted décor not to be too clinical, serious or bland:

"I mean, for a start, the clinical blue curtains, the décor, just scrap it, make it bright, homely."
(Connie, 21, sub-case 1, designated hospital)

Windows were an aesthetic feature of the ward environment that influenced young people's experiences of hospitalisation, and they did not like not being able to look outside or to see daylight:

"I think one of the irritating things about the ward is that there are hardly any windows…it's just so horrible without windows… you don't know what time it is… you're all mucked up."
(Anna, 15, sub-case 3, Principal Treatment Centre)

Healthcare professionals' defined similar aesthetic features as important to young people's care settings; features such as colourful décor created an atmosphere that did not feel as clinical:

"It doesn't feel hospital-y in the same way. The colours and the wall posters and the lighting and the stuff that's in the ward makes it feel completely different and if you go onto the adult ward it's all just white and clinical."
(HCP5, sub-case 1, Principal Treatment Centre)

While the aesthetics of the environment were not tailored specifically to young people in designated hospitals, they were satisfied with spending time in an airy, open environment:

"Like, the environment is very airy. It's open. You know, I was given a room for my treatments, because, I don't know, they thought I'd need the space because I was young or something, or want the space. I wouldn't have minded sitting out in the chairs either with everyone. It was very-, I don't know, just sat around drinking coffee and reading."
(Simon, 21, sub-case 4, designated hospital)

5.2.2.2 Facilities and Internet

Access to technology, particularly the Internet and television, were facilities that young people highlighted as a significant requirement of a hospital ward:

"At [Principal Treatment Centre] you had to pay for tellies after 7pm. I'm sorry, I don't agree with that, it's a home comfort really."
(Alena, 15, sub-case 1, Principal Treatment Centre)

In Principal Treatment Centres there was access to a large range of facilities, suiting all ages and personalities:

"You had everything, it doesn't matter what sort of personality you are…you've got games there, books, a collection of DVDs…there are lots of paints, paintings…if you like to make things, there is lots of that...I don't think I would change anything."
(Monica, 24, sub-case 2, Principal Treatment Centre)

Surroundings that contained facilities, such as games and books, made the environment feel less clinical and more familiar, and promoted a sense of comfort and normality:

"I felt more comfortable than I expected to feel in a hospital… I liked the fact that you could leave the ward and go and sit somewhere else, because we had the games room, it wouldn't feel like you were really in hospital, it would just feel like you were in a room with books and stuff. That was nice."
(Jade, 15, sub-case 1, Principal Treatment Centre)

Additionally, it was recognised that access to the Internet was an important part of providing an age-appropriate environment of care, helping young people to keep in contact with others outside of the hospital:

"It's so important…it makes a big difference about people's ability to cope, being stuck in a room for six weeks…that is a difference with local hospitals often, they don't have Wi-Fi… a lot of them have patchy reception generally…as an inpatient and you can't even rely on people being able to contact you."
(HCP38, sub-case 4, Principal Treatment Centre)

All of the Principal Treatment Centres had Wi-Fi, although sometimes temperamental and described to be *"hit and miss"* (Alena, 15, sub-case 1, Principal Treatment Centre)*,* generally it worked and enabled young people to use social media and Internet messaging to keep in contact with family and peers. In designated hospitals, the absence of Internet access was recognised and highlighted as something that would have improved their experience of care:

"I mean, if I had Internet connection, I'd be in heaven."
(Rhianna, 19, sub-case 2, designated hospital)

"Wi-Fi would've been a big plus, it would've helped me stay better connected with the outside world."
(Simon, 21, sub-case 4, designated hospital)

5.2.2.3 Social space

In Principal Treatment Centres, one of the most essential and valued features of the physical environment was having spaces for young people to go that was away from their beds, such as the social space and kitchen:

"It's nice just to know that there is somewhere to go, if you literally just had the room you feel more trapped, whereas yes it's just having that little walk about…even just walking up and making a cup of tea, you've got out of your room."

(Jen, 21, sub-case 4, Principal Treatment Centre)

"It did just feel like a kitchen in a house, rather than a kitchen in a hospital, which I liked."
(Jade, 15, sub-case 1, Principal Treatment Centre)

In contrast to this, in designated hospitals there was *"nothing at all"* in terms of places for young people to spend time away from their bed and this encouraged young people to just stay in bed:

"There is nothing, no, nothing at all… when I haven't got the chemo on, I will go and have a walk about downstairs, but it's got to the point now where I've seen that much of downstairs, it's not much different to being up here. I would rather stay in bed and save myself the effort of going downstairs in the cold."
(Connie, 21, sub-case 1, designated hospital)

Similarly, young people who received some of their care on a children's ward highlighted that there were no facilities available that were appropriate to their age:

"I think the environment could be better, there's a lot to do down there, but it's for younger children, isn't it, really, the stuff they do down there"
(Alena, 15, sub-case 1, paediatric oncology shared care unit)

Social space on the ward generated an environment that encouraged socialising, in addition to providing distractions from the more clinical aspects of their care:

"Here it's a lot more, 'Come hang out. Come have fun,' which is, kind of, what it has to do when they're here for three years, some of them, for their treatments… they've got tables where they can do work, which obviously they need to do, because they're still at school, a lot of them, so they'll have a lot of school work. They've got crafts and things, just to take their mind off it… you've got piano, pool table, table tennis table."
(HCP7, sub-case 1, Principal Treatment Centre)

5.2.2.4 Flexibility

Environments which promoted age-appropriate care were flexible for young people to bring in personal items from home. This simple aspect of having a flexible approach to the environment of care provided comfort to patients:

"You want to bring stuff that reminds you of home really…I love the fact that I can take my duvet in…just makes it so much more homely."
(Emily, 16, sub-case 1, Principal Treatment Centre)

This flexible and relaxed approach to care provision was recognised by healthcare professionals as an important component of age-appropriate care:

"We try and make it as friendly and relaxed as possible, and that they know they can just have people there with them if they want to…they know they can bring anything in… There are not really any rules as such."
(HCP28, sub-case 3, designated hospital)

There was minor variation in the facilities that were provided at the Principal Treatment Centres in the teenage and young adult services, with most of them being equipped with similar age-appropriate facilities, as they were funded by Teenage Cancer Trust. There was however much greater variation in the facilities provided specifically for young people in designated hospitals and paediatric oncology shared care units visited. Many of these other settings had no facilities, and limited or no Internet access at all. Despite the observed variations between the facilities provided, there was a general agreement among the healthcare professionals working in the designated hospitals that privacy, television, the Internet and a flexible approach to visitors were the main requirements for young people:

> *"There is nothing specialist from an environment point of view. Young adults are treated in side rooms, which are nice, private, with an en-suite shower, TV and Wi-Fi. This is everything a young person could want really. Family and friends are welcome to stay in the rooms with them, as they can across all ages in this hospital."*
> (HCP11, sub-case 1, designated hospital)

5.2.2.5 Bed spaces: bays and side rooms

There was an evident physical difference across other structures within the services provided in the Principal Treatment Centres in the four networks. There were Principal Treatment Centres with teenage and young adult wards with only side rooms and no bays of beds. Alternatively, in other Principal Treatment Centres, a mixture of side rooms and bays were provided on the young people's wards. Young people expressed mixed views about this. There were those who were satisfied with having their own room for privacy:

> *"I'm just happier with the fact that we have our own room and our personal space where we can escape."*
> (Mia, 24, sub-case 2, Principal Treatment Centre)

However, there was also recognition that bays created a valuable social environment:

> *"I felt like sometimes I didn't want to go out… I'd just happily sit in my room all day which to me isn't a productive thing to do. Whereas in the bays, you now you've got other people to talk to, even just good morning or good night."*
> (Jason, 23, sub-case 3, Principal Treatment Centre)

Young people acknowledged that the social aspect of being cared for on a bay could lead to a long-term source of peer support and friendship, and shared positive experiences of this:

"Recently I had one of the best bays I've ever been on, with two other girls… they were so funny and so great to chat to. It was a really nice bay to be on, and we keep in touch now, which is lovely."
(Emily, 16, sub-case 4, Principal Treatment Centre)

Healthcare professionals recognised that both bays and side rooms had their advantages and that ultimately it was a matter of providing what was appropriate for the individual patient and circumstance. Services needed to be flexible and meet the needs of individual patients:

"They've both got advantages. I had a patient recently… he liked the privacy of the side room… but he got really depressed, he was isolated…in the other cycles he ambulated… he wasn't as depressed, he was eating better, he was mobilising better."
(HCP5, sub-case 1, Principal Treatment Centre)

5.2.3 Contribution of the physical environment to the culture of care

As outlined in detail earlier (Chapter 1), young people with cancer are cared for in a wide range of settings and therefore a range of physical environments of care. The physical environment was described by young people, healthcare professionals, and observed to contribute to the culture of care. It affected the atmosphere of the hospital setting, the mood and behaviour of both young people and healthcare professionals. The perspectives of young people and professionals in a range of physical environments provided insight into these less visible 'below the surface' components of care.

5.2.3.1 Atmosphere

Atmosphere emerged as a significant part of the environment of care. The atmosphere in environments specifically tailored to care for young people were described as bright, fun and non-clinical:

"I think because they've put fancy lights and stuff and they've made it not feel like just a hospital…made it feel like a fun place."
(Laura, 16, sub-case 4, Principal Treatment Centre)

Young people described the atmosphere on young people's wards as calm, relaxed and homely. They compared these experiences to when they were cared for in other units or wards where the physical environment was not specialised for young people:

"…in a random bit of a hospital, you feel a bit more vulnerable…as soon as you come on to the teenage unit it just suddenly feels calm and quiet…peaceful really."
(Jen, 21, sub-case 4, Principal Treatment Centre)

Young people who received treatment in adult settings commented on the atmosphere that the adult-focussed environment created:

"When I walk into the [adult outpatient setting] every day for my radiotherapy, as soon as I hit the first corridor, the only things I see is 'hope for cancer'…it's just not a lively atmosphere and for me, to walk in every morning, I only see people aged 50 plus."
(Monica, sub-case 4, Principal Treatment Centre)

At the other end of the age spectrum, young people discussed the atmosphere of the children's wards that they had stayed on. Paediatric Oncology Shared Care Unit settings were described as childish and noisy by some, *"prison-ish"* and lacking atmosphere by others. Young people reported that the atmosphere affected their use of the social space:

"…they [children's ward] have a similar room but it has less atmosphere than this room [Principal Treatment Centre]. We never go in there."
(Jade, 15, sub-case 1, Principal Treatment Centre and
Paediatric Oncology Shared Care Unit)

Through observation and discussions with patients and families, it was evident that the atmosphere created in specialist young-people focussed environments felt homely and comfortable for them. This was endorsed by young people across all four sub-cases who had spent time in a Principal Treatment Centre:

"The piano is wicked… very similar keyboard to what I have at home, so you can block out what's next to you and you can just do it, and it feels like you're at home."
(Jade, 15, sub-case 1, Principal Treatment Centre)

The creation of a homely atmosphere promoted normality for patients:

"It doesn't actually look like a hospital in here…in a way it's just a normal world. It's a sense of normality… like it kind of feels like home. I can kind of like come in and just lie down on the sofa and just chill out like I would do at home."
(Liam, 19, Case 2, Principal Treatment Centre)

Healthcare professionals identified the notion of providing settings that did not feel clinical as important to young people and recognised the positive impacts that a non-clinical social space could have:

"I think that's the whole purpose of units like this. They don't want to feel like they're in hospital… don't want to see other people getting treatment. They don't want to feel like a patient. So, they'll come over here, this could be anywhere… isn't hospital-y at all."
(HCP7, sub-case 1, Principal Treatment Centre)

5.2.3.2 Mood and behaviour

The physical environment and the atmosphere created had a direct effect on the mood of young people being treated there. The atmosphere in the social spaces on the young people's wards influenced the mood of young people and their families who were using them. The researcher observed young people enjoying using the social spaces, participating in activities such playing computer games or pool. Moreover, all young people who accessed a physical environment with facilities specifically for young people described the positive difference that it had made to their hospital experience. Young people who had spent time in both a Principal Treatment Centre on a young people's ward and on an adult ward in their local hospital described the contrast in their experience, for example Terry and Kyle both described their experiences on adult wards:

> *"I wouldn't say I was 'down,' but it's nothing really cheerful, and nothing really to look at."*
> (Terry, 24, sub-case 3, Principal Treatment Centre and local hospital)

> *"That was the worst experience…I was mostly just confined to my room because when I'd go out I just felt like they were sort of looking down on me…there was no-one my age there. When I was in the bay… all I'm hearing is this man, 'Oh you nurses are this and that. Death is better than this.' I told them to move me away because that's the last thing you really want to hear."*
> (Kyle, 23, sub-case 2, Principal Treatment Centre)

Young people who were on specific treatments or trials had to spend some time in an adult inpatient ward in their hospital and their descriptions of their experiences were far less positive than their descriptions of the time they spent in the teenage and young adult ward. This demonstrated the impact the care setting had on young people's experiences of care. Furthermore, another young lady juxtaposed her experiences of two very different care settings and how the décor affected her mood:

> *"Being here [designated hospital], compared to being there [young person's unit], it's like a million worlds apart, because here, it's just a ward where everybody is, any age, whatever age. You've got people with different things, so they've got different things going on. Whereas there, yes, everybody has different things, but they are all the same sort of age…even just the décor, it brightens up your day. Waking up, it's more like a big bedroom rather than a ward and you've got your areas where you can go and just be normal."*
> (Connie, 21, designated hospital & Principal Treatment Centre)

One young lady described how it felt to have her chemotherapy on a young people's ward but following this she had her daily radiotherapy treatment in adult outpatients. There were two different departments in the same hospital. Monica conveyed a powerful message about the comfort she felt through visualising going to the young people's ward instead of the adult outpatient department every day:

"I can close my eyes and come to the [teenage and young adult] ward…I feel better…If I'm going there in the morning every day, I don't feel 'Oh my God!' I'm going to hospital today."
(Monica, 23, sub-case 2, Principal Treatment Centre)

Such negative feelings towards a particular environment of care could have important implications for engaging young people with their treatment and addressing poor adherence to treatment.

The physical environment influenced not only the patients but also the staff working there. This topic was discussed informally during the tours and periods of shadowing with healthcare professionals. Professionals described how the young people's wards in the Principal Treatment Centres provided modern, colourful and well-resourced environments, and these settings facilitated healthcare professionals to enjoy interactions with their patients and colleagues. Healthcare professionals identified that the physical surroundings in which they interact with their patients had an impact on the conversations they had:

"The environment flavours the consultation and flavours the discussion that we have with these patients."
(HCP20, sub-case 2, Principal Treatment Centre)

Moreover, this was identified by the young people being cared for:

"I think because of the environment they [nurses] feel like they can have a bit more of a casual chat with you… they've got that extra bit of confidence because it's a relaxed environment, to be more relaxed…talk about every day stuff rather than just talk about how you're feeling…which is mega."
(Jason, 23, sub-case 3, Principal Treatment Centre)

This provided important insights into the power of the physical environment in influencing the communication, relationships and interactions between healthcare professionals and young people.

5.3 The social environment

Two main themes will be discussed: the important elements of the social environment; and the contribution of the social environment to the culture of care.

There were several sub-themes which emerged, and these are illustrated in the thematic map presented (Figure 5.3).
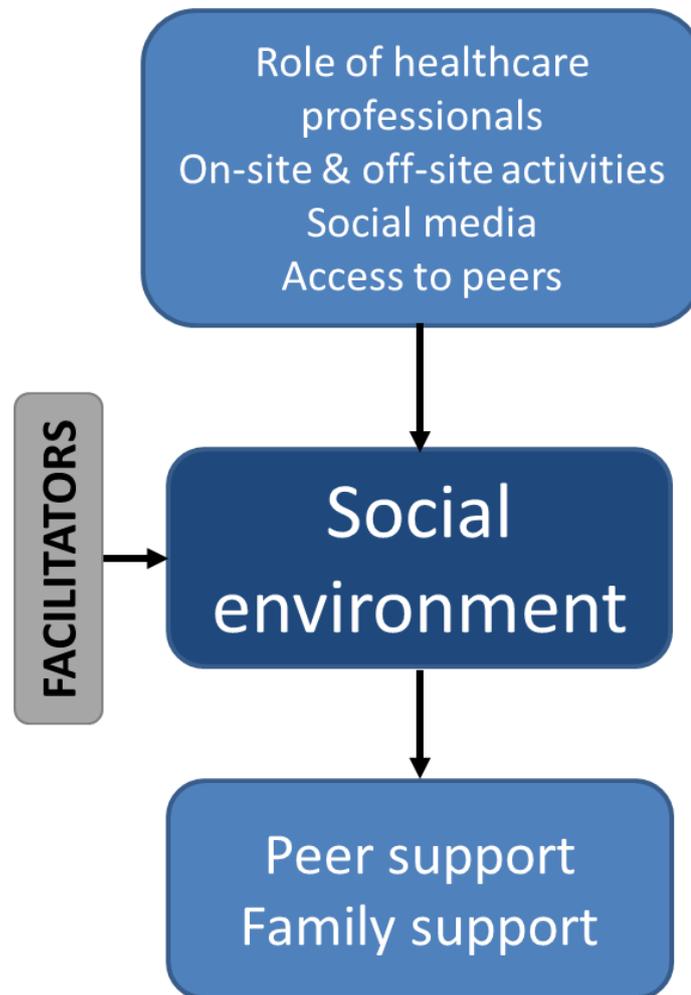
Figure 5.3. A thematic map illustrating study findings about the facilitators leading to a social environment of care, and the impact of the social environment.

5.3.1 Important elements of the social environment

Themes emerged that were described to facilitate the social environment. These were people or processes that assisted young people to socialise and interact with each other, their families and professionals. In turn, these facilitators helped relationships to flourish.

5.3.1.1 Role of healthcare professionals

Youth support co-ordinators are a unique role to the specific teenage and young adult multi-disciplinary teams providing care to young people. The role is therefore predominantly unique to the care provided at Principal Treatment Centres.

Interviews were conducted with youth support co-ordinators across all the Principal Treatment Centres visited and there was some variety and uncertainty when youth support co-ordinators were asked to describe their role in caring for young people. Nonetheless the major commonality was the perception that building relationships both with young people and between young people was central to the role. Young people identified the importance of the relationship they had with their youth support co-ordinator:

> *"So for me it's just about having space, and someone like [Youth support co-ordinator] to chat to - which are both pretty bob on at the moment."*
> (Jason, 23, sub-case 3, Principal Treatment Centre)

The social space provided in teenage and young adult wards enabled youth support co-ordinators to better fulfil their role, where the environment provided the space and facilities to bring young people together. This was frequently observed on the wards, as well as being described in the interviews:

> *"I think the environment, in terms of what Teenage Cancer Trust has created, for my role, is pivotal…before that, I felt like it was almost impossible to do my role."*
> (HCP17, sub-case 2, Principal Treatment Centre)

Other professionals working in environments with social spaces specifically designed for young people recognised that the youth support co-ordinator role was vital to encourage young people to use the social space on the ward:

> *"...the activity/chill-out room has really started being used, because of things that [Youth support co-ordinator] was doing, doing brunch clubs and that sort of thing."*
> (HCP19, sub-case 2, Principal Treatment Centre)

Young people described how youth support co-ordinators organised the social activities that happened both on-site and off the ward, all co-ordinated and advertised by a closed Facebook page for young people run by the youth support co-ordinator. The opportunity to go on off-site social events was very important to young people being treated in designated hospitals: where on-site access to socialise with other young people with cancer was usually limited or non-existent. One young lady treated in a designated hospital described her experience of meeting another young person with the same diagnosis as her on a social event, conveying how positive the experience of being able to access the support of a peer was for her. This was an example of how, for young people in designated hospitals, access to peer support was facilitated by the provision of off-site social activities run by youth support co-ordinators.

In addition to the youth support co-ordinator role, nurses contributed to the development of a social environment. While this was recognised to be a priority in Principal Treatment Centres, designated hospitals and Paediatric Oncology Shared Care Units, Lead nurses and Clinical Nurse Specialists assisted young people to connect. It was common across designated hospitals that they cared for very small numbers of young people, and they usually did not have a youth support co-ordinator, therefore the nurses considered it important to assist young people to meet peers:

"I think that's part of the job. You, kind of, buddy people up and help them connect."
(HCP34, sub-case 4, designated hospital)

Nurses were also included in some of the social activities that were organised at the Principal Treatment Centre, both on-site and off-site. The presence and involvement of nurses during non-clinical social activities assisted nurses to build relationships with young people, in addition to helping bring young people together.

5.3.1.2 On-site and off-site activities

On-site activities for young people were run in the Principal Treatments Centres, and referred to groups or activities, such as arts and crafts or music groups that took place in the areas where young people were cared for. Such activities were described by young people as a welcome distraction during treatment, particularly at times when they felt bored or isolated. All the Principal Treatment Centres across the four networks of care provided on-site activities during the fieldwork period for each sub-case. These were attended by the researcher during her periods of participant observation. Participation in the activities enabled rapport building between the researcher and the young people, which gave the researcher a personal experience of the positive impact that hosting activities for young people in hospital could have on relationship building:

> *Field note entry 30/06/2015*
>
> ***Space:*** *Around the large table in the social space, Principal Treatment Centre, sub-case 2*
> ***Time:*** *Mid-afternoon, there was a 'lull' in the business on the ward, it was a peaceful afternoon, quiet in the social space*
> ***Actors:*** *Myself, youth support co-ordinator, 2 young people and one mother of a patient.*
> ***Activity:*** *the youth support co-ordinator laid out arts and crafts activities for anyone on the ward, patients, friends, family to get involved in. Today we were sewing sock puppets.*
> ***Events:*** *Whilst making my own sock puppet and chatting to young people and the youth support co-ordinator, I spent some time observing a mother*

who had joined us at the table. You could certainly see that the mother (of a 13-year-old patient) emotionally gained a lot from making the sock puppets – she sat there for a good few hours doing it and it was obviously very therapeutic for her. I discussed this with the youth support co-ordinator and she said that doing arts and crafts style activities like that can either promote concentration and silence, allowing young people, parents, siblings to have a peaceful and quiet distraction. Alternatively, activities like that can allow a space to have casual chatter, or even more in-depth conversations. She said that she [youth support co-ordinator] is very much led by the young people or their families and the atmosphere: that is the brilliance of arts and crafts in particular. I participated too and made a sock puppet with them – it was great fun and a creative and relaxed way of building a genuine rapport with the young people and families.
Feelings: *I chatted for a long time with those around me, conversations that I don't think would've happened without this space to get together and a shared focus.*

Similarly, youth support co-ordinators regarded the participation in on-site activities such arts and crafts or pool as a *"vehicle"* to build relationships with young people:

"I may interact with patients playing the games or doing their crafts, and so on. I'm using that as the main rapport-building for my role…it's a very good vehicle to create your relationship."
(HCP 3, sub-case 1, Principal Treatment Centre)

Additionally, off-site activities were hosted, such as day trips, evening meals and social activities, for example bowling or music concerts. Off-site activities of this nature involved young people at different stages (newly diagnosed, on treatment, and finished treatment), providing a chance for young people to give and receive support to their peers. Off-site activities also provided an opportunity for young people from any hospital in the network of care to meet, whether they have received their care in a Principal Treatment Centre, designated hospital or paediatric oncology shared care unit:

"It started quite small and its quite big now, quite a big group, it ranges from thirteen to 24s. What is nice within that is everyone has made little friendship groups...It just gives them a chance to be with other young people in a chilled atmosphere, away from the hospital."
(HCP24, sub-case 3, Principal Treatment Centre)

5.3.1.3 Social media

Access to social media was advocated across all the care settings visited and was regarded as essential to enable young people to stay connected to peers and family. It provided great comfort to those who were separated from family and friends, and

young people that spent time in a hospital with no Internet or telephone signal described how they struggled with feelings of boredom and isolation.

Young people in designated hospitals often did not meet any other young people with cancer and the Internet was therefore a medium for seeking peer support:

"Inpatients you need to be thinking wider, but it's still about having that ability to be in contact with your friends…usually via Facebook. So it's having the technology to be able to do that, the Wi-Fi access to do that. Having the space to be able to entertain friends if they come and visit."
(HCP 34, sub-case 3, designated hospital)

Connecting with others through use of social media was a valuable way of obtaining peer support. However, it was noted that connections between young people, particularly for those in designated hospitals, were often facilitated by a healthcare professional. This highlighted the importance of healthcare professionals recognising the importance of peer support and thereby creating opportunities for young people to connect:

"The lass who's not long finished, I made contact with the previous girl who'd got Hodgkin's. They were on Facebook together, they chatted and I think she did help enormously."
(HCP34, sub-case 4, designated hospital)

5.3.1.4 Access to peers

Specific processes of delivering care were observed and discussed by healthcare professionals that were put in place to facilitate peer-to-peer interactions. In one Principal Treatment Centre, the implementation of a discrete 'young adult clinic' was a unique process which assisted young adults to socialise. Young adult clinic appointments were assigned together and the clinic waiting room was staffed by the youth support co-ordinator and young adult Clinical Nurse Specialists. This enabled and encouraged young adults to meet one another, despite being in an adult outpatient environment. In the same sub-case, a similar methodology was used in the children's outpatient setting. While waiting for their clinic appointments, young people congregated in the teenage and young adult ward and used the facilities in the social space. This maximised their socialisation with other young people, as opposed to waiting for their clinic appointment in a child-focussed environment:

"So that opportunity to come down here, mingle with young people and chill out in the day room, use the Wi-Fi or watch a film while they're waiting. I think it's a much better option."
(HCP24, sub-case 3, Principal Treatment Centre)

Engagement with peers was an important aspect of young people's care experiences. The implementation of simple processes of working like these maximised the time young people spent in the social space with other young people.

5.3.2 Contribution of the social environment to the culture of care

Structures and processes were identified in Theme 5 as important in generating a social environment of care (role of healthcare professionals; on-site and off-site activities; the Internet; and access to peers). This unique social environment created contributed significantly towards the culture of care and provided a supportive context of care for young people, their peers and their families. These two sub-themes will be explored in this section.

5.3.2.1 Peer support

In their interviews, young people described their experiences of having peers from whom they received support, and whom helped them to understand and cope with their cancer treatment. Young people shared experiences of their treatment, and found the relationships they built with other young cancer patients different to their existing friendships:

> *"I was trying to explain to my other friends because they were like, 'Oh you've become all pally with your cancer crew'…you just kind of click because you completely understand each other and you're all in the same position…there's no one here that I don't get on with."*
> (Caroline, 21, sub-case 2, Principal Treatment Centre)

Having access to peers, either existing or a new *"cancer crew"*, encouraged use of the social spaces on the young people's wards and units. Young people had friends visit them and they would often congregate in the social spaces, which contributed to the generation of a lively atmosphere in these areas. Young people talked about the importance of spending time with others, and that just knowing that other young people were around was helpful, promoted normality and positively impacted their care experience:

> *"I spent 10 weeks in isolation on the ward, so, like, people were bringing me things to do, to keep me busy, so I wasn't getting bored and things…when I'm not in isolation…getting up to come up and sit in the day room and do things with everyone else…it's just fun to meet and talk*

*to other patients…gives you a chance to take your mind off it, chill out
like a normal teenager."*
(Nina, 17, sub-case 3, Principal Treatment Centre)

One young person described her environment of care to be like a *"chemo youth club,"* which portrayed a social environment of togetherness and solidarity between young people. Existing friendships were a second type of peer network contributed to a social environment for young people. Young people talked about the advantages of having flexible visiting hours on the young person's ward as it gave more opportunity for friends to visit compared to when they were staying on an adult ward. This showed that flexibility in the way that the environment was used contributed to a culture of care which promoted and enabled peer support.

Likewise, healthcare professionals identified the significance of providing young people with access to peer support: a vital part of supporting young people's social development as it is normal throughout the teenage and young adulthood years to be surrounded by peers:

"I think peer support is a massive thing…access to peer support and social activities because I guess people are at a point in their lives where developmentally so much is happening still and that development happens in the context of peers really."
(HCP9, sub-case 1, Principal Treatment Centre)

5.3.2.2 Family support

The impact of a social and supportive environment of care proved to be important to the family as well as to the patients. Healthcare professionals recognised that parents often felt reassured by the age-appropriate, nurturing nature of the environment:

"I think they feel quite comforted that they know their young person is in the environment that they're in."
(HCP17, sub-case 2, Principal Treatment Centre)

Young people recognised that parents and families also contributed to and appreciated the social space on the young people's wards, using the space to connect with other families and to support each other:

"I think it's quite nice for the mums as well, they always seem to have a bit of a chat up there and see how everyone else is doing and stuff."
(Jen, 22, sub-case 4, Principal Treatment Centre)

The sub-theme of family support was not discussed in any of the interviews with healthcare professionals or patients in the designated hospitals, except for the single designated hospital that had a social space specifically for young people. This

highlighted the influence of providing a physical space to enable families to congregate, a structure that was absent in all the designated hospitals except one.

5.4 The relationship between the physical and social environments

There was evidence of a noteworthy relationship linking young people's physical and social environments as an important theme of the culture of care. A suitable physical environment was one factor found to assist in creating a social environment for young people with cancer. Provision of social space, such as a kitchen, enabled 'normal' teenage interactions to occur:

"I had a friend on the ward and she and I would go in the kitchen and have breakfast together and we'd have a nice chat about things. It was probably one of the best experiences… it made things a lot easier, just to have a chat."
(Jade, 15, sub-case 1, Principal Treatment Centre)

In addition to the provision of social space, for a social environment to really flourish, young people were encouraged to come together by healthcare professionals. The presence of someone to co-ordinate social activities facilitated a social environment where young people became friends and supported each other. This was primarily the role of youth support co-ordinators; a role which also entailed *"picking up issues"* and supporting young people emotionally and psychosocially:

"Part of my role is to encourage peer support… that can be as simple as asking if someone wants to be put in touch with someone that's had a similar diagnosis…peer support could be getting together to do an activity…I would be facilitating from a conversations/picking up issues point of view."
(HCP17, sub-case 2, Principal Treatment Centre)

Young people recognised the value in having healthcare professionals encourage and enable peer-to-peer interactions. Interaction with other young people was a process which was described as daunting when first hospitalised, and therefore having help with this was recognised to improve their experience:

"They really encourage you to talk to each other in here…To begin with I refused to come in here because, to me, if I come in here I have got cancer…I waited until no one was in here and I kind of snuck in…people came in and I started getting talking to them, and I was like, 'this is actually amazing!' I felt so much better…"
(Caroline, 21, sub-case 2, Principal Treatment Centre)

Young people expressed that the dedicated environment on specialist units was very important to their experience of care; in particular providing a communal, social

space in which they would come into contact with other young people. This reduced any feelings of isolation and reminded them that they were not alone:

> *"Well, the number one for me is the environment… seeing other people…having a day ward or just a social space. I think even if you see other people but you don't speak to them, it's like a reminder that you're not the only one that's going through it and that it's not just you in an isolated space."*
> (Laura, 17, sub-case 4, Principal Treatment Centre)

The vast majority of the designated hospitals did not have the additional features of a specialist young person's unit: there was no social space away from the bedside to facilitate patient socialisation; no kitchen to reinforce feelings of normality; and no youth support co-ordinator to bring young people together. Young people in designated hospitals identified the lack of these things, and expressed how they felt they had nowhere to go to escape their hospital bed:

> *"I mean, for a start, the clinical blue curtains, the décor, just scrap it, make it bright, homely. There is nothing, no, nothing at all… when I haven't got the chemo on, I will go and have a walk about downstairs, but it's got to the point now where I've seen that much of downstairs, it's not much different to being up here. I would rather stay in bed and save myself the effort of going downstairs in the cold, I just stay in bed."*
> (Connie, 21, sub-case 1, designated hospital)

> *Field note entry 20/03/2015*
>
> **Feelings:** *I'm observing significant amounts of interaction between staff and young people at the PTCs due to the time I'm spending on the units and the social spaces that I am able to spend time in observing. I'm seeing less in terms of young people interacting with each other and also with healthcare professionals at the designated hospitals. I guess this is both down to the small numbers of young people treated at designated hospitals and the smaller amount of time I'm spending there, and the fact there are not many places to 'hang out' when I am there– most of the time I haven't seen any young people when I've been visiting.*

For young people who received care in both specialist and non-specialist environments, comparisons in their experiences were drawn, and healthcare professionals perceived vast differences in young people's mood and willingness to socialise. The provision of an age-appropriate physical environment and facilitators to encourage peer support had a very positive impact:

> *"We had one or two patients who made the transition from being on the adult ward to…on the teenage unit and they were completely different people…one young lady with an amputation…never even put the prosthesis on to leave the room on the adult ward. As soon as she hit the teenage cancer unit, the leg was on all the time*

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and she was in the recreation room interacting with other patients and staff so much more…"
(HCP20, sub-case 2, Principal Treatment Centre)

The designated hospitals visited in this study had sizeable adult outpatient units, separate to the wards, with high patient throughput. Interview data with young people in designated hospital outpatient/day care settings were accepting of the basic facilities that they were provided with and grateful for the care that they received. Young people were frequently offered side rooms or private bays when receiving day care treatments to give privacy and space away from older adults, however some young people felt that they would have been happy to receive their care alongside adult patients:

"The environment is very airy, open. I was given a room for my treatments…they thought I'd need the space because I was young…I wouldn't have minded sitting out in the chairs either with everyone."
(Simon, 21, sub-case 4, designated hospital outpatient)

In the Principal Treatment Centre where the teenage and young adult outpatient unit was located in a separate building to the ward, both young people and professionals described finding it hard to socialise with others when attending hospital for only a few hours or one day at a time. While youth support coordinator's facilitated social activities, these were often poorly attended and this was suggested to be due to the flow and changing of patients coming in and out throughout the day, all staying for different lengths of time:

"I'm usually one of the few that do have a go. Not many people do it, but I try and have a go at most of the things…sometimes it just comes at the wrong time…we're just leaving and I don't want to hang around because I feel rough."
(Jade, 15, sub-case 1, Principal Treatment Centre inpatient & outpatients)

Healthcare professionals in the Principal Treatment Centres felt that it was harder to facilitate opportunities for peer support in the outpatient/day care settings, compared to the ward where the patients were static:

"I think [social activities] is something we need to work on more in day care… there is that family nurturing, everybody's in it together environment that you have on the ward which is quite difficult to create in outpatients."
(HCP 5, sub-case 1, Principal Treatment Centre)

Differences between the sub-case Principal Treatment Centres emerged in terms of where inpatients and outpatients were treated in relation to each other; and this affected the integration of young people across the two treatment environments. In three of the Principal Treatment Centres, outpatients receiving day treatments were alongside inpatients in an area on the ward. This provided opportunity for integration and socialisation. Alternatively, outpatients attending clinic appointments or patients receiving radiotherapy, were frequently seen in a different part of the hospital with limited or no opportunity for interaction with other young people. In hospitals where the inpatients and outpatients were treated alongside one another, the sharing of the social space promoted the interaction of the two patient groups:

"…this coming together of the outpatient population with the inpatient population. Now that we've got the [social space], if you come into clinic and you have to wait for several hours…they're participating, they discuss things with other patients, they interact with the nursing staff..."
(HCP20, sub-case 2, Principal Treatment Centre)

The advantages of caring for young people in an appropriate and dedicated environment were further highlighted when contrasted to the adult outpatient setting:

"Nice for the staff to see both sides, it's not always been like this. We had to fight to get day care patients up here… over in adults, it's just soulless really, a bit like a cattle market... a conveyer belt."
(HCP 23, Case 3, Principal Treatment Centre)

While Principal Treatment Centres had environments for young people receiving treatment as a day care patient, the adult outpatient *"cattle market"* or *"conveyer belt"* approach was still experienced by all the young people who received their care in regular adult outpatient settings.

"I was aware that, quite often, when I was having treatment, I was the youngest person in the room, but it doesn't really bother me…They have invited me out for things but, to be honest, I didn't go to any…I could've gone to them but, I guess, I felt like I was doing fine."
(Simon, 21, sub-case 4)

There was evidence in all four networks of care of rapid growth of outpatient/day care services, both young people and professionals across all sub-cases described this growth and the challenges this brought (Table 5.4). Healthcare professionals leading services expressed a need to expand day care space for young people to be cared for, and to ensure services were better resourced to meet the needs of this growing patient group. Table 5.4 highlights that all Principal Treatment Centres were busy and full, sometimes working above their bed capacity.

Table 5.4. Evidence showing the growth of teenage and young adult outpatient/day care services.

Sub-case 1	Sub-case 2	Sub-case 3	Sub-case 4
"I think we're getting to the point when we need more beds" (HCP7, Principal Treatment Centre)	*"So our day care activity last year was up 200% and the year before it was up 100% for the TYA age range."* (HCP16, Principal Treatment Centre)	*"We are looking at doing something with here to make it more of a day-case space…there are lots of day-cases that come through…it just needs to be slicker."* (HCP30, Principal Treatment Centre)	*"…I come here [Principal Treatment Centre] when [POSCU] can't do the treatment...it could be a half an hour treatment but then it's so busy that you end up here for five hours."* (Lauren, 16, Principal Treatment Centre)

POSCU: Paediatric Oncology Shared Care Unit

5.5 Summary

The findings presented in this chapter have conveyed the role of the physical environment in providing the context of care to young people with cancer. Findings have illustrated the role and importance of the features of the physical environment in the generation of a social environment, particularly the provision of social space, with the assistance of number of facilitating factors such as the youth support co-ordinator role and availability of the Internet. There was however variation in the structures and facilitators available to young people, dependent on the type of hospital where they received their care, and whether they were in an inpatient or an outpatient setting. Data demonstrated that this variation in care setting impacted on young people's social experience, largely due to the availability of opportunities for peer support. The discussion around these findings has untangled the potential impact place of care can have on a young person's experience of care, relating the findings to existing research and service guidelines. This chapter has provided details as to some of the structures and features that visibly contribute to young people's care, and the next chapter will explore both the 'above the surface' processes and 'below the surface' values which contribute to that overall culture.

Chapter 6

Culture consists of both 'above the surface' processes and 'below the surface' values: communication and core values

6.1 Introduction

The previous chapter presented study findings related to the first of the three core concepts of culture that framed this study conceptually. Chapter 5 described the different contexts of care, and the contribution of both the physical and social environments to the culture of care. This chapter, the second of the finding's chapters, will focus on the second core concept in the conceptual framework: *culture consists of both visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).* Two sub-sections will present the major themes of findings: communication and core values. Communication formed one of the fundamental, visible processes of care, and had an important contribution to the 'above the surface' culture of care. Three sub-themes emerged within this: interpersonal communication, intra-hospital communication and hospital-to-hospital communication. The theme 'communication' also included the interactions and relationships young people described as having with healthcare professionals, and that healthcare professionals had with each other; where the term 'communication' is used, this additionally includes the interactions and relationships between individuals.

The core values of teenage and young adult cancer care, comprised of the sub-themes: recognising individuality, promoting normality, and empowering young people. These three core values emerged as an essential part of the less visible 'below the surface' culture, and were fundamental to the provision of tailored, age-appropriate care for young people.

6.2 Communication

A core concept of culture is that it includes the visible goals, processes, structures, and knowledge of an organisation ('above the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014). Communication was the major visible process of care that occurred between patients and professionals, on both an

individual level, and within groups. Through analysis of the communication and relationships that connected individuals, teams and networks surrounding young people's care pathway, three types of communication emerged: interpersonal, intra-hospital, and hospital-to-hospital. These themes and their respective sub-themes are mapped in Figure 6.1.
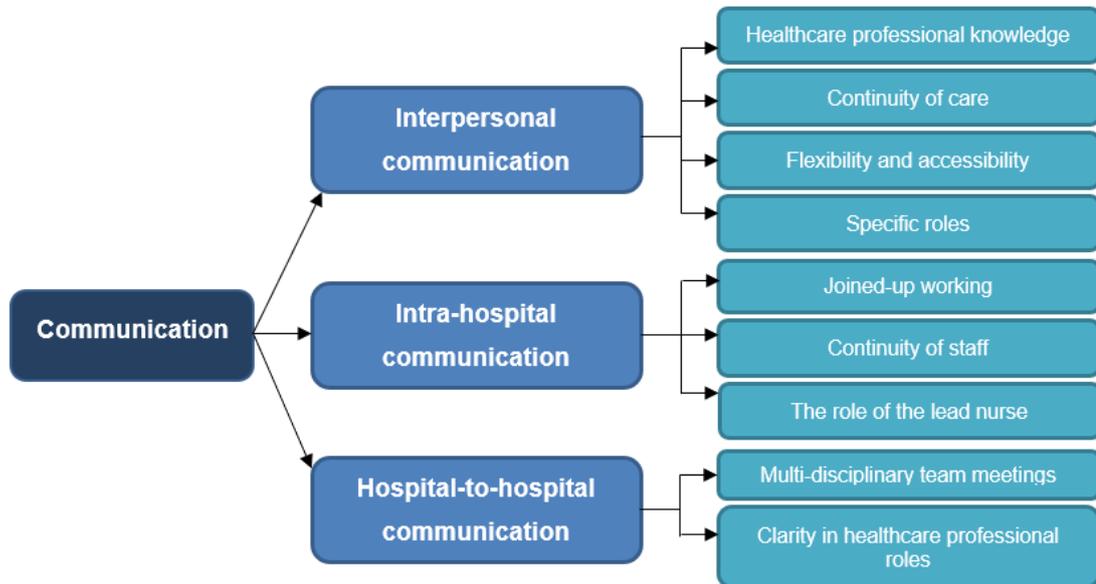
Figure 6.1. A thematic map of the study findings relating to communication.

6.2.1 Interpersonal communication

Interpersonal communication occurred directly between a young person and their healthcare team. When discussing communication in the interviews with young people, this type of communication was the dominant focus. This was likely to be due to the direct effect of these personal communication experiences on their overall experience of care. Young people and healthcare professionals not only highlighted the nature of the conversations they had, but deeper interactions and meaningful relationships were uncovered as part of their positive care experiences.

Effective styles and methods of interpersonal communication assisted the building of relationships between healthcare professionals and young people, and these were influenced by several factors:

- Healthcare professional knowledge
- Continuity of care
- Flexibility and accessibility
- Specific roles

These factors will be discussed in turn, with examples from data to demonstrate how they influenced the interpersonal communication which occurred between young people and healthcare professionals. Different care contexts will also be explored.

6.2.1.1 Healthcare professional knowledge

Healthcare professional's knowledge was connected to the effectiveness of their interpersonal communication with patients. Young people recognised effective communication, and identified and valued the relationships they built with the healthcare professionals who cared for them. Effective communication arose when healthcare professionals understood young people's needs, and had knowledge of how to approach and support them appropriately. Young people recognised and valued the meaningful interactions they had with healthcare professionals, both within Principal Treatment Centres and designated hospitals:

"Not that they're less professional, they're perfectly professional…they've also got that slight element of casual-, I wouldn't say friendship because that's definitely the wrong word, but they've got that kind of casual conversation that you would have if you're anywhere else in real life… I think they're all incredible."
(Jason, 23, sub-case 3, Principal Treatment Centre)

"The nurses and everyone down there [adult cancer ward] … they are the key people because they see you every day, you get to know them on a personal level. It's not just a professional thing for them, it's a lot deeper than that."
(Jake, 20, sub-case 3, designated hospital)

Healthcare professionals proposed a noteworthy link between staff education and experience working with young people, and their comfort and skills of interpersonal communication. It was recognised that a young-person focussed approach to communication was not common practice among all healthcare professionals in all care settings, and was a skill that required focussed development:

"I think we've got to do some work in this region with just looking at people's attitudes and ways of talking to young people and not talking to parents."
(HCP16, sub-case 2, Principal Treatment Centre)

Some young people in designated hospitals described interpersonal communication where healthcare professionals demonstrated sensitivity and adaptability to their personal communication preferences. An example of this was young people who wanted to be spoken to like an adult:

"Everything was really good. Being treated like an adult… Then, I guess, for all intents and purposes, I've felt like an adult since I was sixteen. At eighteen I left home, paid my way, had a flat. So I lived a very adult lifestyle."
(Simon, 21, sub-case 4, designated hospital)

6.2.1.2 Continuity of care

Young people felt that having continuity and consistency in the healthcare professionals that they saw was advantageous, enabling them to build relationships with those caring for them:

> *"They just have basically the same nurses on all the time. It's really great that you can see someone that you know, like consistently, which is really nice."*
> (Emily, 16, sub-case 1, Principal Treatment Centre)

Likewise, healthcare professionals acknowledged that continuity of care was important; youth support co-ordinators working specifically in teenage and young adult services expressed that an essential part of their role was being a *"constant"* for patients:

> *"We are a one constant on the ward. We are there Monday to Friday, nine to five... I'm here to rapport build and to be, kind of, a constant."*
> (HCP3, sub-case 1, Principal Treatment Centre)

Provision of continuity of care by a close-knit and knowledgeable team that regularly cared for young people was a permanent structure in all Principal Treatment Centres, due to the presence of the teenage and young adult multi-disciplinary teams. In designated hospitals, there were attempts to provide continuity of care for young people, however this presented challenges as adult cancer services were much larger than teenage and young adult services. Adult cancer services in designated hospitals had greater numbers of healthcare professionals and a variety of tumour site-specific teams: they described larger numbers of patients as cared for in a *"conveyer belt"* system (HCP27, sub-case 3, Principal Treatment Centre).

Nonetheless, in designated hospitals where teenage and young adult cancer services were growing and evolving, the benefits of continuity of care were being recognised. Efforts were made to designate staff specifically to caring for teenagers and young adults, to enable healthcare professionals to build their interpersonal skills and relationships through consistent caring:

> *"We've got three nurses in particular, when they're on shift they would be placed with the teenagers and young adults. It doesn't give us full coverage obviously, but it does mean that there is that continuity of care for both staff and patients."*
> (HCP29, sub-case 3, designated hospital)

6.2.1.3 Flexibility and accessibility

Two important features of effective communication were to have a flexible approach, and to be accessible as a point of contact:

"What I feel is important, is to be flexible and accessible, in the sense that people can contact you when they want, and in a way that they want to, so the whole text messaging and email..."
(HCP25, sub-case 3, Principal Treatment Centre)

Young people perceived this approach positively. They felt well supported when healthcare professionals were accessible; either making regular contact with them, or being easy to get in contact with:

"We saw her once I think the entire time I was like diagnosed, so it was like harder to feel supported… but this time, she'll just come round for a chat… I really like when people come round just for a chat."
(Emily, 16, sub-case 1, Principal Treatment Centre)

A flexible and individualised approach to communication was advocated by all healthcare professionals. Essential communication skills when working with teenagers and young adults, such as having a flexible approach, were considered to be useful skills for healthcare professionals when working with patients of any age:

"We use what we're used to using with a twenty-year-old…flexibility, negotiation skills…I think all the skills that you pick up by looking after teenagers and young adults I think do have a really positive impact on looking after older adults."
(HCP19, sub-case 2, Principal Treatment Centre and adult ward)

Youth support co-ordinators often used text message to communicate with young people. Flexibility in methods of communication was essential: text message, Facebook, telephone calls, written letters, and face-to-face conversations were all observed or discussed as methods of communicating between healthcare professionals and young people. This demonstrated the variety of communication methods that young people engaged with; and in addition to flexibility, creativity was recognised as helpful to engage young people:

"Think outside the box… tweaking, finding new ways to get young people engaged… sometimes that means doing things a bit unorthodox… you need a group of staff that are able change the way they work to make sure that that young person has got the right level of engagement they need."
(HCP15, sub-case 2, Principal Treatment Centre)

6.2.1.4 Specific roles

Professional roles that focussed on providing holistic, psychosocial and emotional support were essential for creating trusting relationships between healthcare teams and young people. Within designated hospitals, trusting and supportive relationships were frequently formed with clinical nurse specialists and social workers; young

people perceived these healthcare professionals to be the key providers of ongoing holistic support:

> *"[Clinical nurse specialist] and [social worker] have been behind me every step of the way. They've been, you know, I suppose if you look at it as a journey, they've been with me from the start and they've carried on past the finish with me."*
> (Jake, 20, sub-case 3, designated hospital)

Youth support co-ordinators described their role in facilitating conversations and picking up issues with young people, often particularly effective whilst leading one-to-one or group activities. Youth support co-ordinators undertook informal *"day-to-day, one-to-one intervention"* as a vehicle to build relationships, identify issues, offer advice and sign-post young people to other support services, e.g. specialist charities.

> *"I think it's a support role but in many more ways… I think you are an activity coordinator, but you're also there for many other things as well, people's relationships and you help them in any way you possibly can and send them off. You know, not send them off, but direct them to the right avenues for help."*
> (HCP24, sub-case 3, Principal Treatment Centre)

Additionally, young people confided in youth support co-ordinators, sometimes sharing issues that would not have been discussed with any other healthcare professionals. This was valued by other members of the multi-disciplinary team:

> *"They want to talk about how their relationship with their boyfriend is…sometimes you don't feel like you've been able to do that but obviously having [youth support co-ordinator] has allowed that to happen better really...as nurses, there is only so much you can do."*
> (HCP19, sub-case 2, Principal Treatment Centre and adult ward)

This youth support co-ordinator role was essential: the time they were able to give to building meaningful interpersonal relationships with young people frequently exceeded the time healthcare professionals in clinical roles had available to give:

> *"At [adult hospital], I didn't have anybody that was 'there' kind of thing. It was like the nurses on the ward and obviously a doctor. If you had a problem, you didn't really know where to go, but now I've got their [youth support co-ordinator] phone number… It was nice, knowing that there is somebody there…they care. You know they're going to be there all the time, no matter what."*
> (Liam, 19, sub-case 2, Principal Treatment Centre)

Similarly, social workers had a vital role interacting with young people to meet their emotional and social support needs; having the capacity to spend time to have those in-depth discussions and to make plans to be able to support them:

"Then lots of social and emotional support, so I spend quite a lot of time with our young people, and a lot of the conversations we have start off as nothing to do with cancer, but do tend to materialise into those questions and fears that they have, and we'll talk around that, and put plans of support in for them."
(HCP15, sub-case 2, Principal Treatment Centre)

Social workers were observed to have a relaxed, supportive and non-clinical communication style with young people: a relationship which differed to the relationship that young people had with nurses and the doctors. This was possibly because young people had a choice over how much interaction they had with their social worker, a choice they could not have over the interactions they had with those providing them with direct clinical care:

> *Field note entry 16/01/2015*
>
> **Space:** Teenage and young adult inpatient ward
> **Time:** Late afternoon on a weekday
> **Actors:** Several young people who were inpatients, social worker and myself
> **Activity:** Shadowing social worker on the ward during their evening where they were visiting and meeting up with young people who were inpatients
> **Events:** First we saw was a 22-year-old man with a high-grade brain tumour. He was chatty although you could see he was fed up with being there. The interaction he had with the social worker was enjoyable to observe, she clearly knows him well and has a good rapport with him. Second, we went to see was a 17-year-old. He was there on his own. He started the conversation quite reserved and didn't seem that open, with minimal eye contact. As the conversation went on, you could see him physically become more relaxed, his face seemed more relaxed and he smiled and looked at us more. We chatted about silly things like his love of cooking and watching Jamie Oliver, his love of curry and how he was going to have one when he got home the next day. He made a couple of comments about his mother and her lack of trust in his cooking and about how he was going to go and get his own place: and that this illness has messed up all of his plans.
> The social worker was sensitive to these comments and tried to encourage him to think positively, to have those aspirations, though they may be put on hold for now. I asked the social worker about his back ground and she said that he had quite a complicated family life at home – she knows him and his family well.
> The final patient we went to see had his curtain drawn around him in the bay and clearly didn't want to be talked to therefore the social worker just popped her head around and said hello but left him to it.
> **Feelings:** It was noticeable that the social worker is that somebody who can see the patients in a completely non-clinical way, without performing any painful or unpleasant medical procedures. They do not have a uniform and the relationship is very relaxed – the young people can tell them to go away if they want to – which is the big difference to their relationship with nurses and doctors.

6.2.2 Intra-hospital communication

The second layer of communication that emerged was intra-hospital: this involved communication between the healthcare professionals looking after a young person located in one hospital. In Principal Treatment Centres, this predominantly included all of the healthcare professionals in the teenage and young adult multi-disciplinary team, and in some cases, those caring for young people who were based in other areas of the hospital, for example radiotherapy or surgery. If a young person was cared for in a designated hospital, or received shared care between the Principal Treatment Centre and a paediatric oncology shared care unit, there would be multiple, separate circles of intra-professional communication about their care making it much more complex.

6.2.2.1 Joined-up working

Within designated hospitals, there was a variety of intra-hospital communication processes observed. Healthcare professionals working in adult services would hold tumour site-specific multi-disciplinary team meetings to discuss patient's care pathways and needs. Additionally, the lead nurse for teenagers and young adults in the designated hospitals would work closely with the tumour site-specific teams to ensure that all young people in the designated hospital were receiving adequate, age-appropriate support and information:

> *"The majority of our patients are germ cell patients. So, they sit under my tumour sites anyway, I would always pick those up. Then we have monthly Macmillan meetings where all the clinical nurse specialists meet, and then they will-, I will always jog people's memories and say, 'Have you seen any teenage and young adult patients?'…they are usually pretty good at flagging them to me."*
> (HCP1, sub-case 1, designated hospital)

Healthcare professionals in designated hospitals described examples where there were insufficient mechanisms of information sharing between different groups of healthcare professionals. An example of this was a lack of intra-hospital communication between the child and adult clinical teams who cared for young people. It was acknowledged that having more established intra-hospital communication and joined-up working between child and adult teams could improve the care provided to young people within the hospital:

> *"There's paediatric patients as well and it'd be quite interesting to liaise with our paediatric clinical nurse specialist and see how we can work better together in terms of care for the younger teenage and young adult patients as well… just to share ideas, give each other some support and education as well."*
> (HCP18, sub-case 2, designated hospital)

In contrast, there were designated hospitals that demonstrated effective joined-up working between the child and adult teams. This was described as essential to provide quality transitional care for young people who were moving from child to adult cancer services:

"We have a very good relationship… I get a monthly report of all their patients, but obviously they focus on the ones that may, in the next year or two, potentially will be coming up into the adult setting."
(HCP36, sub-case 4, designated hospital)

The situation differed in Principal Treatment Centres, where young people were cared for as a separate and exclusive patient group, with a discrete, specialist multi-disciplinary team of healthcare professionals. While this generally made intra-hospital communication among healthcare professionals easier, the structure of the teenage and young adult multi-disciplinary team was complex: healthcare professionals worked in multiple locations; spanned various clinical specialisms or tumour-specific teams; worked different hours/shift patterns, shared job roles with colleagues; or worked exclusively with sub-divisions of the cohort, e.g. younger teenagers. This complexity was reflected in young people's experiences of intra-hospital communication:

"I think communication is key... I don't think a clinical nurse specialist works with three people doing the role... I just think it's very disjointed. They haven't got the continuity that you need."
(Laura, 17, sub-case 4, Principal Treatment Centre)

Moreover, structures were put in place to combat this complexity and to enable teams of healthcare professionals to come together to discuss young people and to plan their care.

> *Field note entry 20/05/2015*
>
> ***Space:*** *PTC in the MDT/staff room which is located on the TYA ward.*
> ***Actors:*** *Most members of the TYA MDT, including the Lead nurse, CNS's, psychologist and physiotherapist. There were no medics present.*
> ***Event:*** *Observed TYA psychosocial MDT meeting followed by TYA Discussion group. Today was the first one of the TYA discussion group meetings that the team have held – an idea put together by the Lead nurse, a CNS and the psychologist. The idea is to have a meeting for any of the staff involved in TYA care in which they will discuss an 'issue' (a challenging or difficult one) that staff have had to deal with. It offers space for the team to discuss, reflect and perhaps suggest ways to deal with such an issue in future. I discussed with [TYA Lead] about the structure of the psychosocial MDT meetings and the reason that it is nurse and not medically led. She thinks it*

works well the way it does and that if more medical staff were there that they would "take over".
Feelings: *I wonder whether this model is one others follow?... the nurses and other MDT members lead the psychosocial bit and the doctors lead the medical bit? From the Doctor's perspective, when I chatted to [Consultant] in her clinic this morning we talked about her involvement in TYA psychosocial stuff and she said that she very much leaves that to the CNS's and that she likes sticking to discussing the medical treatment, outcomes, medicines etc. Not that she has no interest in their psychosocial needs, but in a short clinic appointment there is often not time to go into all of that and she feels like often young people do not see her as the person to discuss those things with – she is the medical person in their eyes. This is where it is essential that there is communication across the MDT to communicate psychosocial needs, as if not discussed in clinic appointments, surely issues will get missed?*

6.2.2.2 Continuity of staff

Continuity of staff and the implementation of routine communication processes, such as effective handovers between professionals, meetings and discussion groups provided opportunities for a united and knowledgeable healthcare team to form, and to flourish. Young people recognised and commented on the link between the continuity of the staff and how this affected the communication within the team:

"…there's a set team that work here, not as many of the casual agency staff, and so with one team obviously communication is going to be better."
(Jason, 23, sub-case 4, Principal Treatment Centre)

Multiple mechanisms of information sharing between professionals emerged, which influenced the efficacy of intra-hospital communication. Healthcare professionals used techniques for daily information sharing, and expressed how these contributed to the care they provided:

"The first thing that we do is have a handover with the other multi-disciplinary team professionals, so, your occupational therapists, physios, school…we need to have one daily…we don't know who's coming in, who's having a PICC line done…we need that knowledge to be able to support the patient."
(HCP2, sub-case 1, Principal Treatment Centre)

Effective intra-hospital communication was recognised by young people and influenced their experience of care in a positive way:

"Every nurse knows what is going on with me and my treatment, and it makes a difference, as I don't have to tell my story again and again."
(Jade, 15, sub-case 1, Principal Treatment Centre)

The wide range of healthcare professionals who supported young people in the Principal Treatment Centres (e.g. education specialists, youth support co-ordinators

or youth workers, nurse specialists, social workers) meant that information sharing could be challenging. In one Principal Treatment Centre, a healthcare professional teenage and young adult 'discussion group' was held to facilitate communication, interaction and information-sharing between all of the professionals caring for young people. In this group, healthcare professionals brought a psychosocial issue or concern they were dealing with to discuss with the whole team and the team shared knowledge, expertise and discussed the strategies they could use to overcome this issue or concern. This was an example of a unique mechanism of intra-hospital communication focussed on the psychosocial care of patients. Additionally, this meeting was described as a valuable opportunity for the team to develop their knowledge and skills through sharing their experiences and ideas:

> *"I think it works well, I think it has two functions… one function is to talk about patients and make some, kind of, plans for best care. I think the other function is very much around everyone on the team supporting each other and reflecting on what are often really difficult situations that people are having to deal with so I think it works well for those two functions."*
> (HCP25, sub-case 3, Principal Treatment Centre)

6.2.2.3 The role of the lead nurse

Nurses leading teenage and young adult services in designated hospitals described their role as an advocate and source of support for all young people. Tailoring care to meet the needs of teenagers and young adults was a new concept to some designated hospitals:

> *"I very much see this as the start of our journey with the teenage and young adult patients and how, I suppose in a sense I'll be the facilitator. Equally, being a young person's advocate, I get why they want to take that control… only by working with them and listening to them will we get the service right, really."*
> (HCP21, sub-case 2, designated hospital)

The role of a lead nurse as a *"facilitator"* involved attending meetings with tumour-site specific clinical teams caring for young people, such as the breast cancer clinical team meetings, to educate colleagues working in adult care about young people's care pathways, and the specialist services that were available at the Principal Treatment Centre:

> *"I'm on the network coordinating group, at the minute they're trying to sort out the pathways, which is a bit of a nightmare… so the pathways from the general district hospitals to here and to [Principal Treatment Centre]... if I've got a problem, the first person I call is [lead nurse for the whole network], and sometimes she'll know about patients before I do.*
> (HCP9, sub-case 1, designated hospital)

Opportunities for professionals working in the same hospital to communicate and share knowledge facilitated the development of a culture where young people's care needs were recognised as a unique to those of children or adults.

6.2.3 Hospital-to-hospital communication

Communication as a process of care occurred between healthcare professionals from different hospitals. Service specifications state that all teenagers and young adults diagnosed with cancer should be flagged and discussed at the teenage and young adult multi-disciplinary team meeting in their closest Principal Treatment Centre. To achieve this, clinical teams or lead nurses at the designated hospitals were required to communicate with those at the Principal Treatment Centre. Moreover, hospital-to-hospital communication was frequent and recurring when young people had their care shared between a Principal Treatment Centre and a paediatric oncology shared care unit; or had a cancer type which required some of their care to be provided by a specialist service in another hospital, e.g. young people needing specialist surgery for bone cancer. In these cases, communication was back and forth between the teams at the shared care hospital and the Principal Treatment Centre, thus ensuring both the young person's clinical and psychosocial needs were being met. Two key sub-themes assisted with hospital-to-hospital communication: multi-disciplinary team meetings, and clarity in healthcare professional roles.

6.2.3.1 Multi-disciplinary team meetings

The weekly teenage and young adult multi-disciplinary team meeting was an essential forum for network-wide communication between hospitals. These were held weekly in each of the Principal Treatment Centres and provided an opportunity for both intra-hospital and hospital-to-hospital communication. The size, structure and content of the discussion in these multi-disciplinary team meetings varied between the four networks of care.

In three networks of care, a large teenage and young adult multi-disciplinary team meeting was held which discussed both the psychosocial and medical needs of the patients, which was primarily led by Doctors. While this created an opportunity for hospital-to-hospital communication and sharing of expertise, the size and scope of these large network-wide meetings was perceived as challenging:

"It's tricky because it's a very big meeting, there are an awful lot of people with a lot of opinions… it was created for a very good reason but I think, as with all things, it

can become a box ticking exercise, especially when it's been there now for fifteen/
twenty years."
(HCP5, sub-case 1, Principal Treatment Centre)

Not only were these meetings described as challenging in their structure and attendance, healthcare professionals described that the content of the meetings were criticised for being overly medical, rather than focussing on the psychosocial needs of young people:

"I think there's been criticism…that perhaps it's a little bit too medical. It's supposed to be primarily a psycho-social meeting, and sometimes it's very medical…I actually find that quite interesting, but I think some people perhaps can feel that it's too much, scan results and everything, so it's far more medicalised… I think there's a balance there, and I'm actually very happy with it, but there has been criticism."
(HCP14, sub-case 2, Principal Treatment Centre)

These meetings were observed in the Principal Treatment Centre in each of the four networks visited, in addition to being observed and discussed at the designated hospitals, to obtain the perspectives of those outside the Principal Treatment Centres. Teams at designated hospitals and paediatric oncology shared care settings communicated with those at the PTC using teleconference facilities during hospital team meetings:

> *Field note entry 21/11/2014*
> *Space: Large meeting room in the PTC.*
> *Actors: Shadowed the child/TYA CNS for this tumour site. Most of the tumour-site MDT present, including medics, nurses and allied healthcare professionals. This took place across hospitals, where teams in different hospitals linked together via video conference facilities.*
> *Events: Observed a tumour-site specific MDT meeting. There was a large amount of joint decision making– linked by video conference facilities - drawing on the expertise of healthcare professionals in both the PTC and the specialist shared care centre. It was clear to me that [CNS] knows her patients well and their statuses and situations. She explained to me later that she uses the discussions of these meetings to build a picture of her patient's clinical status and diagnosis. She will then use this knowledge to help her discussions with patients when she is asked tricky questions - so she finds these meetings really important.*
> *Feelings: Watching the interaction of the consultants with the CNS was interesting – one came across to her and asked her "Where were you? I needed you!" as she had been away at a course for the 3 preceding days. There is clearly a lot of trust and a good working relationship between [CNS] and her colleagues. Having a CNS who works across the two sites also helps to develop and maintain the communication between the teams.*

The teenage and young adult multi-disciplinary team meeting was helpful for the lead nurses in designated hospitals to obtain support and to know what was going on in and across the networks of care:

> *"We weren't involved in the teenage and young adult multi-disciplinary team before… I didn't know what was expected of me, of the role… I think, knowing who my support network is, that's made it a lot easier. I go to the meeting as well and that helps so I know what's going on within the network."*
> (HCP1, sub-case 1, designated hospital)

One network held a separate psychosocial meeting, attended by all members of the teenage and young adult multi-disciplinary team, except it was less common for doctors to attend. This provided insight into the relationship between the medical professionals, and the nursing, support and allied health professionals. The presence of doctors was described to change the dynamic of the meeting, and ongoing *"politics"* among the medical teams, indicative of the challenges associated with delivering care to a cohort who 'fall between' child and adult cancer services:

> *"I think it works well and it's about sharing that information with the people who work more closely with them. We have had doctors who come and they change the dynamic of the meeting, which is interesting… there's lots of politics from the children side and the adult side, medics mainly, and that's been quite difficult to negotiate."*
> (HCP30, sub-case 3, Principal Treatment Centre)

The input of healthcare professionals at the designated hospitals into the network-wide teenage and young adult multi-disciplinary team meetings was variable. In these meetings, discussions were observed where there had been delays in flagging and discussing young people who were being cared for at the designated hospitals:

> *"It doesn't work quite so well with the designated hospitals because patients are often discussed very late because we don't hear about them quickly enough, although we're putting a lot of work into trying to identify these patients as quickly as possible."*
> (HCP20, sub-case 2, Principal Treatment Centre)

This lead to those young people experiencing delays in the expert involvement and specialist support which could be provided by the team at the Principal Treatment Centre. This was described by some healthcare professionals as the time when young people most required psychosocial care and support.

In addition to network teenage and young adult multi-disciplinary team meetings, healthcare professionals advocated the development of network-wide 'working groups' to build awareness and drive the development of equitable cancer services for young people:

"The idea is to have a regional group…their prime responsibility is to promote the service…get patients to have equitable service wherever they choose to be treated."
(HCP20, sub-case 2, Principal Treatment Centre)

The process of developing a team of healthcare professionals that worked cohesively across an entire network of care took a large amount of effective hospital-to-hospital communication and effort put into developing trusting relationships between the different clinical teams:

"You have and it takes a lot of networking and schmoozing. Talking to people and developing relationships and trust and familiarity is just all part of what we do really and then it all clicks together in the end. It's not just about the nurses, it's about the whole team around you as well. Doctors having credibility with the other doctors, so it's just making one big team and making sure it works, really."
(HCP30, sub-case 3, Principal Treatment Centre)

6.2.3.2 Clarity in healthcare professional roles

The clinical nurse specialist role was often important in the maintenance of the relationships and communication between healthcare professionals in the Principal Treatment Centre and the designated or shared care hospitals. A large tumour-site specific meeting that took place across two hospitals via an Internet-based videoconference format was observed (Appendix 21). This meeting was an efficient mechanism of hospital-to-hospital communication and highlighted the importance of sharing knowledge and expertise for patients who received parts of their care in different hospitals. A clinical nurse specialist worked closely with young people and professionals across both of these hospitals. The importance of having regular videoconference meetings was emphasised to ensure patients had clear, comprehensive and holistic care and smooth care transitions between the two hospitals.

In some designated hospitals, provision of care for teenagers and young adults was underdeveloped, and there was a need for more clarity of the roles and responsibilities of different healthcare professionals in the different hospitals:

"I think unfortunately with the tumour site specific, the clinical nurse specialists or the consultants, I think we probably do need a bit more clarity around roles and responsibilities. I think when the patient's made the decision to stay at the designated hospital, our tumour site-specific nurses are heavily involved, which you would expect and to add someone from the teenage and young adult team, if they choose to have the treatment here, I

don't know if that's always as beneficial… who are the best people to support them?"
(HCP21, sub-case 2, designated hospital)

It was identified that some of the adult doctors caring for young people in designated hospitals could not always attend/dial in to the teenage and young adult multi-disciplinary team meeting due to workload pressures. The lead nurses in designated hospitals suggested that to overcome this the content of the teenage and young adult multi-disciplinary team meetings should be *"more meaningful"* in terms of discussing young people's holistic needs*,* thus encouraging all healthcare professionals caring for young people to attend, or to link in via videoconference. Healthcare professionals recognised that *"open and frank conversations"* between designated hospitals and Principal Treatment Centres were needed to improve the hospital-to-hospital communication and processes of information-sharing to enhance the care of young people across the network.

Another mechanism of improving information sharing was the development of a specific role of a teenage and young adult service co-ordinator. This role was described by colleagues as a unique and valuable addition to the service. The service co-ordinator flagged up young people coming into the service at the Principal Treatment Centre, and worked closely with designated hospitals to identify young people who had not been referred to the Principal Treatment Centre. This ensured that all young people in the network were aware of the specialist services available to them at the Principal Treatment Centre, as caring for young people dispersed across a vast geographical area presented challenges:

"…if we don't have someone to help with that from a clinician's point of view, there's no way we can keep an eye on all these patients and make sure that they're having the service that they deserve."
(HCP20, sub-case 2, Principal Treatment Centre)

The development of this specific role was an example of a strategy to enhance communication and care co-ordination between all of the hospitals in the network. Similarly, the implementation of a 'shared care clinical nurse specialist' role at the Principal Treatment Centre was another strategy employed; this nurse developed links with clinical teams at the designated hospitals and paediatric oncology shared care centres across the network. This role enhanced hospital-to-hospital communication: lead nurses in the designated hospitals found it valuable and reassuring to have one specific nurse as a contact point to the Principal Treatment Centre. One key point of contact helped healthcare professionals with less

experience of working with young people to find the support and resources that they required from the experts at the Principal Treatment Centre, in a *"seamless"* and timely way:

"It does work very well. The clinical nurse specialist will either bleep me or give me a message, 'Such and such is coming to get their dressing done, can we get bloods pre-chemo? Can they come to you? Yes, absolutely, sorted. They'd contact the patient. It's seamless, which is excellent."
(HCP18, sub-case 2, designated hospital)

In contrast, there were cases where there was poor hospital-to-hospital communication provided by the Principal Treatment Centre out to the designated or shared care hospitals. Better information sharing from the Principal Treatment Centre was required to improve young people's experiences during unplanned admissions to their designated hospital:

"I think the communication that maybe we need to improve on is patients that are having treatment in [Principal Treatment Centre]…they come here with an infection and we don't know where they are in their treatment cycles...it's been brought up at meetings and they're working on that."
(HCP18, sub-case 2, designated hospital)

6.3 Core values of teenage and young adult cancer care

Culture is not only created by the observable context, structures and processes of care, but also by the 'below the surface' values, norms and basic assumptions of the individuals within that cultural context (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014). Three core values emerged from data analysis: recognising individuality, promoting normality, and empowering young people (Figure 6.2). These were an essential part of the less visible 'below the surface' culture; and underpinned teenage and young adult cancer care across all settings.
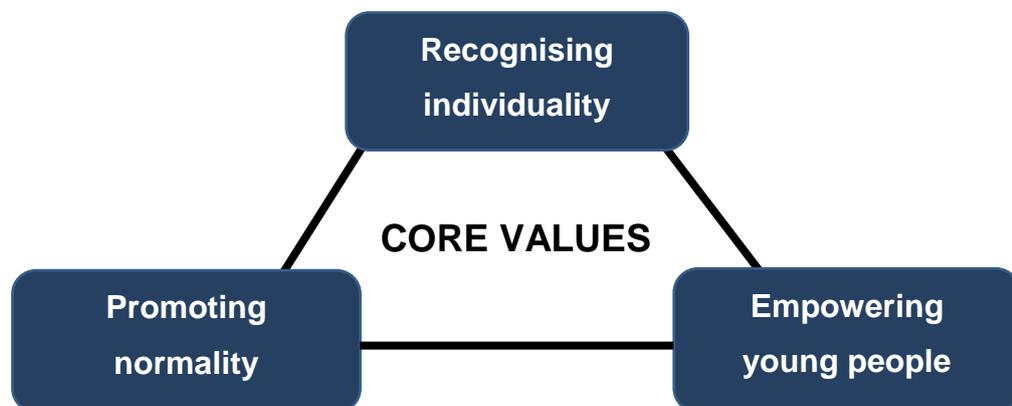
Figure 6.2. A thematic map illustrating core values of teenage and young adult cancer care.

6.3.1 Recognising individuality

There was a strong consensus between healthcare professionals and young people that all care provided should be tailored to the individual patient's needs, regardless of age:

> *"I think it's not even about the number of the age is it? It's about a recognisance…Recognising them as an individual and that they've got different needs."*
> (HCP16, sub-case 2, Principal Treatment Centre)

Similarly, young people across all care settings identified that they would all have individual needs: different ages, circumstances, personalities, diseases and support needs:

> *"Some people would need a lot more support than I did. Some people won't need as much support as I did. Obviously, as an individual, I couldn't say for everyone."*
> (Jake, 20, sub-case 3, designated hospital)

It was identified that young people's individual needs were influenced by a complex combination of factors related to their personal, disease and treatment circumstances, and services should therefore be appropriate and flexible to young people's individual needs. Even in adult cancer services in designated hospitals, it was recognised that a fixed, 'one size fits all' approach would not meet young people's diversity of needs:

> "*It is like with any age group, just because you fall into that age group, it doesn't mean you all have the same needs… Just having the same age in common may not be enough. It should be about the individual patient and their individual needs.*"
> (HCP1, sub-case 1, designated hospital)

6.3.2 Promoting normality

A second core value that emerged was 'promoting normality' for young people during their cancer experience. Healthcare professionals felt it was their role to minimise the disruption of cancer to young people's lives and to encourage them to *"stay on track"* with what they would have been doing prior to their diagnosis:

> *"I suppose age appropriate care is perhaps about us trying to minimise the disruption of that time…helping them stay on track with what they would want to be doing anyway, helping them form that identity that they would want to be forming anyway, with as little disruption from cancer as possible."*
> (HCP28, Principal Treatment Centre)

Encouraging interaction with peers and providing age-appropriate facilities and activities were 'tools' that healthcare professionals described as assisting with the promotion of normality:

"So, there are the sort of facilities that allow people to carry on doing what they would be doing if they were out of the hospital and well…Internet access, access to support with work and education and those sorts of things."
(HCP11, Principal Treatment Centre)

Both healthcare professionals and young people who spent time in the specialist teenage and young adult environments described how the non-clinical décor and 'homely' atmosphere promoted a sense of normality, and was familiar and comforting:

"It doesn't actually look like a hospital in here. In a way it's just a normal world. It's a sense of normality."
(Jade, 15, sub-case 1, Principal Treatment Centre)

"Just to normalise how they're feeling and to give them a sense of normality…"
(HCP9, Principal Treatment Centre)

Young people described specific aspects of their care experience to illustrate this underlying core value, such as access to the Internet, television and computer games. They wanted to feel a *"sense of normality"* when in hospital, including having flexible, age-appropriate surroundings:

"I love the fact that I can take my duvet in... the fact that I have my duvet just makes it so much more homely."
(Emily, 16, sub-case 1, Principal Treatment Centre)

The connection between the environment and young people's desire for 'normality' extended beyond the Principal Treatment Centres. Young people cared for in adult environments also described wanting to feel at home:

"Personally, there was nothing really more. I needed to feel at home and comfortable, but that's about it really".
(Simon, 24, sub-case 4, designated hospital)

Young people receiving their care in designated hospitals had often not been exposed to the features and facilities of a specialist young person's environment of care and therefore did not describe needing extra facilities to feel a sense of normality. While the Wi-Fi in Principal Treatment Centres was not always reported as reliable, access to the Internet was often lacking in

designated hospitals altogether. Internet access would be a simple yet effective mechanism for promoting normality for young people through facilitating their relationships with friends and family:

> *"Wi-Fi would've been a big plus, it would've helped me stay better connected with the outside world."*
> (Simon, 21, sub-case 4, designated hospital outpatient)

6.3.3 Empowering young people

The importance of empowering young people and assisting them to feel involved in their care was a third core value that emerged. Transparent communication and information sharing was one essential mechanism of empowering young people. Young people felt that they should be kept informed of what was going on with their cancer and treatment; as *"at the end of the day it's your body."* Young people wanted to be kept informed and similarly healthcare professionals advocated for the provision of the right resources and information, in the right way, at the right time, to empower young people to be involved in decisions about their care:

> *"It's about knowing your patient and knowing how and when, sort of, to communicate and tell them things, really."*
> (HCP21, sub-case 3, designated hospital)

> *"…make them, as an absolute minimum, the partner within their care."*
> (HCP5, sub-case 1, designated hospital)

Effective provision of information was seen an essential aspect of caring for young people; healthcare professionals wanted to encourage those young people who were cognitively able, to relinquish some control over their care and the decisions made about it:

> *"I think it means that, the age group we have, you look at their age and development, and try and give as much autonomy to them."*
> (HCP18, sub-case 2, Principal Treatment Centre)

Both young people and healthcare professionals advocated for the inclusion of young people in the design and development of cancer services. They described how involving young people would maximise their use and enjoyment of the environment:

> *"I think it would be looking at the people who come in…getting their ideas and questionnaires from them saying what they like…get all their views and opinions you can, kind of, gather a similarity in everyone and things that everyone might enjoy."*

Similarly, several healthcare professionals described the importance of involving young people at 'every level', including the design of the hospital environment:

"When we were looking at the design of this place with particular youth groups, and we asked them what it's about. I mean, it's about involving young people in that at every level, and I think we did."
(HCP7, sub-case 1, Principal Treatment Centre)

This was not only of importance in the Principal Treatment Centres caring for large numbers of teenagers and young adults, the involvement of young people was also mentioned by healthcare professionals in designated hospitals:

"They're offered a designated room, and they all like to go in there…in fact, it was the youngsters that helped us design the room."
(HCP34, sub-case 4, designated hospital)

Despite some hospitals caring for small numbers of young people in comparison to the Principal Treatment Centres, the recognition to involve young people in the design of the service was evident: the core value of empowering young people to be partners in their care was a philosophy of care that extended beyond specialist services and was filtrated into the child and adult services in which young people also receive their care. The importance of young people having a voice and ownership within the ongoing development of teenage and young adult cancer services was an important emerging message:

"I really want the ownership back on the teenagers and them telling me what would be helpful… I think if we can listen to our young people and really hear what they need and what they want, that's the best way to start building the service…
see what they really want."
(HCP21, sub-case 2, designated hospital)

6.4 Summary

This chapter has presented findings related to the second core concept about culture, divided into two sub-sections. The first was communication: one of the fundamental, visible processes of care, and had an important contribution to the 'above the surface' culture of care. Three sub-themes emerged within this: interpersonal communication, intra-hospital communication and hospital-to-hospital communication. The second theme contributed to the less visible 'below the surface' culture: the core values of teenage and young adult cancer care. This comprised of

three core values: recognising individuality, promoting normality and empowering young people.

The synthesised perspectives from young people and healthcare professionals presented in this chapter have provided essential findings to assist this exploration of the culture of teenage and young adult cancer care, and in particular important insights into the less visible 'below the surface' culture. Communication was an essential process, occurring on interpersonal, intra-hospital and hospital-to-hospital levels; impacting young people's care experiences and the way healthcare professionals' experienced care provision. It is a significant finding that the three core values, recognising individuality, promoting normality and empowering young people, underpinned practice in all settings and environments in which young people were cared for. The next chapter will explore study findings in relation to the third core concept of culture: *culture is something that is learned, shared and perpetuated through effective teamwork and leadership.*

Chapter 7

Culture is something that is learned, shared and perpetuated: the development of healthcare professional holistic competence and the culture of care

7.1 Introduction

This chapter will present findings related to the third core concept of culture presented in the conceptual framework: *culture is something that is learned, shared and perpetuated through effective teamwork and leadership (Hall, 1976; Davies et al. 2000; Marshall et al. 2002; Hudelson, 2004; King's Fund, 2017)*. The findings are subdivided into two sections: the first concerns the *learning* of culture and describes the development of healthcare professional holistic competence; the second focusses on the *sharing and perpetuation* of culture and explores the contributing factors: volume of young people, leadership, attitude and time. Together, these two sections convey important insights into how holistic knowledge about caring for teenagers and young adults is learned and developed; and how this knowledge is shared and perpetuated to underpin the culture of care.

7.2 The development of healthcare professional holistic competence

The knowledge, skills and competence of healthcare professionals were central to their caring role. Data indicated that young people wanted to receive care which considered them as a whole person, including their social, emotional and psychological needs, as opposed to care which focussed only on their clinical and physical needs. The core values presented in section 6.3 underpin what it meant to care for young people holistically and therefore assists in defining holistic competence. This chapter will build on this, focussing on how holistic competence and knowledge is *learned*. Findings relating to the learning and development of healthcare professional holistic competence primarily emerged in the interviews with healthcare professionals and through the periods of shadowing, and participant observation.

Development of holistic competence was facilitated by the following four factors (Figure 7.1):

1. Environment
2. Experience continuum
3. Enthusiasm
4. Education
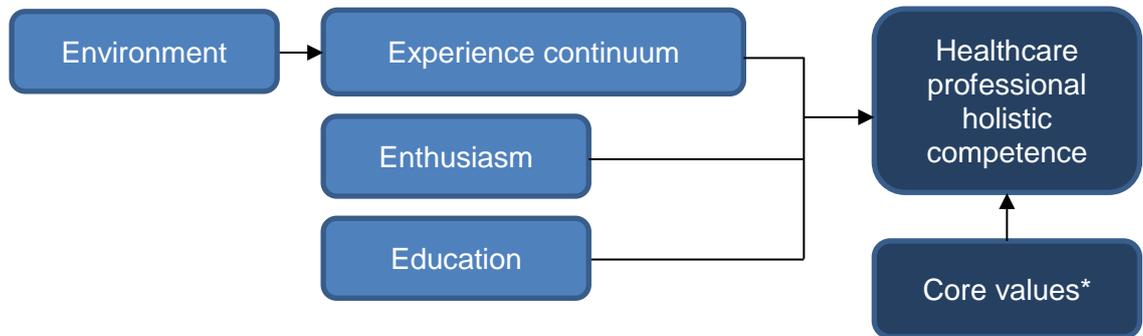
*Chapter 6

Figure 7.1. A thematic map of the factors which influenced the development of healthcare professional holistic competence.

7.2.1 Environment

The impact of the environment was explored in depth in Chapter 5. A further impact of the environment was the influence it had on the development of a holistic approach to caring for young people. Specialist environments provided a dedicated platform from which knowledge and skills could be learned and shared. Healthcare professionals recognised that this was a benefit of having an environment dedicated to the care of young people, and that competence in holistic care was developed by caring for young people in one space:

> *"We're starting to get more exposure to the needs of young adults and exposure for the staff looking after young adults… now that we keep them in one place together because of the nature of the ward."*
> (HCP19, sub-case 2, Principal Treatment Centre)

Healthcare professionals described how young people cared for in Principal Treatment Centres had constant access to a clinical team with competence in providing appropriate emotional support. This was enabled by having a dedicated environment in which care expertise was fostered:

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"I think it's great that the young people are in an environment where most of the people they have contact with feel confident to be able to give them a level of emotional support because they don't want to wait two days for their CLIC Sargent social worker to be available."
(HCP38, sub-case 4, Principal Treatment Centre)

The environment in which healthcare professionals worked influenced their approach to care. Specialist environments provided the space, facilities and atmosphere to enable healthcare professionals to build interpersonal relationships with patients, and encouraged an approach that was holistic:

"…the difference that the environment has made in making it feel like a unit that sort of looks after people's needs rather than just gives them treatment."
(HCP19, sub-case 2, Principal Treatment Centre)

The physical environment facilitated interpersonal relationships between healthcare professionals and young people to flourish. This was frequently observed, particularly in the social spaces:

> *Field note entry 10/07/15*
> ***Space:*** *social space in the Principal Treatment Centre on the teenage and young adult ward (sub-case 3)*
> ***Actors:*** *the youth support co-ordinator, one young person and one of the CNS's sitting at the breakfast table having a chat to begin with*
> ***Activity/time:*** *ward 'brunch club', on a Friday late morning*
> ***Event:*** *I got there and there was crockery, tea, coffee, juice, pastries, fruit all laid out for everyone to help themselves to. Although the ward was quiet-ish, around the table in the day room there was a 'buzz'. Three more young people came in, two parents, and several nurses came around, hovering, chatting to young people, getting coffee – it was such a relaxed atmosphere. A lot of the conversation was around the upcoming summer holidays and everyone's planned holidays.*
> ***Feelings:*** *It was such a lovely, relaxed start to the day – I kind of felt like I was in a coffee shop with a lovely group of people chatting and having brunch – it was as if I forgot I was sitting with patients and nurses.*

It was suggested that it would be beneficial for staff in designated hospitals to draw on the expertise of the Principal Treatment Centres by visiting these specialist care environments. Encouraging such methods of sharing knowledge could inform the competence of those in non-specialist hospitals in order to deliver best-practice and holistic, young person-centred care:

"I suppose from our perspective what I'll certainly do is arrange for them to go to other units and it probably will be the Principal Treatment Centre… I would like to get them, sort of, fast tracked, that knowledge, that experience so that they can see how they can really help deliver that A1 service for the young person."
(HCP21, sub-case 2, designated hospital)

7.2.2 Experience continuum

A factor which contributed to the development of healthcare professional competence was their level of experience in caring for young people. As highlighted in the previous section, whether a professional had less or more experience was primarily a result of the environment they worked in and the role they were employed to undertake. Those working in dedicated teenage and young adult environments had consistent exposure to this cancer population, whereas those in adult cancer services had much less frequent exposure:

"The chances of having two at the same time would be-, I haven't known it in the time I've been doing this job…we've only really had, I think, three that have been treated as inpatients in two years."
(HCP1, sub-case 1, designated hospital)

Healthcare professionals who were less familiar with caring for young people required increased contact with them in order to develop their skills and competence. This was recognised as important in all types of care settings, specialist and non-specialist, such as in Principal Treatment Centres where there were staff members new to the role:

"…we need exposure for the newer staff coming through… you want to build people's skills up, and at the same time expose them to the young adults."
(HCP19, sub-case 2, Principal Treatment Centre)

There were young people who described poor experiences of care, particularly when they spent time in child or adult-focussed settings. Young people experienced situations where they felt their healthcare professionals demonstrated a poor understanding of how to communicate with or care for them:

"I had a few nights where I was moved to an adult ward. I don't think they were really used to children, and that was a horrible experience. They weren't always very nice to you…quite physical, quite unsympathetic about how I was feeling. I don't think they understood and it made me feel scared and upset."
(Anna, 15, sub-case 3, Principal Treatment Centre)

In designated hospitals, the appointment of nurses into the lead nurse role for teenagers and young adults was often influenced by their prior contact and experience working with young people. Frequently, this role was assigned as a part-time addition to a tumour site-specific nurse specialist who worked with the more common cancer types for younger patients, e.g. lymphoma. This was because they saw the majority of the teenage and young adult patients that attended the designated hospitals:

"I think haematology nurses by default tend to take the teenage and young adult role on in the designated hospitals because-, or the lymphoma specialists take it on, because we tend to see the majority of the teenage and young adults… "
(HCP34, sub-case 4, designated hospital)

"I didn't know what was expected of me, of the role. It was, kind of, tacked onto my job because I see the germ cell patients, so it was thought it would make life easier as I saw some of the younger ones anyway."
(HCP 1, sub-case 1, designated hospital)

In designated hospitals, and paediatric oncology shared care units, there was variation in healthcare professionals' competence in providing care. Young people identified this and recognised the variation between more and less experienced healthcare professionals:

"You'd have some nurses that come in, they were ok to talk to… but [Lead nurse for teenagers and young adults] would be the one you'd go to if you had any problems. You could tell she really knew how to look after us."
(Sasha, 24, sub-case 3, designated hospital)

Young people recognised when they had a healthcare professional with experience in effective care and communication. They identified that it took time and experience for those skills to develop, and for them understand how to interact *"brilliantly"*:

"It's getting the right balance of treating you like a teenager… when I was first diagnosed, I was quite mature and it's quite hard for them to gauge how to treat you…it took time but my Consultant does it brilliantly now, he knows exactly how I'm meant to be treated…."
(Emily, 16, sub-case 1, Principal Treatment Centre)

Healthcare professionals with regular and frequent experience caring for young people demonstrated care which encompassed the highest levels of holistic competence. Furthermore, it was important for staff to have an awareness of the complexity and challenges surrounding working with young people:

"Having health professionals there that are aware of, you know, what they're going through, with adolescence and going through to young adulthood. Being aware that communication actually is quite difficult, can be very problematic and very complex with those young people."
(HCP14, sub-case 2, Principal Treatment Centre)

Young people who received care in designated hospitals are described as having 'unhindered access' to age-appropriate care, including holistic expertise. Designated hospitals were able to provide holistic expertise through drawing on several members of the care team. It was a requirement for young people treated in designated hospitals to have access to both a tumour site-specific clinical nurse specialist, and the teenage and young adult lead nurse. While the tumour site-

specific nurse specialist could meet any clinical or treatment-related needs, the lead nurse was deemed to have more experience and competence in supporting young people holistically and therefore could ensure their psychosocial needs were being met:

"If they were different tumour sites, say haematology, they'd still see me and the haematology clinical nurse specialist, because my expertise doesn't lie in that area. I'm looking at more of a social side of things, having a supportive role-, and the site-specific clinical nurse specialist would take over the clinical stuff…"
(HCP1, sub-case 1, designated hospital)

Lead teenage and young adult healthcare professionals reported strategies to increase expertise in looking after young people in designated hospitals. One strategy involved specifically targeting two ward nurses to develop as 'teenage and young adult experts' working within the adult service. It was planned for these nurses to visit Principal Treatment Centres and well-established designated hospitals to learn from others and share expertise. Moreover, these healthcare professionals would be champions for young people, cultivate the knowledge and enthusiasm of others members of the team to enhance the patient experience for all young people in the designated hospitals:

"What I would like to do is get them fast tracked, that knowledge, that experience so that they can see how they can really help deliver that A1 service for the young person, working with the staff on the floor that deliver that treatment."
(HCP21, sub-case 2, designated hospital)

7.2.3 Enthusiasm

Healthcare professionals in all care settings recognised that the delivery of high-quality holistic care to young people required not only competence, but also enthusiasm and passion:

"I think you do have to have, definitely, an understanding, and to some degree a bit of passion for young adults."
(HCP19, sub-case 2, Principal Treatment Centre)

"There's definitely the passion and enthusiasm there. It's about building on that really… the absolute key is that they're individuals and that we need to be working with them and delivering their health care needs, their holistic assessment and almost their care plan to them."
(HCP21, sub-case 2, designated hospital)

Healthcare professionals in Principal Treatment Centres described a *"natural migration"* of staff away from children's or adult cancer wards, to working on the

teenage and young adult ward. Similarly, those in paediatric oncology shared care units also described how they *"love working with teenagers"* and spoke passionately about their role in caring for them. This enthusiastic attitude and shared passion to care for this age group was reflected in young people's care experiences:

"They all stick together, and they all do a similar job, and make sure we're all looked after, and make sure everybody's okay, come and check on us regularly… I mean, all the staff are perfect, you can't fault anything. Everybody helps you as much they can."
(Terry, 24, sub-case 3, Principal Treatment Centre)

Equally, this was identified by healthcare professionals. They advocated the importance of having a workforce with a shared philosophy and passion for caring for this cancer population:

"it's about the staff, if the staff don't get it, it doesn't matter… it's just about the whole ethos of it I think..."
(HCP29, sub-case 3, Principal Treatment Centre)

7.2.4 Education

The role of education in developing competence in caring for young people emerged across all contexts of care from the interview and shadowing data with healthcare professionals. Three categories of education for healthcare professionals were exposed: 1) raising awareness; 2) in-house education and training; 3) formal education.

7.2.4.1 Raising awareness

This form of education was concerned with raising awareness of both the unique physical and psychosocial needs of young people with cancer, and of the support and services available from the teenage and young adult multi-disciplinary team. In the children's and adult cancer services, it was expressed that there was a requirement to heighten the profile of young people's needs, how the teenage and young adult network functioned, and what specialist care for this group encompassed.

Raising awareness in designated hospitals was part of the role of their lead nurses and clinicians for teenage and young adults. Presenting at tumour site-specific team meetings was one strategy identified to raise awareness of the teenage and young adult cancer service to adult nursing colleagues. There were challenges associated with this due to lack of interest and poor engagement:

"We wanted to hold a clinical nurse specialist meeting, to generate interest and to highlight the service, for me to talk about my role, my remit, and how I support patients locally… but there was a lack of interest, so it never happened."
(HCP10, sub-case 1, designated hospital)

Other strategies implemented to increase awareness of young people among clinical teams within designated hospitals included: articles published on the hospital intranet; information shared on hospital computer screensavers; posters displayed around the hospital; and link visits to community and primary care services. A further strategy that was proposed was the creation of "*nurse champions"* on the wards in the designated hospitals. Their role would be to advocate for young people and champion the teenage and young adult service in the designated hospitals. This list of strategies highlighted the motivation in non-specialist settings to raise awareness of what was unique about delivering care to teenagers and young adults.

Healthcare professionals who worked exclusively with young people in the Principal Treatment Centres, such as young people's social workers or specialist nurses, were striving for network-wide awareness of the support services that they offered. There were tumour site-specific clinical teams in the designated hospitals who had very little contact with the specialist teenage and young adult multi-disciplinary team at the Principal Treatment Centre. The specialist teams worked to connect with designated hospitals, to raise awareness and to provide education:

"So, when suddenly we get a patient in [designated hospital] with thyroid cancer, a team who's never really worked with us before… it's about trying to educate people about what we're doing and therefore giving us better access to support the young people."
(HCP38, sub-case 4, Principal Treatment Centre and outreach)

This highlighted that there were gaps in knowledge that needed to be filled, particularly in some tumour site-specific teams at the designated hospitals. This lack of knowledge hindered some young people's access to specialist outreach support from the Principal Treatment Centre.

7.2.4.2 In-house education and training

The second level of education encompassed methods of in-house education and training. This type of education was utilised in both Principal Treatment Centres and designated hospitals:

"I think teenage and young adult patients have got quite complex needs. They're different from any other group of patients. I think you need specialist training to care for those patients, from a nursing point of view.
(HCP18, sub-case 2, designated hospital)

Expert professionals in the Principal Treatment Centres ran 'clinical skills weeks', which brought together healthcare professionals from both child and adult settings. These involved problem-solving and education about what the teenage and young adult service offered to help them to support young people. Training also incorporated psychosocial support services to ensure holistic knowledge was developed as well as clinical knowledge. In-house training was described to effectively advance the holistic competence of the staff, and also promoted team cohesion.

In child or adult services, lead nurses provided in-house training sessions to both educate their teams and to promote the service:

"Sometimes people ask for advice, or I will help out… I have done teaching sessions for the staff, just about general adolescent oncology, to raise awareness."
(HCP9, sub-case 1, paediatric oncology shared care unit)

There were a number of designated hospitals that lacked teenage and young adult-focussed education for healthcare professionals. This was recognised by healthcare professionals as an unmet need, particularly in less well-established designated hospitals:

"It hasn't actually been broached at all. I don't think any of them have had any teenage and young adult training at all. I think that's maybe something we need to look at in the future, is getting everyone up to the same standard. Teenage and young adult patients have got very different needs from other patients."
(HCP18, sub-case 2, designated hospital)

7.2.4.3 Formal education

Healthcare professionals discussed the value of formal education programmes. While this was predominantly highlighted by healthcare professionals at Principal Treatment Centres, there were also designated hospitals who also recognised a need for formal education and expressed an interest in supporting their staff to attend formal courses, such as the Coventry University programme:

"I think education-wise we note that Coventry University do a very good course and we've certainly highlighted somebody from our combined day unit which is our chemo suite and the ward will be attending that hopefully this year, so that'll be really good as well."
(HCP21, sub-case 2, designated hospital)

Those in management roles noted the challenges of facilitating formal education and training, this was often hindered by funding and staffing levels. Additionally, issues such as high staff turnover and service reconfigurations presented further challenges. Nurses and clinicians leading the networks identified that it would be *"impossible"* to enable all healthcare professionals who may come into contact with young people, in every hospital within a network, access to up-to-date, formal education courses. This further advocated the strategy of having *"nurse champions"* , who would then be supported to attend formal education and courses, and then deliver in-house training to further share this knowledge and enhance the competence of the wider workforce.

7.3 The development of the culture of care

There were five emergent themes from the gathered data that influenced the way a culture of care formed: communication; number of young people accessing a service; leadership; attitude; and time (Figure 7.2). The significance and impact of the theme of communication was discussed previously in Chapter 6, therefore this section will focus on the remaining four themes.
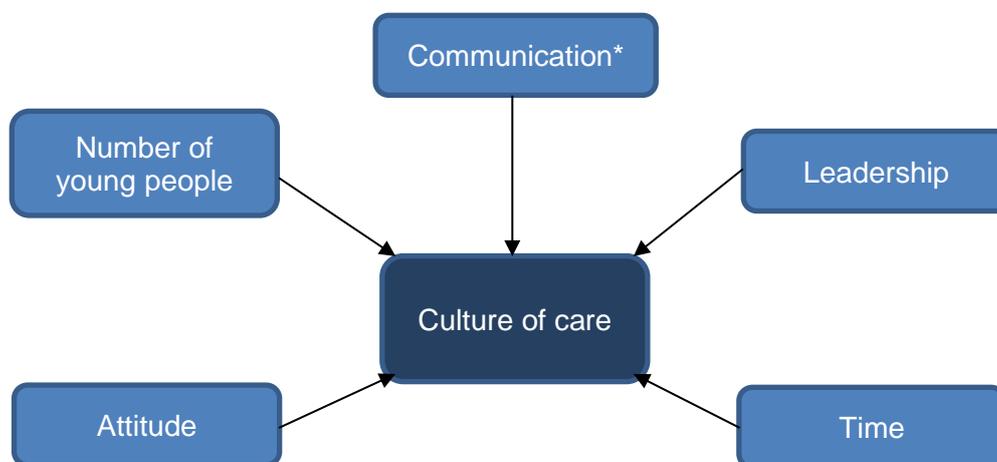
*Chapter 6

Figure 7.2. A thematic map of the factors which influenced the sharing and perpetuation of a culture of care.

7.3.1 Number of young people

Consistency in a high number of young people using a service was a key factor in the formation of an age-appropriate, young-person centred culture of care. It therefore emerged early on as a key defining feature of the main difference between

the settings where young people were cared for. Specialist teenage and young adult units in the Principal Treatment Centres hosted a consistent, concentrated volume of young people, compared to many of the non-specialist children's and adult settings in other hospitals.

The process of building a young-person focussed philosophy of care at designated hospitals was discussed and the impact of the numbers of patients was highlighted as a reason why there was such variation in the care provided at designated hospitals:

"I think it's more about the numbers really. We were looking at the figures the other day and [designated hospital] get about 25 patients a year. That's quite a lot. All the other designated hospitals get one or two…. it works really well with [designated hospital] because they have so many patients there."
(HCP30, sub-case 3, Principal Treatment Centre)

Healthcare professionals explained how the annual numbers of young people they admitted to their service impacted on the support services that they were able to provide. For designated hospitals caring for very low numbers of young people, it made it difficult to prioritise activities such as peer support groups:

"I think we tend to see twos and threes at the same time. I think we're getting to that number now so we hope that, certainly with [Principal Treatment Centre's] support, we will look at doing some sort of support group, I think it's really important that we do that."
(HCP21, sub-case 2, designated hospital)

Similarly, the small numbers of young people being cared for in some designated hospitals and paediatric oncology shared care units meant that commissioning specialist roles was neither practical, nor realistic:

"There are just not enough young people. We would never have enough patients that we would have a clinical nurse specialist in teenage and young adults."
(HCP41, sub-case 4, designated hospital)

Volume, in terms of numbers, provided a patient population from which teams of healthcare professionals could develop their knowledge, practice and a shared set of values. Without the consistent presence of young people as the 'seed' in the centre, the other processes and structures of the culture were less able to flourish. Importantly, the presence of young people also created a vibrant and social environment. Young people described the positive emotions they experienced when they received their care alongside other young people:

"It's a bit of solidarity as well. I'm sitting here having this chemo, but that guy knows exactly how I'm feeling because he's doing the same thing. I think that's quite nice."
(Jade, 15, sub-case 1, Principal Treatment Centre)

7.3.2 Leadership

In all contexts, leadership was essential to shape and perpetuate the culture of care. Leaders were vital in bringing together the whole team, creating a culture in which all healthcare professionals communicated with each other effectively. Leaders were important in assisting the formation of trusting relationships between all members of the team:

"Talking to people and developing relationships, trust and familiarity is just all part of what I do really and then it all clicks together in the end. It's not just about the nurses, it's about the whole team around you as well… making us into one big team and making sure it works. That's a lot of work, because not everyone gets on."
(HCP31, sub-case 3, Principal Treatment Centre)

Leadership, particularly in the designated hospitals, was essential in building a workforce that had awareness of young people's unique and holistic needs, who understood their responsibilities in meeting those needs, and the support services that they could access within the wider network of teenage and young adult care. Additionally, these leaders were integral to the process of 'flagging' all young people in child or adult settings to the multi-disciplinary team at the Principal Treatment Centre. This role was viewed as important for ensuring equitable access to support from the Principal Treatment Centre:

"Some designated trusts, they'll have one or two patients and we'll go out to them. That works well because we've got a lead nurse and a lead doctor in every trust and they let us know almost immediately if they've got a new patient and all that happens. So we know about 100% more patients, and can support them."
(HCP30, sub-case 3, Principal Treatment Centre)

It was highlighted in some networks that the process of 'flagging' was not always efficient; leaving some young people being cared for in child or adult settings with the Principal Treatment Centre remaining unaware of them, therefore unable to provide support at a distance. Leadership was a strategy described as key to a process that would ensure young people were recognised and prioritised as a patient group within the designated hospitals to ensure the Principal Treatment Centre were notified. It was important that someone was *"spearheading"* the service to develop it further, and to raise the awareness to colleagues:

"We did have at one point a designated ward sister for the teenagers and young adults and she also looked after a team of six nurse practitioners, but we lost a ward and there was a reconfiguration of staff so we lost that…it just means you lose your identity a little bit because you haven't got anybody spearheading it."
(HCP29, sub-case 3, designated hospital)

The lead teenage and young adult nurses and clinicians indicated the challenges associated with trying to form a young person-centred culture of care in child or adult care settings. In particular, engaging some colleagues working in adult tumour-specific specialities, and struggling to change their conventional philosophies and systems of working. Leadership and communication skills were used to build relationships and connections between teams of healthcare professionals, particularly with those working independently or in silos. This was discussed by nurses who were working to forge relationships with different clinical teams:

"Yes, I made the links with the clinical nurse specialists from those parties [the haematology and sarcoma teams], it is quite a close working relationship, sort of, a reciprocal, trusting relationship. I've worked to link with palliative care, and that has come on leaps and bounds last year, so we're progressing."
(HCP14, sub-case 2, Principal Treatment Centre

It was evident in the Principal Treatment Centres that those leading the service had a drive and passion for the care of young people. Similarly, the majority of healthcare professionals who were leading services in non-specialist hospitals showed passion and enthusiasm for leading the service. One of the challenges highlighted was the issue of those leading services leaving their roles. There were cases described where there was no succession planning and lead nurses expressed uncertainty as to who would continue to lead the service when they left:

"Particularly as, actually, I'm going part-time next year…so actually this lead role of teenage and young adult nurse is potentially going to alter. I'm not quite sure what's going to happen here."
(HCP34, sub-case 4, designated hospital)

In addition to healthcare professionals leaving their roles, there were challenges as some roles were being removed from hospitals, or being demoted. This challenge was discussed when shadowing the lead teenage and young adult nurse in a strategy meeting in a designated hospital:

Field note entry 04/11/14
Space: *hospital café area, entrance to the designated hospital (sub-case 1)*
Actors: *myself, the lead nurse for the whole network, CLIC Sargent social worker manager from the Principal Treatment Centre, adult urology clinical nurse specialist (the lead Nurse at the designated*

hospital could not attend however the adult urology clinical nurse specialist worked closely with her)
Activity/time: *a meeting to discuss the set-up of the teenage and young adult service at the designated hospital*
Event: *One of the issues discussed was what is going to happen to the role of the lead nurse at the designated hospital– which is being cut. The lead nurse role is currently a band 8a job, however it is being replaced by a band 7 post. There was a discussion around the implications of this for the hospital and for the teenage and young adults being treated there. Other strategies to support young people were discussed, including the need for the social workers to be more present within the hospital to support more young people more regularly.*
Feelings: *This meeting again showed me how important the network lead nurse role is: ensuring that designated hospitals have what they need in terms of support from the Principal Treatment Centre, which has a responsibility to provide support to younger and less developed services. The talk was purely supportive in both directions and showed to me how if health professionals work together, there could definitely be a smooth and well-rounded service provided between the two.*

7.3.3 Attitude

Several concepts emerged as influential to the culture of care; that the culture of care stemmed from the attitudes, beliefs and 'buy-in' of healthcare professionals into what was different and special about caring for young people with cancer. The central message of this theme was:

"You can have the most beautiful unit in the world but if you've got the wrong staff and the wrong attitude then it's not going to work, you can't do it. So it's the people that matter."
(HCP 30, sub-case 3, Principal Treatment Centre)

Healthcare professionals described disparities between individual members of the team in regard to understanding the ethos of teenage and young adult care. Having healthcare professionals who were reluctant to accept a new way of thinking about how they cared for this population was identified as a barrier to establishing an ethos of care. The need for a change in attitudes and beliefs was recognised in some areas, in order to instigate a culture where young people were *"understood"*:

"I think it's understood by some, I mean I think in all areas, there are people who are open to change, and changing philosophy, and changing strategy, and then there's people who don't believe it, and are not prepared to accept change really, it's a bit variable."
(HCP 36, sub-case 4, designated hospital)

This highlighted a challenge faced by healthcare professionals who were leading teenage and young adult services and endeavoured to promote an ethos which

empowered young people and delivered tailored care to meet their individual needs. This acceptance of a *"changing philosophy"* linked to whether healthcare professionals expressed 'buy-in' and acceptance of specialist services for young people. Increased 'buy-in' to what it was to provide services influenced the ethos of the service, and ultimately the culture of care.

Several aspects of the culture of care were influenced by this notion of 'buy in', which was reflected in the attitudes of the healthcare professionals. Communication between the Principal Treatment Centre and other hospitals in the networks was influenced by this. Their attitude and acceptance of what was unique and special about caring for young people influenced the efficacy of the hospital-to-hospital communication across the network:

> *"It depends so much on whether the person treating them has bought into the idea of a teenage and young adult service… we see colleagues who are fantastic who keep us informed…we've got colleagues who haven't bought into this at all, don't really see what extra the teenage and young adult service provides to their patients and I think feel a little bit threatened."*
> (HCP20, sub-case 2, Principal Treatment Centre)

There was a suggestion that communication would be better if doctors, both medical consultants and General Practitioners, learned more about the teenage and young adult service, which was highlighted as a challenging task. One of the biggest challenges reported was obtaining 'buy-in' and acceptance of the need for a young-person centred approach from healthcare professionals who were not at all connected to the teenage and young adult service:

> *"Colleagues who haven't bought into this at all… I think feel a little bit threatened… communication is more difficult and sometimes treatment decisions are not run past the teenage and young adult multi-disciplinary team."*
> (HCP16, sub-case 2, Principal Treatment Centre)

Acceptance from all healthcare professional across the networks was desired by those leading the teenage and young adult services. The right attitude and having 'buy in' was found to be a first, essential step towards the development of a culture of care centred on meeting the needs of young people.

Young people voiced positive experiences on wards where the nurses had a 'young-person friendly' approach and attitude towards the way they delivered care, and that this was a thoughtful attitude which was instilled throughout all of the nurses who cared for them:

"Like, just the nurses on the ward, they're so lovely, when they come in at night it's all done really quietly, they just open the bathroom door and not turn on all the lights, you don't get disrupted the same. Even the way they try and time your drips and stuff so that it's when they'll be coming in to do your obs anyway, just little things like that".
(Jen, 22, sub-case 4, Principal Treatment Centre)

Additionally, interactions were observed where there was undoubtedly a holistic and young person-centred approach to care. In services where the teenage and young adult philosophy of care was well-established among all healthcare professionals, there was an attitude which respected young people and put them at the centre of their care. This was evident in the interactions observed, and the expert care and environment provided on specialist wards were described to be *"where the magic happens"*:

> *Field note entry 17/06/2015*
> ***Space:*** *A clinic room within the adult outpatient part of the hospital – in the Principal Treatment Centre (sub-case 3)*
> ***Actors:*** *Just myself, the Consultant, the young person and a parent*
> ***Event:*** *The Consultant was calm, clear and gentle in his clinical approach and you could see from the way that he spoke that he was very experienced at having difficult discussions - with patients of all ages. Something that he did with his teenage and young adult patients was very much spoke to them directly, not their parents/carers. He asked them where they were in their treatment cycles, giving the patients a sense of ownership of their treatment, and also working out how much knowledge they had. He also showed them all their tumour markers and blood tests on the computer screen. Some patients fully understood this which I think is an indicator that they have been fully involved and aware of all the intricacies of their disease and treatment throughout the whole journey. The Consultant spoke to all his patients about what was going on in their life, home life, work, as well as the medical stuff.*
> *When I first asked to observe his clinic, the Consultant agreed and said I could, but made a memorable comment about ensuring I observed the teenage and young adult team and the social space on the ward. He said that in that space is "where the magic happens."*

7.3.4 Time

It was recognised that it took a long time for an age-appropriate, young person-focussed culture of care to develop. The Principal Treatment Centres and other hospitals visited in the networks were at various stages of maturity, and some of the designated hospitals were less well established than others:

"It's early days, we're only, about two years into designation. Yes, just trying to do our best for them really."
(HCP21, sub-case 2, designated hospital)

Increasing awareness and developing the teenage and young adult services across a whole network was considered to be a process that took considerable time. In less well-established networks it was *"early days"* in terms of the development of care process, systems and attitudes tailored towards young people. In more established networks, it was identified that embedding the systems, processes and values that were now in place had *"taken years to do"* (HCP30, sub-case 4, Principal Treatment Centre). This included building awareness, links and lines of communication between hospitals within the networks, a process which was described to be *"haphazard"* and to take considerable time:

> *"It was a lot more haphazard, so there were clearly colleagues across the region that knew that there were a core team of people here who had an interest in teenagers and young adults… it took a while until people started to know about us and then referrals would come to us."*
> (HCP20, sub-case 2, Principal Treatment Centre)

It also took considerable time for such connections and knowledge about caring for young people to develop on a local level. It was acknowledged that it took time to generate awareness and an accepting attitude among all the healthcare professionals in a hospital, particularly as they could span a variety of specialities: adult, child, and a wide range of tumour site-specific teams. Time was a factor that was highlighted in both designated hospitals and even newer, less established Principal Treatment Centres:

> *"Having [youth support co-ordinator] here now is brilliant and I think she is making a difference. It will take another three to six months before that sinks into the psyche of the clinicians. I think it's starting to change the ward quite significantly and it, it will need to change the paediatric oncology service a bit as well because they, the thinking there is still somewhat different to our, sort of, ethos. It's a matter of time I think".*
> (HCP 20, sub-case 2, Principal Treatment Centre)

7.4 Summary

This chapter has presented findings related to the third core concept of culture, and these were discussed in two sub-sections. Firstly, the development of healthcare professional holistic competence, which was influenced by the environment, healthcare professional's experience and enthusiasm, and education and training. Secondly, data showed that the formation and sharing of a culture where care is responsive to the unique needs of teenagers and young adults was influenced by four factors: a consistent volume of young people using services; effective leadership; an appropriate and accepting attitude; and patience. Together, the

findings presented in this chapter offer substantial insights into how holistic knowledge about caring for teenagers and young adults is learned and developed; and how this knowledge is shared and perpetuated to form optimal care for young people.

The last three chapters have presented the study findings corresponding to the three core concepts of culture that guided the research. This included an exploration of the environments of care, and the powerful influence that the context can have on care experiences. This was followed with a presentation of the components that contributed to the culture of teenage and young adult cancer care, both the more visible 'above the surface' and less visible 'below the surface' components, in addition to how culture of care was learned, shared and perpetuated. The following chapter will draw together these findings, to make visible the contribution of new knowledge about the culture of caring for teenagers and young adult with cancer. The study findings will be examined in relation to existing literature and policy.

Chapter 8

Discussion

8.1 Introduction

The three core concepts of culture provided a unique framework for exploring the findings of this doctoral study, that relate to the delivery of care, and for illustrating young people's and healthcare professionals' experiences across a multitude of care settings. In an earlier chapter of this thesis, the narrative review of the literature presented important existing research about the culture of care. The review highlighted what is already known to be the elements of care that are important to young people, which included: the environment; peer support; professional roles, attitudes and team working; medical expertise; young-person centred and holistic care; and communication, information delivery and patient choice. The narrative review also highlighted the paucity in research exploring the perspectives and experiences of young people cared for in different services and environments within the networks of care; this advocated for more comprehensive empirical research into the culture of care for young people with cancer in the UK. The data presented here as study findings fills that gap.

This chapter will focus on the contribution of this current research to the knowledge about the culture of care for teenagers and young adults with cancer. This discussion, through the application of a conceptual cultural lens, will examine the study findings in relation to existing literature about young people's cancer care, in addition to the wider literature surrounding young people's health services. A critical examination of these findings includes reflections and discussion on the strengths and limitations of the study.

8.2 Re-setting the scene

The focus of this primary research was to answer the following three research questions:

1. How does the context of each Principal Treatment Centre and its network shape young people's individual experience of care?
2. What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care?

3. What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?

These research questions have been answered through a synthesis of study findings, which have been presented and structured using the conceptual framework, including the three core concepts of culture. Table 8.1 presents 'at a glance' a summary, detailing the study research questions, alongside the conceptual framework, relating both to the themes and sub-themes presented previously in the study findings chapters.

Table 8.1 'At a glance' the study research questions and conceptual framework, in relation to the study findings.

Conceptual framework: core concepts of culture	Study research questions	Study findings: themes and sub-themes
Culture takes place within a context, and is therefore dynamic and changeable (Lenburg *et al.* 1995; Kitayama, 2002; Erez and Gati, 2004).	How does the context of each PTC and its network shape young people's individual experience of care? What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?	The important elements of the relationship between the physical and social environments provided the context for young people's cancer care. The relationship, contribution and impact of the physical and social environments of care on young people and healthcare professionals highlighted how these environments (contexts) shaped perceptions and experiences of care and care delivery.
Culture consists of visible goals, processes, structures, knowledge ('above the surface') and behaviours, values, norms and basic assumptions ('below the surface') (Herman, 1970; Hall, 1976; Hofstede, 1991; Schein, 2010; Rick, 2014).	What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care? What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?	Interpersonal communication, how this was reflected in the different settings, provided greater detail to this particular context of care and how it impacted young people's care experiences. Additionally, findings of intra-hospital and hospital-to-hospital communication highlighted some of the processes and structures that are in place which enable care delivery within and between the varieties of care settings and contexts. The core values of teenage and young adult cancer care were presented (recognising individuality, promoting normality and empowering young people), providing understanding of the values and basic assumptions central to care for this group. These represent a common

		theme, as perceived by healthcare professionals and young people, of what values are most important to care for young people with cancer.
Culture is shared and transmitted through learning and teamwork (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; The King's Fund, 2018).	What is different and what is common across the culture of teenage and young adult cancer care in the four Principal Treatment Centres and networks of care? What are the perceptions of care of young people and professionals in each Principal Treatment Centre and its network?	Healthcare professional holistic competence, demonstrated by what was discussed and observed about the development of expertise in care delivery to young people, brought together what was common and different across the range of settings visited. Similarly, commonalities and differences in findings about the development of the culture of care were highlighted in the findings which described how culture was created and perpetuated. Development of a culture was shown to be influenced by the following factors: - Number of young people - Leadership - Attitude - Time Healthcare professional's perceptions of caring for young people were a key part which illuminated this aspect of the study findings.

The findings of this study have provided a fresh lens through which to view both teenage and young adult cancer care, and young people's healthcare in general. There is now an array of policies, reports, service specifications and evaluations, all providing details as to how to care for this group, such as the 'You're Welcome' criteria (PHE, NHS England and DoH, 2017). The AYPH (2017) emphasised the importance of robust evidence evaluating health services for this age group and that young people's ideas and issues regarding health matters should be listened to and acted upon just as readily as other age groups. It is notable that a large proportion of UK research on caring for this age group is within the cancer speciality (NICE, 2005b; Moran and Valiallah, 2013; RCP, 2015). This reflects two things: i) that cancer services are the frontrunners in caring for young people; ii) that there are unique issues that make the care of this group differ slightly to those with other long-term conditions or illness, as cancer is a life-threatening disease which is *treated,* as opposed to a life-limiting disease which is *controlled.* Additionally, evidence

advocating specialist services is steadily growing internationally, particularly in the US, Canada and Australia (Barr *et al.* 2016).

There is also increasing evidence to show great progress in the clinical treatment for cancer, in those aged 15 to 24, with mortality rates in the UK decreasing by 56% over the last four decades (Cancer Research UK, 2018): this is all good news. However, research is yet to evidence whether such improvements have been mirrored in young people's experiences of care, and quality of life, following the policy drive to deliver care in specialist units. While there is some primary research conveying that specialist environments with expert professionals creates the 'recipe' for optimal care (Wilkinson, 2003; Kelly *et al.* 2004; Mulhall *et al.* 2004; Smith *et al.* 2007; Taylor *et al.* 2011; Fern *et al.* 2013; Vindrola-Padros *et al.* 2016); this may not reflect the care experiences of half this patient group, who do not receive their care in a specialist unit (Birch *et al.* 2014). A recent study identified that young people cared for in adult cancer settings had poorer experiences (Marshall *et al.* 2018). This highlighted, once again, how the development of specialist teenage and young adult units have not necessarily improved the experiences for all young people (Marshall *et al.* 2018).

The variety in structure and configuration of services means that young people who have cancer are cared for in a range of environments (O'Hara *et al.* 2013) and two-thirds of young people with cancer are cared for alongside children or adults at either a local hospital or regional cancer centre (Birch *et al.* 2014) (Chapter 1). The findings of this multiple-case study have explored, compared and contrasted perspectives and experiences across a variety of clinical settings; those described as specialist, designated hospitals, and paediatric oncology shared care units. Conducting this research through a critical realist lens enabled the researcher to understand the empirical reality of the culture of teenage and young adult cancer care: inclusive of both the observable and non-observable structures, processes and interactions (Tsoukas, 1989). This has provided rich insights into the *places* in which care is currently delivered and the *people* who deliver it: the two key constituents that together create and shape the culture of care. Findings related to these two constituents contribute to the existing literature on the provision of specialist care for this group, both nationally and internationally. Additionally, findings have also provided new and unique insights about the delivery of care to young people in *places* where there are a small proportion of patients, and the *people* who care for

them as part of a service that cares for much larger numbers of children and older adults.

The third constituent and significant finding relates to *how* the culture is formed. Culture signifies the shared experiences and perspectives that form around a place or phenomenon (Kelly, 2008), and therefore the factors involved in creating and perpetuating a culture are a key contribution of this study: findings framed by the third core concept in the conceptual framework: *culture is something that is learned, shared and perpetuated through effective teamwork and leadership* (Hall, 1976; Davies *et al.* 2000; Marshall *et al.* 2002; Hudelson, 2004; King's Fund, 2017). Previous research has not explored the *learning* and *sharing* of all of the many components which form a culture focussed around caring for teenagers and young adults with cancer. This is, as far as the researcher is aware, the first reported research to do this, providing powerful insights into the *how*, as well as the *place* and the *people*.

Initially this case study was designed with the purpose "*to refine the main components of care, to identify what age-appropriate care means*" (Vindrola-Padros *et al.* 2016, p.365). It has both achieved this purpose and gone beyond it. The findings of this study have refined the main components of care, showing that it is the *place* and the *people* that impact care*.* Early findings depicting this new knowledge have already contributed to a conceptualisation of age-appropriate care (Lea *et al.* 2018b) (Appendix 22). Finally, the distinct contributions of the identified components of care, and the role that they play in creating this culture, are the unique contribution of this study. It is *how* this culture is formed, and how the *place* and the *people* come together around this unique cancer population. This was achieved through the triangulation of data gathered from a wide range of *places* and *people* and through exploring this phenomenon using as a guide the conceptual framework of culture. This provided comprehensive insights to understand the overall case and to discover the empirical reality of not only what comprises the culture of teenage and young adult cancer care in England, but *how* it exists.

These insights into the empirical reality of this culture of care make an important contribution to the overall findings of the BRIGHTLIGHT programme of research. BRIGHTLIGHT sought to answer the overarching question: *"Do specialist teenage and young adult cancer services add value?"* This was a question that could not be answered with only quantitative or qualitative data, nor within one study. It has comprised, therefore, of three workstreams including six interlinked studies. The

understanding of the culture of care, which has come from this doctoral study has enabled us to better understand the context of care, core aspects to its delivery, and what makes teenage and young adult cancer care unique.

Other BRIGHTLIGHT studies have provided findings related to young people's quality of life and psychosocial outcomes in relation to the care they receive, as well as the cost and cost effectiveness of services. The findings presented in this thesis assist in understanding the context of those services in relation to experiences of care. Work is currently being undertaken to bring together the qualitative evidence provided in this multiple-case study together with the quantitative data collected in the longitudinal cohort study. The contribution of this study to the overall BRIGHTLIGHT programme of research is illustrated in Figure 8.1: yet to be fully reported in published work.
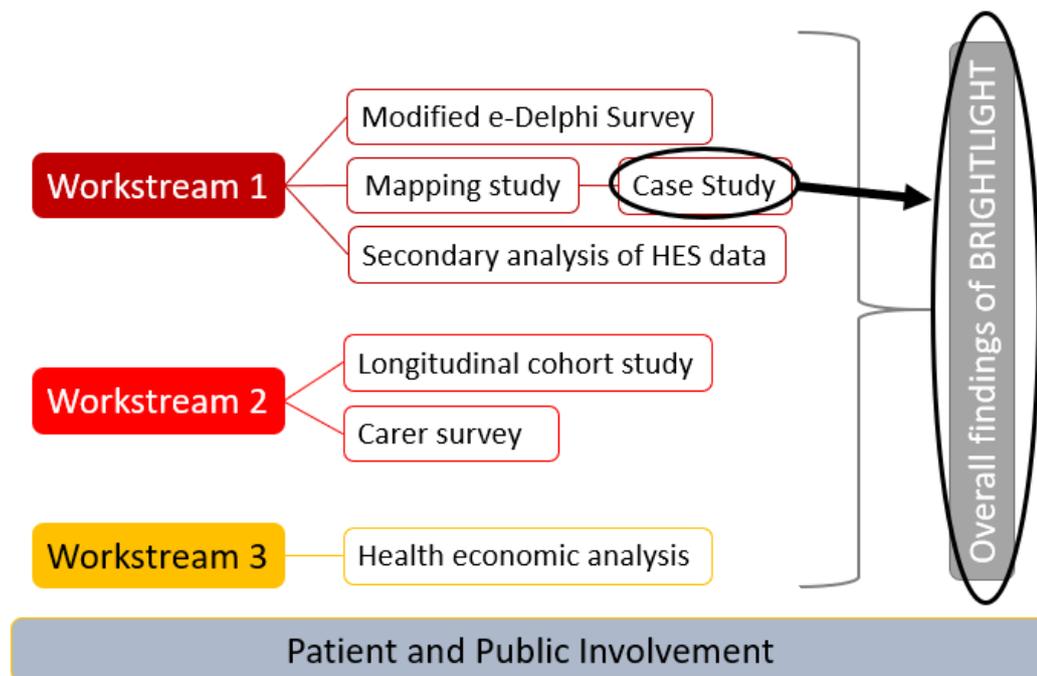
Figure 8.1. A schema illustrating how the findings of the case study contributed to the overall findings of the BRIGHTLIGHT programme of research.

This sets the structure of this chapter, which begins by re-visiting study findings related to place of care: what constitutes a 'young person-friendly' environment; and how the environment can promote normality for patients. The contribution of healthcare professionals in the culture of care follows, reflecting upon: the core values and the provision of person-centred care; the development of holistic competence; and the importance of continuity of care.

8.3 The *place*: environments of care

The environment, the *place* of care, related to the first core concept about culture: *culture takes place within a context, and is therefore dynamic and changeable (Lenburg et al. 1995; Kitayama, 2002; Erez and Gati, 2004).* Exploration of the dynamic and changeable nature of a culture's context was undertaken to address research question one, enabling investigation into the different clinical contexts in which young people's cancer care was delivered. Additionally, research questions two and three were also addressed, examining the differences and commonalities across the environments, and the perceptions of those who experience them.

The environment not only provided a context to frame the culture of care, but also influenced young people's experiences of care. The impact of the environment on a patient's experience in hospital is not a new discovery. It was highlighted as a theme in the existing literature presented in Chapter 3. There is also an increasing recognition of impact of the environment within general adolescent healthcare nationally (HPSET, 2015), and internationally, predominantly in Australia (Hutton, 2005; Bishop, 2010; Payne, 2012).

The findings illustrated in Chapter 6 presented the advantages of having an environment that was both tailored, and dedicated, to young people. This supports previous research in the UK, where the environment, features and facilities provided on specialist wards enhanced experiences of care (Mulhall *et al.* 2004; Mitchell *et al.* 2006; Taylor *et al.* 2011; Fern *et al.* 2013; Vindrola-Padros *et al.* 2016). Findings in this present study highlight the most important of these features and facilities were access to social space and to the Internet. These facilitated the creation of a 'young person-friendly' place of care, and provided young people with access to a social world that is hard to reach when spending large amounts of time in hospital. This concept is discussed in more depth in the following sections.

8.3.1 'Young people-friendly' places of care

Viner (2007) asserted that traditional hospital environments do not work particularly well for any young person in a healthcare setting. Research has shown that their healthcare and illness experiences differ to those of older adults (Tylee *et al.* 2007; Patton *et al.* 2012; Hargreaves, 2011; Ambresin *et al.* 2013). The need to define quality criteria for young people's health services stems from the recognition of their rapid physical and psychosocial development causing unique health needs (Al-Yateem *et al.* 2016). In the UK, service guidelines and research advocates for 'age-

appropriate' and 'young people-friendly' healthcare (NICE, 2005a; HPSET, 2015; RCP, 2015; Smith *et al.* 2016; PHE, NHS England and DoH, 2017), however specialist adolescent wards have also been described as an "expendable luxury" (Mohr, 2001, p.1). The findings in this present study were in support of 'young people-friendly', tailored environments, with age-appropriate features and facilities. They were shown to not be an expendable luxury, but rather a helpful platform from which to develop a holistic and young person-centred culture of care.

The IOG (NICE, 2005a) stated age-appropriate facilities should be paramount; a notion which corresponded with the interviewees reported experiences. Young people in a specialist unit at a Principal Treatment Centre had easy access to age-appropriate facilities, spaces, activities and opportunities to socialise, as previously identified (Wilkinson, 2003; Kelly *et al.* 2004; Mulhall *et al.* 2004; Smith *et al.* 2004; Taylor *et al.* 2011; Fern *et al.* 2013; Vindrola-Padros *et al.* 2016). The findings of this study added to the existing evidence as they highlighted the many ways these specialist features and facilities impacted young people, professionals and the culture of care.

In this study, the features and facilities in specialist units positively influenced atmosphere, mood and behaviour. Features such as bright, fun décor, access to television, games, and a social space or kitchen, were all reported to create a comfortable and homely atmosphere. This 'lifted' the mood of young people, helped with feelings of isolation, and encouraged relaxed interactions between patients and staff. A qualitative evaluation of one teenage and young adult cancer unit (Mulhall *et al.* 2004) described the value of the physical structure of the unit and how it generated a friendly and relaxed atmosphere. The more recent BRIGHTLIGHT 'Mapping' study (Vindrola-Padros *et al.* 2016) found similar experiences, with specialist environments described as positive, comfortable, and offering a "home away from home" (p. 362). Additionally, the impact of the physical environment on patient experience and feelings of well-being in hospital has been identified in the general adolescent patient population (Hutton, 2005; Blumberg and Devlin, 2006; Hutton, 2007; Coad and Coad, 2008; Ullán *et al.* 2012).

It has been suggested that the physical environment *"can make a difference in how quickly the patient recovers from or adapts to specific acute and chronic conditions"* (Stichler, 2001, p. 2). The aesthetics and architectural features of care setting affect the mood, behaviour and ultimately well-being of the individuals within it (Harris *et al.* 2002), as shown by the findings of this present study. Young people and

professionals described windows and 'brightness' to affect the atmosphere and mood on the ward. This agrees with previous work where windows and access to daylight were reported to improve pain control, and reduce anxiety and stress for hospitalised patients (Dijkstra *et al.* 2006). Additionally, the décor was described to have an impact. Young people liked the bright, fun and colourful décor on teenage wards and were comfortable in adult environments that were modern and light, however disliked basic, clinical and "*beige*" adult wards. The décor on children's wards was unpopular when compared with specialist units designed for teenagers. Young people described them childish and patronising. All of these findings support previous research where young people self-reported better satisfaction with the environment and facilities on dedicated adolescent wards in comparison to either adult or children's wards (Viner, 2007; Sadeghi *et al.* 2012).

It is evident that the aesthetic features and décor of a hospital space can impact a young person's experience when in hospital. Through designing and decorating a hospital space that appeals to young people, it will create a more suitable place of care for them. This can be done in conjunction with young service users, a process which can be an empowering opportunity for them (Lea *et al*. 2018b). All of the Teenage Cancer Trust wards were designed in partnership with young people (Teenage Cancer Trust, 2018). In addition to having 'young person-friendly' décor, these specialist environments have been described to create a 'home from home' and to give patients a sense of normality (The Future's Company, 2010; Daly, 2012; Smith *et al.* 2016; Vindrola-Padros *et al.* 2016).

8.3.2 Promoting normality through the place of care

Providing a sense of 'normality' when in hospital was one of the key benefits of dedicated spaces for socialisation, such as lounges or kitchens. This was highlighted in the findings of this study as these spaces allowed young people to come together, build friendships and to stay connected with their friends and family. The provision of social spaces has been recognised as a benefit of these wards (Kelly *et al.* 2004; Mulhall *et al.* 2004; The Future's Company, 2010; Darby *et al.* 2014; Smith *et al.* 2016). In addition to social space, other facilitators were revealed that enabled a positive social environment. Youth support co-ordinators emerged as central to promoting socialisation, bringing young people together and creating opportunities to connect. The findings of this study showed the benefits youth support co-ordinators have on meeting young people's social needs; these benefits often did not reach those cared for beyond the boundaries of the specialist hospitals.

In practice, this has been recognised and, as a consequence, peripatetic roles are being developed (Cable, 2018), even without robust evidence to underpin them.

While play specialists have existed in children's health settings since the late 1960's, youth work/youth support co-ordinator roles, targeted more towards adolescent patients, are a more recent addition to the healthcare teams in UK healthcare settings (Hubbuck, 2009). The Platt Report (Ministry of Health, 1959) was the first document to highlight the importance of recreational activities for children and instigated a drive towards the provision of play specialists for children in hospital. However, the recreational needs of adolescents have remained less well described and met (Royal College of Physicians, 2015). Specialist youth workers in hospital can act as a roving advocate and ambassador for young people, particularly in the absence of a defined adolescent ward or unit (Watson, 2004). The benefits of the one-to-one support, facilitation of activities and group interactions and educational opportunities has been described as essential for this age group (Watson, 2004), and a youth worker is vital to this. The role is unique and age-appropriate: providing personal support, advocating for young people, building self-esteem, and providing diverse opportunities for social and personal development (Watson, 2004). This was corroborated by the findings of this study, where interactions and recreational events were observed that demonstrated the valuable relationships developed between youth support co-ordinators.

Social space was a factor in this study which contributed greatly to the culture of care in the Principal Treatment Centres, both described and observed to enable connection between patients, and to enhance peer and family support. Wilkinson (2003) identified that being near to other young people was one of the biggest priorities for young people receiving cancer care. One of the features of an age-appropriate environment is that it enables and promotes peers support (Lea *et al.* 2018b) through *"separate space set aside for socialising"* (Smith *et al.* 2007, p.366). While social spaces are a visible physical feature in specialist services, this multiple-case study found they were not provided in the majority of adult care settings, and often children's settings only offered a playroom oriented towards younger children. This resulted in young people both in adult and children's care settings having little or no access to other people of their age. Similarly, isolation from peers has been highlighted in other research looking at young people's experiences in adult cancer services (Marshall *et al.* 2018), and on general adult wards (Dean and Black, 2015).

Although there were young people in this study who developed relationships with the adult patients they met, the majority had poor experiences of social interaction in child and adult-focussed care environments, as identified in previous research (Daly, 2012; Dean and Black, 2015; Marshall *et al.* 2018). Thereby, the findings of this study advocate for the provision of dedicated spaces which bring young people together, such as the environments provided on Teenage Cancer Trust units (The Future's Company, 2010). The provision of social space can be a unique addition to optimise healthcare environments for young people. Some healthcare professionals viewed a specialist, age-appropriate physical environment as the *"icing on the cake,"* rather than an essential aspect of care. However, regardless of the setting, specialist or not, young people liked the concept of having a space away from their bed, and where this was not provided, they wished they had somewhere else to go. In other countries, research has emphasised that young people want a social space dedicated to them (Boisen *et al.* 2015) and have shown this has helped to escape the boredom and homogeneity of hospitalisation (Hutton, 2010).

The current findings strongly advocate for the provision of some sort of social space where young people can come together, engage in peer support opportunities, socialise with existing peers, and spend time with their family away from their hospital bed. Findings showed that although the fun, bright décor was beneficial to patients and healthcare professionals, the impact of the social space had greater significance. Adolescent and young adulthood is a period where friends and relationships are at the forefront, as individuals seek to create a social identity for themselves (Tanti *et al.* 2011). These normal developmental processes are interrupted by long periods in hospital (Zebrack, 2011, D'Agostino *et al.* 2011). Hospital environments have been identified to influence social, cognitive, academic and developmental outcomes (Evans, 2006) and the provision of social space would be one way of doing this, as shown in the current study.

This recommendation can be extended to young people in general healthcare, and to patients of all ages. In this study, the provision of social space, such as a kitchen, was suggested as a 'gold-standard' for patients of all ages. This has been indicated in previous research also, where adult hospital inpatients identified a need for access to 'external areas' away from their bed space (Douglas and Douglas, 2004). It could be suggested that access to such space is a way of maintaining a sense of normality and independence throughout time in hospital. There are of course challenges with this in a health system that is already beyond capacity in terms of

space and resource. However, the findings of this research strengthen the evidence in support of such spaces, highlighting their value to patients.

In addition to having dedicated social spaces, access and availability of peer-to-peer interaction and support was enhanced with other facilitators. The two main facilitators that were highlighted were youth support co-ordinators and Internet access to use social media. In the absence of a physical space dedicated to young people, peer support can be facilitated by social media, online forums, and the organisation of social events and support groups (Carr *et al.* 2013; Mooney *et al.* 2016; Abrol *et al.* 2017; Lea *et al.* 2018a). Research has shown that young people who engage in online peer support can experience reduced feelings of isolation (Lea *et al.* 2018a).

Young people in this study cared for on adult wards had mixed experiences in terms of Internet access, however most had poor Internet access or none altogether. Marshall *et al.* (2018) considered adult care settings to be incompatible with the normal activities of youth, in particular a lack of effective Internet access caused young people to feel isolated and out of touch with peers. This mirrored findings across all care settings in this multiple-case study in which both young people and professionals described the importance of Internet access, which has been described as an integral platform for support and information during a young person's experience of cancer (Lea *et al.* 2018a).

The provision of reliable Internet access has the potential to improve a young person's cancer experience significantly, connecting young people with both existing peers, charitable support and other young people with cancer (Lea *et al.* 2018a). This recommendation can be applied to any young person's environment of care, regardless of the physical space, other facilities or staff resource available, as when young people experience isolation they often turn to the Internet to seek comfort and support from peers (Chou and Moskowitz, 2016; Dominguez and Sapina, 2017). In the UK, the NHS is moving into the 'digital age' with the recent implementation of a national Wi-Fi policy (NHS Digital, 2018). The findings of this study are in support of this, and urge international colleagues to take heed and recognise the responsibility they have in supporting the social needs of young people in hospital.

Regardless of the mechanism, face-to-face or online, facilitating and encouraging engagement with peers is something that is both unique and essential to the culture of caring for this age group. Peer support was a key theme identified in the narrative

review as a component of the culture of care (Kelly *et al.* 2004; Mulhall *et al.* 2004; Knott *et al.* 2013). Two further types of peer support were also identified in the narrative review, and were corroborated by data in this multiple-case study. These were: support from existing friends (Wilkinson, 2003; Mitchell *et al.* 2006; Gibson *et al.* 2010) and other young cancer survivors acting as role models (Taylor *et al.* 2011; Fern *et al.* 2013). All of these were described to be valuable sources of support, and young people described connecting with different groups of peers in different ways. While peer support is not a new concept (Kelly *et al.* 2004; Mulhall *et al.* 2004; Knott *et al.* 2013), the study findings corroborate its benefits towards young people's care experiences, in addition to identifying the dynamic nature of peer support for this group consisting of existing friends, peers in treatment, and peers who have finished their treatment. This highlights the depth of peer support that young people may access, particularly if they are exposed to environments which facilitate it.

The findings of this study demonstrate the features and facilities that can be put in place to enable access to these vital sources of peer support, in particular access to social space and the Internet, demonstrating the positive impact such facilities can have on both young people and healthcare professionals. Creating a 'young person-friendly' place of care is about creating opportunities for peer-to-peer support. The findings presented here suggest that this is possible in all settings, regardless of whether it is possible to have all the features and facilities of specialist teenage and young adult units.

8.4 The *people*: healthcare professionals caring for young people

In addition to place of care, study findings emphasised the impact of the *people* who provide it, and their role in creating the culture of care. Findings about the people who deliver care encompassed: processes of communication used; the development of holistic competence; provision of specialist healthcare professional roles; and the importance of continuity of care. Their important contribution to the culture of care is a core aspect of this study's findings.

Not only were the process and structures of the care delivered by healthcare professionals fundamental to shaping young people's experiences; but also, their core values, attitudes and beliefs about care delivery were also essential to experience of care. The importance of a group's values was recognised in the cultural literature, explored in Chapter 2, and "espoused values" were said to

underpin an organisation's culture (Schien, 2010). It has been recognised that nurses should respect and adopt what young people regard as ideal personal attitudes and values (Morgan, 2018), such as having an appropriate sense of humour (Taylor *et al.* 2016b), a caring nature and are willing to 'go the extra mile' (Vindrola-Padros *et al.* 2016). While this was also identified in the findings of this present study, it is essential to note that professional boundaries should always be maintained, and that the relationships developed with professionals are therefore not confused or misunderstood by teenage and young adult patients (Cable, 2016).

8.4.1 The core values and young person-centred care

The importance of healthcare professionals within the delivery of cancer care to young people has previously been identified (Kelly *et al.* 2004; Gibson *et al.* 2012; Fern *et al.* 2013). Underpinning the culture of teenage and young adult cancer services in this study were the values and attitudes of healthcare professionals. Three core values emerged: recognising individuality; promoting normality; and empowering young people; and these underpinned all aspects of the culture of care.

Within the BRIGHTLIGHT programme of research, two other studies have independently identified similar values regarding the delivery of care to young people with cancer. Taylor *et al.* (2016b) advocated for healthcare professionals to have specific skills, including working in partnership with patients, delivering person-centred care, and commitment to caring for young people. Furthermore, the findings presented in the BRIGHTLIGHT Mapping study reported caring and supportive staff were fundamental to specialised care for this group (Vindrola-Padros *et al.* 2016). Young people wanted to be cared for by staff that 'take their time', 'go the extra mile' and 'get to know you' (Vindrola-Padros *et al.* 2016), mirroring the value of recognising young people's individuality through building relationships with them. Together, the current study and the Mapping study were conducted in a total of 30 hospitals across England, and the study by Taylor *et al.* (2016b) was an international survey; therefore across these three studies, the combined agreement of the importance of core values underpinning care enhances the significance of these findings.

While parallels can be drawn, the three core values extend and expand the findings of the Mapping study (Vindrola-Padros *et al.* 2016). The Mapping study collected perspectives of participants delivering and receiving care within Principal Treatment Centres only, thus presenting the most important aspects of the delivery of specialist

care in the UK from the perspectives of those embedded within it (Vindrola-Padros *et al.* 2016), similar to other primary research (Wilkinson *et al.* 2003; Kelly *et al.* 2004; Taylor *et al.* 2011; Knott *et al.* 2013).

An ongoing challenge is that the care of young people often straddles two different approaches: family-centred care with children, and person-centred care with adults (Ferrari *et al.* 2016). Findings in this current study argue for an approach to care that falls between the two. Current best practice guidelines for teenage and young adult cancer care recommend a family-centred approach should be employed, guided by the young person's best interests (Cargill *et al.* 2016). The findings of this case study oppose this and suggest that, for the majority, they should receive care more akin to the adult model of person-centred care. Young people wanted to be at the centre of their care and be involved in all communication and decision-making. This supported previous literature which suggested young people want a young person-centric approach to communication (Gibson *et al.* 2010) and to their clinical care (Knott *et al.* 2013). It is important to highlight that in this present study, significantly fewer younger teenagers (less than 16 years) participated than older teenagers and young adults. This may have caused more of an 'adult-biased' view, and thus resulted in the findings that young people desire to be highly involved and at the centre of their care.

The development of service-user perspective guidelines for 'person-centred co-ordinated care' was commissioned by NHS England to survey what mattered most to patients and users of health and social care services (National Voices, 2013). It stated that, from a service-user perspective, person-centred co-ordinated care means: *"I can plan my care with people who work together to understand me and my carer(s), allow me control, and bring together services to achieve the outcomes important to me"* (National Voices, 2013, p. 3). Looking critically at this definition of person-centred care (National Voices, 2013) and the findings pertaining to the core values in this study, it could be argued that the best terminology for the care of this unique group is 'young person-centred care.' The notion of *"understand me"* reflects the recognition of a patient's individuality and the need for individualised care, a core value which was found to underpin teenage and young adult cancer care both in this study and in previous literature both nationally (NICE, 2014a; Smith *et al.* 2016) and internationally (Zebrack *et al.* 2007, D'Agostino *et al.* 2011). Similarly, the perspective *"allow me control"* (National Voices, 2013, p. 3) was reflected in the findings of this study: the core value empowering young people. These findings

reiterate the importance of viewing the care that these patients require as different to that of young children and older adults: not 'family-centred', nor 'patient-centred' or 'person-centred', but 'young-person centred'.

It has been recognised globally that healthcare professionals acknowledge their role as an advocate for young people (WHO, 2018b), approaching care with a belief that young people should be in the foreground of all communication and decision-making (Gibson *et al.* 2010; Coyne *et al.* 2014). Study findings showed that young people wanted open, honest and meaningful communication and interactions with healthcare professionals to build and establish trusting relationships. This overlapped with previous research in specialist teenage and young adult units (Mulhall *et al.* 2004; Gibson *et al.* 2012; Darby *et al.* 2014) and with wider health literature which has specifically explored the concept of person-centred communication (Wensing *et al.* 2002; Swenson *et al.* 2004; McCormack *et al.* 2011). Person-centred interpersonal communication is a process of care that closely connects to the two underlying core values which emerged in the study: recognising individuality and empowering young people. Use of a communication approach and attitude where decisions are made in partnership with young people has been suggested as a means of empowering them (Gibson *et al.* 2012; Knott *et al.* 2013; Bravo *et al.* 2015; Taylor *et al.* 2016b). Similar recommendations have been posed within young people's mental health care, which advocates training healthcare professionals in providing flexible care which is responsive to the unique needs of young service users (Gondek *et al.* 2017). While this has been advocated, the impact on outcome and benefit to patients has not been evidenced and warrants future investigation.

8.4.2 Development of holistic competence

International literature has advocated for professionals to recognise the developmental stages that young people undergo as part of understanding a patient's individual needs (D'Agostino *et al.* 2011; Zebrack, 2011; WHO, 2002). The competence of healthcare professionals to practice young person-centred care that is holistic emerged as a theme in this present study. Holistic care is increasingly recognised as essential to the care of all cancer patients (Macmillan Cancer Support, 2018). The Cancer Strategy for England 2015-2020 (The Independent Cancer Taskforce, 2015) highlighted the importance of holistic support for all cancer patients, incorporating the psychosocial, emotional, financial and physical needs from the point of diagnosis.

Healthcare professionals in this study recognised the importance of being competent in caring for young people holistically, and that building this competence took experience and education. The provision of holistic care for young people involves understanding their developmental needs (D'Agostino *et al.* 2011), which was also highlighted in the findings of this present study. Specialist teenage and young adult cancer units across the UK are staffed by teams of professionals who are experts in the provision of both clinical and holistic support (Fern and Lea, 2016). However, the challenges of providing care which meets the holistic needs of all young people have been recognised, as young people have such a wide range of needs based on their personal circumstances and life stage (WHO, 2002). Additionally, development of holistic competence is even more challenging for healthcare professionals who have infrequent exposure to young people, therefore not having the opportunity to develop experience caring for them.

A concept analysis offered a definition of holistic nursing care as a practice which *"embraces the mind, body and spirit of the patient, in a culture that supports a therapeutic nurse/patient relationship, resulting in wholeness, harmony and healing. Holistic care is patient-led and patient-focussed in order to provide individualised care, thereby, caring for the patient as a whole person rather than in fragmented parts"* (McEvoy and Duffy, 2008, p. 418). McEvoy and Duffy's (2008) definition of holistic care neatly aligns with having an individualised, young person-centred approach to care. While it should be acknowledged that this definition is solely based on nursing practice, it has relevance here as nurses comprised the majority of healthcare professional participants in the study, and are responsible for a large proportion of the regular care young people experience (Smith and Olsen, 2018.

Teenage and young adult cancer patients are a relatively small cohort, yet the range and distribution of healthcare professionals that may care for them is wide, which can make it challenging to generate opportunities for developing experience, skills, and for formal education (Cable and Pettit, 2018). Alongside the growth in the specialism, more opportunities are emerging for both formal and informal, multi-professional learning around best practice and holistic care (Cable and Pettit, 2018). The findings presented in this doctoral study provide new evidence which will enable a better understanding of the ways in which holistic competence is learned and shared, both organically and intentionally, across a range of cancer care settings. This will be helpful to direct the future development of the workforce. These findings provide evidence to support some of the existing, formal methods of educating the

teenage and young adult cancer workforce; in addition to depicting the experiences of less formal mechanisms of education and knowledge sharing between healthcare professionals in adult and children's cancer care settings.

The development of holistic competence was a result of specific and formal education and training, along with an accumulation of experience through regular and consistent contact with teenage and young adult cancer patients. Viner and Barker (2005) also highlighted the importance of exposure to young people in building the experience, knowledge and skills specific to their care. Viner and Barker (2005) suggested short-term exposure to caring for this age group should be a requirement of all healthcare professional training programmes, enabling healthcare professionals working in either child or adult healthcare settings to have access to caring for young people and education around their needs.

In terms of professional competencies, in nursing it is accepted that the best standards of care are delivered by those who have considerable expertise or specific training in working with this unique patient population (Smith *et al.* 2018). The development of a specialist and expert nursing workforce has been integral to the overall development of teenage and young adult cancer care within the UK (Morgan, 2018). In 2014 a competence framework for teenage and young adult cancer nursing in the UK was published (Teenage Cancer Trust, 2014), which presented the core domains of competence that applied to nurses of all professional levels. At present, there is only a formal competency framework specific to nursing teenagers and young adults with cancer, although youth support co-ordinator roles and competencies have recently been a point of discussion and examination (Cable, 2018). This recent work highlighted a need for clearer roles and responsibilities associated with the role (Cable, 2018). It could be suggested therefore that there is an educational gap for youth support co-ordinators, who often have a background in youth work and thereby could benefit from formal education on cancer care.

The nursing profession therefore has a responsibility to share their knowledge, experience and standards for best practice in caring for young people (Morgan, 2018), and to lead in sharing their expertise to develop the competence of the wider multi-disciplinary team. This is the responsibility of nurses in all settings of care across the networks, perhaps more so outside the Principal Treatment Centre. In designated hospitals that cared for very few young people annually, the lead nurses were often at the forefront of the service, liaising with the team at the Principal Treatment Centre. They described their responsibilities in championing and

developing the service, and striving to meet the recommendation that age-appropriate care and support should be accessible across the networks (NICE, 2005a). Previous literature has shown that young people felt that professionals working on teenage and young adult cancer wards have a shared recognition of what was involved when providing expert care to young people (Mitchell *et al.* 2006; Darby *et al.* 2014; Vindrola-Padros *et al.* 2016). The goal should be for the expertise at the Principal Treatment Centres to be shared with the teams across the networks (Fern and Lea, 2016). The networks of care are therefore intended to be a medium for sharing expertise (Carr *et al.* 2013), however the challenges in hospital-to-hospital communication that were identified in this study and demonstrated the difficulties of team working across a network.

The obvious challenge of hospital-to-hospital communication is the physical distance between professionals. An ethnographic study of an Italian hospital identified 'operational proximity', i.e. working side-by-side, facilitated practice sharing and knowledge transfer between healthcare professionals (Tagliaventi and Mattarelli, 2006). Networks of team working can enable professional groups with different specialisms or from different organisations to confront, consider, discuss, and share their practice and knowledge (Tagliaventi and Mattarelli, 2006). In specialist centres, much of the development of competence is learning through a multi-disciplinary approach focussed solely on teenagers and young adults (Cable and Pettitt, 2018). In child and adult healthcare settings, the focus of the multi-disciplinary teams is different, as they are based on tumour groups rather that age groups. It is therefore more complex to develop a workforce with the knowledge, skills, and values that underpin holistic, young person-centred care in settings outside the Principal Treatment Centre. Findings illuminated natural 'boundaries' between tumour-site specific teams working in adult cancer services, and it could be surmised that this slowed or hindered the diffusion and transfer of knowledge (Tagliaventi and Mattarelli, 2006). Findings alluded to the challenges of educating *all* who care for young people in designated hospitals what it means and entails to provide age-appropriate care to young people. Strategies to build holistic competence among professionals in designated hospitals should include increased exposure to young people, to develop experience and confidence in working with them.

In terms of training and education programmes, this research indicated there was wide variation across the hospitals in access to and types of training provided to healthcare professionals working with young people. Some healthcare professionals

had access to formal education and training; however this was more regularly discussed at the Principal Treatment Centres. This is where the higher volumes of young people are, and therefore the expertise in caring for this group should be, and is, most concentrated (Jones *et al.* 2017). Local or in-house training and education was developed in some hospitals, and was recognised as an important 'next step' for other services to improve the holistic care they provide to young people. Such forms of education can be reinforced and encouraged with the recent generation of evidence-based competencies and frameworks for professionals (Teenage Cancer Trust, 2014; Taylor *et al.* 2016b), in addition to more recent developments in online and e-learning opportunities making formal education about caring holistically for young people more accessible than ever (Cable and Pettitt, 2018). Healthcare professionals leading services in hospitals outside the Principal Treatment Centres need to be creative and innovative with their approach to educating their workforce. If they are to develop a culture of care which encompasses all the *people* who work there, they must find ways to educate healthcare professionals and raise the profile of teenage and young adult care across the whole cancer service, and ideally the hospital.

Study findings indicated that experience, enthusiasm and an environment dedicated to young people's care were influential in the development of workforce expertise in meeting their needs. Lead nurses in designated hospitals described barriers they faced to the development of their workforce. The care of young people was provided by a wide variety of tumour-site specific multi-disciplinary teams spread across the designated hospital, all focussed on their own tumour-site expertise. Designated hospitals were working to raise awareness and knowledge among the whole hospital workforce, a challenge when the enthusiasm and experience caring for young people was varied, or lacking in some cases. Nurse leaders are recognised as essential to driving the development and delivery of models of care (Thomas and While, 2007; Smith and Olsen, 2018), and to lead an organisational culture where professional development and education of staff is encouraged and supported (Curtis and O'Connell, 2011; Knott *et al.* 2013; Cable and Pettitt, 2018).

The 'environment' was another component of care suggested to facilitate person-centred nursing (McCormack and McCance, 2006) and the findings of this study showed the environment to have an impact on the attitude of healthcare professionals and the interactions they had with patients. Hospitalisation can be a stressful experience for someone of any age but for young people, extended periods

of hospitalisation can be lonely and isolating (Michaud *et al.* 2004). A young person's surroundings within a healthcare setting will operate and influence their behaviour and function (HPSET, 2015). As presented in this case study, it was important that staff recognised young people as a distinct population, with individual needs, desires and opinions, as has been discussed in previous work (Alderman *et al.* 2003; Al-Yateem *et al.* 2016). Suggesting that, the environment can act as an enabler for healthcare professionals to adopt a young person-centred approach to their care.

The findings of this study provide useful insights into the network-wide development of a workforce competent in providing holistic care to young people, which puts young people at the centre of their care. While teams at designated hospitals and paediatric oncology shared care units drew on and accessed the expertise at the Principal Treatment Centres, there were limited findings demonstrating a network-wide approach to the sharing of learning, knowledge and values between hospitals and teams. It could be surmised that a lack of network-wide sharing of knowledge was due to the location and proximity of the different hospitals in the networks, as suggested by Tagliaventi and Mattarelli (2006). The geographical distance between specialist services with abundant expertise and some of the non-specialist hospitals was often vast, therefore creating a barrier to the transference of knowledge and values of care (Tagliaventi and Mattarelli, 2006).

Practice, research and policy states that in the UK, teenagers and young adults with cancer should receive care from specialist teams with appropriate education and expertise (Kelly and Gibson, 2008; Fern *et al.* 2013; NICE, 2005a). Mechanisms to effectively share and transfer expertise beyond the confines of the Principal Treatment Centres are required. The experience of healthcare professionals in this doctoral study revealed that this was largely dependent on hospital-to-hospital communication and integrated, collaborative working across the care networks. Best practice care requires effective collaboration between all healthcare professionals caring for a young person, including members of the teenage and young adult multi-disciplinary team and tumour-site specific teams (Pettitt *et al.* 2016). Communication and collaboration were not only found to be integral processes in the sharing and development of healthcare professional competence, but were also central to the facilitation of continuity of care.

8.4.3 The importance of continuity of care

Concerns have been raised about the fragmentation of care for those patients who are seen by a range of professionals in a variety of care settings (Haggerty *et al.* 2003). National policy urges for efforts to enhance integration and continuity of care (Freeman and Hughes, 2010). Additionally, co-ordination of care, continuum of care, seamless care, and integration of services are all terminology that confuses the concept (Haggerty *et al.* 2003). It has been recognised that young people can become subject to shortcomings in communication, co-ordination and collaboration of care, particularly as they do not belong in either the child or adult *"worlds of oncology"* (Ferrari *et al.* 2016, p. 517).

The concept of continuity of care emerged as part of two different themes within the findings of this study: 1) the continuity of the caring relationships young people developed with their healthcare professionals; 2) the continuity and "*joined-up"* approach to the communication and co-ordination of young people's care. Research commissioned by The King's Fund investigated the continuity of care in relation to patient experience within General Practice (Freeman and Hughes, 2010). Two categories of continuity of care were identified: relationship continuity and management continuity (Freeman and Hughes, 2010). Relationship continuity describes a continuous therapeutic relationship with a healthcare professional; and management continuity encompasses the consistency of clinical and holistic care, sharing of information and co-ordination of care (Freeman and Hughes, 2010). These two definitions reflect the findings about continuity of care that emerged in this case study. Meaningful relationships with healthcare professionals and structured processes of working such as multi-disciplinary team meetings, both allowed for continuity of care.

These findings about the two dimensions of continuity of care are valuable to understanding how services can enhance patient's experiences of care. Teenage and young adult cancer services should strive to put systems in place which ensure young people in all care settings have both relationship continuity and management continuity in their care. Management continuity enables consistency of care, communication and co-ordination, which aligns with one of the key objectives presented in the Manual for Cancer Services: Teenage and Young Adult Measures (NHS England, 2014): *"all patients receive co-ordinated care"* (p. 13). Young people described positive experiences of care when they felt communication and co-ordination between healthcare professionals was happening effectively, and

recognised when care was "*joined-up*". Young people who had their care shared between hospitals described mixed experiences, as did healthcare professionals of delivering shared care.

Shared care across hospitals was *"seamless"* in some cases, and *"disjointed"* in others. Hooker and Milburn (2000) identified challenges for healthcare professionals in executing shared care. A descriptive study highlighted concerns with the hospital-to-hospital communication and continuity of care, and strategies were developed to reduce the issues that arose, such as using a specialist shared care nurse to liaise between the hospitals and to promote the use of consistent standards of communication (Hooker and Milburn, 2000). This was a strategy that was described in one of the networks of care visited in this multiple-site case study and was found to be a positive facilitator to assist communication for professionals providing shared care. Such roles have an important place within teenage and young adult cancer networks to facilitate continuity of care, particularly for those having shared care.

8.5 How culture of care is formed, shared and perpetuated?

As discussed, there is an increased acknowledgement of the importance of 'youth-friendly' health services, both nationally (RCP, 2015; PHE, NHS England and DoH, 2017) and globally (Nair *et al.* 2015). For over ten years it has been recognised that adolescent healthcare delivered by knowledgeable *people*, in an appropriate *place*, improves experiences of care (Viner, 2007). Likewise, international colleagues have stated similar ideologies for how to best deliver care to young people (Ferrari *et al.* 2010). Ferrari *et al.* (2010) also stated that care should take place within in a culture that acknowledges the range of developmental maturity and psychosocial issues that arise in this patient population.

8.5.1 The impact of specialisation of services

The limited empirical research to evidence the development of specialist settings for young people with cancer has been questioned (Taylor *et al.* 2011) and it has been highlighted that this specialisation of services was not driven by research (Ferrari *et al.* 2016). Despite advances in knowledge about caring for this age group, young people cared for outside specialist services are still referred to as a 'lost tribe' (Marshall *et al.* 2018). Concerns that were raised about the burden of travel have supported the current structure of the networks (Marris *et al.* 2011), where

designated hospitals offer care to young adults, and shared care is an option for younger patients, both supported by expertise at the specialist centre.

This study presents significant findings regarding the reality for some young people in designated hospitals in accessing the expert holistic support and peer support available to them at the Principal Treatment Centre. This reality was an example of a disparity in the visible and invisible aspects of culture, between *'what we say we do'* and '*what we actually do'* (Herman, 1970). Designated hospitals provided young people with the choice to have their care closer to home, and the perspectives of young people and professionals in this study showed that having this choice was valued by young people. It was recommended that young people who choose to be cared for at a designated hospital should still be able to access the social and support services provided at the Principal Treatment Centre, consequently aiming to deliver *"age-appropriate, safe and effective services as locally as possible, not local services as safely as possible… young people of 19 years and older should also have unhindered access to age-appropriate facilities and support when needed"* (NICE, 2005a, p. 7-8).

Findings of this study revealed that not all young people had "*unhindered access"* to age-appropriate facilities and support. Several reasons emerged that demonstrated how this access was hindered: some young people were not flagged to the teenage and young adult multi-disciplinary team at the Principal Treatment Centre, others were informed about the specialist services provided in the Principal Treatment Centres such as local peer support events but felt they did not need it at the time it was offered and therefore did not engage in it. This highlights two issues, the complexity of working with this age group (Ferrari *et al.* 2010; Taylor *et al.* 2013) and the complexity of having a complex, multi-disciplinary, network-based structure of care (Carr *et al.* 2013) where the boundaries between different organisations can be a barrier to the delivery of care and the sharing of information, as was suggested by Tagliaventi and Mattarelli (2006).

Wilkinson (2003) suggested that previously there was insufficient literature to indicate that specialist teenage and young adult units provide superior care to that offered in non-specialist hospitals. In terms of patient outcomes, a recent study looked at the relationship between children and young people's access to a Principal Treatment Centre and their survival rate in (Fairley *et al.* 2017). This study found no significant difference in survival for most tumour groups, except for children and young people with leukaemia, where better survival was associated with treatment

in a Principal Treatment Centre (Fairley *et al.* 2017). While these findings are limited to one region of the UK and only one disease type, the research advocates for specialisation of teenage and young adult cancer services, in terms of patient survival.

Similarly, patient outcomes in the diagnosis-specific specialisation of services in adult cancer care have been examined (Hillner *et al.* 2000). In a review of the literature, Hillner *et al.* (2000) found that for non-surgical cancers, primarily testicular cancer and lymphomas, research consistently indicated better long-term outcomes related to the hospital having a specialty focus or larger patient volume of that cancer type. Hillner *et al.* (2000) advocated, for all cancer types, that it would be appropriate to concentrate care through specialisation of services. However, it must be noted that patient outcomes, typically survival, are not the same as patient experience or quality of life. While specialisation of services may improve patient outcomes due to the concentration of expertise, this may not influence other, more holistic aspects of a patient's experience. It has been recognised that a lack of research examining the effect of service specialisation on young people's experiences of care (Marris *et al.* 2011). This present study offers some insights into those, however other research designs are required to specifically investigate this on a larger scale.

It has been suggested that having healthcare settings with a concentration of young people in one environment offers *"a critical mass around which training and service development can be built"* (Payne *et al.* 2012, p.45). Findings in this present study indicated that the higher volume of patients attending a specialist centre naturally generates increased interest, enthusiasm, experience and therefore expertise when working with this group. This makes 'young person-friendly' healthcare the norm.

While a *"critical mass"* of young people with cancer facilitates the generation of knowledge, expertise and ultimately a positive and shared culture of care, such a situation could also be at risk of reinforcing a 'darker' and less positive side of these services. As described in Chapter 1, there are challenges associated with caring for patients with cancer. There are emotional challenges for young people, their families and healthcare professionals when they are consistently confronted with illness and death in environments of care. The impact of illness and death was not a key theme which emerged in the findings of this study. In fact, the challenges of providing bereavement support was mentioned only in an informal conversation with a healthcare professional. Although these particular challenges were not witnessed or

discussed with study participants during data collection, there is no suggestion here that these do not exist; future research should be a priority to focus on this impact.

The culture in dedicated teenage cancer services was one of positivity, reflected in the findings presented about the environment and associated expertise within these care settings. This could be a reflection on the way that any discussions regarding culture naturally shies away from 'difficult conversations'. Alternatively, this could be a reflection on this specific experience of culture, and one must be critical of the potential bias of the researcher in the way that culture was viewed, examined, and thus presented. However, illness and death were not an overt part of the culture that was discussed and observed: there were no deaths in any of the sites during data collection when the researcher was present. Therefore it was not possible to view any interactions or care delivery that surrounded illness and death. More importantly, in the stories shared by participants, based on their experiences, this 'darker side' of care did not feature.

8.5.2 Communication and multi-disciplinary team working

Cancer care for young people is organised around a specialist teenage and young adult multi-disciplinary team at the Principal Treatment Centre. "*Young people (aged 16-24 years) with cancer have their diagnosis, treatment and support agreed and delivered by a cancer-site specific multidisciplinary team and a teenage and young adult multidisciplinary team*" (NICE, 2014a, p.11). The narrative review identified previous primary research investigating the communication between healthcare professionals and young people, however there has been no research conducted to examine the hospital-to-hospital communication across teenage and young adult cancer networks in the UK.

The findings of this study demonstrated that for care to be agreed and delivered by multiple teams of professionals, effective and consistent communication had to occur both within and between teams to provide the highest standard of individualised care to young people. A team approach and joined-up healthcare professional working was identified by young people as being of benefit to their experiences of care, as was identified in prior literature to be a key part of caring for young people with cancer (Kelly *et al.* 2004; Mulhall *et al.* 2004; Pini, 2009; Knott *et al.* 2013; Vindrola-Padros *et al.* 2016).

A lack of evidence examining multi-disciplinary team communication was previously highlighted (NICE, 2005b). Clinical guidelines for adult palliative and supportive

cancer care emphasised the importance of effective multi-disciplinary working across the cancer networks as being crucial in co-ordinating and enhancing services to meet patient's unmet psychosocial needs (National Institute for Clinical Excellence, 2004). Moreover, the importance of effective multi-disciplinary team working has been advocated across a range of medical specialities, and has been shown to be affected by the following factors: leadership; team processes; reflexivity and team diversity (Borrill *et al.* 2000; Lamb *et al.* 2011; Knott *et al.* 2013). Leadership in particular was identified by Lamb *et al.* (2011) as crucial to the efficacy and efficiency of the discussions that occur within multi-disciplinary team meetings.

A similar interdisciplinary network approach, with concentrated expertise in one place, was advocated when managing the care of young people with a chronic illness (Michaud *et al.* 2004). Michaud *et al.* (2004) described the importance of a 'reference clinician' to work in a co-ordinating role and to maintain connections between professionals working with that young person, who may be from a range of specialities or roles. This links the two concepts of multi-disciplinary teamwork and leadership: two key themes which contributed to the sharing of the core components of culture in this study, and previously recognised themes as important to the development of a healthy organisational culture (The King's Fund, 2018).

Enhanced leadership can therefore be attributed to the success of the communication and team working of multi-disciplinary teams, in addition to joined-up, collaborative team working and continuity of care. The findings of this study identified that the pathways of communication within some of the teenage and young adult cancer networks were better defined than others. It can be surmised that leadership played a role in how the hospital-to-hospital communication pathways were managed, highlighting the importance of effective leadership.

8.5.3 The importance of effective leadership

Passion, enthusiasm and an ethos for caring for this specific patient population was both observed and described to be inherent to those working within specialist teenage and young adult units. Study findings also recognised that this took time to establish in the same way that it took years of lobbying and championing by local, national and international ambassadors and leaders to establish healthcare provision that meets the needs of young people (WHO, 2002; Carr *et al.* 2013; RCP, 2015).

It has been suggested that the development of a culture can be fundamentally shaped by the personality, communication style and interpersonal characteristics of the individual leading the service (Kelly, 2008). Leaders working in settings where a young person-centred approach to care is not yet widely recognised or practiced are required to be champions for change; engaging both individuals and the organisation as a whole (Alimo-Metcalfe and Alban-Metcalfe, 2008). There were examples in this study where enthusiastic leadership and implementation of innovative strategies were used to champion teenage and young adult services, with the aim of generating greater awareness and 'buy-in' among all healthcare professionals of the need to adapt their approach when caring for this patient population (Marshall *et al.* 2018). The complexity of enabling tumour-site specific specialists to work cohesively with the teenage and young adult multi-disciplinary team at the Principal Treatment Centre confirms the importance of the lead nurse and lead clinician roles; pertinent in bringing the clinical and supportive care of young people together (Carr *et al.* 2013).

Adding to this, the findings of this research have shown that strong and effective leadership was required to grow a culture where every healthcare professional recognises the unique and individual needs of every young person they cared for, empowering and involving them in their care, and promoting normality wherever possible. This requires leaders who are capable of motivating and enthusing those they work with (Curtis and O'Connell, 2011), and obtaining 'buy-in' from those they wish to work closer with.

Obtaining 'buy-in' from healthcare professionals who have never before viewed young people as a distinct patient group presented as a challenge. This was identified by leaders of adult services, who described some adult oncologists as struggling to accept teenagers and young adults as a group with unique needs, thus not willing to adapt their approach. Similar attitudes of Doctors are a challenge that have been acknowledged in other research of young people's experiences in adult settings, both in cancer (Marshall *et al.* 2018) and in general adult services (Dean and Black, 2015). These challenging staff attitudes could be a result of a lack of education and training for all healthcare professionals who work in adult healthcare but see younger patients. Dean and Black (2015) suggested that the levels of training, supervision and support for staff should be examined. Additionally, it has been recognised that it takes time for attitudes and beliefs to change in order to overcome these barriers to collaborative team working (Pettitt *et al.* 2016). Time was

a further finding of this present study which contributed to how a culture was formed. While there is nothing practical professionals and stakeholders can do to control the variable of time, it is important that time is recognised as a factor influencing the development and sharing of a young person-centred culture of care, and that patience is required to enable this.

The three core values (recognising individuality, promoting normality and empowering young people) provide a foundation for a culture where young people are at the centre of their care. In this case, the findings of this study suggest these values are essential to the culture of care, and should be understood and adopted. The present climate of the NHS and the service review currently being undertaken by the Department of Health and Social Care (Hough, 2018) leaves teenage and young adult cancer services in England in a state of uncertainty. During this time it is particularly essential that the importance of strong, authentic and passionate leadership is recognised and encouraged, to support the innovation and evolution of new and existing services (Kelly, 2018) and to challenge existing services through making the voices of young people heard and advocating for them (Marshall *et al.* 2018; WHO, 2018).

8.6 Strengths of this research

The aims of this research were ambitious, but on reflection it feels reasonable to suggest that they were achieved. The findings provide original contributions to the limited, yet growing body of evidence surrounding the delivery of cancer care to young people. A fundamental strength of the study was that it was conducted across multiple sites, and used triangulation of several sources of data; prioritising the voice of those who receive care and those who deliver care. Visiting a range of settings allowed for a broad view, and using focussed, multi-site ethnography enhanced the depth of understanding of the culture of care so results could be more generalisable (Nadai and Maeder, 2005). Use of participant observation and shadowing facilitated the collection of rich data. Where the researcher was temporarily embedded in the teams visited, there was opportunity to be directly involved in the care environment and to see first-hand how care was delivered in these various settings. Moreover, visiting different care settings expanded the context of the study to be more representative of the range of settings where young people receive their cancer care.

The young people who participated in the study were either in hospital or receiving care in an outpatient setting at the time of data collection, allowing their experiences and views to be related to their current or recent experiences of care, as opposed to collecting their views retrospectively. The same applied to healthcare professionals, who were all involved in young people's cancer care at the time of data collection. Furthermore, a wide range of professional roles within the multi-disciplinary team were interviewed, observed and shadowed, giving a breadth of views and enabling an all-encompassing and comprehensive view of culture to be described.

Combining the personal views and experiences of young people and healthcare professionals with observation and shadowing was also a strength of the study. The use of shadowing, interviews and observation complemented the use of multi-site participant observation, and together they facilitated a practical and flexible approach to scheduling data collection (Hannerz, 2003). Additionally, the researcher was fortunate enough to have had sufficient time to reflect on her own experience as a researcher undertaking this multiple-case study.

8.7 Limitations of the research

Traditionally, a limitation of a case study is its size and therefore its generalisability, however it can be argued that the size of this case study is in fact its strength. It has been suggested that multiple-case studies are highly resource-intensive and therefore unlikely to be conducted by a single researcher (Yin, 2014). Fortunately, due to the financial support of the BRIGHTLIGHT programme grant, and the assistance and enthusiasm of the professionals working in the four networks visited, data collection, which spanned 24 hospitals, was made possible. As with all research, the process was not linear, and there were challenges and limitations with the conduct of the research which require recognition.

There were study limitations related to participant sampling. While purposeful sampling was planned and employed where possible, the willingness and availability of potential study participants affected the final sample. For these reasons, younger teenagers, those with a brain tumour and melanoma are all examples of underrepresented patient groups in this study. There were challenges experienced recruiting young people to the study via purposeful sampling, and therefore convenience sampling was used, thus enabling the recruitment of young people who were available, interested and feeling well enough to participate in an interview. This issue has been previously highlighted in the literature around sampling (Palinkas *et*

al. 2015). This may, therefore, have affected the perspectives gathered; as it was likely that those who chose to participate had either very positive or very negative experiences that they wanted to share. While this could have biased the results, this is accepted as a challenge of recruiting this population to research (Fern *et al.* 2014). Also, important to highlight, was that in one of the four sub-cases visited, a total of four young people were interviewed across the network, which was a smaller sample than the other three sub-cases. This was due to delays in the local hospital approval process reducing the amount of time that the researcher could spend recruiting young people in this site. Nonetheless, the interviews and time spent on the ward both with and observing young people through participant observation, provided rich data about this sub-case. The contribution of this sub-case to the overall data set was considered to be comparable to the others sub-cases.

Additionally, there were particular tumour types that were underrepresented in the study due to challenges recruiting young people presenting with the more adult or childhood cancers. The majority of young people were recruited on teenage and young adult units and therefore it was the cancers common to these sites that contributed the largerest proportion of the total sample. It would be beneficial to put structures in place in future research to facilitate the recruitment of young people with the rarer cancer types.: this would have implications for the study timeframe, and would be esentioal to consider at the outset.

In terms of recruiting healthcare professionals, they were frequently time-limited and busy with their clinical and support roles, and in some cases, this affected whether they could be recruited to the study. In particular, these issues impacted on the recruitment of medical staff, from junior doctor level and upwards. In addition to the three doctors interviewed, the researcher observed interactions, clinics and meetings which were led by medical staff. While this could be interpreted as the voice of medical staff being nominal, it is important to balance this alongside the fact that these are not the staff group that are providing the largest proportion of direct care to young people. Medical staff are strongly associated with clinical treatment, which has been shown as important to young people (Lea *et al*. 2018b), however there are other members of the multi-disciplinary team that are responsible for providing frontline care to meet young people's diverse and unique needs. It is questionable therefore whether recruitment of a greater number of medical staff would have altered the underlying messages about the culture of care that are presented in this study.

There was naturally a heavy female bias in the sample of healthcare professionals that participated in this study. The sample of healthcare professionals included only two males (5%). This is likely to be reflective of the gender imbalance in the caring professions, particularly in nursing, where only 13% of registered nurses identify as male (Nursing and Midwifery Council, 2018). It is also important to acknowledge that there were a small number of male healthcare professionals observed in the participant observations, which again reflects the paucity of male healthcare professionals in frontline caring roles in the 24 hospitals visited in the study. While there could be alternative insights into the culture of caring for this group that are gender specific, the culture of care presented in this study is reflective of the perspectives, experiences and observations of the majority present in the healthcare settings visited at the time of data collection.

Eligibility for participation included being able to speak English. This was for pragmatic reasons due to English being the researcher's first language, and the specific challenges that may have been associated with participant observations and the need for real-time translation of information. Collection of the perspectives of young people across a wider range of cultural backgrounds would be hugely valuable. Obtaining the views and experiences of young people who are often seen as the 'unheard voice' in UK health research (Kirk *et al.* 2007) could provide a different perspective on the delivery of care; particularly aspects of care such as communication between healthcare professionals and young people where translation is required.

There have been limitations associated with the concept of using observation techniques across multiple sites. Ethnography is often associated with the study of a single group or 'tribe' and therefore concerns have been expressed that multi-site ethnographic techniques, such as participant observation, can provide a vague or ill-defined research field (Nadai and Maeder, 2005) when compared to traditional ethnography. Conversely, it can be argued that multi-sited research can provide a valuable and less-restrictive qualitative approach (Nadai and Maeder, 2005). In agreement with this second statement, multi-site participant observation was used: it provided the researcher with a flexible and adaptable method, enabling intermittent immersion in the contexts and processes of care, but allowing the researcher to arrange and conduct tours, shadowing and semi-structured interviews around this. While using multi-site participant observation did not provide opportunity for complete research immersion into the sites visited, as would be possible with

traditional ethnographic techniques, it gave potential for concurrent researcher immersion and collection of perspectives. Greater exploration into the deeper, 'less visible' aspects of the culture of the care would be possible with a traditional, fully immersive ethnographic approach; however, this type of ethnography is very time-intensive (Millen, 2000). It could be argued that traditional ethnography would not be as well-suited to an exploration of multiple contexts of care, alongside the collection of multiple perspectives, such as in this study.

While the walking interviews were a successful method with some healthcare professionals, several reasons emerged as to why the method was unsuccessful with other healthcare professionals and the young people who participated; these reasons included:

i)   Healthcare professionals were aware of the sensitive nature of some of the conversations during the interviews and thereforefelt that a private space for the interview discussions was more appropriate, alongside a separate tour of the environment.

ii)   Some young people were in isolation and not allowed to leave their side room due to neutropenia (compromised immune system due to intense treatment) or infection control reasons.

iii)   Some interviews in the Principal Treatment Centres with young people were conducted when the young person was involved in an activity in the day room, such as painting. The researcher joined in the activity with the young person, as a way of increasing rapport and to make it more convenient for them to participate. This meant that a 'walking' approach was not as suitable as a 'static' approach to interviewing.

iv)   Some interviews were with young people with compromised mobility due to surgery and it was not possible for them to walk around the unit.

Although not used in healthcare, Jones *et al.* (2008) expressed similar challenges of the walking interview method and concluded that this method was not appropriate for all participants. A flexible approach was therefore adopted in this present study, some involved some movement around the environment alongside discussion and others a static semi-structured interview which referred to the environment as opposed to travelling around it. A flexible, patient-led and young person-centred approach was therefore adopted (Fern *et al.* 2013); a research approach which aligned with the findings of this study, and emphasises the importance of putting young people at the centre of decision-making.

There are recognised limitations of using shadowing as a method. The first was difficulty in generalising the findings due to the uniqueness of the shadowing situation. With most qualitative methodologies, the aim is to provide rich, contextualised experiences as opposed to generalised findings (Polit and Beck, 2010). This was therefore recognised and addressed through ensuring the context of data was not lost during the process of interpretation. The second challenge of shadowing was observer bias. Brixey *et al.* (2008) addressed this using both participant validation and researcher self-reflection. Participant validation was not a method used in the present study; again a pragmatic decision as it would have been impractical for the study findings to be validated by seventy interviewees. Additionally, it would have been unrealistic to expect the interviewees to accurately recall the content of their discussions with the researcher after, for some of the participants, approximately two years post-interview.

Regular and consistent researcher self-reflection was carried out to minimise observer bias and to facilitate transparent interpretation of the data. Additionally, frequent discussions about the collection, analysis and interpretation of data within the researcher's supervisory team provided further opportunity for transparent thinking and reflection. It was recognised that the researcher was the 'instrument' collecting, analysing and interpretting collected data, a widely recognised issue to be aware of in the undertaking of qualitative research (Baillie, 2015). The researcher's role as a nurse in one of the hospitals in which data was collected would have influenced, not always consciously, both how data were collected and intepreted in that hospital. While the researcher managed this as best possible through a process of reflexive thought and journalling, it was still likely that this impacted the research process at this site. Additionally, the researcher's views and experience as a nurse in this specialty meant she naturally had some preconceived ideas about the delivery of teenage and young adult cancer care. These could have influenced her perception of data, and therefore the study findings. It therefore must be highlighted that this is research conducted by a nurse, with a nurse's perspective on care experience and delivery.

A limitation of interviewing, particularly with young people where there could potentially be a power imbalance, was that the interviewees could have given the answers that they anticipated as suitable or desirable. This highlights the importance of gaining a wide variety of views, in a range of settings, and using observation techniques to further corroborate data and identify commonalities and differences.

The decision was made to include the views of young people and healthcare professionals and to omit the collection of parent/family perspectives in this study. This was another pragmatic decision based on time and resource limitations, thus young people and healthcare professionals' perspectives were prioritised. Collecting the views of parents and families would be a recommendation for future research, providing a third, valuable perspective of the culture of teenage and young adult care.

8.8 Summary

This section has discussed the findings of this study in relation to existing literature surrounding the culture of teenage and young adult care, as well as wider literature on the delivery and structure of other healthcare and services. A paucity of UK-based evidence examining the appropriateness of services which deliver care to young people with cancer has been highlighted (Ferrari *et al.* 2016). The 'Blueprint of Care' recommended that all healthcare professionals should *"know how to provide age-appropriate care"* to young people with cancer (Smith *et al.* 2016, p.53) and that all professionals caring for young people with cancer are in a position where they can make a difference to a patient's experience of care (Marshall *et al.* 2018).

The findings of this study support the notion of young-person centred care which meets the holistic needs of young people. Further to this, the findings suggest that encouraging, educating and sharing the values which underpin a young-person centred approach to care is the most important thing that can be done by both individuals and organisations, to develop a culture of care which meets the needs of young people. In order to do this, importance must be placed on developing the competence of staff; ensuring continuity of care; and building cultures which are perpetuated by effective communication, team work and leadership. These concepts will be reiterated in the next chapter and the original contributions of the research will be highlighted. Additionally, the overarching conclusions and recommendations for policy, practice and future research will be presented.

Chapter 9

Conclusions and recommendations

9.1   Introduction

An exploration of the complex processes which form a culture of care for young people with cancer were the focus of this multi-site case study: gathering primary data in England. The current economic climate of the NHS presents ongoing challenges for specialist health services to demonstrate their 'added value', and therefore robust evidence is crucial for us to better understand the impact of specialist health services and the optimal model of delivering care to young people with cancer. The research questions detailed at the outset of this study enabled the researcher to explore the following:

1) the context of each care setting that shaped young people's experiences of care;

2) what was different and common across the culture of care in those settings;

3) young people and healthcare professionals' perceptions of care in each of the Principal Treatment Centre and their associated hospitals within the four networks of care.

Part A of this thesis provided the context for this research, firstly by explaining the clinical context through a description of what is currently known and understood about this unique cancer population, and about the current service structure and the delivery of care. This highlighted the range of settings where young people are cared for and the resultant complexity of delivering care to this patient group. The meaning of culture was explored and the three core concepts of culture that framed and guided the research were introduced. A narrative literature review identified a limited body of evidence concerning how cancer care is delivered to young people in England, and how the culture of care can influence the experiences of young people; particularly when the experiences of young people cared for in different healthcare settings were compared. Critical realism was presented as the research paradigm, and the research questions were discussed in relation to this paradigm, alongside details of the methodology, sample, setting and methods used.

Part B began with the findings: presented in three chapters (Chapters 5, 6 & 7), and these corresponded to the three core concepts of culture that guided this study. These

included the components that contributed to the culture of teenage and young adult cancer care, both the more visible 'above the surface' and less visible 'below the surface' components, in addition to how culture of care was learned, shared and perpetuated. The preceding chapter discussed the implications of these findings in relation to previous literature. This final chapter concludes this thesis, bringing all the earlier chapters to a close. The original contribution of this study will be re-stated, to make explicit the implications of study findings, and recommendations for policy, practice and future research will be suggested. The dissemination and impact strategy are presented prior to the final concluding remarks of the thesis

9.2   Recommendations for practice, policy and future research

Adolescence and early adulthood is a period of vast physical, psychological and social transformation, all of which can be severely disrupted by a life-altering cancer diagnosis (Whiteson, 2003; Marris *et al.*, 2011; Zebrack, 2011). The unique issues that this patient population face were illustrated at the outset (Figure 1.1). They were multifactorial, inclusive of medical, psychosocial, relationships, peers, financial, family and education/employment issues. The challenge is, therefore, how can we deliver care that meets all of these needs, in all hospitals where young people are cared for? This question was, in part, answered through research question three: what are young people and healthcare professionals' perceptions of care? The perceptions and experiences obtained in the study provided important findings which have improved our understanding about how we can deliver equitable care which meets all the needs of young people. This section will present the recommendations of this research, based on the study findings. The footnotes indicate whether the recommendation described is applicable to practice, policy or future research.

9.2.1 Optimal environments of care for young people

This is the first primary research to definitively illustrate the important influence of the physical environment on the social environment in a multitude of healthcare settings, through answering research question one by exploring the context of each care setting that shaped young people's experiences of care. While previous research has drawn attention to the impact of the environment on patient experience and well-being in hospital (Hutton, 2005; Blumberg and Devlin, 2006; Hutton, 2007; Coad and Coad, 2008; Ullán *et al.* 2012; Fern *et al.* 2013; Vindrola-Padros *et al.* 2016), the findings of this study have further expanded this concept, and illustrated several significant ways that the physical environment can contribute to the overall culture of care.

[1]Recommendation for practice; [2]Recommendation for policy; [3]Recommendation for future research

Specialist environments include dedicated social space to bring young people together, giving a sense of community and connectedness. The experience of receiving care in these specialist environments has been documented, but no research to date has compared this experience to that received in settings without social spaces or age-appropriate facilities, and the impact of this on meeting the social needs of young people. This comparison of environments has illuminated the powerful influence of the physical environment on the creation of a social environment: in non-specialist settings without dedicated social space, findings indicated that young people had significantly hindered opportunities for socialisation or to meet other young people with cancer. This, therefore, supports previous service guidelines which recommend the provision of an age-appropriate environment of care for young people[2]. Further to this, the findings advocate for the creation and protection of a social space in all hospital settings where resource and space allows[2]; and young people should be encouraged by healthcare professionals to congregate with peers and to use these spaces to their potential[1].

A need was identified for young people in designated hospitals and shared care settings to have access to a youth support co-ordinator as a source of emotional support, and able to facilitate social opportunities. Youth support co-ordinators and other non-clinical supportive roles, such as social workers, should be highlighted within local and national policy as core to the delivery of care to young people[2]. Strategies should be implemented to expand these roles and increase their presence across the networks of care, particularly in designated hospitals where young people experience the most social isolation[2]. These healthcare professionals could work to increase access to and prevalence of peer-to-peer support for young people outside the Principal Treatment Centres thus better meeting their psychosocial support needs[1]. Additionally, further research would be beneficial to specifically evaluate the impact of youth support co-ordinators on young people's experiences of care[3].

The Internet was integral to young people's social connectivity: providing a medium for regular connection with existing friends, family and peers with cancer, and therefore reducing the sense of isolation. Previous research has identified that the use of the Internet by young people in hospital has been shown to be driven by emotions such as boredom and isolation (Lea *et al.* 2018a), and therefore the power of reliable, good-quality Internet access for comfort and support cannot be underestimated. Though not always reliable, it was standard practice to at least provide the Internet on all teenage and young adult cancer units, yet the majority of young people in designated hospitals did not have access to the Internet and described powerfully the absence that this created. Online platforms and social media will not negate the need for opportunities to socialise with other cancer patients face-to-face; however the Internet can provide

[1]Recommendation for practice; [2]Recommendation for policy; [3]Recommendation for future research

unlimited access to a social world, irrespective of the location of care. In environments where the creation of dedicated social spaces for young people is unfeasible, the Internet is a viable facility that those leading and managing services should strive to deliver to enhance the age-appropriateness of care[1].

9.2.2 Optimal workforce to care for young people

National drivers, such as the 'You're welcome pilot' (PHE, NHS England and DoH, 2017) aim to improve the care received by young people in all healthcare services: providing a helpful framework against which services can objectively assess their structures, processes and workforce in terms of whether they are 'young person-friendly'. Another 'layer' can be added to this through the exploration 'below the surface' of the culture of care in this present study: the three core values underpinning a culture of care which comprehensively meets the holistic needs of young people. These were recognising the individuality of young people; promoting normality throughout their care; and empowering them.

The general concepts conveyed by these values are not entirely novel, and have appeared in previous and current literature and some areas of practice. However, the findings of this doctoral study add a multitude of perspectives, all of which identified their significance. These core values emerged from data that spanned all care settings, a variety of healthcare professionals and young people themselves: which demonstrates their strength. These findings are the deeper, 'below the surface' values which should be embraced and executed by a workforce who strive to deliver a young person-focussed philosophy of care[1]. These values should be upheld by all who work with young people and be visible in all their actions, behaviours and processes of care[1].

Furthermore, the values should be viewed as a trilogy of unique 'quality criteria' which can be used by all healthcare professionals and organisations to assess their underlying philosophy when caring for young people. Those delivering services should use these core values as a framework to assess and plan their strategies and facilities for the care of young people[1], for example the appointment of youth support co-ordinators who can provide outreach services to young people not cared for in the Principal Treatment Centre.

The use of the three concepts of culture as a conceptual framework for the study structured this exploration of care to include these deeper, 'below the surface' values and behaviours, as well as the 'above the surface' processes and structures involved in the delivery of care. Communication was a process fundamental to the delivery of care

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and was identified to occur on several levels. Findings about interpersonal communication resonated with previous work which has shown that effective styles and methods of interpersonal communication developed positive relationships between healthcare professionals and young people (Gibson *et al.* 2012; Knott *et al.* 2013; Vindrola-Padros *et al.* 2016); however, the findings which help us to understand *how* healthcare professionals can optimise interpersonal communication with young people were of greater significance.

Key aspects included delivering greater continuity of staff and having specific roles such as youth support co-ordinators whose job is to build supportive relationships with young people. Additionally, findings support greater creativity and flexibility in methods and media for communication with teenage and young adult patients. Use of digital technology is recognised as helpful in making services more accessible to young people, therefore healthcare organisations have a responsibility to educate their staff to take a more creative, flexible and age-appropriate approach to communicating with young people in all healthcare settings[1].

9.2.3 Developing a young person-centred culture of care

The findings of this research have presented an essential contribution to knowledge of both the component parts of a culture of care, and the factors which influence the development and perpetuation of this. Through seeking to answer research question two, which was to explore what was the different and common across the culture of care in the settings explored, this also enabled the researcher to develop an understanding of the factors which effectively contributed to developing and sustaining a culture of care. Although these were pragmatically segregated and presented in sequence, this section draws these isolated elements together to characterise the situation within the overall context; achieved through implementing a force field analysis approach.

The frontrunner in force field analysis, Lewin (1951) asserted that all change is a consequence of particular forces in a given environment. There are two sets of opposing forces that can impact the changes that occur within an organisation or environment: there are driving forces which positively encourage change and static, restraining forces that act as barriers to change (Lewin, 1951). Force field analysis corresponds with a critical realist viewpoint: a paradigm which encourages exploration of the nature and causes of social processes, to assist theory development and influence cultural change (Easton, 2010).

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The diagram presented (Figure 9.1) illustrates the aspects that both facilitate and impede the creation of a young person-centred culture of care, through a blend of the perspectives of young people and healthcare professionals from the range of contexts encompassed in this research. It offers a novel contribution as a 'tool' to assist hospitals and other care settings that care for young people to understand how to create a culture which delivers optimal, holistic, young person-centred care; and likewise, the barriers to achieving this[1]. To successfully achieve this, organisations need to broaden their view to look beyond their structures and processes; and instead view the organisational culture as a whole (Allen *et al.* 2002), and therefore to acknowledge what elements are at the heart of providing young person-centred healthcare.

While it is based on the overall concept of a force field analysis, it has not been conducted using traditional force field analysis methodology (Bozak, 2003). The diagram presents both the 'forces for change' and the 'forces against change' as equal, static arrows, however it must be recognised that these forces are dynamic (Lewin, 1951).
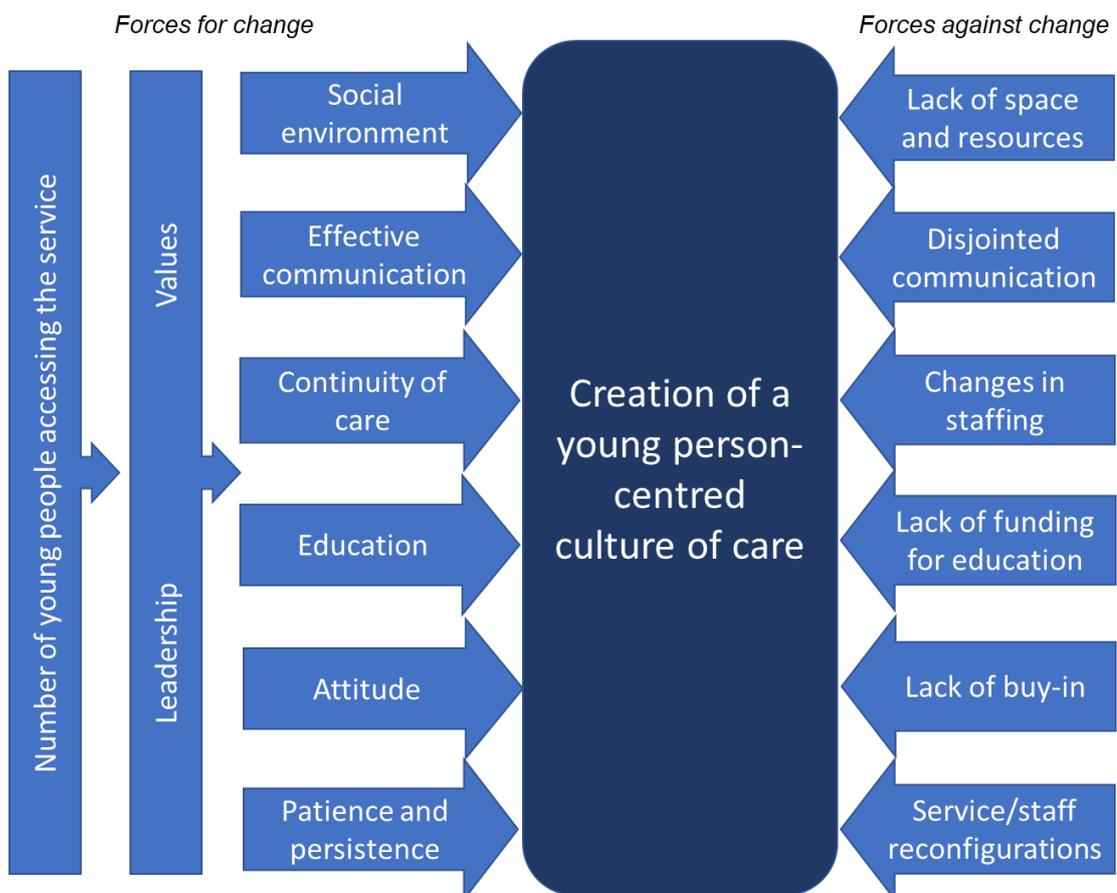
Figure 9.1 An adapted force field analysis illustrating the barriers and enablers to creating a young person-centred culture of care.

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Traditional force field analysis uses measures to determine the strength and direction of forces, and this is depicted with different sized arrows to demonstrate the impact a force has on the proposed change (Bozak, 2003). The findings of this multiple-case study indicated that the strength of the 'forces' which influenced a culture of care varied depending on the context, however this was not measured, in alignment with the epistemological proposition that the culture of care was not measurable (Easton, 2010). For this reason, the arrows are all the same shape and size, with the exception of the three overarching themes: young people, values and leadership. These three themes span the depth of the diagram to indicate their significance as the three overarching 'forces', affecting the other factors that enable the creation of a young person-centred culture.

Findings highlighted that, fundamental to the delivery of specialist care, is having a sufficient number of young people regularly accessing the service. It has been suggested that the success of teenage and young adult cancer services is dependent on having a sufficient number of young people, *"critical mass"*, to guarantee staff expertise and experience (Whelan, 2003). For years, the centralisation of cancer services has been recommended, largely due to the consequent rise in patient volumes enhancing the knowledge and expertise of staff (DoH, 2001). Figure 9.1 illustrates the importance of first having a volume of young people, to permit opportunities and resources for staff education and experience in providing holistic care to young people.

More in-depth research focussing specifically on the culture of care in designated hospitals is required to better ascertain the relationship between the culture of care that exists, in relation to the numbers of young people they care for[3]. This would provide greater insight into whether defining cancer services as 'specialist' or 'non-specialist' is a fair and accurate representation of the care provided. Components of age-appropriate care for young people can exist in child, adult and young people's units and the findings presented in this thesis described a spectrum of specialism and expertise within the variety of hospitals visited. Research to determine where designated hospitals and paediatric oncology shared care units sit on this spectrum; how many young people they care for; and to what extent they deliver age-appropriate and young person-centred care would be of importance to policymakers and stakeholders to assist in the ongoing development and configuration of services[2,3].

Second to the presence of young people, leadership was critical in the creation of a culture of care. In the case of teenage and young adult cancer services, leading a change in a culture requires a leader to show persistence, passion and to underpin their own practice with the core values that they wish others to inherit: it has been

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identified that leaders need to be a role model to facilitate change (Bailey and Bevan, 2017). Leaders should have a thorough understanding and an authentic belief in why and how young people with cancer have unique holistic needs if they are to 'buy-in' colleagues who are resistant to change. Moreover, culture in healthcare services must be able to adapt in response to the dynamic nature of health organisations, particularly within the NHS. It can therefore be argued that leaders of specialist services within NHS hospitals must also be dynamic and creative; to achieve and sustain momentum when developing a culture within an ever-evolving landscape of health services.

Leaders should foster an attitude among their workforce where they themselves advocate, adopt and employ the required attitude, values and persistence, if they are to influence healthcare systems and policies. This has been recognised among the teenage and young adult nursing workforce (Soanes, 2018), however all members of the wider multi-disciplinary team are all responsible for advocating young people and leading change within health services. This links to the study findings about the significance of educating staff. For some teams and services, education should begin at a 'grassroots' level, raising awareness of the speciality; and supported by formal training and certified courses. A lack of funding can be a barrier to sending healthcare professionals on formal education programmes: a potential strategy could be that all teenage and young adult cancer networks have certain members of the multi-disciplinary team funded to receive training, who then act as an 'education champion', educating others across their organisation, or even the network[1]. Their focus would be to develop the awareness, knowledge and skills of *all* healthcare professionals delivering care to young people; with an aim to improve the standards of care delivered to patients outside specialist teenagers and young adult settings, which are known to have frequently been described as sub-optimal.

The acceptance and execution of the three core values that underpin the care of young people was another fundamental aspect of the culture: these included recognising individuality, promoting normality and empowering young people. The shared collection of values and attitudes within a society or organisation both influences and reinforces its operation and function (Hudelson, 2004; Schein, 2010). Accordingly, this trilogy of values therefore presents the shared collection of values that should influence and reinforce the operation and function of all services caring for teenagers and young adults[1].

The wide geographical spread of young people with cancer is a challenge that will not pass, and nor will the challenges of providing specialist, tailored care to a small and unique patient cohort. It is essential therefore that the specialist teams at Principal

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Treatment Centres detect and utilise mechanisms through which they can share the key aspects of their culture of care with all hospitals across the networks, and that all hospitals caring for young people identify what they can do to adopt these key aspects of care delivery, and therefore perpetuate the culture. Additionally, communication and continuity of care are key to enabling high quality, holistic care experiences. Conversely, disjointed multi-disciplinary team working, and changes and reconfigurations in both staffing and services, were factors which impeded successful creation of a young person-centred culture of care. Mechanisms for communication and collaboration between teams across networks of care should be reviewed[3], such as the network-wide multi-disciplinary team meetings, to ensure that they act as an effective platform for joined-up working and continuity of care[2]: both identified as central concepts of the provision of age-appropriate care to young people with cancer (Lea *et al.* 2018b).

More research needs to occur to look at greater depth on the factors which impact communication and collaborative working between the hospitals in a teenage and young adult cancer network[3]. This would help to identify more detail around the strategies that enhance the engagement of healthcare professionals in fully engaging in a network-wide approach to the delivery of care for young people, particular where care is shared between hospital teams and sites.

It has been suggested that even within large health service organisations with equivalent and comparable structures, processes, environments and caseloads; successes, outcomes and experiences will vary, due to differences in their cultural compositions. The 'force field' diagram (Figure 9.1) could provide a 'framework' to assist us to examine and understand the reasons why young people's health services have different cultural compositions. Research to examine the value of this 'framework' would be beneficial[3], potentially in several contexts: young people's cancer care; in other young health populations, such as young people with chronic illnesses; and even in healthcare cultures working with other specific patient groups with unique needs, for example dementia care.

Figure 9.1 provides a discrete and operational 'tool' to assist policymakers and stakeholders planning and delivering young people's health services; providing a way for services to systematically evaluate the barriers present within their organisation that are acting as forces resisting a cultural change to delivering care that is centred around the holistic needs of young people[1]. Moreover, these findings extend beyond the confines of teenage and young adult cancer care; understanding how a culture of care

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is shared and fostered has implications for those developing and growing teenage and young adult cancer services

9.2.4 Summary of recommendations

The following table presents an overview of the recommendations of the research that have been discussed (Table 9.1).

Table 9.1. A summary of the key recommendations of this doctoral research.

Recommendations for…		
Practice	**Policy**	**Future research**
• Young people should be encouraged by healthcare professionals to congregate with peers and to use these spaces to their potential. • The Internet is a feasible facility that those leading and managing services should strive to deliver to enhance the age-appropriateness of care. • The three core values should be embraced and executed by all workforces who strive to deliver a young person-focussed philosophy of care: they can be used as a framework to assess and plan strategies for the care of young people. • Figure 9.1 of the factors which enable and impede the creation of a culture of care can be used as a 'tool' to assist organisations build a culture which delivers optimal, holistic, young person-centred care. • All teenage and young adult cancer networks fund members of the multi-disciplinary team to receive formal training in young people's care, and to then act as an 'education champion', educating others across their organisation, or even the network.	• Youth support co-ordinators and other non-clinical supportive roles, such as social workers, should be highlighted within local and national policy as core to the delivery of holistic care to young people. • Strategies should be implemented to expand youth support co-ordinator roles and increase their presence across the networks of care, particularly in designated hospitals where young people experience the most social isolation. • The guidelines for intra-hospital and hospital-to-hospital communication, such as the network-wide multi-disciplinary team meetings, should be reviewed, to ensure that they act as an effective platform for joined-up working and continuity of care. • Advocate for the creation and protection of a social space in all hospital settings where resource and space will allow. • Reliable Internet access is a feasible age-appropriate facility that should be a mandatory part of care provision within policy.	• Formal evaluation of the impact of youth support co-ordinators on young people's experiences of care. • Exploration of the factors which impact communication and collaborative working between the hospitals in a teenage and young adult cancer network. • More in-depth research focussing specifically on the culture of care in designated hospitals: to better ascertain the relationship between the culture of care that exists, in relation to the numbers of young people they care for. • Research to determine where designated hospitals and paediatric oncology shared care units sit on this spectrum: e.g. how many young people they care for; and to what extent they deliver age-appropriate and young person-centred care, to assist in the ongoing development and configuration of services. • The applicability of the findings should be researched in other healthcare cultures where young people are cared for, e.g. the creation of a young person- centred culture of care for those with chronic disease.

[1]Recommendation for practice; [2]Recommendation for policy; [3]Recommendation for future research

9.3 Dissemination strategy and impact goals

Within complex healthcare systems and organisations, the translation of new knowledge from research into everyday practice is not a linear process, and one that therefore requires strategy and planning (Curtis *et al.* 2017). It is recognised that dissemination is more effective, and therefore research impact is greater when a multitude of vehicles are used (Reed, 2018). This study has previously, and will continue to, utilise multiple dissemination methods. Figure 9.2 illustrates the dissemination objectives, target audiences, content and strategies; the dissemination that has taken place to date; and the impact goals of the study.

In addition to the researcher's specific dissemination strategy for this study, through collaborative working with the BRIGHTLIGHT research team, the recommendations of this research will contribute to the dissemination of the overall BRIGHTLIGHT study findings. The team will generate actionable messages and recommendations for wider dissemination of these doctoral study findings. BRIGHTLIGHT is a mixed-methods programme grant inclusive of three workstreams with multiple studies. There is no single data set that is able to answer the complex question: *"Do specialist cancer services for teenage and young adults add value?"* The findings of this study are one of six studies which together will hopefully achieve this. The BRIGHTLIGHT research team are currently synthesising the findings of the different studies and to answer the overarching question (Figure 9.2). Additionally, the researcher's specific and detailed dissemination strategy for this doctoral study is presented (Figure 9.3).


Figure 9.2. A schema illustrating how the findings of the case study contributed to the overall findings of the BRIGHTLIGHT programme of research.

Dissemination strategy and impact goals

Dissemination objectives

- Assist future directions and commissioning of teenage and young adult cancer care in the UK
- Assist development of teenage and young adult cancer care in other countries
- Improve overall understanding of how healthcare culture is formed
- Enhance understanding of the variation in teenage and young adult cancer care from different perspectives and its impact on patient experience.
- Transition of findings into practice

Dissemination content

- The key elements of 'age-appropriate care'
- Extensive knowledge on young people's experiences of cancer care
- Extensive knowledge on healthcare professional's experiences of healthcare delivery
- Recommendations for policy, practice and future research (as described in Chapter 9)
- Processes of developing and sustaining a culture of care, to pilot change, particularly within child and adult cancer care settings

Dissemination channels/tools

- Interpersonal communication
- Local events, e.g. local conferences such as the 'in-house' hospital research conference
- Research conferences, e.g. the RCN International Research Conference
- Specific teenage and young adult cancer conferences, e.g. TYAC, Adolescent and Young Adult Global Congress
- Additional cancer conferences with a wider range of audiences e.g. SIOP, EONS
- The BRIGHTLIGHT and TYAC websites
- The BRIGHTLIGHT Conference (March 2019)
- Social media – use twitter to share papers and conference proceedings
- Peer-reviewed publications
- This thesis will be publicly available in the RCN library and online repositories

Target audience

- Patients and the public
- Researchers and the research community, not only in teenage and young adult cancer care, but also child and adult colleagues
- Policy makers and commissioning organisations for cancer services, e.g. Clinical Commissioning Groups, NHS England
- Professional organisations, e.g. TYAC, RCPCH
- External statutory organisations that play a role in service recommendations, e.g. NICE
- Practitioners and frontline care staff caring for this patient population
- Leaders and managers of services which care for teenage and young adult cancer patients
- Commissioners, leaders, practitioners and researchers in other areas of adolescent healthcare

Dissemination to date

- In 2017 the findings of this study contributed to 'There is a light: BRIGHTLIGHT'. This was a theatrical interpretation of BRIGHTLIGHT findings, developed alongside and performed by young people, including four young people with cancer. The performance played for 11 nights, across 22 cities in England. This equated to a total audience of approximately 1300 people. A section of the script which originates from findings of this study is presented in Appendix 23.
- In July 2017 the findings conceptualising age-appropriate care, early emerging evidence from this study, were presented at the TYAC-BRIGHTLIGHT Conference, and these were also presented at the RCN International Research Conference, 2018. These are now published in a peer-reviewed journal (Lea *et al.* 2018b) (Appendix 22).

Impact goals

- The impact will be national and international.
- Influence the outcomes of care for young people with cancer irrespective of where they receive their care.
- Stronger professional awareness of the relationship between the physical environment and social environment.
- Guide education and training of professionals who care for this cancer population.
- Enable organisations to better assess their own culture and performance, and to work towards developing an optimal culture of care for young people.
- Contribute to national debates on the impact of organisational culture on patient's care experiences.

EONS: European Oncology Nursing Society; NICE: The National Institute for Health and Care Excellence; RCN: Royal College of Nursing; RCPCH: Royal College of Paediatrics and Child Health; SIOP: International Society of Paediatric Oncology; TYAC: Teenagers and Young Adults with Cancer.

Figure 9.3. Diagram presenting the dissemination strategy and impact goals of this research.

9.4 Conclusion

The future of teenage and young adult cancer services in England remains somewhat uncertain, as currently services are under review. While previous research has suggested that there are not disadvantages to centralising teenage and young adult cancer care in England, the specialisation of teenage and young adult cancer services still presents a complex debate in equality of care provision. Despite the development of 13 specialist Principal Treatment Centres in England over the last two decades, half of all young people diagnosed with cancer will receive their care in hospitals outside the Principal Treatment Centre. Young people continue to report having poor experiences in such settings, despite three decades of global progression in expertise and research surrounding the specialism.

Environments without specialist teenage and young adult cancer services and expertise can provide adequate care to young people, particularly services with established services, greater numbers of young people and passionate leaders advocating for young people. Nevertheless, an optimal culture of care for young people includes access to environments which promote normality and facilitate socialisation and access to peers; healthcare professionals with holistic competence, skilled interpersonal communication; underpinned by the core values associated with caring for young people; and perpetuated over time by ongoing education, a critical mass of young people, and proactive leadership.

The adapted force field analysis depicting the creation of this culture of care (Figure 9.1) offers an original contribution to shaping and enhancing the culture of healthcare services which deliver care to young people with cancer. This has significant implications for healthcare professionals, stakeholders, policymakers and commissioners of teenage and young adult cancer services. It provides an operational 'tool' to examine the barriers present within their organisation that are resisting a cultural change to delivering care that is centred around the holistic needs of young people.

In the literature defining culture, societal culture was suggested to be *"the blueprint of human living"* (Kao *et al.* 2004, p. 271); it was therefore proposed that culture within a health setting could represent 'the blueprint of care'. However, while a 'blueprint' serves as a valuable template to guide the development and creation of an entity or phenomenon, such as the delivery of care; it is arguable that such a template is redundant unless we understand *how* it can be used and implemented. The findings of this study offer this *how*: providing evidence to assist all healthcare professionals and services to plant, grow and nurture a culture of care that meets the unique needs of

young people with cancer, and to improve their experiences of care; and further progress healthcare organisations towards a future where specialist, holistic care is accessible for all young people.

Epilogue

In the final months of my postgraduate nursing course, my interest in research, an inquiring mind and a hunger for a challenge, led me to an opportunity to undertake this doctoral study. This field of study was of great interest to me, as was the opportunity for personal and academic development, and ultimately, career progression. At the time, I was on my final student nursing placement and eager to receive my professional registration and to progress clinically. I discussed these concerns with Professor Faith Gibson and Dr Rachel Taylor, who are both strong advocates of clinical academic nursing careers, and they facilitated the creation of a part time clinical role for me on a teenage and young adult cancer ward. This meant that for several years, my work comprised of two discrete but complementary roles: clinical practice and academic research (Lea, 2015) (Appendix 24).

There were limitations associated with having these two roles: my identity as a nurse at times conflicting with my role as a researcher. I overcame this through adopting an open, honest and transparent attitude as a researcher, being clear with others that I was a nurse, but also clear regarding what my role as a researcher entailed. In particular, I felt this was important for the young people who were research participants, as I wanted to be clear that I was not able to provide clinical care for them, and that as a researcher I had no impact on the clinical care they received. I am, of course, aware that being a nurse may have influenced the way patients, families and professionals interacted with me compared to a researcher who was not from a health professional background. I have reflected on the potential biases that, as a nurse, I may have naturally imposed on the study findings: potential for bias can be expected, and accepted, and more importantly serve as a reminder that one should always be self-critical towards ones' actions and decision-making as a researcher.

My motivation for conducting this research was both driven by the BRIGHTLIGHT programme of research and from my own clinical nursing practice. I have cared for many teenagers and young adults who were going through cancer treatment, and as part of my nursing role I have connected with young people and their families, as I expected I would, when I entered the profession. Naively, I had not expected to experience this as a researcher. I had not anticipated a similar connection, to their experiences and their stories, in the way that I did. Not only during data collection but through the entire write up and analysis process; it was my connection to those young people's stories that has kept me inspired and motivated the whole way to the finish line.

As BRIGHTLIGHT's doctoral student, I recognise that my situation has been unusual. The support I have had around me to develop as a researcher throughout my time with the team has been invaluable. This position has exposed me to the supportive and collaborative aspect of research, working as part of a research team, yet all the while being given the space, independence and autonomy to evolve and achieve as a doctoral researcher. I have had the opportunity to attend and present at conferences, contribute to publications and have been involved in shaping other aspects of the study and the dissemination of findings. Some of the data presented in this thesis was interpreted and performed by a youth theatre company. In July 2017, the research team co-hosted the TYAC-BRIGHTLIGHT Conference in Leeds, in which I presented some of the findings of this study: a conceptualisation of 'age-appropriate care' for teenagers and young adults with cancer, which has now been published (Lea *et al.* 2018b). Further highlights of my time as a doctoral student have been attending the 1st and 2nd AYA Global Cancer Congress in December 2016 and 2017. These conferences positively impacted on my learning, enthusiasm and pride in my specialty: reminding me why the work that we do as researchers is so important as the audience and presenters comprised of both professionals and patients. I intend to disseminate the findings through further conference presentations, including the 'BRIGHTLIGHT Conference' in March 2019; several peer-reviewed papers; and more locally and informally through my discussions with colleagues and hopefully to patients at their annual conference: 'Find Your Sense of Tumour'.

At the risk of sounding incredibly cliché, I want to highlight at this point that I did not anticipate experiencing such personal growth over the last five years; in fact, I underestimated the impact that the doctoral research journey would have on all areas of my life. My personal and professional development has moved me from the novice graduate level of academia, towards an 'early career researcher.' Throughout this, I must admit, that I have a propensity to succumb to the well-known 'imposter syndrome', which is a common struggle for doctoral students. I have begun to overcome some of these personal insecurities in my ability through my experiences in the last two years working as a 'research facilitator' within the BRIGHLIGHT research team. The support and guidance of my fellow research colleagues has enabled me to grow as a researcher, and to develop a greater breadth and depth of research knowledge and capability across a multitude of projects. For this I am very grateful, and even more determined continue my development as a researcher.

The process and findings of this doctoral research was entirely shaped by my unique and personal approach and experience: the way I interacted with others and the way I viewed and interpreted the things I saw. I made sense of this using reflective practice.

There were others who assisted with this reflective practice: academic supervisors, experts in the field, colleagues, patients, friends and family. I now see how all the conversations I have had about my work over the years were also a method of thinking analytically about the data and findings. While the narrative of this thesis would imply that the analytical process of the study findings was linear, it was in fact a cyclical process, and each cycle through the data brought me closer to the interpretation and understanding of the concepts presented in this thesis. I have learned, while time and work management are crucial to all research, that flexibility, patience and open-mindedness are also required; particularly when interpreting complex, multifaceted data.

Over the last 15 years I have participated in many endurance sports events and thoroughly enjoy the training, the event itself, and the feeling of accomplishment at the end. A colleague described the concept of undertaking a doctorate as similar to an endurance event: requiring a tenacious and determined spirit. This process has indeed been an endurance event and a test of my endurance in interacting with people, literature and data. The finish line is never, however, 'the end' but rather the beginning of another challenge; the completion and dissemination of this research is just the start of what I would like to accomplish within young people's healthcare. I am motivated and excited to build on the research skills I have developed and continue to conduct research which impacts the experiences of young people in the healthcare system.

To close this thesis, I offer my final reflections about what this work had given me, and what I hope it will give to others. This process has given me professional courage, enabling me to be braver in my decision-making. I have obtained a range of valuable knowledge and skills, both generally, and more specifically in young people's health research; in addition to creating an identity and recognition in the field. This work has given me pride to call myself a nurse; a nurse that undertakes research that has impact, is benefitting nursing practice and ultimately improving patient outcomes. I hope the concepts introduced in this study will give other nurses a lens through which to view and reflect on the care they deliver to patients and strive to consistently provide the highest standards of care.

From here, I aim to combine my two key areas of interest and qualifications: sport, fitness and health; and cancer care delivery and services for young people; as platforms to enable me to research the role of exercise and sport in young people's experience of going through cancer. I now aim to create a future career where I can combine three things: the passion I have for encouraging and enabling others to live a

healthy and active lifestyle; the enjoyment of working with young people; and the excitement of acquiring new knowledge through conducting research.

References

Abrol, E., Groszmann, M., Pitman, A., Hough, R., Taylor, R. M. and Aref-Adib, G. (2017) Exploring the Digital Technology Preferences of Teenagers and Young Adults (TYA) With Cancer and Survivors: A Cross-Sectional Service Evaluation Questionnaire, *Journal of Cancer Survivorship,* 11 (6), pp. 670-682.

Alimo-Metcalfe, B. and Alban-Metcalfe, J. (2008) Research Insight. Engaging Leadership: creating organisations that maximise the potential of their people, in: *Shaping the Future,* London: Chartered Institute of Personnel and Development.

Allen, D., Kern, T. and Mattison, D. (2002) Culture, power and politics in ICT outsourcing in higher education institutions, *European Journal of Information Systems,* 11 (2), pp. 159-173.

Allen, D. (2004) Ethnomethodological insights into insider–outsider relationships in nursing ethnographies of healthcare settings, *Nursing Inquiry,* 11 (1), pp. 14-24.

Alvesson, M. and Billing, Y. D. (1992) Gender and Organization: Towards a Differentiated Understanding, *Organization Studies,* 13 (1), pp. 73-103.

Al-Yateem, N., Docherty, C. and Rossiter, R. (2016) Determinants of Quality of Care for Adolescents and Young Adults with Chronic Illnesses: A Mixed Methods Study, *Journal of Paediatric Nursing*, 31 (3), pp. 255-266.

Ambresin, A. E., Bennett, K., Patton, G. C., Sanci, L. A. and Sawyer, S. M. (2013) Assessment of youth-friendly health care: A systematic review of indicators drawn from young people's perspectives, *Journal of Adolescent Health,* 52, pp. 670.

Archer, M., Decoteau, C., Gorski, P., Little, D., Porpora, D., Rutzou, T. *et al.* (2016) What is Critical Realism? *Perspectives,* 38 (2), pp. 4-9.

Arnett, J. J. (2000) Emerging adulthood: A theory of development from the late teens through the twenties, *American Psychologist,* 55 (5), pp. 469-480.

Asselin, M. E. (2003) Insider Research: Issues to Consider When Doing Qualitative Research in Your Own Setting, *Journal for Nurses in Staff Development,* 19 (2), pp. 99-103.

Association for Young People's Health (2017) *Young People's Health, where are we up to? Update 2017.* London, UK: Association for Young People's Health.

Baillie, L. (2015) Promoting and evaluating scientific rigour in qualitative research, *Nursing Standard,* 29 (46), pp. 36-37-42.

Barling, J.A., Stevens, J.A. & Davies, K.M. (2014) The reality of hospitalisation: Stories from family members of their hospital experience for adolescents and young adults living with and dying from cancer. *Contemporary Nurse*, 46(2), pp. 150-160.

Barosh, L., Church, T., Morgan, D., Bianchetti, M., Hu, J. M., Tripathy, D. *et al.* (2015) Bridging the Care Gap Between Pediatric and Young Adult Cancer, *The American Journal of Managed Care,* 21 (2), pp. 155-164.

Barr, R. D., Ries, L., Whelan, J. and Bleyer, W. A. (2016) Cancer in Adolescents and Young Adults: A Narrative Review of the Current Status and a View of the Future, *JAMA Paediatrics,* 170 (5), pp. 495-501.

Baxter, P. and Jack, S. (2008) Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers, *The Qualitative Report,* 13 (4), pp. 544-559.

Bhaskar, R. (1978) *A realist theory of science.* Hemel Hempstead: Harvester Press.

Birch, R. J., Morris, E. A., Stark, D. P., Morgan, S., Lewis, I. J., West, R. M. *et al.* (2014) Geographical Factors Affecting the Admission of Teenagers and Young Adults to Age-Specialist Inpatient Cancer Care in England, *Journal of Adolescent and Young Adult Oncology,* 3 (1), pp. 28-36.

Bishop, K. (2010) Through the eyes of children and young people: the components of a supportive hospital environment, *Neonatal, Paediatric and Child Health Nursing,* 13 (2), pp. 17.

Bleyer, A. (2011) Trailblazers in Adolescent and Young Adult Oncology, *Journal of Adolescent and Young Adult Oncology,* 1 (1), pp. 13-18.

Bleyer, W. A. (1996) The adolescent gap in cancer treatment, *Journal of Registry Management,* 23, pp. 114-115.

Blumberg, R. and Devlin, A. S. (2006) Design Issues in Hospitals: The Adolescent Client, *Environment and Behavior,* 38 (3), pp. 293-317.

Boblin, S. L., Ireland, S., Kirkpatrick, H. and Robertson, K. (2013) Using Stake's Qualitative Case Study Approach to Explore Implementation of Evidence-Based Practice, *Qualitative Health Research,* 23 (9), pp. 1267-1275.

Boisen, K. A., Boisen, A., Thomsen, S. L., Matthiesen, S. M., Hjerming, M. and Hertz, P. G. (2015) Hacking the hospital environment: young adults designing youth-friendly hospital rooms together with young people with cancer experiences, *International Journal of Adolescent Medicine and Health,* 29 (4), pp. 72.

Borrill, C., West, M., Shapiro, D. and Rees, A. (2000) Team working and effectiveness in health care, *British Journal of Healthcare Management,* 6 (8), pp. 364-371.

Bortetrou, X., Truchot, D. and Rascle, N. (2014) Development and validation of the Work Stressor Inventory for Nurses in Oncology: preliminary findings. *Journal of Advanced Nursing*, 70(2), pp. 433–453.

Bowling, A. (2012) *Research Methods in Health.* 4th ed. Berkshire, England: Open University Press.

Bozak, M.G. (2003) Using Lewin's Force Field Analysis in Implementing a Nursing Information System. *Computers, Informatics, Nursing,* 21 (2), pp. 80-85.

Braithwaite, J., Westbrook, M. T., Iedema, R., Mallock, N. A., Forsyth, R. and Zhang, K. (2005) A tale of two hospitals: assessing cultural landscapes and compositions, *Social Science & Medicine,* 60 (5), pp. 1149-1162.

Braithwaite, J., Herkes, J., Ludlow, K., Testa, L. and Lamprell, G. (2016) Association between organisational and workplace cultures, and patient outcomes: systematic review, *BMJ Open,* 6, pp. e013758.

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology,* 3 (2), pp. 77-101.

Bravo, P., Edwards, A., Barr, P. J., Scholl, I., Elwyn, G. and McAllister, M. (2015) Conceptualising patient empowerment: a mixed methods study, *BMC Health Services Research,* 15 (1), pp. 252-266.

BRIGHTLIGHT (2018) *Our Research.* Available from: http://www.brightlightstudy.com/. [Accessed 11 September 2017].

Brinkmann, S. (2014) Doing Without Data, *Qualitative Inquiry,* 20 (6), pp. 720-725.

Brixey, J., Tang, Z., Robinson, D., Johnson, C., Johnson, T., Turley, J. *et al.* (2008) Interruptions in a Level One Trauma Center: A Case Study, *International Journal of Medical Informatics,* 7 (4), pp. 235-241.

Byrne, E., Daykin, N. and Coad, J. (2016) Participatory photography in qualitative research: a methodological review, *Visual Methodologies,* 4 (2), pp. 1-12.

Cable, M. (2016) Chapter 5: Staffing considerations, in: Smith, S., Mooney, S., Cable, M. and Taylor, R. M. (eds.) *The Blueprint of Care for Teenagers and Young Adults with Cancer,* 2nd ed. London, UK.: Teenage Cancer Trust, pp. 53-61.

Cable, M. (2018) A complex adaptive system perspective on the role of the youth support co-ordinator in teenage/young adult cancer care in the United Kingdom, in: *Adolescent and Young Adult Global Congress,* Sydney, Australia.

Cable, M. and Pettitt, N. (2018) Educating and Developing AYA Cancer Nurses, in: Olsen, P. and Smith, S. (eds.) *Nursing Adolescents and Young Adults with Cancer,* 1st ed. Cham: Springer, pp. 41-62.

Callen, J. L., Braithwaite, J. and Westbrook, J. I. (2009) The Importance of Medical and Nursing Sub-cultures in the Implementation of Clinical Information Systems, *Methods of Information in Medicine,* 48, pp. 196-202.

Cancer Research UK (2017) *Cancer incidence by age.* Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/age. [Accessed 19 November 2017].

Cancer Research UK (2018) *Young people's cancer incidence.* Available from: https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/young-peoples-cancers#heading-Zero. [Accessed14 September 2018].

Cargill, J., Cheshire, J. and Hewitt-Avison, S. (2016) Holistic needs and supportive care, in: Holistic needs and supportive care, in: *The Blueprint of Care for Teenagers and Young Adults with Cancer,* 2nd ed. London, UK.: Teenage Cancer Trust, pp. 63-76.

Carpiano, R. M. (2009) Come take a walk with me: The "Go-Along" interview as a novel method for studying the implications of place for health and well-being. *Health & Place,* 15 (1), pp. 263-264-272.

Carr, R., Whiteson, M., Edwards, M. and Morgan, S. (2013) Young adult cancer services in the UK: the journey to a national network, *Clinical Medicine,* 13 (3), pp. 258.

Center for Evidence Based Management (2014) *Critical Appraisal of a Cross-Sectional Study (Survey).* Available from: https://www.cebma.org/wp-content/uploads/Critical-Appraisal-Questions-for-a-Cross-Sectional-Study-july-2014.pdf. [Accessed 17 June 2016].

Centre for Reviews and Dissemination (2009) *Systematic Reviews: CRD's guidance for undertaking reviews in health care.* 3rd ed. University of York: Centre for Reviews and Dissemination.

Children's Cancer and Leukaemia Group. (2016) *Specialist hospitals.* Available from: http://www.cclg.org.uk/In-hospital/Specialist-hospitals. [Accessed 30 June 2016].

Chou, W. S. and Moskowitz, M. (2016) Social media use in adolescent and young adult (AYA) cancer survivors, *Current Opinion in Psychology,* 9, pp. 88-91.

Christian, B. J., Pearce, P. F., Roberson, A. J. and Rothwell, E. (2010) It's a Small, Small World: Data Collection Strategies for Research with Children and Adolescents, *Journal of Paediatric Nursing,* June 2010, 25 (3), pp. 202-214. DOI: https://doi.org/10.1016/j.pedn.2009.01.003.

Christie, MJ, Rowe, PA, Perry, C & Chamard, J 2000, 'Implementation of realism in case study research methodology', in E Douglas (ed.), *Proceedings of Entrepreneurial SMES - engines for growth in the millennium: International Council for Small Business. World Conference*, 7-10 June, Brisbane, Australia.

Cialdini, R. B. and Trost, M. R. (1998) Social influence: Social norms, conformity and compliance, in: Social influence: Social norms, conformity and compliance, in: New York, NY, US: McGraw-Hill, pp. 151-192.

Clark, A. and Emmel, N. (2010) Using walking interviews, *Realities: Part of the Economic and Social Research Council National Centre for Research Methods,* 13, pp. 1-2-6.

Coad, J. (2007) Using art-based techniques in engaging children and young people in health care consultations and/or research, *Journal of Research in Nursing,* 12 (5), pp. 487-497.

Coad, J. and Coad, N. (2008) Children and young people's preference of thematic design and colour for their hospital environment, *Journal of Child Health Care,* 12 (1), pp. 33-48.

Coventry University (2018) *Teenager/Young Adults Cancer Care.* Available from: https://www.coventry.ac.uk/study-at-coventry/faculties-and-schools/health-and-life-sciences/nursing-midwifery-and-health/teenager-young-adults-cancer-care/. [Accessed 22 September 2018].

Coyne, I., Amory, A., Kiernan, G. and Gibson, F. (2014) Children's participation in shared decision-making: Children, adolescents, parents and healthcare professionals' perspectives and experiences, *European Journal of Oncology Nursing,* 18, pp. 273-280.

Coyne, I. (1997) Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries? *Journal of Advanced Nursing,* 26 (3), pp. 623-630.

Creswell, J. W. and Poth, C. N. (2013) *Qualitative Inquiry and Research Design.* 4th ed. United States of America: SAGE Publications.

Critical Appraisal Skills Programme (2017) *CASP Checklist: 10 questions to help you make sense of a Qualitative research.* Available from: https://casp-uk.net/wp-content/uploads/2018/01/CASP-Qualitative-Checklist-2018.pdf. [Accessed 5 October 2017].

Crossan, F. (2003) Research philosophy: towards an understanding, *Nurse Researcher,* 11 (1), pp. 46-55.

Cunningham, J. B. and Kempling, J. S. (2009) Implementing change in public sector organizations, *Management Decision,* 47 (2), pp. 330.

Curtis, E. and O'Connell, R. (2011) Essential leadership skills for motivating and developing staff, *Nursing Management,* 18 (5), pp. 32-35.

Curtis, K., Fry, M., Shaban, R. Z. and Considine, J. (2017) Translating research findings to clinical nursing practice, *Journal of Clinical Nursing,* 26 (5-6), pp. 862-872.

Czarniawska, B. (2007) *Shadowing: And Other Techniques for Doing Fieldwork in Modern Societies.* Oxfordshire: Marston Book Services.

D'Agostino, N. M., Penney, A. and Zebrack, B. (2011) Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors, *Cancer,* 117 (10), pp. 2329.

Daly, S. (2012) *Young Voices: Transforming the lives of young people with cancer.* London, UK: Teenage Cancer Trust.

Darby, K., Nash, P. and Nash, S. (2014) Understanding and responding to spiritual and religious needs of young people with cancer, *Cancer Nursing Practice,* 13 (2), pp. 32-37.

Data Protection Act (2018) *Data Protection Act, 2018*. Available from: http://www.legislation.gov.uk/ukpga/2018/12/contents/enacted. [Accessed 11 December 2018].

Davies, H. and Mannion, R. (2013) Will prescriptions for cultural change improve the NHS? *British Medical Journal,* 346, pp. f1305.

Davies, H. T. O., Nutley, S. M. and Mannion, R. (2000) Organisational culture and quality of health care, *Quality Health Care,* 9 (2), pp. 111-119.

Day, E., Jones, L., Langner, R., Stirling, L. C., Hough, R. and Bluebond-Langner, M. (2018) "We just follow the patients' lead": Healthcare professional perspectives on the involvement of teenagers with cancer in decision making, *Pediatric Blood & Cancer,* 65 (3), pp. e26898.

De Leon, J. P. and Cohen, J. H. (2005) Object and Walking Probes in Ethnographic Interviewing, *Field Methods,* 17 (2), pp. 200-204.

Dean, L. and Black, S. (2015) Exploring the experiences of young people nursed on adult wards, *British Journal of Nursing,* 24 (4), pp. 16-23.

Denzin, N. K. and Lincoln, Y. S. (2005) Introduction: The Discipline and Practice of Qualitative Research. in: Denzin, N. K. and Lincoln, Y. S. (eds.) *Handbook of Qualitative Research,* 3rd ed. Thousand Oaks: Sage, pp. 1-32.

Denzin, N. K. and Lincoln, Y. S. (2011) *The Sage Handbook of Qualitative Research.* 4th ed. London, UK: Sage Publications Ltd.

Department of Health (2015) *Culture Change in the NHS: Applying the lessons of the Francis Inquiries.* London, UK: Williams Lea Group on behalf of the Controller of Her Majesty's Stationery Office.

Department of Health (2012) *The NHS Outcomes Framework 2013-14.* London, UK.: Department of Health.

Department of Health (1995) *A policy framework for commissioning cancer services: a report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales.* London: Department of Health.

DeWalt, M. and DeWalt, B. (2011) Participant Observation. A Guide for Fieldworkers. (2nd Ed.) Plymouth, United Kingdom: Alta Mira Press.

DiCicco-Bloom, B. and Crabtree, B. (2006) The qualitative research interview, *Medical Education,* 40, pp. 314-321.

Dijkstra, K., Pieterse, M. and Pruyn, A. (2006) Physical environmental stimuli that turn healthcare facilities into healing environments through psychologically mediated effects: systematic review, *Journal of Advanced Nursing,* 56 (2), pp. 166-181.

Dixon-Woods, M., Agarwal, S., Jones, D., Young, B. and Sutton, A. (2005) Synthesising qualitative and quantitative evidence: a review of possible methods, *Journal of Health Services Research Policy,* 10, pp. 45-53.

Dominguez, M. and Sapina, L. (2016) "Others Like Me". An Approach to the Use of the Internet and Social Networks in Adolescents and Young Adults Diagnosed with Cancer. *Journal of Cancer Education,* 32(4), pp. 885-891.

Douglas, C. H. and Douglas, M. R. (2004) Patient-friendly hospital environments: exploring the patients' perspective, *Health Expectations,* 7 (1), pp. 61-73.

Dumontheil, I. (2016) Adolescent brain development, *Current Opinion in Behavioral Sciences,* August 2016, 10, pp. 39-44.

Easton, G. (2010) Critical realism in case study research, *Industrial Marketing Management,* 39, pp. 118-128.

Egener, B. E., Mason, D. J., McDonald, W. J., Okun, S., Gaines, M. E., Fleming, D. A. *et al.* (2017) The Charter on Professionalism for Health Care Organizations, *Academic Medicine: Journal of the Association of American Medical Colleges,* 92 (8), pp. 1091-1099.

Elwood, S. A. and Martin, D. G. (2000) "Placing" Interviews: Location and Scales of Power in Qualitative Research, *The Professional Geographer,* 52 (4), pp. 649-657.

Emerson, R. M., Fretz, R. I. and Shaw, L. L. (1995) *Writing Ethnographic Fieldnotes.* Chicago: University of Chicago Press.

Erez, M. and Gati, E. (2004) A Dynamic, Multi-Level Model of Culture: From the Micro Level of the Individual to the Macro Level of a Global Culture, *Applied Psychology: An International Review,* 53 (4), pp. 538.

Evans, G. W. (2006) Child development and the physical environment. *Annual Review of Psychology,* 57, pp. 423-451.

Fairley, L., Stark, D., Yeomanson, D., Kinsey, S. E., Glaser, A., Picton, S. V. *et al.* (2017) Access to principal treatment centres and survival rates for children and young people with cancer in Yorkshire, UK, *BMC Cancer,* 17, pp. 168-177.

Feltbower, R. G., Siller, C., Woodward, E., McKinney, P. A., Picton, S. V., Joffe, J. *et al.* (2011) Treatment and survival patterns for germ cell tumors among 13- to 24-year olds in Yorkshire, UK, *Pediatric Blood and Cancer,* 56(2), pp. 282-288.

Fern, L., Taylor, R., Whelan, J., Pearce, S., Grew, T., Brooman, K. *et al.* (2013) The Art of Age-Appropriate Care: Reflecting on a Conceptual Model of the Cancer Experience for Teenagers and Young Adults, *Cancer Nursing,* 36 (5), pp. E27.

Fern, L. A., Lewandowski, J. A., Coxon, K. M. and Whelan, J. (2014) Available, accessible, aware, appropriate, and acceptable: a strategy to improve participation of teenagers and young adults in cancer trials, *The Lancet Oncology,* 15 (8), pp. e341-e350.

Fernandez, C., Fraser, G. A. M., Freeman, C., Grunfeld, E., Gupta, A., Mery, L. S. *et al.* (2011) Principles and Recommendations for the Provision of Healthcare in Canada to Adolescent and Young Adult Aged Cancer Patients and Survivors, *Journal of Adolescent and Young Adult Oncology,* 1 (1), pp. 53-59.

Ferrari, A., Albritton, K., Osborn, M., Barr, R., Johnson, R. H., Stark, D. *et al.* (2016) Access and Models of Care, in: Bleyer, A., Barr, R., Ries, L., Whelan, J. and Ferrari, A. (eds.) *Cancer in Adolescents and Young Adults.* 2nd ed. Switzerland: Springer International Publishing.

Ferrari, A. and Barr, R. D. (2017) International evolution in AYA oncology: Current status and future expectations, *Pediatric Blood & Cancer,* 64 (9), pp. e26528.

Ferrari, R. (2015) Writing narrative style literature reviews, *Medical Writing,* 24 (4), pp. 230-235.

Fielding, N. and Thomas, H. (2008) Qualitative Interviewing, in: Gilbert, N. (ed.) *Researching Social Life.* 3rd ed. London, UK: SAGE Publications, pp. 123-144.

Flood, G. (1999) *Beyond Phenomenology: Rethinking the Study of Religion.* London: Cassell Religious Studies.

Flyvbjerg, B. (2006) Five Misunderstandings About Case-Study Research, *Qualitative Inquiry,* 12 (2), pp. 219-245.

Freeman, G. and Hughes, J. (2010) *Continuity of care and the patient experience.* London, UK: The King's Fund.

Furness, C. L., Smith, L., Morris, E., Brocklehurst, C., Daly, S. and Hough, R. E. (2017) Cancer Patient Experience in the Teenage Young Adult Population— Key Issues and Trends Over Time: An Analysis of the United Kingdom National Cancer Patient

Experience Surveys 2010–2014, *Journal of Adolescent and Young Adult Oncology,* 6 (3), pp. 450-458.

Garcia, C. M., Eisenberg, M. E., Frerich, E. A., Lechner, K. E. and Lust, K. (2012) Conducting Go-Along Interviews to Understand Context and Promote Health, *Qualitative Health Research,* 22(10), pp. 1395.

Gerring, J. (2007) *Case Study Research: Principles and Practices.* USA: Cambridge University Press.

Gibson, F., Aldiss, S., Horstman, M., Kumpunen, S. and Richardson, A. (2010) Children and young people's experiences of cancer care: A qualitative research study using participatory methods, *International Journal of Nursing Studies,* 47(11), pp. 1397-1407.

Gibson, F., Fern, L., Whelan, J., Pearce, S., Lewis, I., Hobin, D. *et al.* (2012) A scoping exercise of favourable characteristics of professionals working in teenage and young adult cancer care: 'thinking outside of the box', *European Journal of Cancer Care,* 21, pp. 330-339.

Gibson, F. and Twycross, A. (2007) Children's participation in research, *Paediatric Nursing,* 19 (4), pp. 14-17.

Gill, R., Barbour, J. and Dean, M. (2014) Shadowing In/As Work: Ten Recommendations for Shadowing Fieldwork Practice, *Qualitative Research in Organizations and Management,* 9 (1), pp. 69-89.

Golafshani, N. (2003) Understanding Reliability and Validity in Qualitative Research. *The Qualitative Report,* 8 (4), pp. 597-606.

Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D. *et al.* (2017) Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review, *Clinical Psychology & Psychotherapy,* 24 (4), pp. 870-886.

Govier, I. and Nash, S. (2009) Examining transformational approaches to effective leadership in healthcare settings, *Nursing Times,* 105 (18), pp. 24-27.

Green, B. N., Johnson, C. D. and Adams, A. (2001) Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *The Journal of Sports, Chiropractic and Rehabilitation,* 15(3), pp. 5-19.

Grinyer, A. (2009) Contrasting parental perspectives with those of teenagers and young adults with cancer: Comparing the findings from two qualitative studies, *European Journal of Oncology Nursing,* 13(3), pp. 200-206.

Gustafsson, J. (2017) *Single case studies vs. multiple case studies: A comparative study.* Thesis, Sweden: Halmstad University, School of Business, Engineering and Science.

Hagell, A., Coleman, J. and Brooks, F. (2015) *Key Data on Adolescence 2015.* London: Association for Young People's Health.

Haggerty, J. L., Reid, R. J., Freeman, G. K., Starfield, B. H., Adair, C. E. and McKendry, R. (2003) Continuity of care: a multidisciplinary review, *British Medical Journal,* 327 (7425), pp. 1219.

Hall, E. (1976) *Beyond Culture.* 1st ed. USA.: Anchor.

Hamo, M. (2004) From Observation to Transcription and Back: Theory, Practice, and Interpretation in the Analysis of Children's Naturally Occurring Discourse, *Research on Language and Social Interaction,* 37 (1), pp. 71-92.

Hannerz, U. (2003) Being there . . . and there . . . and there! Reflections on multi-site ethnography, *Ethnography,* 4 (2), pp. 201-216.

Hargreaves, D. (2011) Revised You're Welcome Criteria and Future Developments in Adolescent Healthcare. *Journal of Clinical Research in Paediatric Endocrinology,* 3 (2), 43-50.

Harper, D. (2002) Talking about pictures: A case for photo elicitation. *Visual Studies*, 17(1), pp. 13-26.

Harris, M. (2001) *The Rise of Anthropological Theory: A History of Theories of Culture.* 2nd ed. Walnut Creek, California, USA: Alta Mira Press.

Harris, P. B., McBride, G., Ross, C. and Curtis, L. (2002) A place to heal: environmental sources of satisfaction among hospital patients. *Journal of Applied Social Psychology,* 32 (6), pp. 1276-1299.

Haward, R. A. (2006) The Calman–Hine report: a personal retrospective on the UK's first comprehensive policy on cancer services, *The Lancet Oncology,* April 2006, 7 (4), pp. 336-346.

Hay, A. E., Fern, L., Meyer, R., Seibel, N. and Barr, R. (2016) Clinical Trials, in: Bleyer, A., Barr, R., Ries, L., Whelan, J. and Ferrari, A. (eds.) *Cancer in Adolescents and Young Adults.* 2nd ed. Switzerland: Springer International Publishing, pp. 549.

Health Education England (2018) *Person-centred care.* Available from: https://www.hee.nhs.uk/our-work/person-centred-care. [Accessed 22 July 2018].

Health Research Authority (2018) *Principles of consent: Children and Young People.* Available from: http://www.hra-decisiontools.org.uk/consent/principles-children.html. [Accessed 4 August 2017].

Healthcare Play Specialist Education Trust (2015) *Exploring the impact environments have on children and young people's experience of healthcare: a review of the literature.* Edinburgh, Scotland: Healthcare Play Specialist Education Trust.

Herman, S. M. (1970) The Organization as an Iceberg: Proceedings of Organizational Development Network Conference. in: *Organizational Development Network Conference,* Chicago, USA.

Hofstede, G. (1994) The Business of International Business is Culture, *International Business Review,* 3 (1), pp. 1.

Hofstede, G. (2019) *Organisational Culture.* Available from: https://www.hofstede-insights.com/models/organisational-culture/. [Accessed on 4 August 2017].

Hogan, S. J. and Coote, L. V. (2014) Organizational culture, innovation, and performance: A test of Schein's model, *Journal of Business Research,* 67 (8), pp. 1609.

Hollis, R. and Morgan, S. (2001) The adolescent with cancer—at the edge of no-man's land, *The Lancet Oncology,* 2 (1), pp. 43.

Holm, G. (2014) Photography as a research method. in: Leavy, P. (ed.) *The Oxford Handbook of Qualitative Research,* Oxford, UK: Oxford University Press, pp. 380-402.

Hooker, L. and Milburn, M. (2000) Taking practice forward in paediatric oncology: the impact of a newly developed education programme for nurses working in shared-care hospitals. *European Journal of Oncology Nursing,* 4 (1), pp. 48-54.

Hough, R. (2018) Children and Young People's Cancer Services: National Service Review, in: *TYAC Conference,* Birmingham, September 2018.

Hubbuck, C. (2009) *Play for sick children: Play specialists in hospitals and beyond.* London, United Kingdom: Jessica Kingsley Publishers.

Hudelson, P. M. (2004) Culture and quality: an anthropological perspective, *International Journal for Quality in Health Care,* 16 (5), pp. 345-346.

Hutton, A. (2008) An adolescent ward; 'in name only?', *Journal of Clinical Nursing,* 17 (23), pp. 3142-3149.

Hutton, A. (2010) How adolescent patients use ward space. *Journal of Advanced Nursing*, 66(8), pp. 1802-1809.

Jacobs, R., Mannion, R., Davies, H., Harrison, S., Konteh, F. and Walshe, K. (2012) The Relationship between Organizational Culture and Performance in Acute Hospitals*, Social Science and Medicine,* 76(1), pp. 115-125.

Jahoda, G. (2012) Critical reflections on some recent definitions of "culture". *Culture & Psychology,* 18 (3), pp. 289-303.

Joffe, H. (2012) Thematic Analysis, in: Harper, D. and Thompson, A. (eds.) *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners.* Chichester: Wiley-Blackwell, pp. 209-223.

Jones, P., Bunce, G., Evans, J., Gibbs, H. and Ricketts Hein, J. (2008) Research Design: Exploring Space and Place with Walking Interviews, *Journal of Research Practice,* 4 (2), pp. D2.

Jones, L. J. W., Pini, S. A., Morgan, S. J., Birk, G. K. and Stark, D. P. (2017) How Do Teenagers and Young Adults with Cancer Experience Their Care? A European Survey, *Journal of Adolescent and Young Adult Oncology,* 6 (1), pp. 102-110.

Jung, T., Scott, T., Davies, H. T. O., Bower, P., Whalley, D., McNally, R. *et al.* (2009) Instruments for Exploring Organizational Culture: A Review of the Literature, *Public Administration Review,* 69 (6), pp. 1087-1096.

Kao, H., Hsu, M. and Clark, L. (2004) Conceptualizing and Critiquing Culture in Health Research, *Journal of Transcultural Nursing,* 15 (4), pp. 269-277.

Kelly, D. (2008) The Physical and Emotional Impact of Cancer, in: Kelly, D. and Gibson, F. (eds.) *Cancer Care for Adolescents and Young Adults,* Oxford, UK: Blackwell Publishing, pp. 23-43.

Kelly, D., Pearce, S. and Mulhall, A. (2004) 'Being in the same boat': ethnographic insights into an adolescent cancer unit. *International Journal of Nursing Studies,* 41, pp. 847-857.

Kennedy, I. (2010) *Getting it right for children and young people Overcoming cultural barriers in the NHS so as to meet their needs.* London, UK: Department of Health.

Kenten, C., Martins, A., Fern, L. A., Gibson, F., Lea, S., Ngwenya, N. *et al.* (2017) Qualitative study to understand the barriers to recruiting young people with cancer to BRIGHTLIGHT: a national cohort study in England, *BMJ Open,* 7 (11), pp. e018291.

Kidder, D. L. (2002) The Influence of Gender on the Performance of Organizational Citizenship Behaviors, *Journal of Management,* 28 (5), pp. 629-648.

Kirk, S. (2007) Methodological and ethical issues in conducting qualitative research with children and young people: A literature review, *International Journal of Nursing Studies,* 44(7), pp. 1250-1260.

Kitayama, S. (2002) Culture and basic psychological processes--Toward a system view of culture: Comment on Oyserman et al. (2002), *Psychological Bulletin,* 128 (1), pp. 89-96.

Knoblauch, H. (2005) Focused Ethnography, *Forum: Qualitative Social Research,* 6 (3), pp. 44.

Knott, C., Brown, L. and Hardy, S. (2013) Introducing a self-monitoring process in a teenage and young adult cancer ward: impact and implications for a team culture and practice change, *International Practice Development Journal,* 3 (2), pp. 1-12.

Krauss, S. E. (2005) Research Paradigms and Meaning Making: A Primer. *The Qualitative Report,* 10 (4), pp. 758-770.

Kroeber, A. L. and Kluckhohn, C. (1952) *Culture: A Critical Review of Concepts and Definitions.* Cambridge, MA, U.S.A.: Peabody Museum.

Lamb, B. W., Brown, K. F., Nagpal, K., Vincent, C., Green, J. S. A. and Sevdalis, N. (2011) Quality of Care Management Decisions by Multidisciplinary Cancer Teams: A Systematic Review, *Annals of Surgical Oncology,* 18 (8), pp. 2116-2125.

Langfield-Smith, K. (1995) Organisational culture and control, in: Berry, A. J., Broadbent, J. and Otley, D. (eds.) *Management Control: Theories, Issues and Practices,* London: Macmillan Education UK, pp. 179-200.

Language and Culture Worldwide (2015) *The Cultural Iceberg.* Available from: https://www.languageandculture.com/cultural-iceberg. [Accessed August 27 2017].

Latney, C. R. (2016) High reliability organizations: The need for a paradigm shift in healthcare culture. *Full Text Available, Reflections on Nursing Leadership,* 42 (2), pp. 1.

Lea, S. (2015) Perspectives: A newly-qualified nurse's experience of starting a clinical academic career, *Journal of Research in Nursing,* 20 (3), pp. 252-255.

Lea, S. and Fern, L. A. (2016) Introduction, in: Introduction, in: *The Blueprint of Care for Teenagers and Young Adults with Cancer,* 2nd ed. London, UK.: Teenage Cancer Trust, pp. 13-15.

Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M. and Fern, L. A. (2018a) Online information and support needs of young people with cancer: a participatory action research study, *Adolescent Health, Medicine and Therapeutics,* 9, pp. 121-135.

Lea, S., Taylor, R. M., Martins, A., Fern, L. A., Whelan, J. S. and Gibson, F. (2018b) Conceptualizing age-appropriate care for teenagers and young adults with cancer: a qualitative mixed-methods study, *Adolescent Health, Medicine and Therapeutics,* 9, pp. 149-166.

Lenburg, C. B., Lipson, J., Demi, A., Blaney, D., Stern, P., Schultz, P. *et al.* (1995) *Promoting cultural competence in nursing education.* Washington DC: American Academy of Nursing.

Lewin, K. (1951) *Field Theory in Social Science.* New York, USA: Harper and Row.

Lewis, I. and Morgan, S. (2007) Models of Care and Specialized Units, in: Bleyer, A. W. and Barr, R. D. (eds.) *Cancer in Adolescents and Young Adults,* London: Springer-Verlag Berlin Heidelberg, pp. 341-352.

Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry.* Beverly Hill, CA, USA: SAGE Publications.

Lundy, O. and Cowling, A. (1996) *Strategic Human Resource Management.* London, UK: Routledge.

Maben, J. (2013) *The Impact of culture on staff and patient experiences.* London, UK: King's College London.

Mackland, A. and Wright, L. (2018) Remembering friends: addressing bereavement support for teenage & young adults diagnosed with cancer experiencing the loss of a peer. Psycho-oncology, 27(S2), pp. 4.

Macmillan Cancer Support (2012) *The role of cancer networks in the new NHS.* London, U.K.: Macmillan Cancer Support.

Macmillan Cancer Support (2018) *Holistic Needs Assessment, care and support plan folder.* Available from: https://be.macmillan.org.uk/be/p-20153-holistic-needs-assessment-care-and-support-plan-folder.aspx. [Accessed 15 September 2018].

Marris, S., Morgan, S. and Stark, D. (2011) 'Listening to Patients': what is the value of age-appropriate care to teenagers and young adults with cancer? *European Journal of Cancer Care,* 20, pp. 145-151.

Marshall, M., Sheaff, R., Rogers, A., Campbell, S., Halliwell, S., Pickard, S. *et al.* (2002) A qualitative study of the cultural changes in primary care organisations needed to implement clinical governance, *British Journal of General Practice,* 52 (481), pp. 641-645.

Marshall, N., Siddall, J., Law, K. and Kenten, C. (2016) Palliative and end of life care, in: *The Blueprint of Care for Teenagers and Young Adults with Cancer,* 2nd ed. London, UK.: Teenage Cancer Trust, pp. 105-111.

Marshall, S., Grinyer, A. and Limmer, M. (2018) The Experience of Adolescents and Young Adults Treated for Cancer in an Adult Setting: A Review of the Literature, *Journal of Adolescent and Young Adult Oncology,* 7 (3), pp. 283-291.

Martins, A., Taylor, R. M., Morgan, S. and Fern, L. A. (2017) Being normal, not vulnerable: case study of a 2-day residential programme for young adults with cancer, *BMJ Open,* 7 (7), pp. e015309.

Mason, J. (2002) *Qualitative Researching.* 2nd ed. London: Sage Publications Ltd.

McCormack, B., Dewing, J. and McCance, T. V. (2011) Developing Person-Centred Care: Addressing Contextual Challenges Through Practice Development, *The Online Journal of Issues in Nursing,* 16 (2), pp. 3.

McCormack, B. and McCance, T. V. (2006) Development of a framework for person-centred nursing, *Journal of Advanced Nursing,* 56 (5), pp. 472-479.

McDonagh, J. E. and Viner, R. M. (2006) Lost in transition? Between paediatric and adult services, *BMJ (Clinical Research Ed.),* 332 (7539), pp. 435-436.

McDonald, S. and Simpson, B. (2014) Shadowing research in organizations: the methodological debates, *Qualitative Research in Organizations and Management: An International Journal,* 9 (1), pp. 3-20.

McEvoy, P. and Richards, D. (2006) A critical realist rationale for using a combination of quantitative and qualitative methods, *Journal of Research in Nursing,* 11 (1), pp. 66-78.

McEvoy, L. and Duffy, A. (2008) Holistic practice – A concept analysis, *Nurse Education in Practice,* November 2008, 8 (6), pp. 412-419.

Merriam, S. B. (1998) *Qualitative research and case study applications in education.* San Francisco, CA, USA: Jossey-Bass.

Meyrick, J. (2006) What is Good Qualitative Research?: A First Step towards a Comprehensive Approach to Judging Rigour/Quality, *Journal of Health Psychology,* 11 (5), pp. 799-808.

Michaud, P. A., Suris, J. C. and Viner, R. (2004) The adolescent with a chronic condition. Part II: healthcare provision, *Archives of Disease in Childhood,* 89 (10), pp. 943-949.

Miles, M. B. and Huberman, A. M. (1994) *Qualitative data analysis: An expanded source book.* 2nd ed. Thousand Oaks, CA, USA: SAGE Publications

Miles, M., Huberman, A., M. and Saldana, J. (2014) *Qualitative data analysis: A methods sourcebook.* Thousand Oaks, CA, USA: SAGE Publications.

Millen, D. R. (2000) Rapid ethnography: time deepening strategies for HCI field research. in: *3rd conference on Designing interactive systems.* New York.

Ministry of Health (1959) *The Welfare of Children in Hospital, Platt Report.* London: Her Majesty's Stationery Office.

Mintzberg, H. (1970) Structured observation as a method to study managerial work. *Journal of Management Studies,* 7 (1), pp. 87-104.

Mitchell, W., Clarke, S. and Sloper, P. (2006) Care and Support Needs of Children and Young People with Cancer and their Parents, *Psycho-Oncology,* 15, pp. 805-816.

Mohr, P. (2001) National survey of use of hospital beds by adolescents aged 12 to 19 in the United Kingdom: response, *British Medical Journal,* 322, pp. 957.

Moran, O. and Valiallah, N. (2013) *An Evaluation of Age-Appropriate Care for Teenagers and Young Adults with Cancer in Leeds Teaching Hospitals Trust, Paying Particular Attention to In-Patient Physical Environment and Peer Support.* Masters, Quality in Care Programme: University of Leeds.

Morgan, S. (2018) The development of adolescent and young adult nursing: the UK experience. in: Smith, S. and Olsen, P. (eds.) *Nursing Adolescents and Young Adults with Cancer,* Cham, Switzerland: Springer International Publishing, pp. 9-28.

Morgan, S. (2009) 'What colour is my cancer?' The experience of teenagers and young adults who are shown their cancer samples through a microscope, *European Journal of Oncology Nursing,* 13 (3), pp. 179-186.

Morgan, S. (2011) What Should the Age Range Be for AYA Oncology? *Journal of Adolescent and Young Adult Oncology,* 1 (1), pp. 3-10.

Morgan, S., Smith, S., Mooney, S. and McCann, B. (2016) Age-appropriate care, in: *The Blueprint of Care for Teenagers and Young Adults with Cancer,* 2nd ed. London, UK.: Teenage Cancer Trust, pp. 39-52.

Morse, J. M. (2000) Determining Sample Size, *Qualitative Health Research,* 10 (1), pp. 3-5.

Mulhall, A. (2003) In the field: notes on observation in qualitative research, *Journal of Advanced Nursing,* 41 (3), pp. 306-313.

Mulhall, A., Kelly, D. and Pearce, S. (2004) A qualitative evaluation of an adolescent cancer unit, *European Journal of Cancer Care,* 13 (1), pp. 16.

Nadai, E. and Maeder, C. (2005) Fuzzy Fields. Multi-Sited Ethnography in Sociological Research, *Forum: Qualitative Social Research,* 6 (3), pp. 28.

Nair, M., Baltag, V., Bose, K., Boschi-Pinto, C., Lambrechts, T. and Mathai, M. (2015) Improving the Quality of Health Care Services for Adolescents, Globally: A Standards-Driven Approach, *Journal of Adolescent Health,* September 2015, 57 (3), pp. 288-298.

National Cancer Peer Review Programme (2013) *National Peer Review Report: Teenage and Young Adult Cancer Services Report 2012/2013.* London, UK: NHS Improving Quality.

National Cancer Peer Review Team - National Cancer Action Team (2011) *Manual for Cancer Services: Teenagers and Young Adult Measures.* London, UK: National Health Service.

National Cancer Research Institute (2012) *Impact of Patient, Carer and Public Involvement in Cancer Research.* London, UK: National Institute for Health Research.

National Institute for Clinical Excellence (2004) *Improving supportive and palliative care for adults with cancer* London, UK: National Institute for Clinical Excellence.

National Institute for Health and Care Excellence (2005a) *Improving Outcomes in Children and Young People with Cancer.* National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence (2005b) *Improving Outcomes in Children and Young People with Cancer: The Evidence Review.* National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence (2014a) *Children and Young People with Cancer - NICE Quality Standard 55.* London, UK: National Institute for Health and Care Excellence.

National Institute for Health and Care Excellence (2014b) *Centre for Clinical Practice – Surveillance review of cancer service guidance – Improving Outcomes for Children and Young People with Cancer.* London, UK: National Institute for Health and Care Excellence.

National Voices (2013) *A narrative for person-centred coordinated care.* Available from: https://www.nationalvoices.org.uk/sites/default/files/public/publications/narrative-for-person-centred-coordinated-care.pdf. [Accessed 16 October 2018].

NHS Digital (2018) *NHS WiFi.* Available from: https://digital.nhs.uk/services/nhs-wifi. [Accessed 22 October 2018].

NHS England (2013) *NHS Standard Contract for Cancer: Teenagers and Young Adults.* London, UK: NHS England.

NHS England (2014) *Manual for Cancer Services: Teenage and Young Adults Measures.* London, UK: NHS England.

Noble, H. and Smith, J. (2015) Issues of validity and reliability in qualitative research, *Evidence Based Nursing,* 18 (2), pp. 34.

Nottingham University Hospitals Trust (2017) Available from: https://www.nuh.nhs.uk/. [Accessed 18 July 2017].

Nursing and Midwifery Council (2015) *The Code: Professional standards of practice and behaviour for nurses and midwives.* London, UK: Nursing and Midwifery Council.

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A. and Cook, D. A. (2014) Standards for Reporting Qualitative Research: A Synthesis of Recommendations, *Academic Medicine,* 89 (9), pp. 1-7.

O'Hara, C., Khan, M., McCabe, M., Francis, L. and Moran, T. (2013) *Notifications of teenagers and young adults with cancer to a Principal Treatment Centre 2009-2010.* North West Cancer Intelligence Service. Available from: www.ncin.org.uk/view?rid=2124. [Accessed 13 February 2017).

Osborn, M., Little, C., Bowering, S. and Orme, L. (2013) Youth Cancer Services in Australia: Development and Implementation. International Perspectives on AYAO, Part 3, *Journal of Adolescent and Young Adult Oncology,* 2 (3), pp. 118-124.

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N. and Hoagwood, K. (2015) Purposeful Sampling for Qualitative Data Collection and Analysis in Mixed Method Implementation Research, *Administration and Policy in Mental Health,* 42 (5), pp. 533-544.

Patton, M. (2002) *Qualitative Research and Evaluation Methods.* 3rd ed. Thousand Oaks, CA, USA: SAGE Publications.

Patton, G. C., Coffey, C., Cappa, C., Currie, D., Riley, L., Gore, F. *et al.* (2012) Health of the world's adolescents: a synthesis of internationally comparable data, *The Lancet,* 379 (9826), pp. 1665-1675.

Paulus, T. M., Lester, J. N. and Dempster, P. G. (2014) *Digital Tools for Qualitative Research.* London: SAGE Publications.

Payne, S. (2007) Grounded theory, in: Lyons, E. and Coyle, A. (eds.) *Analysing qualitative data in psychology,* London: SAGE Publications, pp. 65-86.

Payne, D., Kennedy, A., Kretzer, V., Turner, E., Shannon, P. and Viner, R. (2012) Developing and running an adolescent inpatient ward, *Archives of Disease in Childhood - Education and Practice Edition,* 97 (2), pp. 42-47.

Perry, C. (1998) Processes of a case study methodology for postgraduate research in marketing. *The European Journal of Marketing,* 32 (9), pp. 785-802.

Phillippi, J., & Lauderdale, J. (2018). A Guide to Field Notes for Qualitative Research: Context and Conversation. *Qualitative Health Research*, *28*(3), pp. 381–388.

Pini, S. (2009) Education and mentoring for teenagers and young adults with cancer, *British Journal of Nursing,* 18 (11), pp. 690-693.

Pini, S. A., Gibson, F., Fern, L. A., Morgan, S. J., Phillips, R. S. and Stark, D. P. (2017) Multi-Professional Perspectives on Adolescent and Young Adult Oncology Across Europe: An e-Delphi Survey, *Journal of Adolescent and Young Adult Oncology,* 6 (1), pp. 178-185.

Polit, D. F. and Beck, C. T. (2010) Generalization in quantitative and qualitative research: Myths and strategies, *International Journal of Nursing Studies,* 47 (11), pp. 1451-1458.

Public Health England, NHS England and the Department of Health (2017) You're Welcome Pilot 2017: Refreshed standards for piloting. London: Public Health England, NHS England and the Department of Health.

Pugh, G., Hough, R., Gravestock, H., Williams, K. and Fisher, A. (2017) Lifestyle advice provision to teenager and young adult cancer patients: the perspective of health professionals in the UK, *Supportive Care Cancer,* 25(3), pp. 3823-3832.

Punch, S. (2002) Research with children: The same or different from research with adults? *Childhood,* 9 (3), pp. 321-341.

Quinlan, E. (2008) Conspicuous Invisibility: Shadowing as a Data Collection Strategy, *Qualitative Inquiry,* 14 (8), pp. 1480-1499.

Raingruber, B. and Wolf, T. (2015) Nurse Perspectives Regarding the Meaningfulness of Oncology Nursing Practice, *Clinical Journal of Oncology Nursing*, 19(3), pp. 292-296.

Rajani, S., Young, A., McGoldrick, D., Pearce, D. and Sharaf, S. (2011) The International Charter of Rights for Young People with Cancer, *Journal of Adolescent and Young Adult Oncology,* 1 (1), pp. 49-52.

Reed, M. (2017) *Enhancing Your Impact.* Available from: https://www.fasttrackimpact.com/resources. [Accessed 20 November 2018].

Rick, T. (2014) Organizational culture is like an iceberg. Available from: https://www.torbenrick.eu/blog/culture/organizational-culture-is-like-an-iceberg/. [Accessed September 1 2017].

Ross, N. J., Renold, E., Holland, S. and Hillman, A. (2009) Moving stories: using mobile methods to explore the everyday lives of young people in public care, *Qualitative Research,* 9 (5), pp. 605-623.

Royal College of Paediatrics and Child Health (2003) *Bridging the Gaps: Health Care for Adolescents.* London, U.K.: Royal College of Paediatrics and Child Health.

Royal College of Physicians (2015) *On the margins of medical care. Why young adults and adolescents need better healthcare.* London: Royal College of Physicians.

Sadeghi, N., Abdeyazdan, Z., Motaghi, M., Rad, M. Z. and Torkan, B. (2012) Satisfaction levels about hospital wards' environment among adolescents hospitalized in adult wards vs. pediatric ones, *Iranian Journal of Nursing and Midwifery Research,* 17 (6), pp. 430-433.

Saloustros, E., Stark, D. P., Michailidou, K., Mountzios, G., Brugieres, L., Peccatori, F. A. *et al.* (2017) The care of adolescents and young adults with cancer: results of the ESMO/SIOPE survey, *ESMO Open,* 2 (4).

Sawyer, S. M., Drew, S., Yeo, M. S. and Britto, M. T. (2007) Adolescents with a chronic condition: challenges living, challenges treating, *The Lancet,* 369 (9571), pp. 1481-1489.

Sayer, A. (2000) *Realism and Social Science.* 1st ed. London, UK: SAGE Publications.

Schein, E. (1992) *Corporate culture and leadership.* San Francisco, USA: Jossey Bass.

Schein, E. H. (2010) *Organizational Culture and Leadership.* 4th ed. West Sussex, UK: John Wiley & Sons.

Schein, E. H. (1984) Coming to a New Awareness of Organizational Culture, *Sloan Management Review,* 25 (3), pp. 3-16.

Schmidt, C. (2004) The analysis of semi-structured interviews, in: Flick, U., von Kardoff, E. and Steinke, I. (eds.) *A Companion to Qualitative Research.* London, UK: SAGE Publications.

Scott, T., Mannion, R., Davies, H. and Marshall, M. (2003) The quantitative measurement of organizational culture in health care: a review of the available instruments, *Health Services Research,* 38 (3), pp. 923-945.

Seale, B. (2016) *Patients as partners.* London: The King's Fund.

Seale, C. (1999) Quality in qualitative research. *Qualitative Inquiry,* 5 (4), pp. 465-478.

Selby, P. and Bailey, C. (1996) *Cancer in Adolescents and Young Adults.* London: BMJ Publishing.

Shamseer, L., Moher, D., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M. *et al.* (2015) Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015: elaboration and explanation, *British Medical Journal,* 349, pp. g7647.

Shaw, P., Reed, D., Yeager, N., Zebrack, B., Castenllino, S. and Bleyer, A. (2015) Adolescent and Young Adult (AYA) Oncology in the United States, *Journal of Pediatric hematology/oncology,* 37 (10), pp. 1097.

Siehl, C. and Martin, J. (1984) The role of symbolic management: How can managers effectively transit organizational culture? in: Hunt, J. (ed.) *Leaders and managers: International perspectives on managerial behaviour and leadership.* Elmsford, NY, USA: Pergamon, pp. 227-239.

Silverman, D. (2016) *Qualitative Research.* 4th ed. London, UK.: SAGE Publications.

Smircich, L. (1983) Concepts of Culture and Organizational Analysis, *Administrative Sciences Quarterly,* 28 (3), pp. 339.

Smith, S., Cable, M., Morgan, S., Siddall, J. and Chamley, C. (2014) *Competencies: Caring for Teenagers and Young Adults with Cancer: A Competence and Career Framework for Nursing.* England, Wales and Scotland: Teenage Cancer Trust.

Smith, S., Davies, S., Wright, D., Chapman, C. and Whiteson, M. (2007) The experiences of teenagers and young adults with cancer - Results of 2004 conference survey, *European Journal of Oncology Nursing,* 11 (4), pp. 362-368.

Smith, S. and Olsen, P. (2018) Introduction: Beyond No-man's land: The Development of AYA Cancer Nursing. in: Smith, S. and Olsen, P. (eds.) *Nursing Adolescents and Young Adults with Cancer,* Cham, Switzerland: Springer International Publishing, pp. 1-8.

Snilstveit, B., Oliver, S. and Vojtkova, M. (2012) Narrative approaches to systematic review and synthesis of evidence for international development policy and practice, *Journal of Development Effectiveness,* 4 (3), pp. 409-429.

Soanes, L. (2018) Challenges for Nursing, in: Smith, S. and Olsen, P. (eds.) *Nursing Adolescents and Young Adults with Cancer,* Cham, Switzerland: Springer International Publishing, pp. 219-226.

Sobo, E. J. (2009) *Culture and Meaning in Health Services Research.* London, UK: Routledge.

Sobo, E. J. and Loustaunau, M. O. (2010) *The Cultural Context of Health, Illness, and Medicine.* 2nd ed. California, USA: Praeger, ABC-CLIO.

Spector, R. E. (2002) Cultural Diversity in Health and Illness, *Journal of Transcultural Nursing,* 13 (3), pp. 197-199.

Spradley, J. P. (1980) *Participant Observation.* Minnesota, USA: Holt, Rinehart and Winston.

Stake, R. E. (1995) *The Art of Case Study Research.* London, UK: Sage Publications.

Stake, R. E. (2005) *Multiple Case Study Analysis.* New York, USA: Guilford Publications.

Stark, D., Bielack, S., Brugieres, L., Dirksen, U., Duarte, X., Dunn, S. *et al.* (2016) Teenagers and young adults with cancer in Europe: from national programmes to a European integrated coordinated project, *European Journal of Cancer Care,* 25 (3), pp. 419-427.

Stark, D., Bowen, D., Dunwoodie, E., Feltbower, R., Johnson, R., Moran, A. *et al.* (2015) Survival patterns in teenagers and young adults with cancer in the United Kingdom: Comparisons with younger and older age groups, *European Journal of Cancer,* 5 1(17), 2643-2654.

Steinbeck, K. and Brodie, L. (2006) Bringing in the voices: a transition forum for young people with chronic disability, *Neonatal, Paediatric and Child Health Nursing,* 9 (1), pp. 22-26.

Stevens, M. C. (2006) The 'Lost Tribe' and the need for a promised land: The challenge of cancer in teenagers and young adults, *European Journal of Cancer,* 42 (3), pp. 280-281.

Stichler, J. F. (2001) Creating Healing Environments in Critical Care Units, *Critical Care Nursing Quarterly,* 24 (3).

Sun, S. (2008) Organizational Culture and Its Themes, *International Journal of Business and Management,* 3 (12), pp. 137-141.

Swenson, S. L., Buell, S., Zettler, P., White, M., Ruston, D. C. and Lo, B. (2004) Patient-centered Communication, *Journal of General Internal Medicine,* 19 (11), pp. 1069-1079.

Tagliaventi, M. R. and Mattarelli, E. (2006) The role of networks of practice, value sharing, and operational proximity in knowledge flows between professional groups, *Human Relations,* 59 (3), pp. 291-319.

Tanti, C., Stukas, A. A., Halloran, M. J. and Foddy, M. (2011) Social identity change: Shifts in social identity during adolescence, *Journal of Adolescence,* 34 (3), pp. 555-567.

Tarlier, D. (2005) Mediating the meaning of evidence through epistemological diversity, *Nursing Inquiry,* 12 (2), pp. 126-134.

Taylor, R., Fern, L., Whelan, J., Pearce, S., Grew, T., Millington, H. *et al.* (2011) "Your Place or Mine?" Priorities for a Specialist Teenage and Young Adult (TYA) Cancer Unit: Disparity Between TYA and Professional Perceptions, *Journal of Adolescent and Young Adult Oncology,* 1 (2), pp. 145-151.

Taylor, R., Pearce, S., Gibson, F., Fern, L. and Whelan, J. (2013) Developing a conceptual model of teenage and young adult experiences of cancer through meta-synthesis, *International Journal of Nursing Studies,* 50, pp. 832-846.

Taylor, R. M., Feltbower, R. G., Aslam, N., Raine, R., Whelan, J. S. and Gibson, F. (2016b) Modified international e-Delphi survey to define healthcare professional competencies for working with teenagers and young adults with cancer, *BMJ Open,* 6 (5), pp. e011361.

Taylor, R. M., Solanki, A., Aslam, N., Whelan, J. S. and Fern, L. A. (2016a) A participatory study of teenagers and young adults views on access and participation in cancer research. *European Journal of Oncology Nursing,* 20, pp. 156-164.

Taylor, R. M., Fern, L. A., Solanki, A., Hooker, L., Carluccio, A., Pye, J. *et al.* (2015) Development and validation of the BRIGHTLIGHT Survey, a patient-reported experience measure for young people with cancer, *Health and Quality of Life Outcomes,* 13 (107), pp. 1-12.

Tedlock, B. (2000). Ethnography and Ethnographic Representation, in: *Handbook of Qualitative Research*, 2nd ed. Thousand Oaks, CA, USA: Sage.

Teenagers and Young Adults with Cancer. Uniting Professionals, Improving Practice (2016) *What we do.* Available from: https://www.tyac.org.uk/What-we-do. [Accessed 15 July 2016].

Teenage Cancer Trust (2018) *Our Units.* Available from: https://www.teenagecancertrust.org/get-help/how-we-can-help/our-units. [Accessed 30 June 2016].

The Futures Company (2010) *Exploring the impact of the built environment.* United Kingdom: Teenage Cancer Trust.

The Independent Cancer Taskforce (2015) Achieving world-class cancer outcomes: a strategy for England 2015-2020. London, UK: NHS England.

The King's Fund (2018) *Improving NHS Culture.* Available from: https://www.kingsfund.org.uk/projects/culture. [Accessed September 7 2017].

The Stationery Office (2013) *Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry.* London, UK: The Stationery Office.

Thomas, G. (2011) *How to do your Case Study.* London, UK: SAGE Publications.

Thomas, P. and While, A. (2007) Should nurses be leaders of integrated health care? *Journal of Nursing Management,* 15 (6), pp. 643-648.

Thomson, P. (2008) *Doing Visual Research with Children and Young People.* New York, USA: Routledge.

Trochim, W. (2006) *Web Centre for Social Research Methods.* Available from: https://www.socialresearchmethods.net/kb/positvsm.php. [Accessed 22 July 2016].

Tsoukas, H. (1989) The validity of ideograph research explanations, *Academy of Management Review,* 14 (4), pp. 551-561.

Tylee, A., Haller, D. M., Graham, T., Churchill, R. and Sanci, L. A. (2007) Youth-friendly primary-care services: How are we doing and what more needs to be done? *The Lancet,* 369 (9572), pp. 1565-1573.

Ullan, A. M., Belver, M. H., Fernandez, E., Serrano, I., Delgado, J. and Herrero, C. (2012) Hospital Designs for Patients of Different Ages: Preferences of Hospitalized Adolescents, Non-hospitalized Adolescents, Parents, and Clinical Staff, *Environment and Behavior,* 44 (5), pp. 668-694.

Van Maanen, J. (2011) *Tales of the Field: On Writing Ethnography.* 2nd ed. Chicago, USA: University of Chicago Press.

Van Thiel, J., Kraan, H. F. and Van, d. V. (1991) Reliability and feasibility of measuring medical interviewing skills: the revised Maastricht history-taking and advice checklist, *Medical Education,* 25 (3), 224-229.

Vespa, J. (2017) *Young Adults Delay Milestones of Adulthood.* Available from: https://www.census.gov/library/stories/2017/08/young-adult-video.html. [Accessed 6 July 2018].

Vindrola-Padros, C., Taylor, R. M., Lea, S., Hooker, L., Pearce, S., Whelan, J. *et al.* (2016) Mapping Adolescent Cancer Services: How Do Young People, Their Families, and Staff Describe Specialized Cancer Care in England? *Cancer Nursing,* 39 (5), pp. 358-366.

Viner, R. (2007) Do adolescent inpatient units make a difference? Findings from a national young patient survey. *Paediatrics,* 120 (4), pp. 749.

Viner, R. M. (2001) National survey of use of hospital beds by adolescents aged 12 to 19 in the United Kingdom, *British Medical Journal,* 322, pp. 957-958.

Viner, R. M. and Barker, M. (2005) Young people's health: the need for action, *British Medical Journal,* 330 (7496), pp. 901.

Wainwright, D. (1997) Can Sociological Research Be Qualitative, Critical and Valid? *The Qualitative Report,* 3 (2), pp. 1-17.

Watson, A.R. (2004) Hospital youth work and adolescent support. *Archives of Disease in Childhood*, 89, pp. 440-442.

Weber, K. and Dacin, M. T. (2011) The Cultural Construction of Organizational Life: Introduction to the Special Issue, *Organization Science,* 22 (2), pp. 287-298.

Wensing, M., Elwyn, G., Edwards, A., Vingerhoets, E. and Grol, R. (2002) Deconstructing patient centred communication and uncovering shared decision making: an observational study, *BMC Medical Informatics and Decision Making,* 2 (1), pp. 2.

Whelan, J. (2003) Where should teenagers with cancer be treated? *European Journal of Cancer,* 39 (18), pp. 2573-2578.

Whelan, J., Dolbear, C., Mak, V., Moller, H. and Davies, E. (2007) Where do teenagers and young adults receive treatment for cancer? *Journal of Public Health,* 29 (2), pp. 178-182.

Whelan, J. and Fern, L. A. (2008) Cancer in Adolescence: Incidence and Policy Issues, in: Kelly, D. and Gibson, F. (eds.) *Cancer Care for Adolescents and Young Adults,* Oxford, UK: Blackwell Publishing Cancer, pp. 7-22.

Whiteson, M. (2003) The Teenage Cancer Trust - advocating a model for teenage cancer services, *European Journal of Cancer,* 39 (18), pp. 2688-2693.

Wikfeldt, E. (1993) *Generalising from Case Studies.* Dissertation: Halmstad University. pp. 1-11.

Wilkinson, J. (2003) Young people with cancer – how should their care be organized? *European Journal of Cancer Care,* 12 (1), pp. 65-70.

Willgens, A. M., Cooper, R., Jadotte, D., Lilyea, B., Langtiw, C. L., and Obenchain-Leeson, A. (2016) How to Enhance Qualitative Research Appraisal: Development of the Methodological Congruence Instrument, *The Qualitative Report,* 21 (12), pp. 2380-2395.

Willig, C. (2013) *Introducing Qualitative Research in Psychology.* Berkshire, UK: Open University Press.

Wolf, J., Niederhauser, V., Marshburn, D. and LaVela, S. L. (2018) *Defining Patient Experience: A Critical Decision for Healthcare Organizations.* Available from: https://www.theberylinstitute.org/.

World Health Organization (2002) *Adolescent friendly health services: an agenda for change.* Geneva, Switzerland: World Health Organization.

World Health Organization (2018a) *World Health Statistics 2018.* Luxembourg: World Health Organization.

World Health Organization (2018b) *Advocating for Change for Adolescents! A Practical Toolkit for Young People to Advocate for Improved Adolescent Health and Wellbeing.* Geneva, Switzerland: World Health Organization.

Yazan, B. (2015) Three Approaches to Case Study Methods in Education: Yin, Merriam, and Stake. *The Qualitative Report,* 20 (2), pp. 134-152.

Yin, R. K. (2014) *Case Study Research.* 5th ed. London, UK: SAGE Publications.

Yin, R. K. (2009) *Case Study Research: Design and Methods.* 4th ed. Thousand Oaks, CA, USA: SAGE Publications.

Zebrack, B. (2011) Psychological, social, and behavioral issues for young adults with cancer, *Cancer,* 117 (10), pp. 2289-2294.

Zebrack, B. J., Mills, J. and Weitzman, T. S. (2007) Health and supportive care needs of young adult cancer patients and survivors. *Journal of Cancer Survivorship,* 1, pp. 137-145.

Appendices

Appendix 1: BRIGHTLIGHT Mapping study final report

Whole report available:

http://www.brightlightstudy.com/wp-content/uploads/2015/10/Mapping.pdf

Appendix 2: Mapping study: published paper of findings

Whole paper available:

https://www.ncbi.nlm.nih.gov/pubmed/26513609

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Mapping Adolescent Cancer Services

How Do Young People, Their Families, and Staff Describe Specialized Cancer Care in England?

KEY WORDS

Adolescent

Age-appropriate

BRIGHTLIGHT

Specialized

Teenage

Young adult

Background: Specialized cancer services for adolescents and young adults (AYAs) are being developed in a number of countries to address the particular needs of this population. However, the evidence base to inform service design and associated care delivery is inadequate. **Objective:** The aim of this study was to undertake a mapping study to identify the main components of AYA cancer care to be studied further to reflect the range of approaches to service delivery currently provided in England. **Methods:** Semistructured interviews were conducted with young people, their family members, and staff in 11 AYA principal treatment centers. Using different levels of extraction, these data were drawn together to illuminate the main components of AYA cancer care and the range of approaches to service delivery. **Results:** Young people, family members, and staff consistently identified and valued similar areas of AYA cancer care: caring and supportive staff, activities designed for AYAs, and an environment that feels like home. **Conclusion:** The mapping exercise successfully informed the selection of 4 sites for an in-depth case study. The main components of specialized AYA care have been described. **Implications for Practice:** This description can assist clinical teams interested in developing or refining their approach to AYA cancer care. It could also offer a way to agree priorities, based on the key components young people consider as being essential for their care, and facilitate services to benchmark against these key components, and it could also go some way to address international AYA goals to support global change to reduce the current disparities in care.

Appendix 3: Assessment form for case study site selection

Mapping Teenage and Young Adult Cancer Services in England: The BRIGHTLIGHT Directory of Care

Selection of sites for case study

Six sites need to be chosen for the case study research from the following list:

[list removed to ensure sites remain non-identifiable]

You have been sent a packet containing a brief overview of the characteristics of each site. We would like you to look at this information and select 6 sites based on the criteria outlined below. In the selection of these 6 sites we are aiming to represent the diverse nature of Principal Treatment Centres (PTCs) across England.

Criteria for selection:

1. Patient population
2. Geographical coverage
3. TYA services available
4. Distribution of TYA services across different age groups
   a. Are all 13-24 yrs. olds treated in the same facility or with the same team?
   b. Are 13-24 yrs. divided among paediatric, TYA, and adult services?
5. Arrangement of shared management[1]
6. Size of the service (number of patients, number of healthcare professionals, represented disciplines)
7. History of the service (amount of time since TYA services were established, amount of time since TCT unit opened)

Site selection

Patient population
   1. _____
   2. _____
   3. _____
   4. _____
   5. _____
   6. _____

---

[1] Refers to the care provided by other designated and non-designated hospitals.

Geographical coverage

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

TYA services available

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Distribution of TYA services across different age groups

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Arrangement of shared management

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Size of the service

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

History of the service

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Appendix 4: Interview topic guide for healthcare professionals

Interviews with healthcare professional's topic guide

Thank you for meeting with me.

Can you start by telling me a bit about your role?
In terms of your role(s) in the care of TYAs with cancer, which are the environments in which you spend the most time?

Can you describe these in a little more detail?

Can you think about key environments that play a role in the care provided to TYA patients?

What are the things which work well in the care provided to TYA patients?
Which things do you think work less well, which could be improved?
It may be good to think about this particularly in terms of the needs of TYA with cancer and their families.

It would be good now to find out a bit more about any key events specifically in TYA cancer care that take place within your unit, can you describe these? *This could be key events for the TYA MDT; key events on the inpatient unit, in day care or within your disease specific clinical teams.*

Could you tell me a little bit more about these and when and where they take place?

Can you think about key professionals that play a role in the care provided to TYA patients?

Are you a Keyworker/ Named Nurse? Do you know if your patients are allocated a Keyworker/ Named Nurse and what their role is?

What is the nature of your relationship to other settings for TYAs with cancer within your network? (i.e. if you work in a PTC, then to shared care settings, or vice versa). Do you have much contact with other health care teams, such as community teams?

Can you describe what the lines of communication are like between hospitals and units?

Do you have any commissioning information for TYA cancer care for the network as a whole that you can share with us?

Finally, what does 'age-appropriate' care mean to you?

Thank you for your time.

Appendix 5: Interview topic guide for teenagers and young adults

Interview with teenagers and young adults
 topic guide

Thank you for meeting with me.

Diagnosis

Let's start with how and where you received your diagnosis

>Where did you first go?

>Did you have to get tests or go anywhere else?

>Did you have to see other professionals?

Treatment environment

Where did you start your treatment?

Did you receive all of your care there or have you received care anywhere else?

Can you tell me about some of your experiences of being in other areas that we did not explore in our walking interview?

>Examples: day care or ambulatory care settings, outpatient department or clinics, other key settings – Radiotherapy

Are there any particular things in these environments or particular things that stand out to you?

Was there a school you had access to? What was it like? *(Ask if aged 13-18)*

Did you have any support with your university studies? (*If in further education*)

Health Professionals

Who would you say have been the key professionals involved in your care?

Can you tell me more about these people and why they might be important to you?

Do you have a Keyworker of key nurse that you know of? How much contact do you have with them?

Before we finish is there anything else which comes to mind about your experience of care which you think is important and I have not asked you about?

Many thanks for your all of your time and help.

Appendix 6: Information for participants taking photographs

London South Bank University

Faculty of Health and Social Care
103 Borough Road
London SE1 0AA
T: 020 7928 8989
F: 020 7815 809
www.lsbu.ac.uk

BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Information for taking photographs, version 2 (December 18th 2013)

You will have already read in the information you have been given that this study involves taking some photographs of the places you have received care in [hospital name]. This is to understand the hospital from your perspective, helping us to see it through your eyes.

If you take part, we will lend you a digital camera to take photographs throughout the day of anything connected to the environment you are currently in. This could mean going to different places such as the inpatient ward, outpatients department, day care unit or anywhere else that you might think is important. Below are a few things to help you and a few things you must avoid:

To Help:

- Take the photographs in the way that is most natural to you.
- Take photographs of whatever seems important to you in the environment. That might include objects and places. You may think before about your photographs or they may be quite spontaneous.
- Talk through with Sarah your ideas if you need further guidance, or help with 'what to avoid' in your photographs, then Sarah can be sure verbal permissions have been granted in those clinical areas you might like to visit before you do take photographs.

You must not:

- We need to protect both staff, and other patients who are on the same ward as you, so to do that you must be considerate when taking pictures, that just means being aware of where you are and who is near to you.
- In this project we unfortunately cannot use photographs which have people in who can be recognised. Don't worry if in some cases there are people in, it might just mean that, that particular photograph can't be used or that there maybe a way in which we can pixilate their faces so that they cannot be recognised.

- You must also avoid photographs that show any identifying features that can be linked to your ward, such as ward name, or photograph board of staff.

Towards the end of the day in which you have been taking photographs, Sarah will upload your photographs onto a computer so you can look at them together. She will ask you to describe them. You will get a digital copy of the photographs, which you have taken (if you want them), although those with people in will be deleted.

This is just a guide; please ask Sarah who will be on the unit if you need more information, have questions or need to talk anything through. She will also be there if you would like someone to walk with you while you take your photographs.

When we are finished, the photographs will be put into a report for the unit to keep.

Contact details:

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Appendix 7: Participant information sheet for healthcare professionals

London South Bank University

BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Information for healthcare professionals

Title: The Culture of Teenage and Young Adult Cancer Care Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

We would like to invite you to take part in a research study. Before you decide if you want to take part it is important to understand why the research is being done and what it will mean for you to take part. So please read this leaflet carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?
We have funding from the National Institute for Health Research (NIHR) to undertake a large amount of work evaluating the healthcare teenagers and young adults with cancer in England receive. This is a five-year research project, and includes many different parts. You may have heard of BRIGHTLIGHT or be part of it (see www.brightlightstudy.com for more information).

This study is linked to BRIGHTLIGHT but is looking at the places that young people receive care rather than how this care affects your future outcome. We are collecting detailed information from four principal treatment centres (PTCs) in England and the hospitals that they link with in their care networks. We will be talking to 6 young people and 6 healthcare professionals in each of the five networks. We will ask these young people and healthcare professionals to give tours of the areas where young people receive care, whilst discussing the environments of care. We will also carry out observations in these areas.

Why have I been asked to take part?
You have been asked to take part because you are a staff member in one of the Trusts involved in this study. It is essential to capture staff members' experiences and their descriptions of cancer services particularly in regard to the environments of care. Your views are essential.

Do I have to take part?
No, it is up to you whether or not to take part. If you do take part then you will be asked to sign a consent form. You will be given a copy of the consent form and this information sheet to keep. You are completely free to withdraw from the project at any time and without giving a reason.

What will happen to me if I take part?

If you decide to take part, Sarah, the researcher, will ask you some questions about your role, the place where you work, and the services you provide to young people. The discussion will firstly take place whilst walking around the areas where you work, to help us understand your views and experiences of these areas, before sitting down to continue the discussion. This discussion will be audio taped with your permission. The audio files will be saved on a University encrypted, password protected laptop. They will then be transferred to the transcriber via a password protected USB stick. They will be deleted from the audio recorder and after transcription the files will be deleted from the laptop and USB stick. We will store securely the transcripts and any other information we collect for a total of 15 years at London South Bank University. After this time, the data will be destroyed.

What are the possible disadvantages and risks of taking part?

We do not think that there is anything to be worried about in taking part. If you find that you experience any discomfort because of taking part in this study you will be free to stop taking part. We are asking you to give up some of your time to take part in this study; the interview will take about 60 minutes in total.

What are the possible benefits of taking part?

At this time there is no direct benefit to you from taking part in this project although people sometimes find some enjoyment in taking part in an activity like this one.

What if there is a problem?

If you have any problems about the study you can contact the research team, whose details are at the end of this information sheet. If you have any complaints about the way in which this project has been, or is being carried out, please try to discuss them with the researchers. If problems are not resolved, or you wish to comment in any other way, please contact [hospital complaints department details].

Will my taking part in the project be confidential?

All information will be treated in the strictest of confidence. Only the researchers will have access to the data collected during the study. The data will also be anonymous. There will be nothing that can be linked to any individual.

Who has reviewed the project?

This study has been reviewed by an NHS Ethics Committee.

What if I have any questions?

If you have questions about this project please contact any of the team listed below, but first try Sarah Lea.

Contact details for this study
Student's name
Sarah Lea
Department of Children's Nursing, Faculty of Health & Social Care, London South Bank University
Telephone: 020 7815 8371

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Professor Faith Gibson
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Appendix 8: Consent form for healthcare professionals

BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Centre study number:

CONSENT FORM for HEALTHCARE PROFESSIONALS

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Research team contacts: Sarah Lea, Professor Faith Gibson & Dr Rachel Taylor

Please initial box

1. I confirm that I have read and understood the information sheet dated August 14, 2014 (version 1.1) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.

2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

4. I understand that any information/direct quotations used from this study included in a report or publication will be completely anonymous, and I will not be able to be identified.

5. I agree to take part in the above study.

-------------------------- ---------------- ----------------------------
Name of professional   Date   Signature

-------------------------- ---------------- ----------------------------
Name of person taking consent   Date   Signature

Appendix 9: Participant information sheet for young people

London South Bank University

BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Information for Young People

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

We would like to invite you to take part in a research study. Before you decide if you want to take part it is important to understand why the research is being done and what it will mean for you to take part. So please read this leaflet carefully. Talk to others about the study if you wish.

Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of this study?
We have funding from the National Institute for Health Research (NIHR) to undertake a large amount of work evaluating the healthcare teenagers and young adults with cancer in England receive. This is a five-year research project, and includes many different parts. You may have heard of BRIGHTLIGHT or be part of it (see www.brightlightstudy.com for more information).

This study is linked to BRIGHTLIGHT but is looking at the places that you receive care rather than how this care affects your future outcome. We are collecting detailed information from five principal treatment centres (PTC) in four networks in England that care for young people like you and the other hospitals that they link with. We will be talking to approximately six young people and eight healthcare professionals at each PTC and their networks. We will ask one young person and one healthcare professional to give us a tour of the areas where young people receive care and we will also carry out observations in these areas.

Why have I been asked to take part?
You have been asked to take part because you are currently receiving care on one of the Trusts that is involved in this study. It is essential to capture young people's experiences and their descriptions of cancer services particularly in regard to the environments of their care. Your views are essential.

Do I have to take part?
No, it is up to you whether or not to take part. Your current and future care within the health service will not be affected in any way if you decide not to take part. If you do take part then you will be asked to sign a consent form. You will be given a copy of the consent form and this information sheet to keep. You are completely free to withdraw from the project at any time and without giving a reason.

What will happen to me if I take part?

If you decide to take part, Sarah, the researcher, will ask if you would like to take photographs of the areas around the ward you have found helpful or unhelpful. This will be optional and you will not have to take the photographs if you do not want to. If you decide to take the photographs, Sarah might accompany you as you take the photographs and talk to you about your experiences of care. More details on the taking of photographs are in a separate information sheet, but just to emphasize here, you will not be allowed to take photographs of people. If any photographs of people are taken, these will be either removed or modified to avoid their identification. After you have finished taking the photographs, you will look at them together and Sarah will ask you to describe them.

Sarah will ask you some questions about your experience of care. This discussion will be audio taped with your permission. This discussion can take place sitting in a quiet place of your choosing, possibly a quiet room or side room, and if you would like to walk around your areas of care whilst talking to Sarah you have the choice to do so. The audio files will be transferred to a server at our university (London South Bank University) and stored as password protected files until they have been transcribed. After transfer to the server, they will be deleted from the recorder and after transcription, the files will be deleted from the server. We will store securely the transcripts, photographs and any other information we collect for a total of 15 years at London South Bank University. After this time, the data will be destroyed.

What are the possible disadvantages and risks of taking part?

We do not think that there is anything to be worried about in taking part. If you find that you experience any discomfort because of taking part in this study you will be free to stop taking part and this will not have any effect on your future treatment and care. We are asking you to give up some of your time to take part in this study; the photographs and the interview will take about 90-120 minutes in total.

What are the possible benefits of taking part?

At this time there is no direct benefit to you from taking part in this project although people sometimes find some benefit in taking part in an activity like this one.

What if there is a problem?

If you have any problems about the study you can contact the people whose details are at the end of this information sheet. If you have any complaints about the way in which this project has been, or is being carried out, please try to discuss them with the researchers. If problems are not resolved, or you wish to comment in any other way, please either contact one of the nurses or doctors on your unit or contact [hospital complaints department details].

Will my taking part in the project be confidential?

All information will be treated in the strictest of confidence. Only the researchers will have access to the data collected during the study. The data will also be anonymous. There will be nothing on any of the maps, or any words used in any of the reports or newsletters that can be linked to any individual.

Who has reviewed the project?

This study has been reviewed by an NHS Ethics Committee.

What if I have any questions?

If you have questions about this project please contact any of the team listed below, but first try Sarah Lea.

Contact details for this study
Student's name
Sarah Lea
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Appendix 10: Consent form for young people (aged 16 years or more)

London South Bank University

Centre study number: [   ]

CONSENT FORM for YOUNG PEOPLE older than 16 years

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Research team contacts: Sarah Lea, Professor Faith Gibson & Dr Rachel Taylor

Please initial box

1. I confirm that I have read and understood the information sheet dated June 17, 2013 (version 1) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily. [ ]

2. I confirm that I have had sufficient time to consider whether or not I want to be included in the study. [ ]

3. I understand that participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. [ ]

4. I agree to my contact details being kept by the LSBU research team. [ ]

5. I agree that my main consultant can be informed of my participation in this study. [ ]

6. I understand that any information/direct quotations used from this study in a report or publication will be completely anonymous, and I will not be able to be identified. [ ]

7. I understand that if I decide to stop taking part, information that has already been collected will still be used unless I ask for it to be deleted. [ ]

8. I agree to take part in the above study. [ ]

---------------------------   ----------------   ----------------------------
Name of young person   Date   Signature

---------------------------   ----------------   ----------------------------
Name of Person taking consent Date   Signature

Appendix 11: Assent form for young people (aged <16 years)

London South Bank University

Faculty of Health and Social Care
103 Borough Road
London SE1 0AA
T: 020 7928 8989
F: 020 7815 809
www.lsbu.ac.uk

BRIGHTLIGHT
Do specialist services for TYA with cancer add value?

Centre Identification Number: [   ]

ASSENT FORM FOR YOUNG PEOPLE AGED 13 - 15 YEARS

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Research team contacts: Sarah Lea, Professor Faith Gibson & Dr Rachel Taylor

Please circle the answer you agree with:

Have you read the information sheet about this project?	Yes/No
Has someone explained this project to you?	Yes/No
Do you understand what this project is about?	Yes/No
Have you asked all the questions you want?	Yes/No
Have you had your questions answered in a way that you understand?	Yes/No
Do you understand it is okay to stop taking part at any time?	Yes/No
Do you understand that if you leave the study, any information that has been collected about you will be kept and used unless you ask for it to be destroyed?	Yes/No
Do you understand that your main consultant will be told that you are taking part in this study?	Yes/No
Do you understand that quotes (exact words) you use in this study may be used in publications and presentations by the research team but no one will be able to tell it comes from you?	Yes/No
Are you happy to take part?	Yes/No

If any answers are 'no' or you **don't** want to take part, **don't** sign your name.
If you **do** want to take part, please sign your name and today's date:

Print Name   _____

Sign   _____

Date   _____

The researcher who explained this project to you needs to sign too:

Print Name   _____

Sign   _____

Date   _____

Appendix 12: Consent form for parents of young people (aged <16 years)

London South Bank University

Faculty of Health and Social Care
103 Borough Road
London SE1 0AA
T: 020 7928 8989
F: 020 7815 809
www.lsbu.ac.uk

Centre study number: [   ]

CONSENT FORM for PARENTS/GUARDIANS

Title: The Culture of Teenage and Young Adult Cancer Care across Four Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Research team contacts: Sarah Lea, Professor Faith Gibson & Dr Rachel Taylor

Please initial box

1. I confirm that I have read and understood the information sheet dated June 17, 2013 (version 1) for the above study and have had the opportunity to ask questions and have had these answered satisfactorily.

2. I confirm that I have had sufficient time to consider whether or not I want my child to be included in the study

3. I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.

4. I agree to my child's contact details being kept by the LSBU research team.

5. I agree that my child's oncologist/haematologist and GP are informed of their participation in this study.

6. I understand that any information/direct quotations used from this study in a report or publication will be completely anonymous, and my child will not be able to be identified.

7. I agree to my child …………………………………………….. (name) taking part in the above study.

Young person's name: _____

_____   _____   _____
Name of Parent   Date   Signature

_____   _____   _____
Name of Person taking consent   Date   Signature

Appendix 13: Thematic analysis: reducing and displaying phases

13a) This presents an example of the thematic analysis: 'reducing phase'. This involved working with the individual units of analysis by hand to code each transcript and draw out initial themes, through a colour-coding process, alongside memoing and notetaking.
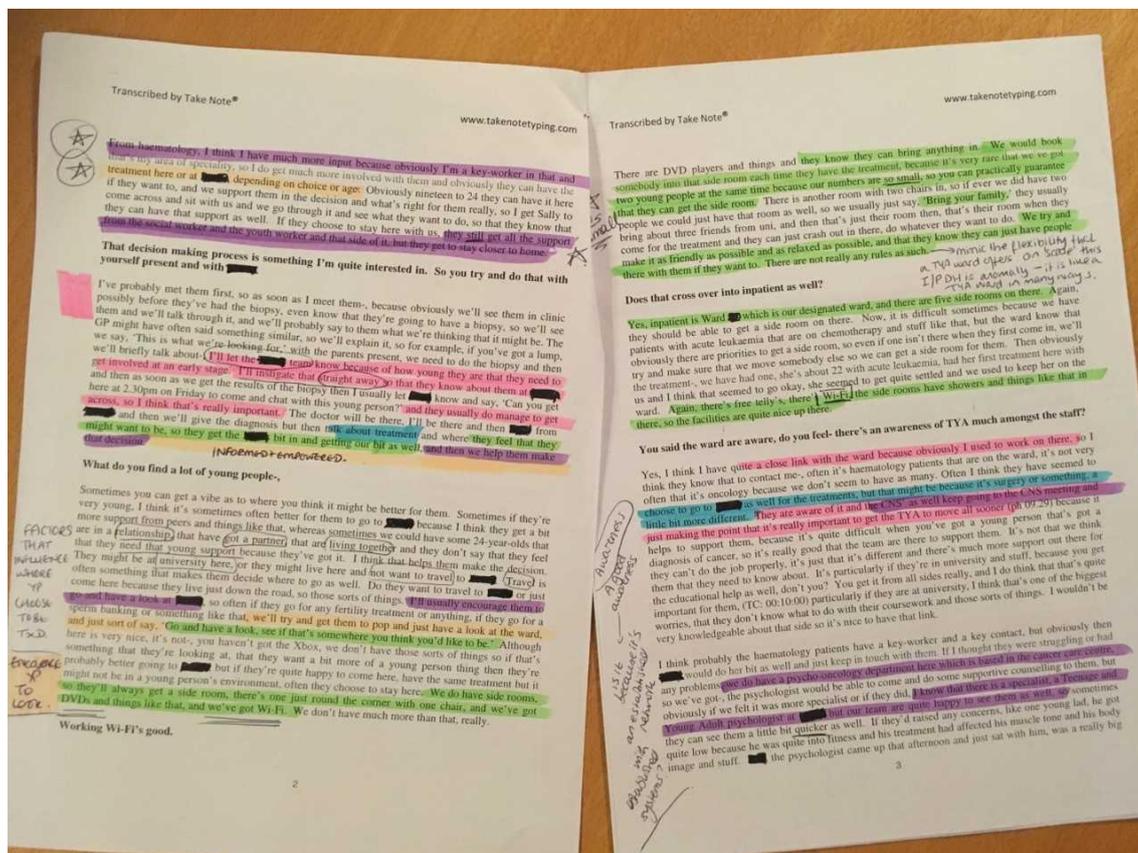
13b) Phrases were extracted, the meanings were identified and 'reduced' to themes and displayed in tables for each sub-case. These themes were the early-stage, emerging themes. This is an example of collated young person's data from one sub-case.

Reducing the data ➡️

Phrase	Meaning/code	Theme
Age-appropriate means technology, like having TVs and having the PlayStation and stuff… IPads and phones and that kind of thing… they're just great for teenagers really.	Means technology, TVs, PlayStation, IPads and phones	Facilities/Technology
It's just the activities that they have, I mean, you wouldn't see a 50-year-old sitting here with an X-Box, unless he's come to play with a	Xbox, the environment and facilities	

grandkid or something, so it's just the environment and facilities.		
Taking age away, I think the main thing is having television, something everybody does.	Having a television	
Not having stuff that seems too young	Not too young	
No Peppa Pig. Teenagers don't want to listen to that	Not childish or babyish	
For a teenager it needs not to be patronising.	Not patronising	Age-appropriate décor
Because people aren't entirely sure what teenagers might actually have, it can sometimes be quite bland. Which, for me, I like colour, I like bright things, and I like fun. So it can often come off as quite serious and too adult. When you try and design in a teenage way, you can take an adult base, but then you need to add a less serious something. It's hard to explain. Not baby-ish.	Not babyish or serious	
	Colour, bright, fun, take an adult base and make it less serious	Colourful, fun and bright
It's just sometimes the setting, but obviously there's not lots of young people with cancer, so it doesn't… because the ward I was on was for older people, so I was like, they're not going to have like colours and pools tables everywhere for them.	Treated on a ward for older people and had no colours or pool tables	
Nothing else, physically, in the environment that I can think of.	TYA unit environment meets needs	TYA unit fit for purpose
I think this is a pretty good environment		
For me it's just having space, space to move. I like having space… I can get out of my room. I don't like the feeling of being trapped…. It's just having space.	Get out of my room , having space	
A set, separate area, with somewhere just nice to relax with sofas and stuff and games that you can play. Just stuff that gets you away from the bed.	Separate area, somewhere to relax, away from bed	Space away from bed
I can move from bed and stay when I want and come back.	Move away from bed	
Because they're (HCPs) in a kind of de-hospitalised environment, you know its colourful, it's not like a typical hospital, I think it means they retain a bit more of their own personality… it just allows them to be themselves really.	Dehospitalised environment means HCPs retain more personality	Environment influences HCPs behaviour/mood
It's good for this as well, they've got like visitor time, ten to ten. Especially this ward, it's so good. You've got a long time with them. It's so good this thing to visit here. It doesn't matter how many people are here or who you are, they still can let people see you.	They allow lots of visitors and are flexible with their visiting times	Flexible with visitors

I've been on the baby ward at one point because they didn't have any isolation suites at the (shared care hospital)… so they put me into the baby ward. It was horrendous because you don't have anyone to talk to and seeing a little two year old having chemo and looking as ill as you do feels worse than seeing another teenager because you think, 'Oh God, they're so small, they shouldn't have to deal with this.' That's quite scary, when you see little babies sick and the also when you see adults just as ill because you feel like you're a nuisance if you're a teenager in a room full of adults, because that's kind of how adults sometimes make you feel, but just having teenagers makes it a lot better. It feels almost as if you're going to a 'chemo youth club' rather than going to a hospital. It feels quite nice that you can actually have a chat.	Baby ward horrendous, no one to talk to, scary seeing little babies sick and having chemo	Environment facilitates peer support
	Feel like a nuisance in a room full of adults, that's how adults can sometimes make you feel	
	Just having teenagers, you can have a chat, feels like a 'chemo youth club'	
	You can actually have a chat with other teenagers Teenagers together	
Occasionally they call that like, "a wiggly line". I found that quite, I don't know, not a nice way of referring to it but irritating. It was babyish and irritating, and I didn't like it. Apart from that, and that didn't happen very often at all, it was generally very good.	Irritating when nurses talk to you in a babyish way	You're not a child
I mean, I chat to every single nurse about different things, you know we all chat about different things. I know a little bit about their life, they know quite a lot about my life now. We can form an actual conversation about that rather than the kind of stilted half-hearted conversations you get on a normal ward.	Chat about different things, HCPs and patients getting to know each other, having actual conversations	Building a relationship with HCPs
I don't think I should be treated any differently to anybody else… so to be spoken to like an adult, be kept informed of what's going on is important. Sometimes, especially for me when I was at [local hospital name] it was like they treated me like I wasn't old enough to know what was going on. Age-appropriate care, as a young person you shouldn't be treated or spoken to any differently as to an adult in the same situation. You should be kept informed of what's going on the whole time, because at the end of the day it's your body. You're old enough to go through having all this pumped into your body, but you're not old enough to be told that that's what's going to happen, and what's going on inside you, to me, is wrong.	Not treated any differently to anybody else, or to any adult, in the same situation	Treated as an adult
		Honest, transparent communication
	Kept informed of what is going on	
		YP recognise themselves as an individual

I know it's the teenage and young adult ward, but you do still need to be treated like an adult. A lot of young people can freak out with this… there's never been any point where a doctor has sugar-coated it, watered it down for me. You know, I've always been told, 'Right these are the facts, this is what is wrong with you, this is what we're going to do to make it better,' and they've never sugar-coated it. … The honesty is what you need, but I mean, that's just me. Some people would need a lot more support than I did. Some people won't need as much support as I did. Obviously, as an individual, I couldn't say for everyone.	Need to be treated like and adult Honesty is what you need Recognises his views are individual to him and are not those of everyone	291
A lot of the staff, like the female staff, they were really good, like if I was upset and things like that, which was most days, so I don't really know, because they always had really good advice because I think a lot of them had children and things like that. Which to me, being in the situation I was in, which wouldn't be to a normal twenty-year old, who didn't have kids, you know? They'd probably say something completely different, but to me they were giving me the best advice that I needed and things like that, because they'd already had kids and things.	Female staff provide good advice, had families and therefore had something in common with her Recognises she is not in a normal situation, being a mum of three children at 20 years old.	HCPs providing good advice YP recognises themselves as an individual
Well, it differs for everyone doesn't it?	Recognises all TYAs different	
It just depends on the level of care you need really, without defining age	Can't define age – all have individual needs	

Appendix 14: Sample of cross-case analysis

This table is an example of cross-case analysis of one emerging over-arching theme: the environment. This involved collating both young people's and healthcare professional data from the individual tables of each sub-case, to enable identification of the themes which were emerging from the data, as a whole, and enable the researcher to identify their location in the raw data. This allowed the iterative process of returning to the raw data as the researcher spent time interpreting and understanding the data.

Themes	Subthemes	Subcase 1	Subcase 2	Subcase 3	Subcase 4
Décor/aesthetics	Décor -non-clinical -fun -bright -colourful -too jazzy -light -airy -impacts mood	PTC Jade, p4 Alena, p5 Emily, p3 Harry, p3 HCP2, p6 HCP4, p5 HCP5, p5 HCP7, p 3 HCP 10, p4 DH Connie, p5 HCP1, p4 Shared care Alena, p5 HCP8, p7 HCP12, p4	PTC Mia, p2, 4 Liam, p2 Jack, p2, 3 HCP14, p4,6 HCP16, p7 HCP17, p2 HCP20, p5,6 DH Rhianna, p7 HCP18, p5,6 HCP21, p7	PTC Jason, p2 Molly, p2 HCP27, p9 HCP25, p4 Nina, p3 HCP30, p4 Ali, p5 DH Jake, p5,6 Sasha p3 HCP29, p7 HCP30, p5 HCP32, p1,11	PTC Laura, p9, 10 Jen p11, 12 Nicole, p7 HCP38, p2,3 HCP39, p9 HCP33, p6 DH HCP34, p8 Simon p3 HCP34, 01 HCP35, p8 HCP40, p6
Facilities and equipment	Facilities and equipment specifically for young people -televisions -pool table -instruments -computers -games -arts and crafts	PTC Emily, p3 Harry, p3 Lucy, p2 Jade, p2 HCP2, p6 HCP3, p4 HCP4, p5 HCP5, p5 HCP7, p 3 HCP6, p4 Shared care Alena, p5,6 HCP 8, p5 HCP12, p6 HCP13, p9	PTC Julia, p1 Mia, p1, 2 Jack, p2 HCP17, p6 DH Rhianna, p7 HCP18, p5,6 HCP21, p7	PTC Jason p7, p8 HCP27 p9 HCP25 p7 HCP24 p3 Kelly p9 Anna p10 Nina p2,3 DH HCP28, p2 Jake, p5 Sasha p3,6 Shared care Anna, p10 HCP32, p7,8	PTC Jen p2,7,12,17 Nicole, p5 Laura, p2,3 HCP33, p5 HCP37, p4 HCP38, p5 HCP 39, p6 HCP40, p2 DH HCP34, p4
	No TYA facilities and equipment	DH HCP 9, p5,6 HCP10, p2 HCP 11, p9 Connie, p5 Shared care HCP12, p7	DH Rhianna, p7 HCP 21, p8 HCP22, p4,5	DH HCP26, p2 HCP23 p4 Shared care HCP29, p9	DH Simon p4 DH HCP34, p4

		HCP13, p9 Jade, p7		PTC O/P Anna p10	
Internet	Access to the internet	<u>PTC</u> Emily, p4 Harry, p3 Lucy, p2 Jade, p1 HCP2, p7 HCP3, p4 HCP4, p5 HCP7, p 3 HCP6, p4,5 <u>Shared care</u> Alena, p4 HCP 8, p5 HCP12, p7 HCP13, p9	<u>PTC</u> Mia Caroline Monica Natalia <u>DH</u> Rhianna, p7	<u>PTC</u> HCP25 p8 Terry, p4 Anna p3 Kelly p6 Nina p4,5 <u>DH</u> HCP28, p2 Jake, p6	<u>PTC</u> HCP38 p7 HCP39 p7, 13 <u>DH</u> HCP36, p5 HCP34, p7 Simon p4
Flexibility	Flexibility -ward routine -visiting times -staying overnight -duvet -home from home -easy for family to stay	<u>PTC</u> Emily, p3 Jade, p5 Lucy, p4 HCP5, p7,9 HCP1, p7 HCP3, p8 <u>Shared care</u> Alena, p3,4 HCP12, p6	<u>PTC</u> Mia p6 HCP17 p7 HCP20, p3 Julia, p6 Jack, p7	<u>DH</u> HCP28, p2,13,14 Jake, p5 Sasha p4, 14 HCP29 p11 <u>PTC</u> Jason/Abdi, p11 Terry p5 Anna p12	<u>DH</u> HCP36, p5 <u>PTC</u> Nicole p6 HCP39 p8 Jen p2, 7, 9
	-Feels like home -comfortable	<u>PTC</u> Jade, p5 Emily, p9 HCP2, p5 HCP3, p6 HCP8, p11	<u>PTC</u> Julia, p5 Jack, p6	<u>PTC</u> Jason/Abdi, p8 Molly, p4 <u>DH</u> Sasha p14	<u>PTC</u> Laura, p9, 10 Jen p9 <u>DH</u> Simon p8

Appendix 15: Sample of field notes

(Purple text: reflective comments) (TYA: teenage and young adult)

02/10/2014 – Shadowing Lead nurse for the network at an MDT meeting at [designated hospital]
Space
The meeting was held in a room, no windows, dingy, but appropriate for the needs of the meeting. We sat around a square table, which was just big enough for all of us. No technology was used, a discussion using a paper agenda and minutes only.
Actors
Myself, Lead nurse, CLIC Sargent Manager, CLIC Sargent Community worker, CLIC Sargent Social worker, Lead TYA Nurse at [hospital] and a nurse who was second to her, Peer Review Co-ordinator, the Matron of the ward where TYAs are treated, Lead TYA Clinician, Head and Neck CNS.
Activity
MDT meeting in which the team discussed how to move forward with the TYA care provided at the hospital.
Acts and events
Discussion points
- A recent event within TYA care at [hospital] is the appointment of the 2 Trust specific CLIC Sargent workers (social and community). This is, in part, to ensure that the hospital meets the peer review standards. However the Trust is not going to meet the peer review standards as there is no age-appropriate environment for the TYAs to currently be treated in.
- This brings me on to another activity that was discussed at the meeting – the refurbishment of a room to make it a TYA specific space for young people to relax in. This process is underway – a small pot of money from the TCT to do so however they have lost the funding for any kind of equipment in terms of electronic devices etc. The team discussed the donation of a duke box from the TCT – this was the TCT's suggestion – however the team made it clear that this was not the best use of this money and that perhaps games/TVs/tablets would be more appropriate. They are involving young people in the planning and design of this room. It was interesting to hear them discuss ways of trying to acquire some resources for young people such as a TV/ computer games – they simply do not have funding. It shows the difference in resources between designated hospitals and the Principal Treatment Centre. At [Principal Treatment Centre] there is an abundance of TYA focussed games and activities whereas currently at this designated hospital they can provide nothing for a teenager who is an inpatient in the Trust.
In relation to resources – the lead nurse asked the questions how much would the young people who are being treated at [designated hospital] be willing to link up with the services provided at [Principal Treatment Centre] in terms of activities, patient groups, psycho-social support. This could be something that the 2 new CLIC social workers could look into – as if they cannot provide some of these things on site then perhaps they could facilitate the use of linking into the TYA focussed activities that are already in place at [Principal Treatment Centre].
- They discussed ways to raise the profile of TYA care in the Trust and among HCPs – one idea is to encourage the new TYA social workers to attend the regular Safeguarding meetings.
- The current method of linking in to the TYA MDT at the Principal Treatment Centre was discussed – this is via a video conference format. The MDT at [hospital] think this method works – one professional showed concern towards the confidential aspect of video conferencing however these fears were allayed by [lead nurse] who is at the other end of the video conference at UCLH and knows well how the system works. They also demonstrated some confusion in a brief discussion about the standard operating procedures for TYAs. I felt that the lead nurse had to explain and dictate a lot of things to this group of people – mainly as she has a much better understanding of how the network structure works than the HCPs that are newer to the idea of TYA pathways and their different structure of care to the adults. I think maybe the expectations upon the TYA Lead nurses need to be assessed – think about the other designated hospitals and that they are CNS first and foremost in other specialities yet they need to find time to

meet the needs of the TYAs in their hospital as well as educate colleagues about TYA care pathways, needs, etc.

- Something that was clear and that was really encouraging to see is that the whole team understood and wanted to promote that TYAs are a group with specialised needs and that this is not just a tick box exercise to fulfil peer review standards etc. They all were keen to work with the hospitals outside the TYA pathways and their associated hospitals to get more people aware that TYA pathways are different to the adult cancer pathways. I chatted to [lead nurse for network] about this when we were travelling and it was evident that she was frustrated – she sent out the TYA pathways and information to every CEO of every hospital in the area so that this information could be filtered down to the lead clinicians yet clearly there are young people being treated on the incorrect pathways.

- For >19 to <25 year olds Information prescriptions: I was really interested to learn about this – I did not know this happened and I will be keen to see if this is a model that other networks use and if not, how do they provide this information to their young people. Information prescriptions are when the information required for a young person is discussed and the CNS is sent an "information prescription" and a bespoke pack of information in a nice folder is created for the young person. This takes into account both holistic needs and treatment needs.

- At [designated hospital] that have an isolation room – the fact that they are in need of some funding in order to refurbish this to make it a TYA specific room was discussed. They are talking about allocating one side room and making this the room for a TYA patient when they are admitted. They do not have any facilities for relatives to stay – if the patient is <18years then their parents can stay in a side room with them however the bed is very uncomfortable. They discussed the idea of obtaining some pull out/Z-bed type things. Again, this reminded me how lucky they are at [Principal Treatment Centre] having a fairly comfortable mattress on a Z-bed beside each bed space so that the young people can have somebody stay comfortably with them.(I am yet to discover what the case is on the young adult 19-24 unit).

- Once the main meeting was finished the Head and Neck CNS had a brief discussion with the lead nurse – and she told me that the head and neck pathways are very unclear and one of the ones that causes her the most problems. The two nurses were discussing that when the patients receive radiotherapy for their cancer they are not seen by the head and neck CNS but by the radiotherapy CNS'. These CNS' are less aware of the TYA pathways and needs and it is therefore these CNS' that need to be targeted and educated. [Non-designated hospital] do head and neck surgery on TYA patients however they are NOT a designated Trust on the TYA head and neck pathway – these TYAs are being treated on an adult pathway. They discussed how this needs to be addressed and more education and awareness needs to happen. But who can do this? [Lead nurse] is only one person and she does all she can – I was thinking and reflecting and I feel like some kind of educator role needs to be formed. To go around teach about the TYA pathways and the way the network is structured – it is very complicated -how are others supposed to understand it without properly being educated?

Time
The whole meeting went on for approximately 1 hour, 45 minutes. It was an in-depth discussion in places – [lead nurse] made a comment at the end to me that it was a long meeting therefore I think perhaps meetings at other Trusts are not always that long. They were very thorough though.

Goals
The goals of the meeting were very clearly laid out from the agenda and it was clear that the team were happy that they met these goals.

Feelings – my reflection
Why is it so complicated? This meeting really highlighted to me how complicated the whole TYA system and pathway structure is. I found it incredible that [lead nurse] had to explain the system to a large portion of her colleagues at [designated hospital]. They are simply not even aware of TYA and what TYA means, let alone what needs to be done to ensure they have the best care. What she kept reiterating is that she does not care *where* they are treated and that some designated hospitals seem to think that the PTC wants to take all of their patients. This is not that case at all, all that we care about is that the TYAs receive the *best* care possible and that all of their needs are met. [Principal Treatment Centre] is reaching its capacity (at times) and we need young people to be treated elsewhere, however we need to ensure these young people

are receiving the *best* care possible and are being offered the same services. I completely agree with this. My biggest thought for the day is that I have been so blinkered, and I think we all are, at [Principal Treatment Centre]The facilities we have are incredible and I would imagine that a lot of the staff do not have a clue what it is like at the designated hospitals (unless they have worked in one!) I feel very fortunate to be doing this project as I now have a much clearer idea of what is provided for TYAs outside of the PTC and that the environment in the PTC is brilliantly age-appropriate…. Although *is the care better* and is there a *difference in patient experience*? I need to find this out!! Even after 2 days of data collection, my knowledge on the network is expanding rapidly and I am understanding my research questions much more too! I am feeling very positive.

Appendix 16: NHS Ethics approval for the study

NHS
Health Research Authority

NRES Committee London - Central
Skipton House
80 London Road
London
SE1 6LH

Telephone:
Facsimile:

07 January 2014

Prof Faith Gibson
Clinical Professor of Children and Young People's Cancer Care
Great Ormond Street Hospital for Children and London South Bank University
Department of Children's Nursing, Faculty of Health & Social Care
London South Bank University
103 Borough Road, London
SE1 0AA

Dear Prof Gibson

Study title:	The Culture of TYA Care across Five Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study
REC reference:	13/LO/1869
Protocol number:	N/A
IRAS project ID:	141496

Thank you for your letter of 18th December 2013 responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the NRESCommittee.London-Central@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management

permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

<u>Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.</u>

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <u>http://www.rdforum.nhs.uk</u>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations.

<u>Registration of Clinical Trials</u>

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (<u>catherineblewett@nhs.net</u>), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers.   The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The documents reviewed and approved by the Committee are:

Document	Version	Date
Covering Letter		18 December 2013
Evidence of insurance or indemnity		18 July 2013
Investigator CV	Faith Gibson	27 July 2013
Letter from Sponsor		07 November 2013
Other: Student CV- Sarah Finlayson		11 November 2013
Other: Letter from Funder		22 September 2011
Other: Appendix 1Interview Script- Young People	1	06 October 2013
Other: Appendix 2-Script- Healthcare Professional	1	06 October 2013
Other: Appendix 12 Poster for Unit	1	01 October 2013
Other: Appendix 8- Letter of Introduction for PTC	1	17 June 2013
Participant Consent Form: Appendix 4- Healthcare Professionals	1	01 October 2013
Participant Consent Form: Appendix 6-Young People	1	01 October 2013
Participant Consent Form: Appendix 10- Parents/Guardian	1	01 October 2013
Participant Consent Form: Appendix 11- Assent Young People	1	01 October 2013
Participant Information Sheet: Appendix 3- Healthcare Professionals	1	17 June 2013
Participant Information Sheet: Appendix 13- Summary of Study Information	1	17 June 2013
Participant Information Sheet: Appendix 9- Information for Parents	1	17 June 2013
Participant Information Sheet: Young People	2	18 December 2013
Participant Information Sheet: for camera use/taking photographs	2	18 December 2013
Protocol		17 June 2013
REC application	141496/5271 39/1/821	11 November 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments

- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/LO/1869	Please quote this number on all correspondence

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

Alison O'Kane
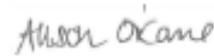
Dr   Andrew Hilson
Chair

Enclosures: *"After ethical review – guidance for researchers" [SL-AR2]*

Copy to: *Prof Nicola Crichton*

                          Ms Emma Clark, Joint UCLH/UCL Biomedical Research Centre

Appendix 17: NHS Ethics approval of amendment

NHS
Health Research Authority

National Research Ethics Service

NRES Committee London - Central

3rd Floor, 4 Minshull Street
Manchester
M1 3DZ

Tel: 0161 625 7821
Fax: 0161 625 7299

04 September 2014

Mrs Sarah Lea
Department of Children's Nursing, Faculty of Health & Social Care
London South Bank University
103 Borough Road, London
SE1 0AA

Dear Mrs Lea

Study title:	The Culture of TYA Care across Five Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study
REC reference:	13/LO/1869
Protocol number:	N/A
Amendment number:	2
Amendment date:	14 August 2014
IRAS project ID:	141496

- Change of CI to Sarah Lea
- Established a PhD Steering committee
- Setting reduced to 4 sites (out of the original 5)
- Change in young person sampling from by age group to cancer type.
- Observation will be both participant and nonparticipant in nature
- Added detail of data analysis methods
- Alteration to data protection information
- Alteration to the timeline of the study due to the time taken for preparation of the PhD student
- Minor changes in wording have been made to study documents.

The above amendment was reviewed on 03 September 2014 by the Sub-Committee in correspondence.

Ethical opinion

No ethical issues were raised.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

A Research Ethics Committee established by the Health Research Authority

The documents reviewed and approved at the meeting were:

Document	Version	Date
Interview schedules or topic guides for participants [Young People]	1.1	14 August 2014
Interview schedules or topic guides for participants [Healthcare Professionals]	1.1	14 August 2014
Notice of Substantial Amendment (non-CTIMP)	2	14 August 2014
Other [Summary Table of Changes to the Protocol]	1	14 August 2014
Other [Signed CI Declaration IRAS Form]		
Participant consent form [Assent Form]	1.1	14 August 2014
Participant consent form [Young People]	1.1	14 August 2014
Participant consent form [Parents/Guardians]	1.1	14 August 2014
Participant consent form [Healthcare Professionals]	1.1	14 August 2014
Participant information sheet (PIS) [Parents/Guardians]	1.1	14 August 2014
Participant information sheet (PIS) [Young People]	1.1	14 August 2014
Participant information sheet (PIS) [Healthcare Professionals]	1.1	14 August 2014
Research protocol or project proposal	2	14 August 2014
Summary CV for Chief Investigator (CI) [Sarah Lea]		
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Appendix 1]	1	14 August 2014

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

13/LO/1869:	Please quote this number on all correspondence

Yours sincerely

Signed on behalf
Dr Andrew Hilson
Chair

E-mail: NRESCommittee.London-Central@nhs.net

Appendix 18: NHS to NHS researcher letter of access

NHS to NHS letter of access: proforma confirmation of pre-engagement checks Version 1

For NHS researchers who have a substantive NHS contract of employment or clinical academics with an honorary clinical contract with an NHS organisation, and who need an NHS to NHS letter of access from an NHS organisation hosting their research.

CONFIRMATION OF PRE-ENGAGEMENT CHECKS

To: Research and Development Department [hospital]

Re: Sarah Lea (née Finlayson)

Job title: Staff Nurse, Children's and Young People's Cancer Services

Contract end-date: Permanent Staff

Workplace and postal address:
University College London Hospital NHS Foundation Trust,
235 Euston Road,
London,
NW1 2BU

Electronic Staff Record number: 24200602

As the representative of the NHS employer of the above-named person, I can confirm that s/he is employed by this organisation. I understand that the responsibility for ensuring that the appropriate pre-engagement checks have been undertaken rests with us as the individual's substantive employer. I can confirm that the appropriate pre-engagement checks have been completed, commensurate with her/his job description and proposed research role in your NHS organisation, and in line with NHS employment checks standards.

Name of employer's representative: Anika Patel

Job Title: HR Administrator

Workplace address: 250 Euston Road, NW1 2PG

Tel: 0203 447 7381

Email: anika.patel2@hotmail.com

Appendix 19: University ethics committee approval

London South Bank
University

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Friday 12 September 2014

Dear Sarah

RE: The Culture of TYA Care across Five Principal Treatment Centres and their Networks: BRIGHTLIGHT Case Study

Thank you for submitting this proposal and for your response to the reviewers' comments.

I am pleased to inform you that Full Chair's Approval has been given by Chair on behalf of the University Research Ethics Committee.

I wish you every success with your research.

Yours sincerely,

Nicola Mitchell

Secretary, LSBU Research Ethics Committee

cc:

Prof Shushma Patel, Chair, LSBU Research Ethics Committee

Appendix 20: Poster for the units

Hello, my name is Sarah.

I am a researcher who would like to learn more about the specialist care that young people receive on a unit like this one. I will be on your unit on occasions.

How will I be doing this?

You will see me around. You may not notice me at all. I will be talking to staff on the unit, and I will be looking around the unit and meeting young people and healthcare professionals. I will be walking around the unit with young people as they tell me about what they see, and what is important to them on the unit. I will not be watching or evaluating anyone as an individual person. Anything that we talk about is private and I will not link to any one person when I write about it. I will ask young people to take photographs, so that I can get an idea of the areas of the unit that have been helpful or unhelpful during your treatment. You will not be able to photograph people, if people appear in them these will either be deleted or modified.

If you see me, I will introduce myself and make sure you are happy for me to be around. It is quite ok if you would rather I was not around. Please do ask me any questions at any time.

Thank you!

Appendix 21: Field notes from videoconference tumour-site specific multi-disciplinary team meeting

(Purple text: reflective comments) (TYA: teenage and young adult)

21/11/2014 – Observed Sarcoma MDT at [shared care hospital] 8.00-10.30am alongside Children's and Teenagers Lead Nurse.

Space
The meeting took place in a seminar room in the 'education and training centre' – one of the buildings at [hospital]. The room was fairly small and when more health professionals came it was a little cramped.

Actors
Signed on the MDT register:
- Lead C&YP cancer nurse (0-19 years)

- MDT secretary

- Consultant Orthopaedic surgeons x 2

- Sarcoma nurse specialists x 3

- Consultant histopathologist x 3 (a large part of this meeting was looking at slides and lab results to discuss the diagnosis/staging)

- Cancer team co-ordinator

- Staff nurse and a student nurse

- Consultant spinal surgeon

- Consultant radiologist – again important to have these HPs there as the meeting involves looking at slides of x-rays and scans to work out diagnosis and treatment

- A few other staff members joined the meeting throughout and I was unsure of their roles

- The meeting involved a video link with the sarcoma team at the Principal Treatment Centre, including Doctors and administrators/ MDT co-ordinators.

- The meeting had a large input from both teams through the videoconference link – I was actually a little surprised at how essential both teams were to the discussion and to the decision-making process.

- A personal observation was that [Consultant] led in the decision making process and appeared to be the overall chair of the meeting, moving the conversation on where he felt appropriate.

Activity
- There was a mix of adult, TYA and paediatric patients discussed in this meeting – all sarcoma patients that are referred to either hospital. The two hospitals and teams clearly work closely together and there is a fairly well established patient pathway here.

- I think it must help the status of TYA patients to have [Consultant] chairing the meeting who is an advocate of the TYA specialism.

- Convergence of expertise - Surgeons can give details of about the mechanics, pros and cons of the surgical treatment options.

- The meeting was split into two sections:

- 08.30 until 10.00 discusses existing patients presenting with new issues, relapses and new diagnoses. This first meeting involves both teams (via video link).

- 10.00 until 12.30 the new referrals are discussed- these are patients that have been referred by GPs and other hospitals where perhaps they feel that the patient fits under the domain of [shared care hospital] or local teams need a second opinion from a group of experts. Some of these patients also present directly at [hospital]. The second meeting is only the [hospital] team.

- It is important to note that in the first meeting the young people and children are discussed in amongst the adult patients – there is no order that prioritises them or highlights them – it is partially dependent on whether the appropriate professional is in the room at the time. With the second meeting, there can be up to 100 patients referred to discuss in any one week, therefore the children and TYAs are discussed first on the list so that these specific professionals can leave the meeting after these patients have been discussed.

Events
- The first item discussed was an adult patient presented by a CNS and consultant at [shared care hospital] to the team at [Principal Treatment Centre]. The patients status and treatment plan was discussed and the conversation was moved on by [Consultant] as he suggested that another professional should review the patient also.

- It seemed to be that there was a large amount of joint decision making by the team – drawing on the expertise of both sets of HCPs

- Another 13 year old patient was discussed as the tumour is progressing into the knee joint therefore a decision needed regarding surgery – again the [Principal Treatment Centre] team asked for the opinion of the surgeons at [shared care hospital]. Surgical teams asked whether there is metastases in his chest and the CNS/ lead nurse chips in to answer this as she knows the patient's status. It was clear to me that [CNS and lead nurse] knows her patients well and their statuses and situations. She explained to me later that she uses the discussions of these meetings to build a picture of her patient's clinical status and diagnosis – which she often discusses with patients and is asked questions on therefore she finds these meetings really important.

- The Consultant still made the ultimate decision here to go ahead with the surgery. There is integrated working here but it is clear that there is a need for someone to make final decisions – I should imagine there are times where the teams struggle to come to final decisions when perhaps there are conflicting opinions.

- In the second meeting the new referrals were discussed and the children and young people were discussed first- in order to let CNS leave. There are a lot more adult referrals than young ones. It was her job to type into the system the outcome of the discussion – she was explaining this to me and told me it could be quite a stressful job as quite often the discussion would move on and she would still be frantically be typing into the form. She needed to type in if clinic appointment needs to me made, check the boxes of the scans/ investigations that need to be requested, any other things that are relevant such as crutches, mobility, transport etc.

Goals
The goal of the session for me was to gain an understanding as to how the processes work in terms of TYA care at [shared care hospital], to observe the patient pathway between their and the Principal Treatment Centre. I wanted to see the way that the HCPs interacted across the two sites and how treatment decisions were made between the two teams, particularly as there is a geographical dilemma here.

Feelings – my reflection
This was a very useful meeting to observe. Watching the interaction of the consultants with [CNS/lead nurse] was interesting – one came across to her and asked her "Where were you? I needed you!" as she had been away at a course for the 3 preceding days. There is clearly a lot of trust and a good relationship between her and her colleagues.
The patient pathway for sarcoma patients is clearly set out for TYAs – perhaps this is because there is an adult pathway that is similar? Maybe I need to have a look at the adult sarcoma pathway?
It will be very interesting to see what the sarcoma pathway is like at the other networks.

Appendix 22: Published findings from this study

Whole paper can be accessed here (open access):

https://www.dovepress.com/conceptualizing-age-appropriate-care-for-teenagers-and-young-adults-wi-peer-reviewed-article-AHMT

Open Access Full Text Article

ORIGINAL RESEARCH

Conceptualizing age-appropriate care for teenagers and young adults with cancer: a qualitative mixed-methods study

This article was published in the following Dove Press journal:
Adolescent Health, Medicine and Therapeutics

Sarah Lea[1]
Rachel M Taylor[1]
Ana Martins[1]
Lorna A Fern[1]
Jeremy S Whelan[1]
Faith Gibson[2,3]

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Video abstract

Point your SmartPhone at the code above. If you have a QR code reader the video abstract will appear. Or use: http://youtu.be/htkSsrB0D9

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Purpose: Teenage and young adult cancer care in England is centralized around 13 principal treatment centers, alongside linked "designated" hospitals, following recommendations that this population should have access to age-appropriate care. The term age-appropriate care has not yet been defined; it is however the explicit term used when communicating the nature of specialist care. The aim of this study was to develop an evidence-based, contextually relevant and operational model defining age-appropriate care for teenagers and young adults with cancer.
Materials and methods: A mixed-methods study was conducted comprising 1) semi-structured interview data from young people with cancer and health care professionals involved in their care; 2) an integrative literature review to identify the current understanding and use of the term age-appropriate care; 3) synthesis of both sets of data to form a conceptual model of age-appropriate care. A combination of qualitative content, thematic and framework analysis techniques was used to analyze and integrate data.
Results: Analysis and synthesis across data sources enabled identification of seven core components of age-appropriate care, which were presented as a conceptual model: best treatment; health care professional knowledge; communication, interactions and relationships; recognizing individuality; empowering young people; promoting normality; and the environment. Subthemes emerged which included healthcare professionals clinical and holistic expertise, and the environment comprising both physical and social elements.
Conclusion: The proposed model, necessarily constructed from multiple components, presents an evidence-based comprehensive structure for understanding the nature of age-appropriate care. It will be useful for clinicians, health service managers and researchers who are designing, implementing and evaluating interventions that might contribute to the provision of age-appropriate care. While the individual elements of age-appropriate care can exist independently or in part, age-appropriate care is optimal when all seven elements are present and could be applied to the care of young people with long-term conditions other than cancer.
Keywords: age-appropriate care, teenagers, adolescents, young adults, young people, cancer, health care delivery, BRIGHTLIGHT

Introduction

There is increasing recognition of the need for health care for young people to be different from that received by children and adults.[1] The term age-appropriate care is one term used to explain what these services should consist of. In England, teenage and young adult (TYA) cancer care is centralized around 13 Principal Treatment Centers, alongside linked "designated" hospitals. This service configuration was directed by the *Improving Outcomes Guidance* (IOG) for children and young people,

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Appendix 23: An excerpt of the script from 'There is a light: BRIGHTLIGHT' which is an interpretation of an aspect of the findings of this study.

CIARA ENTERS.

CIARA: First there's Diagnosis. Then there's After The Shock. Then there's Support. Support. I'm a young person. In a hospital. And I'm sick. (Cough). And I've been on the ward…

MILLICENT ENTERS

M: And we are your environment.

JOE ENTERS

M + J: We are your environments.

MILLICENT: Physical.

JOE: Social.

MILLICENT AND JOE START CIRCLING CIARA.

MILLICENT: Physical.

JOE: Social.

MILLICENT: Chill out room.

JOE: Pizza night.

MILLICENT: Videogames.

JOE: Alone time.

MILLICENT: Physical.

JOE: Social.

MILLICENT: Physical.

JOE: Social.

CIARA: Yeah OK we get it. I think we get it, don't we? The physical and social environments are as important to someone as being treated in hospital.

Appendix 24: My experience of starting a clinical academic career

Whole paper can be accessed here (open access):

https://journals.sagepub.com/doi/pdf/10.1177/1744987115580896

Perspectives: A newly-qualified nurse's experience of starting a clinical academic career

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The start of my journey

From the moment I began my undergraduate degree in Sports Therapy, I have had an intellectual curiosity and a keen interest in research. In the final months of my postgraduate nursing course I saw an opportunity for a funded PhD exploring the culture of teenage and young adult cancer care in England, as part of a larger National Institute for Health Research funded programme of research. This field of study was of great interest to me, as was the opportunity for personal and academic development and career progression. Discussing the opportunity with University tutors confirmed that this would be a smart career move, with the potential to open many doors. However, at the time I was on my final student nursing placement and eager to receive my Nursing and Midwifery Council (NMC) PIN and to progress clinically. I discussed these concerns with my two potential PhD supervisors, who fortunately are strong advocates of clinical academic careers in nursing. They were sensitive to this and, through academic contacts, facilitated the creation of a part-time clinical role within the teenage and young adult cancer field. In reality this means that my work comprises two distinct but complementary roles (see Box 1).

The 'ladder of professional development'

As a professional who is at a very early stage in both aspects of my career, the past 18 months have been the steepest learning curve I have ever faced. I have found that my clinical nursing practice has connected with the research skills that I am developing through my training as a PhD student. Prior to beginning my clinical academic career, I would never have understood how strong the connection between the two roles could be. I like to think of it as a 'professional development ladder.' I am climbing two ladders simultaneously, one clinical and one academic. The synergistic application of the skills and knowledge I have acquired on both ladders makes each step more manageable and thus the ladder becomes easier to climb (Figure 1).

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