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# EXPLORING CARE NAVIGATORS EXPERIENCE OF ROLE

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## Abstract

#### Background

The Care Act 2014 necessitated an integrated approach with planning of care across a person's whole care needs, not separate ones for health and social care as the Department of Health and Social Care (DHSC) perceive health and social care as one system. From September 2014 people with the most complex health and social care needs were placed on the Proactive Care Programme in order to receive personalised, joined up care and support. People on the programme have a personalised proactive care and support plan developed and supported by a care navigator who identifies available local services, signposts the individual to the services and supports access. The aim of the study was to explore how care navigators make sense of their experience of role and to examine the extent to which these experiences influence individual perceptions as the role was new to the health and social care workforce.

#### Method

This was achieved by exploring dominant discourse surrounding care navigators and reported experiences associated with care navigators to provide robust and credible empirical evidence of the key themes of care navigator role and identity. Through the use of interpretative phenomenological analysis to address the study aims and objectives, five interviews were conducted with five care navigators working across two sectors of an Inner London Borough.

#### Results

Three superordinate themes emerged from the interview transcripts, compassionate carer, holistic assessor and engagement enabler. These themes were interrelated

across all five participants' lifeworld experiences. Nine subordinate themes emerged from the superordinate themes. Person centred, active listener, and explorer emerging from compassionate carer, active observer, home visit, and prevention and isolation from holistic assessor, with direct to groups, attend groups and local community from engagement enabler.

# Conclusion

The study provides new empirical evidence regarding care navigator role and identity within the health and social care workforce. This unique identity is formed through the participants' lifeworld experience and was understood through interpretation of participants' interview transcripts. This provides care navigators with a defined role, distinct from others within the multidisciplinary health and social care workforce.

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#### **Chapter One: Introduction to the thesis**

#### 1. Introduction

The role of care navigator has been introduced to the health and social care system [figure 1] across a number settings in England to support service users and professionals in using the health and social care system for their best advantage. Care navigators work with individual service users to identify their personal health and social needs. This allows the care navigator to refer individuals to information about services available from National Health Service (NHS) and social care providers as well the wider care and support sector, including the third sector. Where appropriate, they navigate the individual through the process to access appropriate support services. Care navigators do not make clinical diagnoses, offer clinical advice or deliver clinical services (Health Education England 2016). Their goal is to ensure that service users get the right care at the right time in the right place with the right outcome for the individual (Health Education England 2016). Care navigators often utilise social prescribing to support service users in accessing a range of services. These services can include groups or social activities available in the local community with the aim of improving the individuals social and emotional wellbeing, this being beneficial to their overall physical and mental health (Health Education England 2016). Through social prescribing and navigation, care navigators can support service users and their significant others through complex health and social care systems (Health Education England 2016).



Figure 1: The health and social care system (Department of Health and Social Care 2020)

The opening chapter provides an overview of the contextual socio-political health and social care environment in England. This provides an understanding of the background to the introduction of the care navigator role at the time of undertaking the study. The chapter focuses on the business of health and social care policy that influences the lifeworld of care navigators. The chapter confers the motivation and purpose of the thesis by providing the aims and objectives for my original contribution to the developing care navigator knowledge base.

#### 1.1 Introduction of the care navigator role

Health and social care strategy and policy in England over the last decade has led to changes in how community and primary health and social care services are delivered and who provides them. This change came about with the introduction of The Care Act 2014 that necessitated an integrated approach with planning of care across a person's whole care needs, not separate ones for health and social care. The Act came into effect from April 2015 outlining the way in which local authorities should carry out needs assessments in order to determine who was eligible for support and how services users would be charged for both care in the community and residential care should the need arise. The King's Fund (2014) supported the idea that change was required to transform services for older people and that this would require a fundamental shift towards co-ordinated care supporting the full range of an individual's needs (rather than care based around the traditional medical model focused on single diseases). The Kings Fund (2014) stated that older people deserved care that truly prioritised prevention and supported them in maintaining independence. This would be achieved by the introduction of new models of integrated working across health and social care, ensuring that the right mix of services was available in the right place at the right time (King's Fund 2014).

The NHS England National Clinical Director for Dementia, Professor Alistair Burns (National Voices 2018) stated '*It's true to say that our health and social care system is difficult to navigate, even for clinicians at times. There is a growing consensus, across integrated care systems particularly, that this must change. Patients should* 

only need to tell their story once before they get the right care, at the right time, in the right place'.

Gail Scott-Spicer, Chief Executive Officer of the Carers Trust, said, "The stories that carers are telling us are shocking. Five different appointments in one week in different locations and stories of not being able to get to their appointments because of difficulties getting to the location due to lack of transport" "We've launched our Where's my care coordinator' campaign to appeal to health and social care professionals to make life easier for carers by working closer together to help them overcome some of the frustrations they face" "Many carers want a single point of contact or for someone to take responsibility for coordinating the care" (Carers Trust 2018). Care navigators can support individuals in navigating the health and social care system by acting as the single point of contact, helping people to get the right support at the right time to help manage a wide range of needs (Health Education England 2016). This includes support with long term conditions, help with finances and signposting service users to a range of public, private and third sector services. Care navigation is an emerging concept in England intertwined with that of care coordination. The introduction of the care navigator role represents the idea that simply having services and trained people in place are not enough to deliver health and social care. What really matters is how individuals, teams, services and systems work together in a 'joined up' way to support peoples independence (Health Education England 2016).

Our Healthier South East London (OHSEL) (NHS 2016) undertook a project to understand the various models of care co-ordination and navigation that were in existence in South East London. The project's overall aim was to address three problems identified in the local healthcare economy. The first problem identified was a health and wellbeing gap, with the project aiming to help people to lead healthier and longer lives. The second problem identified was a care and quality gap, with the aim to improve the accessibility and quality of care delivered in South East London. The third problem identified was a funding and efficiency gap, with the project aim of the local health economy being more efficient and making better use of money available for health and social care in the local economy. The project (NHS 2016) found a diverse number of roles and job titles for staff undertaking care coordinator/navigator duties that included care management, signposting, health advice and administrative management of care plans and coordination of multiple agencies for those with complex physical and mental health care needs. The diverse number of roles and job titles were not formally recognised in the health and social care professional workforce as the individuals undertaking the care navigator role did not require registration with a health or social care professional body to undertake care navigation duties.

The regulation of health and social care professionals is intended to limit the risk of harm occurring to the public when receiving treatment or care. However registration with a professional regulation body cannot fully eradicate the risk of harm. Therefore the main objective of a professional regulation body is to protect the public. This can be broken down into three broad goals, protecting the public, maintaining public confidence in the profession and/or declaring and upholding professional standards (Professional Standards Authority 2018). Despite the role not being formally recognised or registration with a professional body being a requirement to practice, empirical research (Macredie et al 2014) has shown the need for the care navigator

role is paramount in supporting service users and their significant others at a time when national and local health and social care policy endorses a shift toward preventative integrated care. Even with a growing number of reports providing evidence of the effectiveness of embedding prevention in older peoples' services, such as the introduction of the care navigator coordination model Allan and Glasby (2013) believe that the evidence base remains underdeveloped with ambiguity around which models (processes or structures) in reality demonstrate improved outcomes. However there is a promising body of evidence from health and social care services that the introduction of a care navigation model and care navigators has had a positive impact for service users and providers.

West Wakefield Health and Wellbeing [now Wakefield Clinical Commissioning Group] through work as a Prime Ministers' Challenge Fund (NHS England 2015) site and subsequently a Multi-specialty Community Provider (MCP) introduced care navigators into the workforce as part of an integrated care model approach to delivering health and social care services. The MCP combined the delivery of primary care and community-based health and care services alongside planning and budgets and budget responsibilities. The MCP incorporated a wide range of services and specialists. This included the provision of a number of services traditionally based in hospitals, such as outpatient clinics and care for frail older people services as well as associated diagnostics and day surgery. Mental health as well as physical health services with the potential for social care services were delivered together within the one health and social care provider (NHS England 2016). Twenty six General Practitioner (GP) practices across Wakefield currently provide a care navigation service, delivered by 260 trained Care Navigators. From April 2017 to March 2018, over 22,600 patients were supported by a care navigator ensuring GP appointments were available for patients who required GP intervention (Wakefield Clinical Commissioning Group 2019). The navigation service supported improved patient outcomes with 97% of patients surveyed stating they were happy to see the alternative healthcare professional they were signposted to by their care navigator (Wakefield Clinical Commissioning Group 2019). Wakefield Clinical Commissioning Group (Wakefield Clinical Commissioning Group 2019) define care navigation as; "A person-centred approach that uses signposting and information to help primary care patients and their carers move through the health and social care system, as smoothly as possible, to ensure that unmet needs are met". One Wakefield based General Practitioner practice trained up reception staff to signpost patients to appropriate services, speeding up their access to care and freeing up General Practitioner appointments. The practice was seeing an increasing number of patients with complex and long-term conditions that required them to receive input from a number of health and social care professionals. These patients relied on their GP as a first point of contact, however it was recognised that sometimes it would be more appropriate for them to access other services directly. The practice adopted the care navigation programme established by West Wakefield Health and Wellbeing. The programme provided training so frontline non-clinical practice staff could provide patients with information about local health and wellbeing services. When a patient calls or visits the practice the care navigator asks them why they need to see a GP. Without being intrusive or offering clinical advice, they discuss the patient's needs and, where appropriate, help them to access other services directly. Importantly, if the patient feels they still require a GP appointment they are supported to arrange one. From April to September 2017 care navigators at the practice dealt with 1,951

referrals which would have otherwise resulted in 1,951 General Practitioner (GP) appointments over the five-month period. One hundred percent of patients accepted navigations to sexual health clinics, the nurse practitioner, the stop-smoking service and the local social prescribing service (Harries 2017). Social prescribing provides a way of linking patients' in primary care and their carers with non-medical sources of support within the community. It is tailor-made for community and third sector sector led interventions and can result in better social and clinical outcomes for people with long-term conditions and their carers. It is viewed as a more cost-efficient and effective use of NHS and social care resources allowing for a wider, more diverse and responsive local provider base (Centre for Regional Economic and Social Research 2014).

The health and social care system in the Wirral has also seen the benefits of rolling out a care navigation service in the local area through their GP Federations. Primary Care Wirral (GP Federation) trained 156 general practice staff, receptionists and administrators across its practices to undertake care navigator duties alongside their usual role responsibilities (Murphy 2019). In collaboration with Healthwatch Wirral, Wirral member general practices received accredited, specialist targeted training in care navigation. The training enhanced participants' skills in directing patients to the most appropriate source of support at the point of contact. The introduction of care navigation into the primary care system in the Wirral has seen numerous benefits for patients, primary care healthcare professionals and providers utilising the care navigation programme. Using the care navigation programme ensures patients are directed to appropriate support when they first contact their GP practice. This allows for more patients to be seen by a GP and facilitates timely access to appointments. Those who would have previously been seen by a GP benefit from an improved and more efficient patient journey by being redirected to services that are more appropriate for their needs (Murphy 2019). Administrators and receptionists that have been trained as part of the care navigation training programme report that they have an increased sense of job satisfaction in being able to directly affect patient and carer care and support by utilising their additional skills (Murphy 2019). Dr Kieran Murphy, NHS England Medical Director (Cheshire and Merseyside) said "Across Cheshire and Merseyside we are working hard to make sure that when people need to see a GP, they have access to one quickly and in a way that suits them, be that in person or over the phone. We know that sometimes patients find navigating health services difficult and in some cases, another health or care professional might be better suited to look after them. Sometimes patients could be seen and treated quicker by a nurse, dentist or a pharmacist for example. That's where care navigation comes in. The primary goal of care navigation is to ensure that patients get the right care at the right time in the right place with the right treatment or advice" (NHS England 2019). From the examples given regarding the impact of the introduction of the care navigator role into local health and social care settings in England I believe we need to gain a better understanding of the role and the impact of care navigation to add to the development of the care navigation evidence base. To do this it is essential the lifeworld of the care navigator is observed to capture their experience of it. Lifeworld being a fundamental concept, is the world of lived experience inhabited by conscious beings incorporating the way in which phenomena (events, objects, emotions) appear to the conscious experience or everyday life (Brooks 2015). To enable this I undertook an Interpretative phenomenological analysis study with the aim to provide an in-depth and nuanced

analysis (Brooks 2015) of the participant care navigator's lifeworld experience when working in the third sector in two sectors of an inner London borough.

#### 1.2 Study setting: health and social care in London

It is frequently stated that London has unique health and social care service delivery issues that are attributed to the growing, transient, and diverse population it serves (NHS England 2013). The London Health Commission (2014) created a high-level delivery plan for health and social care built upon the foundations of NHS England's Five Year Forward View, in order to improve health and social care service delivery in London. This led to 32 Clinical Commissioning Groups (CCGs), 33 Local Authorities, the Greater London Authority, NHS England London Region and Public Health England London Region, coming together under the collective name of The London Partners. The collective agreed to shared and individual actions to help London become the healthiest major global city. This prodigious partnership had the shared vision to see the widest and fastest improvement in the health and well-being of 8.6 million Londoners through a transformation in the way that health and care services were delivered, how they were used and how service user need for them could be prevented (London Health and Care Collaboration Agreement 2015).

Evidence from navigation models across England such as the Blackburn with Darwen Clinical Commissioning Group (2019) model demonstrates that care navigators are well placed to support transformation in service delivery by navigating service users through the health and social care system, promoting prevention to maintain an individual's independence. Blackburn with Darwen Clinical Commissioning Group (2019) view care navigation as a tried and tested model of care that improves access to primary care services for patients and reduces pressure on primary care delivered General Practitioner services. The use of care navigation allows front line staff to provide patients with information about local health and wellbeing services, available within and outside of primary care, in a safe, effective way.

The co-commissioning of health and wellbeing services including care navigation services by the London Clinical Commissioning Groups (CCGs) together with local authority health and wellbeing boards, bring together the NHS, public health, adult social care and children's services, including elected representatives and the Local Healthwatch. This collective holds the responsibility to tackle local inequalities in health in individual London Boroughs (London Health and Care Collaboration Agreement 2015).

Healthwatch County Durham (2018) produced a report for the County Clinical Commissioning Groups evaluating the Care Navigation system. Service users and staff reported care Navigation as being a positive development. Healthwatch Central West London (2018) held a series of public meetings to ask local people about their experiences of their local health and care services. The meetings found people felt there was little support to help them stay well and manage their long-term health conditions. The meetings also reported that they were unsure of how to access additional support when living with or caring for someone with long-term health conditions. Concerns were raised that friends and neighbours were slipping through the net and not getting the support they needed. At the time of the meetings taking place, care coordination services attached to General Practitioner (GP) practices across Westminster were changing. A new Care Coordination Service was launched with a social prescription element being piloted in selected GP practices. This service was subsequently rolled out across a number of GP practices based in the Central London CCG. In the new service care navigators contacted service users by telephone after receiving a request from a GP who maintained responsibility for the service users' care. The care navigators would link service users into local community and voluntary organisations to help them manage their long-term health condition. In doing this the care navigators would contribute to preparing an individualised care plan for the service user. The care navigator would not become the named person responsible for the service user but they would coordinate services if required. The introduction of the care navigator role was part of Westminster City Council and Central London CCGs joint plan for creating an integrated care system that brought together local health, social care and third sector partners to support the local populations health and wellbeing (Healthwatch Central West London 2018).

## 1.3 London demographics

London's diverse population has an extensive increasing range of health and social care needs with a long history of failure in attempting to close the inequalities gap (NHS England 2013). The majority of health and social care provision for the 8.2 million and growing population continues to be provided in acute hospitals that will not be able to meet the growing health and social care needs of Londoners in the future. The average life expectancy of Londoners has risen by 5.2 years since 1990 with the average age of a Londoner being 37 (NHS England 2013). However, there is a variation between and within London Boroughs of the health and wellbeing of the

local population (Greater London Authority 2009). The average life expectancy for a man living in London is 79.3 years and women 83.6 years this is higher than the national average [figure 2] (Greater London Authority 2009). There is however, a significant variation in life expectancy and the length of time people can expect to live healthy lives, without developing a physical or mental illness across Greater London (Greater London Authority 2009). Women in Richmond-upon-Thames have a life expectancy of 72.1 years compared to women in Tower Hamlets who have a life expectancy of 54.1 years (Greater London Authority 2009). By 2020 it is expected the 65 and over age group will see an increase by at least 19%, having an impact on health and social care provision across Greater London as this age group are the most substantial consumers of health and social care services (Office for National Statistics 2012) and therefore potential users of care navigator services.



Figure 2: Life expectancy (LE) at birth by London borough 2009–2011 ranked by quintiles (Crown 2013)

Greater London has the uppermost average income in the United Kingdom but is also the most differentiated with people in the top 10% of households earning around five and a half times more than those in the bottom 10% (Indices of Deprivation, 2010). As would be anticipated people who live in the deprived Greater London boroughs, have poorer health (Greater London Authority 2009). Patient turnover for general practice can be as high as 30% in some Greater London boroughs, as London accounts for 37% of the nation's short-term residents (Office for National Statistics 2011). This adds to the difficulty of supporting people in managing their own health and wellbeing while maintaining continuity in health and social care provision across Greater London's complex NHS services *[figure 3]*.

There are diverse health and social issues across inner and outer London. Inner London has high levels of adults who smoke and binge drink, leading to heart disease and cancer, however its population also leads a vigorous lifestyle, by being physically active and eating sensibly, conversely outer London has raising problems with obesity (Greater London Authority 2009).

An estimated 1.5 million Londoners live with a long-term condition (NHS England 2013). The number of people living with dementia in London rose from 65,000 to nearly 80,000 between 2007 and 2011 with less than half having a definite diagnosis meaning they did not receive the correct care and treatment, this number is expected to increase by 16% over the next 10 years (Alzheimer's Society 2012).

To combat this in the Inner London Borough of Islington the Camden and Islington NHS Foundation Trust (2019) offer a Dementia Navigator one-off contact to all people who have a new diagnosis of dementia. Long-term support is also available to anyone with dementia who lives in Islington, is registered with an Islington GP, and has been diagnosed with dementia by the Dementia Navigators. The Dementia Navigator visits the service user at home to talk about what help or support is needed and agrees a plan with the service user to work on these areas. This may include accessing day centres, arranging help from social services support, support with housing issues, benefits information and signpost to appropriate services. The Dementia Navigator provides information that is relevant to the service user and their condition. If the service user does not have a named worker in the Memory Service or Community Mental Health Team, the Dementia Navigator will provide on-going contact to address any service user concerns or additional needs which may arise (Camden and Islington NHS Foundation Trust 2019).

Mental ill-health costs London an estimated £5.5 billion a year in loss of working days, and £2.5 billion a year in health and social care costs (Independent Commission on Mental Health and Policing 2013). Naylor et al (2012) emphasised that when compared with the rest of the population, people with a physical health condition are two to three times more probable to have a mental illness. This with a number of social elements that are particularly pertinent to London, including deprivation and homelessness leads to a predicted 1.5 million Londoners living with a mental health problem (Independent Commission on Mental Health and Policing 2013).



Figure 3: Complex NHS services in London (NHS England 2013)

Adults with mental health and wellbeing needs registered with a GP in the Royal Borough of Kensington and Chelsea, or the Queen's Park and Paddington areas of Westminster can access Community Living Well Navigators based in primary care (Community Living Well 2019). The NHS service offers practical support with a range of issues. The Living Well Navigators support service users to access specialist advice, information and community based services (Community Living Well 2019).

An estimated 90% of all health and social contacts in Greater London occur within primary and community care (Greater London Authority 2009). This care and support is delivered by general practitioners (GP), pharmacists, dentists, nurses, social workers and other health and social care professionals (Greater London Authority 2009). The care and treatment delivered is frequently uncoordinated and not individualised to the service user (Greater London Authority 2009). Almost 16% of London's GP workforce is closer to retirement age compared with 10% nationally (Royal College of General Practitioners 2013). Eighty-two percent of Londoners rate their GP practice as being very good or good, there is however substantial variation in quality with a number of boroughs having a greater percentage of practices with poor quality indicators when compared with the rest of England (NHS England 2013). Londoners believe that it is more difficult to see a GP of choice than anywhere else in England (NHS England 2013). Twenty-two of the 30 worst rated boroughs in England for the ability of patients to see a GP of their choice are in London (National GP Patient Survey 2012). This is unacceptable when GP practices are fundamental in providing care to individuals with long-term conditions and supporting people to remain independent and healthy in their local communities (NHS England 2013). London has the largest number of single-handed general practitioner practices in the country with this varying from 5% to 40% across London's Clinical Commissioning Groups (NHS England 2013). Improving access and services to meet public expectations is becoming increasingly difficult so the model of delivery needs to be changed (NHS England 2013). General practitioners are unable to manage patients with long-term conditions without the support of the wider multidisciplinary team (NHS England 2013). Health and social care needs to be coordinated between GPs, hospitals, community and social care services to support patients in managing their own conditions by providing seamless individual centred care (NHS England 2013). Demand on hospitals across England has increased intensely in the past 10 years; with a 35% increase in emergency admissions and a 65% increase in hospital episodes for those over 75 years of age (Royal College of Physicians 2012). The lack of routine services at weekends in hospital and community settings has had an impact on this growing demand (Royal

College of Physicians 2012). A number of specialised services providing consultantdelivered care seven days a week have evident benefits to patient outcomes and service efficiency (Royal College of Physicians 2012). Despite the need for this model of care the health and social care system continues to practice a five day working week (NHS England 2013). Generally in the United Kingdom patient experience rates highly when compared to other countries, however studies untaken in Greater London show individuals to be less satisfied with NHS services with patient satisfaction within primary care being 7% lower in Greater London than nationally (NHS England 2013).

London's health and social care commissioners and providers are working to move away from the historical hospital-centred delivery of services to deliver more coordinated care for the local community (NHS England 2013). Evidence confirms that up to 25% of urgent patient admissions could be circumvented with supported management of their condition in their own home or within a community facility (Kings Fund 2012).

Age UK Camden (2019) provide Care Navigators who support service users to remain in their own home by delivering up to 6 weeks of personalised case management. This support is available and accessible for Camden residents who are aged 18 upwards, are registered with a Camden GP, and living with one or more long-term health conditions. Service users receive assessment and personalised support from a named care navigator identifying their individual needs and providing navigation through the local care systems. The Care Navigators also provide dedicated support for multi-disciplinary teams (practice, neighbourhood, frailty and high intensity users (HIU)), providing advice, information, and co-ordination across clinicians based in the third sector and community services. This service supports older people to remain independent in their own home. It reduces the need for a hospital admission (Age UK Camden 2019).

Over two-thirds of all emergency bed days in London hospitals are attributable to older people (Kings Fund 2012). A hospital admission can be a bewildering environment for an older person that carries the risk of infection, loss of mobility and other day-to-day activities of daily living (Kings Fund 2012). This can often stop the older person from returning home after a protracted hospital stay (Kings Fund 2012).

In East London Care Navigators working for the East London NHS Foundation Trust [ELFT] (2019) facilitate integrated working across the Extended Primary Care Teams, GP's and other stakeholders to ensure care delivery is of a high quality for the local population. The Care Navigators have been commissioned to work with people who are at high risk of admission to hospital and are on an integrated care pathway. By working collaboratively with colleagues in primary care the Care Navigators actively seek out patients who will benefit from care navigation and coordination. The service enables individuals to avoid unplanned hospital admissions, reduce the length of a hospital stay and support and promote independence at home (ELFT 2019). The Care Navigators are the central point of contact for individuals who fall into this category. They provide the interface between primary and secondary care providers as well as social care and third sector organisations. The Care Navigators Identify and report any new problems, changes or concerns in individuals or carer's circumstances to the GP, Operational Manager and Clinical Leads. Care Navigators provide sign posting and link patients and their carer's to other services that would benefit the individuals quality of life, this includes promoting service users rights and recognising and respecting their contributions to care planning and delivery. The assessment outcomes are discussed with the individual, carer's and other involved health and social care professionals and third sector services to agree care plans (ELFT 2019). This model of care navigation reflects the need for individuals to receive support from health and social care planning and social care professionals working together to develop and deliver effective care planning and lifestyle.

There is some evidence however that this model of promoting self-care and selfmanagement through the development of a personalised care plan is not being endorsed by all health and social care professionals where it would be appropriate and beneficial to the individual (Kennedy et al 2012). Nationally 12% of individuals with long-term conditions are aware they have a care plan this percentage is considerably lower in Greater London than elsewhere in England (Department of Health 2012). Evidence shows that there is a major opportunity to reduce an individual's dependency on formal health and social care services by increasing the use of care plans and improving the way they are co-ordinated and implemented (NHS England 2013).

Ealing Clinical Commissioning Group (2019) promotes that effective care navigation ensures individuals and family needs and preferences for care are understood. The provision of care navigation services ensures accountable structures and processes are in place for communication that integrates a comprehensive plan of care across providers and settings. Well coordinated care when delivered by different providers avoids duplication, waste, and conflicting plans of care. The ability to access care navigation services is particularly important for those with long-term conditions and older people as it is this group that often attempts to navigate complex health and social care systems. Individuals often transition from one care setting to another where they are often unprepared or unable to manage their care (Ealing Clinical Commissioning Group 2019). Incomplete or inaccurate transfer of information, poor communication and a lack of appropriate follow-up care, can lead to confusion and poor outcomes, including medication errors and preventable Accident and Emergency visits and hospital admissions (Ealing Clinical Commissioning Group 2019).

The introduction of the care navigator role to a health and social care system can support service users to take an active role in their own care and assist in maintaining their independence. Health and social care in England has a long history of introducing innovative roles into the workforce to meet perceived and actual long and short-term workforce and service delivery pressures, often without sufficient planning.

#### 1.4 Health and social care workforce planning

In 2017 the health service in England for the first time in almost a quarter of a century, set about producing a workforce strategy (Health Education England 2017). The document produced was not a decisive strategy but a draft produced to present facts and stimulate debate (Health Education England 2017).

The workforce strategy built upon concepts found in Health Education England's (HEE) Framework 15, published in 2014. The strategy pronounced the current state of the National Health Service (NHS) including the health and care workforce and highlighted strategic workforce interventions and decisions that would affect the future workforce through to 2027 (Health Education England 2017). Health Education England co-ordinated the production of the strategy providing a whole national system viewpoint with content from NHS England, NHS Improvement, Public Health England, the Care Quality Commission, National Institute for Health and Care Excellence and the Department of Health (Health Education England 2017).

#### 1.5 Current workforce

The NHS spent almost 65% of its operational budget on its workforce in 2017 with over 40,000 more clinicians substantively employed than in 2012, a 7.3% increase (Health Education England 2017). There were 14,306 more adult general nurses (8.6%); 445 more emergency medicine consultants (37.5%); 2,130 more mental health therapists (83.7%); 2,248 more health visitors (27.4%); 1,146 more community mental health nurses (7.2%), and 1,692 more physiotherapists (9.1%) (Health Education England 2017). The ratio of qualified nurses to occupied NHS beds has also increased from 1.86 to 2.02 (Health Education England 2017). Not all professions saw an increase in numbers at a time when national health and social care strategy and policy promoted care and treatment in the community there were 1,674 fewer district nurses (26.1%), 842 fewer learning disability nurses (36.5%) and a 1% reduction in General Practitioner numbers (Health Education England 2017). It is difficult to estimate the size of the care navigator workforce in England for a

number of reasons. Those undertaking care navigation are given a number of titles, care navigators work for a number of statutory and third sector organisations, and the duties and responsibilities of a care navigator are often undertaken alongside a main role such as GP practice receptionist or administrator (Health Education England 2016).

General Practitioner Practices in Bromley South East London introduced 'care navigator' roles to re-direct unnecessary face-to-face consultations by signposting individuals to more appropriate services both inside and outside the practice in the local community (Bromley Clinical Commissioning Group 2018). For the production of the Bromley GP Practice Workforce Analysis 2017-18 report Bromley Clinical Commissioning Group (2018) asked Bromley GP practices if they had a care navigator, and if they did, were these existing staff up-skilled or recruited for this specific role [figure 4]. Seventeen out of forty-five practices had introduced care navigator posts, and of these fifteen practices trained the staff up from existing roles.



Do you have care navigators working in your practice?

Figure 4: Do you have care navigators working in your practice? (Bromley Clinical Commissioning Group 2018)

Bromley Clinical Commissioning Group (2018) state that 'as primary care looks to manage capacity in the most efficient way possible, care navigator roles may become increasingly popular. It is worth noting that other providers have similar roles or similar organisational functions and so these roles will need to be systematically integrated to ensure patients are seen in the appropriate place dependent on their care needs'.

To manage the demands on the health and Social System in England the NHS requires further staff (Health Education England 2017). These staff are required to meet the expanding and changing needs of the population's health (Health Education England 2017). Since 2012 England's population has grown by 2.1 million (around 4%), and continued to see an increase in longevity (Health Education England 2017). The number of people with long-term conditions has grown sharply due to advances in medical care and treatment keeping more people alive for longer. Following the Mid-Staffordshire Trust Inquiry the related drive for safer staffing saw over 40,000 additional posts for registered nurses created in the whole of the NHS (Health Education England 2017). The Inquiry, governed by the Inquiries Act 2005, examined the commissioning, supervisory and regulatory organisations in relation to their monitoring role at Mid Staffordshire NHS Foundation Trust between January 2005 and March 2009. It considered why serious problems at the Trust were not identified and acted on sooner, and identified important lessons to be learnt for future patient care. As the inquiry and subsequent report prompted a demand for more nurses at a time when the output from nurse training was low as student nurse training commissions had been reduced between 2009 and 2012. Action was taken

to correct supply shortfalls with student nurse training commissions raising by over 15% within a 3-year timeframe (Health Education England 2017).

## 1.6 Key workforce drivers

The National Health Service has regularly reported recruitment gaps in its professionally registered clinical workforce. This gap between workforce demand and supply is to some extent due to a disconnect between service planning, financial planning and workforce planning (Health Education England 2917). Between 2012 and 2017 the total number of staff in primary care in the United Kingdom was estimated to grow by more than 6,000, with clinicians and other clinical support staff responsible for about 3,500 of the growth and receptionists and other staff, such as care navigators, making up the other 2,500 (Health Education England 2017). However in September 2017 NHS Digital indicated that the number of General Practitioners working in general practice had fallen to below 2012 levels (Health Education England 2017).

Care navigators are not currently required to register with a professional regulation body in England and is there is no formal set of standards of competence and conduct which must be met in order to practise. There is no regulation body checking the quality of education and training courses to make sure they give care navigator students the skills and knowledge to practise safely and competently (Health Education England 2016). Health Education England (2016) found care navigators had a high variability in training time, content and methods. Health Education England (2016) reported care navigators described various methods of training undertaken to perform the role, such as local induction, informal mentorship and 'inhouse' 'on the job' training by the employing organisation. One community based care navigation team invited a hospital based palliative care team to the practice, to deliver some teaching sessions about the end of life issues. A number of care navigators had attended locally provided courses to develop communication skills, including motivational interviewing and goal setting skills (Health Education England 2016). Many individuals reported taking their own initiative and responsibility to attend local or online courses, especially to fill common 'knowledge gaps' such as issues around mental health or dementia training (Health Education England 2016). Primary care dementia navigators undertook a blended approach to learning including e-learning, day workshop attendance and some follow up mentor support (Health Education England 2016).

To support care navigators in practice Health Education England (2016) produced the Care Navigation Competency Framework. The purpose of the framework was to provide a core, common set of competencies for care navigation. The core competencies are offered in a tiered competency framework, recognising three successive levels; essential, enhanced and expert. The set of standards were produced to ensure relevant staff receive the necessary education, training and support to work effectively. This framework is intended for use by employers, education providers and individuals. It also lays the foundations for a career pathway framework for non-clinical staff, within primary and secondary care sectors. This assists with a sustainable current and future workforce (Health Education England 2016). The competencies are not considered all encompassing and comprehensive; as depending on the local population care navigation needs there may be need for additional training such as working with condition-specific individuals. The Framework was developed as a guide and it is envisaged it will continue to evolve over time (Health Education England 2016).

Croydon CEPN (Croydon GP Collaborative NHS Trust 2018) received funding from Health Education England, South London to run a one-year pilot care navigator programme, to test a new career pathway for non-clinically trained staff working in health, social and voluntary care sectors. The Care Navigators work in a variety of settings to improve patient and public experience of health and social care. The actual role of the Care Navigator is determined by the organisation that employs them. The overall purpose of the role is to work in collaboration with service users to determine their needs and how best they can be supported. Training for the role took place for a whole day each week over the course of a year. The sessions addressed the skills required by a Care Navigator and introduced the Care Navigators to a wide range of local services. Participants were allocated to an external mentor to support them as they developed into their role. It was expected that the employing organisations would create opportunities for the Care Navigators to share their knowledge and use their new skills back in the workplace. Participants in the pilot came from a number of different backgrounds; Nine from Croydon GP Practices, 2 from Croydon Care Homes and 4 from Croydon Community Support Services. Croydon GP Collaborative NHS Trust (2018) found that to enable Care Navigators to perform their role to full potential access to community health and social care services such as community nursing, therapy and care services is vital. However, nationally, capacity in community health is challenged with shortages in the health and social care workforce (Health Education England 2017). This obviously negatively affects service user's outcomes, often leaving them with unmet needs affecting their experience and the quality of care received (Health Education
England 2017). While oversupply in some areas of the workforce has led to unemployment and wasted resources (Health Education England 2017).

#### 1.7 Vacancies

In March 2018 there were 28,998 advertised National Health Service vacancy fulltime equivalents across all service roles in England published, this compares to 30,613 in 2017, 26,424 in 2016 and 26,406 in 2015 (Health and Social Care Information Centre 2018). The number of advertised vacancy full time equivalents varied between the National Workforce Data Set (NWD) Staff Groups. In March 2018 the highest percentage was seen in the 'Nursing and Midwifery Registered' Staff Group which accounted for 40 per cent (11,483 out of 28,998) of vacancy full-time equivalents followed by 21 per cent (6,092 out of 28,998) in the 'Administrative and Clerical' Staff Group in which care navigator data will feature (Health and Social Care Information Centre 2018). A large number of clinical post vacancies are covered by the use of in house bank or expensive external agency staff often adding to a lack of continuity and therefore quality of care. Vacancy shifts not covered lead to increasing pressure on existing staff covering their own workload and that of others. Vacancies typically vary by region. For example, nurse vacancy rates are 8% in North East England but a persistently growing 15% in London. Currently the West Midland Ambulance Service has no paramedic vacancies, whilst in the rest of England almost one third of paramedic posts are vacant. Adding to this a growing number of clinicians are choosing to leave substantive NHS roles, often returning to the same post as locums, driving up both vacancies and costs (Health Education England 2017). The reasons behind this needs to be explored as it adds to the

mounting concerns surrounding workforce supply and the ability to deliver new models of care.

#### 1.8 Delivering new models of care

The Five Year Forward View (NHS England 2014) outlined new models of care by highlighting integrated out of hospital care based on general practice aligning with hospital services (primary and acute care systems) and social and mental health services working together across community and acute mental health care hospitals. This focus on integrated out of hospital care requires a workforce that meets the needs of service users in primary and community care. This includes the ability to deliver care across traditional organisational boundaries and address inequalities in service user outcomes across physical and mental health services (NHS England 2014). The care navigator role is focused on working across health and social care and statutory and third sector boundaries to improve service user outcomes (Health Education England 2016). Constantly shifting strategy and policy ambitions to fundamentally transform the organisation and delivery of care requires an adaptable workforce. A flexible workforce needs to be capable of a greater breadth of responsibilities to meet service user needs while working in teams across multidisciplinary health and social care providers (NHS England 2014). This highlights the challenge for health and social service providers to ensure there is adequate staff for current models of care while looking to the future. The Care Quality Commission found (2018) found employees working within an area were not always knowledgeable about the services available to make referrals to the right service, in a timely way. The commission believe the role of primary health care teams in providing signposting and information is critical. When observing practice

the commission saw successful systems embedding signposting within practices. This was due to the introduction of specialist coordinator care navigator roles to help people access support and services in the community (Care Quality Commission 2018). The care navigator role fits well into the future workforce model by being adaptable to service user needs taking on responsibilities across health and social care providers (Health Education England 2016).

#### 1.9 Workforce of the future

Health Education England (2017) acknowledges the gap between workforce demand and supply occurs because of an ongoing disconnect between service planning, financial planning and workforce planning. It acknowledges that to be able to plan a workforce suitable for future needs requires sufficient knowledge of service delivery models and commissioning intentions. As The Five Year Forward View described service transformation plans Health Education England was able to produce supporting workforce plans. Health Education England (2017) recognised this as the first time a strategic workforce plan had been developed to define future service delivery models. The plan considered the likely demand for NHS staff using growth projections for the economy rather than the usual aggregation of employer demand as this method had always under-estimated future workforce demand Health Education England (2017). To demonstrate the NHS Constitution's values and behaviours Health Education England wanted to offer 'careers not jobs' to ensure a future workforce representative of the population for all clinical and non-clinical staff.

#### 1.10 Non-clinical staff

Health Education England (2017) believe the wider non-clinical workforce are critical to the running of the NHS. The health service has over 350 different roles including secretaries, porters, receptionists, managers, catering, estates staff and care navigators. The National Health Service provides the most diverse range of roles of any employer in the world. Buchan et al (2017) support Health Education Englands (2017) belief that the most important asset to health and social care in the United Kingdom is its workforce, asserting that the 2.5 million people working across England are highly varied and vital. They state that health and social care are major contributors to the wider economy accounting for about one in 10 jobs. This varies across the country, from 6% in London to over 12% in the North East.

Practice nurses working in Gateshead North East of England played a fundamental part in setting up a pioneering Primary Care navigator role to help support the needs of service users and carers living with dementia (NHS England 2018). Healthcare assistants (HCAs) led changes in practice to deliver a range of positive outcomes for both service users and carers, including increased access to health and social care services, improved dementia screening, individualised care plans and social prescribing (NHS England 2018). The Gateshead based practice serves about 15,000 patients in a largely deprived urban area. Nurses and General Practitioners (GPs) realised they required an original approach to deal with the pressures they were facing, principally for the increasing numbers of patients with dementia. Nationally there is unwarranted variation in the services and outcomes for people with dementia (NHS England 2018). The practice was experiencing a higher than average level of unplanned hospital admissions, associated with the complexity of

service user conditions in the local area (NHS England 2018). Senior nurses and GPs began to look for an alternate approach to the conventional ten-minute appointment as the level of diagnoses of dementia increased. Most service users' needs related to social care and wellbeing rather than acute clinical issues. Senior nurses and GPs generally undertook case finding with carers not being identified and the correct support not being received (NHS England 2018). This led to a number of service users and carers becoming frustrated, and the quality of care was at risk of being compromised (NHS England 2018). The practice manager and her team working with the National Association of Primary Care developed the Primary Care navigator role. The role was predominantly developed to support dementia sufferers, their families and carers to improve their access to the health and social care system. The navigator role signposted service users to wellbeing services through social rather than clinical prescribing (NHS England 2018). This Primary Care navigator role was introduced into practice without additional funding (NHS England 2018). Current health care assistant and receptionist roles were redesigned to include navigation. Staff were trained to communicate with service users and carers, including how to ask relevant questions and to actively listen. Staff were also taught how to guide people to sources of help and support provided by local and national organisations and support case finding through clinical referrals and opportunistic screening. The navigators also develop and maintain a directory of third sector and other community services available (NHS England 2018). The Navigators provide additional service user support including fortnightly calls or visits, invitations to "catch up" events, contacting support organisations for those who are unable to do so themselves, and making contact within three days of discharge from hospital (NHS England 2018). Due to its success, the practice extended the navigator role to

support all service users with multifaceted needs requiring social prescribing. This has set the foundation for implementing a 'House of Care' approach to long-term conditions supporting self-care and self-management. Gateshead Clinical Commissioning Group has included the introduction of the Primary Care navigator role into its primary care strategy (NHS England 2018). The introduction of the navigator role into the practice has prompted better communication within the practice, created a single point of contact for care homes, reduced issues with prescription, and allowed for longer consultations for vulnerable service users, and provision of co-ordinated care planning (NHS England 2018). Within three months of the introduction of the navigator role dementia screening increased by 117 patients, assessments for dementia by 38, registered carers by 43 and the veterans' register by 20 with 396 care plans and 95 NHS Health Checks completed. Within sixth months there were fewer hospital discharge letters which indicated a reduction in admissions from 7-8 a day to 2-3 a day (NHS England 2018). Primary Care navigator intervention ensures service users now receive better-coordinated and personalised care. The Primary Care navigator now handles post hospital discharge calls that previously would have gone to the on-call General Practitioner. This has improved staff motivation and morale increasing productivity (NHS England 2018). When commencing their additional responsibilities care assistants and receptionists were worried about their lack of experience when taking on the navigator role. After just three months, care assistants and receptionists reported being confident, valued and positive about their job (NHS England 2018). Due to its achievements at the Gateshead Practice a navigator service has been introduced to three other practices in the area (NHS England 2018).

#### 1.11 Definitions

Despite the introduction of care navigation across England, there is no countrywide accepted description or definition of 'care navigation' or that of the role of 'care navigator' (Health Education England 2016). This is despite the basic concept and associated roles being in existence for a rising number of years within England's public and third sector health and social care system (Health Education England). The navigator role has no single nationwide recognised job title, with numerous titles found across statutory and third sector health and social care services (Health Education England 2016). The aim of undertaking the study in partnership with the participants' is to provide an interpretation of the lifeworld experience of a group of care navigators employed in the third sector working across statutory and nonstatutory service boundaries to meet service user individual needs. Thus consequently serving to pronounce the role within health and social care practice. For the benefit of the reader and ease of understanding, I will use the title care navigator throughout the thesis as the participants' in the study are called care navigator in practice. The word 'navigator' derives from Latin navis 'ship' and agere 'drive' meaning 'a person who steers a ship' (Health Education England 2016). The care navigator can be respected as having a role in driving and directing health and social care coordination for service users (Health Education England 2016). Health Education England (2016) describes a key component of the care navigator role as bridging the void between health and social care steering integrated care provision to improve an individual's health and well-being. The role of a care navigator will frequently be based in a multidisciplinary team, helping to identify and signpost service users to local accessible health and social care services,

subsequently acting as a link worker between the service user and the service provider (Health Education England 2016).

As the examples presented from local health and social care systems demonstrate, care navigators perform a crucial role in transforming service user health and social care system experience. However given their positive impact in practice very little was known about the care navigator lifeworld experience, when I commenced this study. To address this my aims and objectives for the thesis are to gain an understanding of care navigators' lifeworld, as they understand it by interpreting their experience (Smith 2015). The fundamental concept of lifeworld is the world of lived experience inhabited by us as conscious beings, and incorporating the way in which phenomena (events, objects, emotions) appear to us in our conscious experience or everyday life (Brooks 2015).

## 1.12 Aims and objectives of the thesis

### Aims

In order to explicate an understanding of care navigators I aim to explore by the use of interpretation their lifeworld experience. To do this I use interpretive phenomenological analysis as a methodology to find out (Smith 2015):

- The way in which care navigators make sense of their experience of their role
- The extent to which these experiences impact on individual perceptions

## **Objectives**

The study is guided by the subjectivist ontological paradigms intrinsic to interpretative phenomenological analysis (Smith et al 2009). Interpretive phenomenological analysis adopts an interpretive ontological approach, not viewing reality as objective nor as a methodological approach at the positivist end of the ontological continuum (Vicary 2017). The epistemological stance rests on the person's subjective account of experience (Vicary 2017). The study strongly draws upon the philosophical assumptions of interpretative phenomenological analysis (IPA) by the systematic exploration of personal experience (Tomkins, 2017 pp.86-100). Through the two complimentary commitments of IPA 'giving voice' and 'making sense', my overall objective was to give an 'insider perspective' of the participants lived experiences (Noon, 2018) by:

- Exploring dominant discourse surrounding care navigators;
- Exploring the reported experiences associated with care navigators within the literature;
- Providing robust and credible evidence of the key features of care navigation as understood by care navigators working within two localities within a London Borough in the United Kingdom.

To explore what was already known about care navigators I undertook a scoping review of literature. Scoping reviews describe existing literature and other sources of information and commonly include findings from a range of different study designs and methods (Sucharew and Macaluso 2019). The results of the scoping review focus on the range of content identified with the quantitative assessment limited to a tally of the number of sources reporting on care navigators (Sucharew and Macaluso 2019).

In contrast if I have undertaken a systematic review I would have selected the information sources by specific study types, such as randomized controlled trials, that require quality standards, such as allocation concealment, placing emphasis on synthesizing data to address my research question (Sucharew and Macaluso 2019). The scoping review put my study into perspective; I was undertaking something entirely new, by looking at the lived lifeworld experience of the care navigator generating new evidence of this subject, the care navigators view of their world. Literature found during the scoping review mainly focused on the outcomes and impact of the care navigator role for service users, carers, health and social professionals and service delivery.

Undertaking the literature review demonstrated my research abilities, as not only did I find out about the care navigator role from the available evidence, I also developed my skills in finding and accessing evidence as the scoping review identified information and ideas relevant to my chosen subject area.

This opening chapter provided an overview of the socio-political health and social care environment in England that serves as a contextual background to the introduction to the care navigator role. The chapter focused on business delivery and policies of health and social care that influence the life world of care navigators. The chapter also conferred the motivation and purpose of the thesis. It provided the aims and objectives for my original contribution to care navigator knowledge placed in the context of relevant contemporary health and social care policy. The chapter introduced the prerequisite of undertaking the literature review to support the study.

In Chapter 2, I will explore existing literature to find out what is identified about the lifeworld of the care navigator to contextualise my study findings and consolidate what is already known.

### **Chapter Two: Literature Review**

### 2. Introduction

Chapter one provided the contextual background of the thesis giving an overview of the socio-political health and social care environment in England into which the care navigator role was introduced. The chapter introduced the overall aims and objectives of my original contribution to care navigator knowledge.

In this chapter, I scope existing literature to identify gaps in current knowledge about the lifeworld (Brooks 2015) of the care navigator allowing my study to build upon existing knowledge and ideas to contextualise the study findings and consolidate what is already known. For the purpose of the scoping review lifeworld refers to the fundamental concept that lifeworld is the world of lived experience inhabited by us as conscious beings, and incorporating the way in which phenomena (events, objects, emotions) appear to us in our conscious experience or everyday life (Brooks 2015). The scoping review provided literature that put my own work into perspective. By undertaking the study, I am providing new knowledge about the lifeworld experiences of care navigators. Performing the scoping review allowed me to demonstrate research abilities by presenting my knowledge of care navigator literature and how to access it. Undertaking the literature review allowed me to frame my study question, review my findings relevance and usability and confirmed my preconceived opinion that there was at the time of the study commencing a limited amount of published literature available exploring the lifeworld experience of care navigators working in the United Kingdom. This lack of available literature made the process of reading peer-reviewed published original research undertaken in the

United Kingdom challenging. Therefore I chose to undertake a scoping review of available literature. Scoping reviews describe existing literature and other sources of information and commonly include findings from a range of different study designs and methods (Sucharew and Macaluso 2019). The scoping review results, presented in chronological order, *[table3]* focus on the range of content identified with the quantitative assessment limited to a tally of the number of sources reporting on care navigators (Sucharew and Macaluso 2019). Undertaking the scoping review was particularly helpful as at the time of commencing the study as the subject had not been comprehensively reviewed and was complex and diverse (Peters et al 2015).

#### 2.1 Undertaking the literature search

Because of this I found undertaking the scoping review a complex and timeconsuming process, that continued throughout the study. Undertaking a scoping approach reduced the probability of me introducing personal preconception to the literature review (Sucharew and Malcaluso 2019) as I have prior professional experience of working with care navigators in practice and within an academic setting. I had previously developed and delivered a programme of professional development workshops for care navigators working within three Greater London Boroughs [this did not include the study participants]. Because of this prior exposure to care navigators I acknowledged that my personal lifeworld experience would affect my subconscious and that would lead me to have preconceived ideas of the subject area (Barrett et al 2020). These preconceived ideas could influence my own position in relation to the study in this context (Barrett et al 2020). My subconscious preconceived ideas may have unintentionally influenced all stages of the scoping review, from the initial identification of literature sources to the selection of the

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literature, right through to my evaluation and presentation of the literature found (Barrett et al 2020). Utilising the scoping review approach to the review moderated my personally acknowledged known preconception (Barrett et al 2020). Munn et al (2018) propose several objectives that can be achieved by utilising a scoping review framework. These include identifying types of existing evidence in the subject field, clarifying key concepts or definitions found in the literature, observing how research is conducted, identifying key characteristics related to the subject under review and identifying knowledge gaps (Munn et al 2018).

It was important that the scoping review approach aligned with the objective of my thesis needs, exploring care navigators experience of their lifeworld (Sucharew and Macaluso 2019). Using the scoping review framework allowed me to address my study enquiry by identifying accessible pertinent studies and literature in order to provide an overview of available literature and research evidence without providing a summary answer to my study question (Munn et al 2018). The scoping review permitted me to establish what existing literature was available about the role of the care navigator. The scoping review allowed me to identify relations, contradictions, gaps, similarities and inconsistencies in the literature found (Munn et al 2018). This assisted in the development of my understanding of the lifeworld experience of the care navigator (Munn et al 2018). From this understanding and interpretation of the findings the study would have implications for future care navigator practice and policy and help to guide further research in to the role of the care navigator by 'giving voice' and 'making sense' of their lifeworld experience (Noon 2018). I followed Arksey and O'Malley's framework (2015) for scoping reviews that consists of the following six steps:

Step 1: Identify the research question

Step 2: Identify relevant studies

Step 3: Study selection

Step 4: Chart the data

Step 5: Collate, summarise, and report the results

In addition to moderating my known preconception, I felt it important to use a scoping review framework approach to the review as in the field of research a literature review is widely recognised as scholarly writing (Winchester and Salji 2016). Winchester and Salji (2016) state formal literature reviews provide a critical appraisal of a subject and are not only an academic requirement but are also needed when planning a research project to place research findings into context. This provides an understanding of the landscape in which the researcher is functioning and supports them in making a valuable contribution to the field. They believe writing a literature review requires the researcher to hold a range of skills to enable them to gather, sort, evaluate and summarise peer-reviewed published data into a relevant and informative unbiased narrative. In support of this belief, each reviewer must select his or her own inclusion/exclusion criteria when searching for literature (Winchester and Salji 2016).

I wanted to explore the dominant discourse surrounding care navigators and the reported experiences associated with care navigators within the literature. This to facilitate my objective to provide robust and credible evidence of the key features of care navigation as experienced and understood by care navigators employed in the third sector working within two localities in a Borough of London in the United Kingdom.

### 2.2 Care navigator literature

From a previous encounter with the care navigator report Care Navigation. A report on research into patient and carer perspectives on the nature, effectiveness and impact of care navigation systems in Bradford, Airedale, Wharfedale and Craven (Macredie et al 2014), as part of my professional work, I was aware that there was a limited amount of available literature relating to care navigation and/or care navigators working in the United Kingdom at the time of commencing the study and undertaking the first steps of the scoping review. The majority of what was available was published in English and originated from North America where patient navigators perform different roles in a health and social care system unlike that of the United Kingdom. Patient navigators originated from oncology care in the United States of America as a response to remove barriers in facilitating timely diagnosis, treatment and care (Freeman 2006).

To review a sufficient amount of literature and include what I believe to be significant care navigator literature relevant to my study I expanded the publication date period searched from my initial choice of 2010 to 2017 to 2000 to 2018 during the writing up and amending period of the thesis development. Because of this, I was very conscious not to introduce my lifeworld experience preconception (Tuffour 2017) into my search to only find and review literature that supported my viewpoint or purposely corroborated my study findings. In an attempt to circumvent this, I used inclusion and

exclusion criteria. This facilitated a consistent approach to literature selection and inclusion. However, on reflection, I am mindful this does not completely eradicate my preconception, as the literature review is a reflection of my personal interpretation of the material found. I designated the following inclusion and exclusion criteria guided by my study's objectives [page 43]:

# 2.3 Inclusion criteria

- Published in English
- Published between 2000 and 2017
- Must include the following: Navigator, navigation process, navigation role by professional or lay navigators
- Was an accessible published or unpublished primary study, descriptive paper, report, literature review using any type of method

# 2.4 Exclusion criteria

- Published in a language other than English
- If navigation was a secondary outcome
- Literature did not address navigator or navigator process
- Literature did not include a navigation role by professional or paraprofessional
- Literature is an editorial, commentary or book review

I employed electronic databases to search for relevant literature. I purposely chose to concentrate the search to electronic databases rather than hard copy articles or research papers as electronic resources generally hold the most recently published contemporary literature and I believe this approach allowed me to access a wider range of journals and research papers than a traditional hard copy library search (Walsh 2016). I utilised the online resources CINAHL, MEDLINE, and PsychInfo available through the London South Bank University library search engines. During the time taken to complete the thesis, several new papers have been published regarding care navigation and care navigators within the United Kingdom.

I found numerous navigator job titles such as care coordinator, social prescriber and link worker (Health Education England 2016) when choosing key search words to guide my search for literature for the review. This reflects the findings of a study undertaken by Leary et al (2017) who found similar variation in job titles within the nursing workforce. The study concluded that the variation and lack of clarity in job titles could cause confusion for commissioners of services, colleagues and employers. This leads to confusion for patients as job titles do not confer assurance of educational or levels of expertise (Leary et al 2017). These findings are relevant to the role of care navigator as there is a need to identify and clarify the role in health and social care (Tierney teal (2019). Many authors (Bryant-Lukosius et al., 2004; Duffield et al., 2011; Lowe et al., 2012; Read, 2015) have examined issues around professional identity, role clarity and its impact on the enhancement of healthcare provision and inter-professional issues.

To alleviate this in the study my chosen search keywords were steered by the Health Education England (2016) Care Navigation Competency Framework *[table 1]*. I was a contributor to the Framework as I had originated and delivered care navigator training in my professional role of Associate Professor in a higher education institution. These keywords were important as they directed my literature search and influenced the material I acquired. I chose to remove key words that related to a

specific patient group e.g. 'Primary care navigators for dementia' to allow a wider generic search.

Care coordinator
Care navigator
Community connector
Health and social navigator
Locality navigator
Non-clinical navigators
Patient/primary care navigator

# 2.5 Keywords for electronic database search

Table 1: Keywords for electronic database search

Given that the Care Navigation Competency Framework was not found via the library 'academic' search engines, I questioned what other relevant statutory body published health and social care literature was available online via other search engines on the World Wide Web. I therefore undertook a general web search using Google in order to locate United Kingdom based statutory and third sector health and social care organisations literature. I chose Google as it is the most used search engine on the World Wide Web at the time of writing the thesis with 92.74% market share (StatCounter 2018) handling more than 3.5 billion searches each day (Internet Live Stats 2018). Literature found this way is referred to as 'grey literature'. The 'Luxembourg definition' of grey literature is 'that which is produced on all levels of government, academic, business and industry in print and electronic formats, but which is not controlled by commercial publishers, i.e., where publishing is not the primary activity of the producing body' (Farace and Frantzen 2005). The Cochrane Handbook for Systematic Reviews of Interventions recommend incorporating grey literature in systematic reviews (Higgins and Green 2011) as including purely peer-reviewed literature in literature reviews could omit potentially relevant work (Pappas and Williams 2011). To improve the quality of the review I applied the scoping review method to the grey literature search, allowing a more comprehensive search of available literature to be examined (Pappas and Williams 2011).

My initial search terms generated 675 articles from electronic databases [figure 5] and I added 8 records following the grey literature search and colleague recommendation. I removed 370 duplicates, leaving 313 records to be screened.. Of these, 275 records and 10 full text articles were excluded based on the title and/or abstract review, as they were not relevant to my research question, did not meet inclusion criteria or only an abstract was available. This resulted in 28 records being selected for inclusion in the scoping review.

This scoping review has several limitations. Although a scoping review is iterative and involves revisiting the research question and key terms during searches, my search strategy may have missed studies that reported on interventions not clearly connected with my inclusion search criteria. Additionally, information in the title and abstracts of such studies may not have referred to the scoping review search terms. This approach, however, allowed me to undertake a more targeted scoping review. My search strategy sought to include all terms I determined could be synonymous with care navigators I may have missed studies where different names were used for the same function.



Figure 5: PRISMA (2019) Flow diagram showing review process (Moher et al The PRISMA Group 2009)

### 2.6 Quality of evidence

Munn et al (2018) propose that authors need to consider how they wish to use the results of a literature review to influence whether they undertake a systematic or scoping review to provide evidence to inform practice. A systematic review is the most valid approach to address feasibility, appropriateness, meaningfulness or effectiveness of a certain treatment or practice (Munn et al 2018). As I was more interested in the identification of care navigators characteristics and discussion of these, I considered a scoping review was the better approach to the literature review (Munn et al 2018).

The scoping review I undertook did not formally evaluate the quality of evidence as it gathered information from a wide range of studies differing in design and method (Sucharew and Macaluso 2019). Because of this the scoping review provided a descriptive overview account of the available literature and not a synthesized answer to my study question (Sucharew and Macaluso 2019).

The scoping review found grey literature that was produced by authors who may not have academic training and therefore the information reviewed may not follow the the peer review norms of scholarly journals (Adams et al 2017). Adams et al (2017) argue that grey literature not subject to traditional academic peer-review processes can make a positive contribution to subsequent inquiry and practice by incorporating relevant contemporary material into fields of enquiry and can validate or corroborate findings from the academic literature.

# 2.7 Synthesis

To synthesise the information found to provide a descriptive overview, I used the methodological framework developed by Arksey and O'Malley's (2015) for scoping reviews following five steps:

- Step 1: Identified the research question—the research question was defined and broad enough in scope to provide extensive coverage.
- Step 2: Identified relevant studies—my search strategy was thorough and broad in scope using electronic databases including grey literature (formally published but not peer-reviewed).
- Step 3: Study selection—the study selection was guided by inclusion and exclusion criteria with new ideas emerging during the initial process of gathering and reviewing information.
- Step 4: Charted the data— I used a data charting form to extract the relevant information from the reviewed literature.
- Step 5: Collated, summarised, and reported the results in the table presented *[table 3].*

# 2.8 Extracting findings from the literature

Extracting findings in scoping reviews is termed 'charting' this provides a descriptive summary of the findings of the review (Galibarf et al 2017). To support the scoping review a data charting form was produced by identifying descriptive theme variables that corresponded with the study question (Wong 2008).

My charting form recorded the following information:

- Author(s)
- Year of publication
- Origin/country of origin (where the study was published or conducted)
- Title
- Study population and sample size (if applicable and available)
- Methodology/methods
- Key findings that relate to the scoping review question

Coding or categorising the information found was the most important stage in the scoping review process (Wong 2008). The coding involved subdividing the huge amount of information found during the scoping review and then subsequently assigning it into categories (Wong 2008). The codes provided labels to allocate the identified information too (Wong 2008). In order to determine variables and promote validity and reliability I entered the information found into QSR International Pty Ltd. (2015) NVivo (Version 11) software for data analysis (Hilal and Alabri 2013). The process was undertaken in three stages that overlapped; with the free line-by-line coding of the findings of the information, the organisation of these 'free codes' into related areas to construct 'descriptive' themes; and the development of 'start codes' [*table 2*] (Hilal and Alabri 2013).

Descriptive Theme	Start Code
Communication	СМ
Co-ordination (Continuity)	СО
Educational support	ES
Information giving	IG
Patient assessment	PA
Practical support	PS

## Table 2: Start codes bank

The coding of variables created a 'bank' of descriptive theme start codes to which I added new ones if the process prompted (Hilal and Alabri 2013). Throughout the process, I re-examined the text that I had an applied a code to check consistency of interpretation and to see whether additional levels of coding were needed (Hilal and Alabri 2013). The descriptive themes identified were, communication, co-ordination (continuity), educational support, information giving, patient assessment and practical support in the literature.

### 2.9 Care navigator literature overview

Much of the published literature *[table 3]* from the last two decades I found when performing the scoping review at the start of the study in 2016 was North American in origin and was primarily focussed within the specialist health field of oncology (Smith and Kautz 2015). Care navigation in North America is commonly known as patient navigation. The term "patient navigation" was created by Dr. Harold P. Freeman, who partnered with the American Cancer Society (ACS) to create the first patient navigation program in Harlem, New York (Freeman et al 1995). Paskett et al (2011) in their paper Patient Navigation: An update on the state of the science, claim there is a lack of consensus regarding the definition of patient navigation, qualifications required of patient navigators and the impact on the continuum of cancer care (Paskett et al 2011). Services provided by patient navigators varies by patient group but often include facilitating communication between patients, significant others and healthcare providers (Jean-Pierre et al 2011). Services also include coordinating care between providers and arranging financial support and assisting with associated paperwork (Lin et al 2008), arranging support to enable patients to attend appointments such as transportation and childcare and facilitating initial appointments and follow up appointments and ensuring medical records are available (Institute for Alternative Futures 2007). Patient navigators also build relationships in the local community by providing community outreach and partnership working with resident agencies and groups (Institute for Alternative Futures 2007).

If the role of the patient navigator required a professionally qualified individual to perform the role in North America it was often a state registered nurse who performed this (Carter 2018). This being similar to a Australian nurse navigator model supporting patients health literacy to enable them to navigate their way through healthcare services (McMurray and Cooper 2017). At the time of undertaking the scoping review there was no nationally recognised navigator license, credential or certification (Carter 2018) required to perform the role in North America. However while there is no set education or registration requirements to be able to undertake a patient navigator role the Institute for Alternative Futures (2007) believes a successful patient navigator should be compassionate, sensitive, and culturally understanding of the people and community being served to enable effective communication. Patient navigators need to be knowledgeable about the environment and in addition the healthcare system in which they work (Institute for Alternative Futures 2007). This is reflected in the United Kingdom where there are currently no professional body set education or registration requirements required to perform the care navigator role (Health Education England 2016). Care navigators often come from a wide professional and lay background (Health Education England 2016). However, core competencies are available in a tiered competency framework in Care Navigation: A Competency Framework (Health Education England 2016) that provides a common set of competencies for care navigation.

Health Education England (2016) consider care navigator day-to-day tasks vary depending on local context and local population need. Care navigators may work in many different settings including hospitals where the focus is on discharging people safely from hospital to home (Health Education England 2016). Care navigators can also be part of a multidisciplinary team working in general practice in the community (Health Education England 2016). Health Education England (2016) state there is no 'one size fits all' navigation service with numerous delivery models being found across the United Kingdom. The role of the care navigator in the United Kingdom is often associated with social prescribing (Tierney et al 2019). Social prescribing links patients in primary care with sources of non-clinical support within the community. It provides General Practitioners with a non-medical referral option alongside existing treatments to increase health and well-being. While there are no commonly agreed definition of social prescribing, reports on social prescribing include an extensive range of prescribed interventions and activities (Wilson and Booth 2015).

# 2.10 Social prescribing

The Department of Health (2006) have long recommended the use of social prescribing for people with long-term conditions to promote partnership working between community services and the third sector encouraging integrated health and social care delivery. NHS England (2014) describe social prescribing as a way of sustaining general practice by promoting access to non-clinical interventions delivered by community services and the third sector. There is growing evidence that social prescribing can considerably improve people's health and wellbeing (Polley et al 2017). This is predominantly seen in those with complex health and social needs (Polley et al 2017). Care navigators provide support to service users, particularly those with complex health and social needs in these situations, care navigators coordinate the socially prescribed services across health and social care providers (Health Education England 2016).

Author (Year/Location)	Title	Methodological Approach/Method	Data Collection	Sample	Findings
Cancer Care	Clearing a Path for	Multi-Method:	Multiple stakeholder	(N = 344)	Patient Navigation is
Nova Scotia	Patients: Patient	The evaluation incorporated	groups participated in		described as a client
(2002)	Navigation	qualitative and quantitative	the evaluation, including		centred outcome-focused
North America	Evaluation	research methods.	patients and families,		case management
	Framework		community partners,		approach put in place to
			such as continuing care		help health professionals,
			services, Canadian		patients and their families
			Cancer Society		and district health leaders
			staff/volunteers,		deal more effectively with
			physicians, other		cancer and the cancer
			community health		system.
			professionals, staff at		
			the three tertiary cancer		
			centres, Patient		
			Navigators, senior		
			leaders in the "early		
			adopter" districts, and		
			key CCNS staff. Data for		
			the evaluation was		
			collected through 16		
			focus groups, 57 one-		
			on-one interviews, 162		
			patient surveys, and a		
			review of 808 records in		
			the patient navigation		
			database.		
Till, JE	Evaluation of	Commentary: Literature	Literature on evaluations	NA	Application of the concept
(2003)	support groups for	Review	of community-based		of a "navigator role" to
North America	women with breast	(Dates not provided)	cancer support groups		support groups in general,
	cancer: importance		both face-to-face and		and to unmoderated online
	of the navigator		online social support		ones in particular, has
	role		groups.		received little or no
					attention in the research
					literature. The navigator
					role should be taken into
					account in research on
					this increasingly important
					aspect of cancer
					communication.
Wells, K. J.,	Patient Navigation	Qualitative:	The authors conducted	NA	Overall there is evidence
Battaglia, T. A.,	Research Program	Literature Review	a qualitative synthesis of		for some degree of
Dudley, D. J.,	-		published literature on		efficacy for patient
Garcia, R.,			cancer patient		navigation in increasing
Greene, A.,			navigation. Using the		participation in cancer
Calhoun, E.,			keywords "navigator" or		screening and adherence
Mandelblatt, J.			"navigation" and		to diagnostic follow-up
S., Paskett, E.			"cancer" identifying 45		care following an
D., Raich, P. C.,			articles from Pubmed		abnormality, with
.,,,					,

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(2008)			and reference searches		increases in screening
North America			that were published or in		ranging from 10.8% to
			press through October		17.1% and increases in
			2007. 16 provided data		adherence to diagnostic
			on efficacy of navigation		follow-up care ranging
			in improving timeliness		from 21% to 29.2%, when
			and receipt of cancer		compared to control
			screening, diagnostic		patients. There is less
			follow-up care, and		evidence regarding
			treatment. Patient		efficacy of patient
			navigation services are		navigation in reducing
			defined and		either late stage cancer
			differentiated from other		diagnosis or delays in
			outreach services.		initiation of cancer
					treatment or improving
					outcomes during cancer
					survivorship. There were
					methodological limitations
					in most studies, such as
					lack of control groups,
					small sample sizes, and
					contamination with other
					interventions.
Andersen JE,	Navigating the	Qualitative:	This community action	(N = 11)	The community supported
Larke SC	mental health and	Action Research	research model, used		navigator service model
(2009)	addictions		multiple sources of		was effective in improving
North America	maze: a		information and iterative		service access,
	community-based		enquiry to evaluate and		assessment and linkage
	pilot project of		modify the service on an		for citizens with mental
	a new role in		ongoing basis. Data was		health and addictions
	primary mental		collected from		concerns, and connecting
	health care		consented, structured		a range of community
			client assessments,		services into a more
			semi-structured		effective network of care.
			interviews with		
			community service		
			providers and local		
			physicians, client		
			feedback forms, and		
			regularly documented		
			informal		
			communications with		
			service providers and		
			members of the steering		
			committee.		
Campbell C,	Implementing and	Qualitative:	A 10-item survey with	Patients	Patients who received
Craig J	Measuring the	Program evaluation with	Likert scale format was	(N = 48)	navigation services
Eggat J,	Impact of Patient	patient and staff surveys.	sent to a stratified	Staff	responded more positively
Bailley-Dorkan	Navigation at a		sample of 100 newly	(N = 26)	to survey statements.
C	Comprehensive		diagnosed patients with	` <i>'</i>	Statistical significance (p >
	,				0.05) was identified in 7 of
(2010)			cancer. A five-item		0.00) was identified in 7 of

North America	Community Cancer		survey with the same		10 statements when
North America	-				-
	Centre		format was sent to 40		patient groups were
			staff working with the		compared. Provider
			patients. 48 patients (28		responses indicated
			navigator and 20 non-		agreement with all five
			navigator) and 26		statements included in the
			employees, including		survey. Patients with
			physicians, nurses, and		cancer and oncology staff
			other support staff		reported that patient
			responded.		navigation is effective in
					increasing patient
					satisfaction and
					decreasing barriers to
					care.
Lubetking E,	Exploring Primary	Qualitative:	The authors examined	(N = 105)	Most providers believe
Wei-Hsi L,	Care Providers'	Survey	attitudes and practices		they can help patients quit
Krebs P,	Interest in Using		regarding tobacco		smoking; they also
Yeung H,	Patient Navigators		cessation interventions		recognise the potential
Ostroff J	to Assist in the		of primary care		benefit of having a patient
(2010)	Delivery of		physicians serving low		navigator connect their
North America	Tobacco Cessation		income, minority		patients with evidence-
	Treatment to Low		patients living in urban		based cessation services
	Income,		areas with a high		in their community.
	Ethnic/Racial		smoking prevalence.		
	Minority Patients		Barriers and facilitators		
			to physicians providing		
			smoking cessation		
			counselling to determine		
			the need for and interest		
			in deploying a tobacco-		
			focused patient		
			navigator at community-		
			based primary care		
			practice sites was		
			undertaken by the use of		
			a self-administered		
			survey. Provider		
			attitudes were assessed		
			by a decisional balance		
			scale comprising 10		
			positive (Pros) and 10		
			negative (Cons)		
			perceptions of tobacco		
			cessation counselling.		
Penderson A,	Pilots of Oncology	Concept Analysis:	Published research	NA	The role of a patient
Hack T.F	Health Care: A	Summarises the current	articles, clinical articles,		navigator includes
(2010)	Concept Analysis	scientific literature	and Internet sources on		removing barriers to care,
North America	of the Patient	pertaining to the role of the	patient navigator roles		improving patient
	Navigator Role	patient navigator in	and pro- grams.		outcomes, and
		oncology using the concept	Literature was obtained		ameliorating the overall

		analysis framework	from CINAHL®,		quality of healthcare
		developed by Walker and	PubMed, PsycINFO, the		delivery.
		Avant (2005).	Cochrane Library, and		
		/ want (2000).	Google ScholarTM,		
			incorporating reports in		
			English from 1990–		
			2008.		
Robinson KL,	Bridging the	Qualitative: Assessment of	The Hospital Consumer	NA	The role of the Patient
Watters S	Communication	Healthcare Providers and	Assessment of	INA	
		Systems (HCAHPS) survey	Healthcare Providers		Navigator is to help
(2010) North America	Gap Through the Implementation of	a national standardised			disseminate important
North America			and Systems (HCAHPS)		information that may prove
	a Patient Navigator	survey instrument.	is a national		useful to the patient and
	Program		standardised survey		their loved ones, the
	Pennsylvania		instrument designed to		contents of which can
	Nurse		assess the patients'		ultimately impact patient
			perspective of hospital		satisfaction outcomes.
			care for public reporting		Patient Navigators serve
			purposes. There are a		as patient educators,
			total of 27 survey items		formal greeters and work
			that are divided into six		as an extension of PR in
			composite measures,		an effort to help assess
			two individual items and		patient satisfaction, alert
			two global ratings.		PR staff of any potential
					problems and help to avert
					formal complaints. They
					also conduct Wellness
					visits to determine the
					quality of the patient's stay and assist the care
					provider staff with the
					performance of some non-
					clinical functions such as
					filling and delivering water
					pitchers.
Korber SF,	A Breast Navigator	Qualitative:	Researchers used	(N = 13)	Completion of breast
Padula C,	Program: Barriers,	Focus group methodology	semistructured, open-		cancer therapy and care
Gray J,	Enhancers and	and telephone interview.	ended questioning to		can be improved by
Powell M	Nursing		guide the interviews and		recognizing the value the
(2011) North America	Interventions		elicit identification of		nurse navigator role brings
North America			barriers to and		to the patient experience
			enhancers of treatment.		and enhancing that role.
			A flexible approach was		
			used and the interviews		
			were recorded. Content		
			analysis was used to		
			identify themes.		
		Quant			Definition
Natale-Pereira	The Role of Patient	Commentary:	This supplement article	NA	Patient navigators can not
		Article	is based on		only facilitate improved
А,	Navigators in				
A, Enard KR,	Eliminating Health		presentations at the		health care
А,	-		presentations at the "National Patient Navigator Leadership		

(2011)			Summit"; March 23-24,		through advocacy and
North America			2010; Atlanta, GA.		care coordination, but they
All All Child			ZUTU, Adama, GA.		can also address deep-
					rooted issues related to
					distrust in providers and
					the health system that
					often lead to avoidance of
					health problems and non-
					-
					compliance with treatment recommendations.
		-			
Paskett ED,	Patient navigation:	Qualitative:	The authors of the	NA	Although patient
Harrop JP,	an update on the	Literature Review	review conducted a		navigation was introduced
Wells KJ.	state of the science		search by using the		2 decades ago, there
(2011)			keywords "navigation" or		remains a lack of
North America			"navigator" and "cancer."		consensus regarding its
			Thirty-three articles		definition, the necessary
			published from		qualifications of patient
			November 2007 through		navigators, and its impact
			July 2010 met the		on the continuum of
			search criteria.		cancer care. There is
					building evidence of some
					degree of efficacy of
					patient navigation in terms
					of increasing cancer
					screening rates.
					However, there is less
					recent evidence
					concerning the benefit of
					patient navigation with
					regard to diagnostic follow
					up and in the treatment
					setting, and a paucity of
					research focusing on
					patient navigation in
					cancer survivorship
					remains. Methodological
					limitations were noted in
					many studies, including
					small sample sizes and a
					lack of control groups. As
					patient navigation
					programs continue to
					develop across North
					America and beyond,
					further research will be
					required to determine the
					efficacy of cancer patient
					navigation across all
					aspects of the cancer care
					continuum.
					· · · · · · · · · · · · · · · · · · ·

Pieters HC,	Older Women's	Qualitative: Descriptive	Semistructured,	(N = 18)	Three interconnected,
Heiemann M,	Reflections re	study guided by grounded	individual interviews.		age-related barriers to
Grant M,	Accessing Care	theory.	The analytic approach		care were described by
Maly RC	Across the Breast		was constructivist		the women throughout
(2011)	Care Trajectory :		grounded theory.		their cancer trajectories:
North America	Navigating Beyond				knowledge deficits, pre-
	the Triple Barriers				existing comorbid
					diseases, and multiple
					appointments with
					healthcare providers. The
					women navigated beyond
					the triple barriers to life
					•
					after cancer. Women
					described how the
					services of an oncology
					nurse navigator facilitated
					their progress.
Freeman, H.P.	The Origin,	Article:	The article uses the	NA	The basic goal of
(2012)	Evolution, and	The goal of the editorial	findings of the National		navigation is to facilitate
North America	Principles of	was to place patient	Cancer institute (NCI)		timely access for all to
	Patient Navigation	navigation in historical	Patient Navigation		quality standard care in a
	5	perspective, discuss the	Research Program		culturally sensitive
		philosophy and principles of	(PNRP). This research		manner.
		patient navigation, and	program was designed		manner.
		-			
		show how this relatively	to develop interventions		
		new health care delivery	to reduce the time to		
		support strategy has	diagnosis and treatment		
		evolved since its inception	of cancer after		
		in 1990.	identifying an abnormal		
			finding from a cancer		
			detection procedure.		
Hacking B,	Testing the	Quantitative:	Two hundred eighty-nine	(N = 63)	Compared to control
Wallace L,	Feasibility,	Randomised Controlled	newly diagnosed		patients, navigated
Scott S,	Acceptability and	Trial	prostate cancer patients		patients were more
Kosmala-	Effectiveness of a		were eligible. 123		confident in making
Anderson J,	Decision		consented and were		decisions about cancer
Belkora J,	Navigation		randomised to usual		treatment, were more
McNeill A	Intervention for		care ( <i>n</i> = 60) or		certain they had made the
(2013)	Early Stage		navigation $(n = 63)$ .		right decision after the
United Kingdom	Prostate Cancer in				consultation and had less
	Scotland – A				
					regret about their decision
	Randomised				6 months later. Decision
	Controlled Trial				navigation was feasible,
					acceptable and effective
					for newly diagnosed
					prostate cancer patients in
					Scotland.
Horner K,	An Oncology Nurse	Quantitative: Randomised	The authors designed	(N = 251)	The nurse navigator
Lundara e u 📼 l	Navigator Program	Controlled Trial	an oncology nurse		program was organised to
Ludman EJ,	0 0				
Ludman EJ, McCorkle R,	Designed to		navigator program to		eliminate gaps in families'
			navigator program to proactively address		eliminate gaps in families' psychosocial,

Flaherty L,   Eliminate Gaps in   perceived gaps in care   informational and care     Min J,   Early Cancer Care   and tested the   coordination needs for     Miyoshi J,   program's effectiveness   patients entering a can     Laphan B,   in providing high-quality   care centre.     Aiello Bowles   randomised, controlled   care centre.     EJ, Wagner EH   randomised, controlled   trial. The program's     (2013)   model was informed by   research synthesising     North America   clinicians, and experts   throughout the country.     The authors   systematically   incorporated feedback     from participating clinical   departments to improve   departments to improve     Merdith SM   Disparities in   Literature Review:   The author conducted a   NA
Miyoshi J, Laphan B, Aiello Bowlesprogram's effectiveness in providing high-quality cancer care through a randomised, controlled trial. The program'spatients entering a can care centre.(2013)rial. The program's model was informed by research synthesising the perspectives of patients, families, clinicians, and experts throughout the country. The authors systematically incorporated feedback from participating clinical departments to improve the effectiveness of the program.patients entering a can care centre.
Laphan B, Aiello Bowlesin providing high-quality cancer care through a randomised, controlled trial. The program's model was informed by research synthesising the perspectives of patients, families, clinicians, and experts throughout the country. The authors systematically incorporated feedback from participating clinical departments to improve the effectiveness of the program.care centre.
Aiello Bowlescancer care through a randomised, controlledEJ, Wagner EH (2013)randomised, controlledNorth Americamodel was informed by research synthesising the perspectives of patients, families, clinicians, and expertsI I I I I I I I I I I I I I I I I I I
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program.
(2013) Breast Cancer and (45 published articles. review of the literature programs have shown a
of Patient CINAHL® databases cancer patients through
Navigator with the follow- ing screening, diagnosis, a
Programs keywords: health treatment phases.
disparities, breast
cancer care, patient
navigator programs,
ethnicity, and
socioeconomic status.
Percad-Lima S, The Impact of a Quantitative: Between January 2004 (N = 786) Patient navigation can
Benner C.S, Culturally Tailored Randomised Controlled and April 2011, 533 prevent cervical cancer
Lui R, Patient Navigation Trial Latina women with an Latina women by
Aldrich LS, Program on abnormal Pap smear increasing colposcopy
Oo SA, Cervical Cancer requiring colposcopy clinic attendance,
Regan N, Prevention in received patient shortening time to
Chabner BA Latina Women navigation from their colposcopy, and
(2013) healthcare centre in decreasing severity of
Massachusetts, to the two time periods, 2004
Massachusetts General 2007 and 2008-2011.
Hospital (MGH). The
comparison group
comprised 253 non-
navigated Latinas from
other primary care
practices at MGH

Gunn CM, Clarke JA, Battaglia TA, Freund KM, Parker VA (2014)	An Assessment of Patient Navigator Activities in Breast Cancer Patient Navigation Programs Using a Nine Principle Framework	Qualitative: An exploratory study evaluated a model framework for patient navigation published by Harold Freeman by using an a priori coding scheme based on model domains.	referred to the same MGH colposcopy clinic. Observational field notes describing patient navigator activities collected from 10 purposefully sampled, foundation-funded breast cancer navigation programs in 2008–2009. Field notes were compiled and coded. Inductive codes were added during analysis to characterise activities not included in the	NA	Programs were consistent with individual-level principles representing tasks focused on individual patients. There was variation with respect to program-level principles that related to program organisation and structure. Program characteristics such as the use of volunteer or clinical navigators were identified as contributors to patterns
Kelly E , Fulginiti A, Pahwa R, Tallen L, Duan L, Brekke JS (2014) North America	A Pilot Test of a Peer Navigator Intervention for Improving the Health of Individuals with Serious Mental Illness	Mixed Method: Questionnaire and Randomised Controlled Trial	To examine the preliminary efficacy and promise of the health navigation intervention, measures of health status, healthcare utilisation, and barriers to healthcare were included. Demographic information was obtained for ethnicity, gender, age, education level, income and marital status using a questionnaire at baseline.	(N = 23)	of model concordance. Navigators encouraged development of self- management of healthcare through a series of psycho-education and behavioural strategies Outcomes included a range of health consequences, as well as health utilisation indices.
Macredie S Hewitt R Booton B (2014) United Kingdom	Care Navigation A report on research into patient and carer perspectives on the nature, effectiveness and impact of Care Navigation systems in Bradford, Airedale, Wharfedale and Craven	Qualitative: Questerview Technique	Literature review (since 2009), questionnaire and focus groups: 52 patients 18 carers 36 professionals	(N = 106)	The way in which Care Navigation support had an impact was shown in the findings from all the research groups: Patients had increased regular contact with the different services, had a better understanding of their condition, used the right services sooner and felt that their condition would have got worse more quickly without that support. Carers stated using the right services and support sooner and
Pedersen, A.E Hack, T.F McClement, S.E Taylor-Brown, J (2014) North America	An Exploration of the Patient Navigator Role: Perspectives of Younger Women With Breast Cancer	Qualitative: Interpretive and Descriptive	Face-to-face semistructured interviews explored patient experiences with the cancer care system, including problems encountered, unmet needs, and opinions about the functions of the patient navigator role. The audio-recorded interviews were transcribed and data were broken down and inductively coded into four categories. Constant comparative techniques also were	(N = 12)	that the condition of the person they care for would have got worse more quickly without the support. All Carers stated that they had an increased understanding of the condition of the person they were caring for. Professionals perceived that the main benefit of Care Navigation for patients and/or their carers was having greater choice and control over managing their condition. Despite the small sample in the exploratory study, the findings provide insight and guidance toward the expansion of current roles in oncology nursing and patient navigation. The study implies that, despite the tremendous effort and research directed toward advancing care for younger women with breast cancer, gaps continue to exist for some of these women. These findings can be used to provide direction for current patient navigation
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			four categories.		findings can be used to
Kelly, E. Ivers, N. Zawi, R. Barnieh, L. Manns, B. Lorenzetti, D. Nicholas, D. Tonelli, M. Hemmelgarn, B. Lewanczuk, R. Edwards, A. Braun, T. McBrien, KA. (2015) North America	Patient navigators for people with chronic disease: protocol for a systematic review and meta-analysis	Literature Review: Systematic Review Meta-analysis	The authors included RCTs, cluster RCTs, and quasi-randomised RCTs that study the effects of patient navigator programs on clinical outcomes, patient experience, and markers of adherence to care. Studies were identified by searching MEDLINE, Embase, the Cochrane Central Register of Controlled	NA	A comprehensive review of patient navigator programs, including a summary of the elements of programs that are associated with a successful intervention, does not yet exist. This systematic review synthesises the evidence of the effect of patient navigator interventions on clinical and patient- oriented outcomes in

			Trials (CENTRAL),		populations across a
			CINAHL, PsycINFO,		comprehensive set of
			Social Work Abstracts,		chronic diseases
			and the references of		
			included studies. No		
			dates provided.		
Ranaghan C,	Effectiveness of a	Literature Review:	The literature search	NA	There is a paucity of
Boyle K,	patient navigator	Systematic Review	included published and		evidence on the
Meehan M,	on patient		unpublished studies in		effectiveness of a patient
Moustapha S,	satisfaction in adult		the English Language		navigator on patient
Fraser P,	patients in an		from 1990 through July		satisfaction. In the four
Concert C	ambulatory care		2015. A search of		studies selected for
(2016)	setting: a		PubMed, CINAHL,		inclusion, a patient
	systematic review		Excerpta Medica		navigator had a positive
			Database (EMBASE),		effect on patient
			Academic Search		satisfaction, although none
			Premier, Cochrane		of the studies
			Library, PsycINFO and		demonstrated statistical
			Health Source:		significance with a patient
			Nursing/Academic		navigator on patient
			Edition, Social Work		satisfaction. The effect of
			Abstracts and Web of		a patient navigator
			Science was conducted.		remains questionable with
			A search for gray		differences in perceptions
			literature and electronic		on the best individual for
			hand searching of		the role and the expected
			relevant journals was		role perception and
			also performed.		performance. A
					standardised approach to
					the role of the patient
					navigator may maximise
					health outcomes and
					positively affect the quality
					of life for all patients.
Carter N,	An environmental	Qualitative: Descriptive	Online questionnaire to	(N =145)	The results of this survey
Valaitis RK,	scan of health and	Study	understand health and		provides a snapshot of
Feather J,	social system		social system navigation		what various providers
Nicholl J,	navigation services		in the community by		from different disciplines
Lam A,	in an urban		exploring the topics		and organisations are
Cleghorn L.	Canadian		identified in the		doing to provide
(2017)	community.		aforementioned		navigation support to
North America			objectives.		clients in a large urban
			The majority of		Canadian
			respondents were social		community. Although the
			workers (40.7%), social		characteristics of clients
			services workers		from the provider's
			(17.9%), or nurses		perspective are described
			(17.2%). Participants		the views of clients
			were employed in a		themselves are a critical
			variety of settings		

Nichol, J. Cleghorn, L.	scoping literature review		and include a navigator or navigation process in a primary care setting		the majority originated in the US. Most of the
Lam, A. Feather, J.	navigators in primary care: a		published in English between 1990 and 2013,		most of which were descriptive papers, and
Valaitis, R.K.	models and roles of	Scoping Review	review studies had to be		papers in the review,
Carter, N.	Navigation delivery	Literature Review:	To be included in the	NA	The authors included 34
			Occupational Therapist and Staff Nurse)		Merton Social Prescribing Pilot, ensuing that this pilot was able to start quickly, supporting its success.
			the HARI Team (Advance Nurse Practitioner,		the GP. Learning from the Community Navigator Service was fed into the
			(CNS main liaison) Members of staff within		Assessment Rapid Investigation Team and
(2017) United Kingdom	Navigator Service (CNS) Evaluation	Technique	data collected and surveys, feedback was collated from: A GP within a GP Practice		Navigation Service connected 363 people (March 2016 - July 2017) across the Holistic
Yusuf. B	Community	Qualitative: Questerview	In addition to the patient	Not Available	The Community
			navigation services as a volunteer activity (3.4%). The average length of time respondents had been providing systems navigation support was 11.9 years.		
			secondary function of their role (53.8%). A small number of participants provided		
			was their primary function (35.9%) and half of respondents reported it as a		
			social work background. Over a third of respondents reported that systems navigation		greater needs.
			services (13.1%). Of the respondents working in acute care, 93% had a		address the larger systemic issues that have created inequities and
			community health services (22.1%), public health (17.9%), and police or emergency		The work of navigators is meant to alleviate the barriers to health and social care, but does not
			including acute care organisations (30.3%),		missing piece of this picture.

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			services beyond the		developed to meet the
			health care system.		needs of specific patient
					populations. The authors
					make make an important
					contribution to the
					literature by highlighting
					navigation models that
					address both health and
					social service navigation.
					The emergence and
					development of system
					navigation signals an
					important shift in the
					recognition that health
					care and social care are
					inextricably linked
					especially to address the
					social determinants of
					health.
Peart, A. Lewis,	Patient navigators	Literature Review: The	Searches were	NA	Patient navigators may
V. Brown, T.	facilitating access	authors used the Arksey	conducted in MEDLINE,		assist to connect people
Russell, G.	to primary care: a	and O'Malley scoping	Embase, ProQuest		requiring primary care to
(2018)	scoping review	review method.	Medical, other key		appropriate providers and
Australia	-		databases and grey		extend the concept of
			literature for studies		patient-centred care
			reported in English from		' across different healthcare
			January 2000 to April		settings. Navigation
			2016.		requires further study to
					determine impact and
					cost-effectiveness and
					explore the experience of
					patients and their families.
Wessex	Independent	Qualitative:	The four components	(N = 121)	The comprehensive
Academic	evaluation of Care	Evidence from four	are:		qualitative evaluation
Health Science	Navigators on the	qualitative method	i) Staff interviews –		found good evidence of a
Network (2018)	Isle of Wight	components have been	these sought to		positive impact on the
United Kingdom		brought together into the	understand the		people supported, staff
-		single synthesised	development,		and the system. For the
		qualitative set of findings.	implementation, barriers,		people it found that it
		Ŭ ,	facilitators, and gather		improved their confidence
			perceptions of impact on		to self-manage, make
			patients, staff, general		healthy lifestyle choices,
			practice and the wider		improve safety in their
			system.		home, reduce social
			ii) Person interviews –		isolation and improve their
			these sought to		quality of life. For staff, the
			understand people's		CNs are helping connect
			general experience of		and join up services and
			receiving care navigation support.		help reduce the workload in general practice while
					I III OPOPIAL DIACUCE While

	iii) Case studies	giving them improved
	,	
	provided by staff – these	knowledge of their
	sought to collect in-	patients. For the system it
	depth stories to	is improving the
	compliment other	knowledge and integration
	qualitative and	of health, care and
	quantitative data	voluntary services.
	collected.	
	iv) Staff survey – this	
	sought to gather views	
	of the service from other	
	professionals who	
	engage with care	
	navigators on a regular	
	basis.	



# 2.11 Care navigator scoping review discussion

Harold Freeman introduced the concept of care navigators or patient navigators, as they are more commonly known in the United States of America (USA) into the oncology care setting in the 1990's (Freeman, 2012). The overall aim of introducing patient navigators was to eliminate barriers to patients receiving timely diagnosis, treatment and care (Freeman, 2012) *[figure 7]*. Patient navigators provide one-on-one guidance and assistance to individuals as they move through the health care continuum from prevention up until to end-of-life care (Freeman, 2012). Patient navigators provide support to patients during screening, diagnosis, and treatment tailoring the support to an individual's needs (Freeman 2012). Patient navigators act as the support hub for all aspects of patients' movement through the health care system (Freeman, 2012). The patient navigator's role is to uphold smooth and timely continuity of care to the point of resolution (Freeman, 2012). The care navigator role was introduced into the United Kingdom in 2009 as part of the National Health Service London workforce transformation programme (Leveaux et al. 2012). The care navigator was to have flexible, generalist capabilities and skills to support people to move from dependent care towards self-care by removing barriers in the health and social care setting (Leveaux et al. 2012). Freeman (2012) states there are a number of barriers that can be

eliminated through patient navigation in the North American health system. Communication barriers, such as lack of understanding, language and culture. Financial barriers including patients who are uninsured or under insured. Medical system barriers such as a fragmented medical system, missed appointments, and lost results. Other barriers that can be eliminated by patient navigation (Freeman, 2012) include transportation difficulties, the need for child care and psychological barriers such as fear and distrust.





Health Education England (2016) state that published literature regarding care navigation is sparse within the United Kingdom but from what is available it would appear the care navigator role can reduce barriers to care. There is evolving evidence that shows care navigation can improve patient and carer experience and reduce unnecessary hospital admissions and General Practitioner attendance (Health Education England, 2016). There is also emerging evidence that care navigators help professionals to work more effectively by sharing key information and workload, and can reduce the cost of care by avoiding duplication (Health Education England 2016). This removes barriers in the health and social care system getting people timely help based on their holistic needs (Health Education England 2016). By addressing barriers, patient

navigators can foster trust and empowerment within the communities they serve (Natale-Pereira et al, 2011).

There are a number of recurring themes found in the roles of patient navigators within the available literature (Natale-Pereira et al, 2011). The themes are communication, continuity and co-ordination, educational support, information giving, patient assessment and practical support (Natale-Pereira et al, 2011).

## 2.12 Descriptive theme: Communication

Natale-Pereira et al (2011) state that despite efforts to increase equity in the United States health care system not all Americans have equal access to health care or comparable health outcomes. Many of the most vulnerable in society continue to struggle in accessing and navigating the complex health care delivery system. However Natale-Pereira et al (2011) did find that patient navigation can assist in improving health outcomes for racial and ethnic minorities, and other underserved populations, in the context of an ever changing healthcare environment. Natale-Pereira et al (2011) found patient navigators cannot only facilitate improved health care access and quality for underserved populations through advocacy and care coordination, but they can also address deep-rooted issues related to distrust in providers and the health system that often lead to avoidance of health problems and non-compliance with treatment recommendations. Skilled patient navigators are able to lead and facilitate effective communication between care providers and service users, which Horner et al (2013) suggest may prevent treatment delays through the early identification and recommendation of resources. McCabe and Timmins (2013 pp. 71-92) recognise that effective communication is an important aspect of care provision leading to positive interactions between service users and health and social care staff [table 4]. They state effective communication reduced patient anxiety, giving them greater control leading to increased confidence in the care provision and improved outcomes. Effective communication supported

patients in following medical recommendations allowing for self-management of long-term conditions often with the adoption of preventative health behaviours. This prompted improved job satisfaction for health and social care staff. The lack of interaction through written or telephone correspondence and the absence of clearly explained communication routes are found in Harding & McCone's (2013) study as an area of dissatisfaction adding to the stress of individuals with breast cancer. These findings support the recommendations of Meredith (2013) who concluded that patient navigator programmes are valuable in addressing communication barriers between patient and service providers across the different health and social care environments. The communication between the navigator and patient should be individualised to reflect the patient's holistic needs, including supporting the patient through medical consultations with the overall goal to improve communication between doctors and patients (Korber et al, 2011) and also to manage the connection between different elements and areas of care (Penderson and Hack 2011). Within mental health care the importance of effective and timely communication is seen by Kelly et al (2014) as vital in supporting clients with dual diagnoses to make appropriate choices in relation to accessing primary health or mental health care services with navigators providing continuity and co-ordination of support given. A study of 52 service users, 18 carers, and 36 professionals by Macredie et al (2014) undertaken in the North of England to gather, analyse, collate, and make recommendations to commissioners of a care navigation service and evidence its impact on earlier access to intervention and prevention services, found eighty two percent [N=18] of care navigation service users felt that care navigation assistance should be delivered face to face. Eighty seven percent [N=6] of carers and eighty three percent [N=14] of professionals supported this. The study found that service users valued the use of phone, email, text messaging and Skype as a means of communication. It was emphasised that the means of communication should match the service user and carers needs. Ninety three percent [N=20] of service users and one hundred percent [N=54] of carers and professionals believed everyone with long-term condition needs should have someone to co-ordinate them through health and social care services. A literature review by Till (2003) found application of the concept of a navigator role to cancer support groups

and to unmoderated online ones in particular, had received little or no attention in research literature. Till (2003) states that a navigator role should be taken into account in research in the important aspect of cancer communication.

McCabe and Timmins (2013) indicate that	Reduced patient anxiety
positive interactions in a healthcare	Greater feelings of control
setting can lead to:	Increased confidence
	Improved health outcomes
	Follow through with medical
	recommendations
	Self-manage a long term condition
	Adopt preventative health
	behaviours
	Improved job satisfaction among
	staff
	Improved patient safety

Table 4: Communicating care McCabe and Timmins (2013)

# 2.13 Descriptive theme: Co-ordination

Harding & McCrone (2013) identified that patients' understanding of processes and how they work was of concern for those experiencing long-term care interventions, including multiple hospital visits. Kelly et al (2015) state Individuals with chronic diseases may have difficulty optimising their health and getting the care they need due to a combination of patient, provider, and health system level barriers. Patient navigators may assist to connect people requiring primary care to appropriate providers and extend the concept of patient-centred care across different healthcare settings (Kelly et al 2015). Kelly et al (2014) and Gunn et al (2014) found patient navigators to be instrumental in helping patients navigate across a variety of services, supporting a seamless care episode, and improving their overall experience of care. This reflected the work of Lubetkin et al (2010) and Korber et al (2011) who found that the introduction of a navigator helped patient's coordinate service usage in relation to smoking cessation. Patients valued the education and information received from the navigator alongside assistance with managing symptoms and supported access to financial and community resources. A program evaluation survey undertaken by Campbell et al (2010) with patients with cancer (N = 48) (28 navigator and 20 non-navigator) and oncology staff (N = 26) found patients who received navigation services responded more positively to statements. The patient survey consisted of 10 statements directly related to the goals of patient navigation using a 10-item Likert scale format. Statistical significance (p > 0.05) was identified in 7 of 10 statements when compared with patient groups who had not received navigation. Overall patients with cancer and oncology staff reported that patient navigation is effective in increasing patient satisfaction and decreasing barriers to care. Further consideration of the importance of patient navigator co-ordination of services was found by Percac-Lima et al (2013) who identified that Latina women with abnormal Papanicolaou (Pap) smears, who had the support of navigators missed fewer appointments and had a shorter follow up period than those in the non-patient navigated group. While this randomised controlled trial study concerns a specific population, it could be replicated across a number of health and social care environments in order to examine the transferability of these results. Penderson et al (2014) found by undertaking interpretative, descriptive, gualitative face to face semi-structured interviews, patients in a number of health and social care environments identified the value of having one person to co-ordinate their care and underpin their journey through the care trajectory. Penderson et al (2014) describe the person undertaking the co-ordination as a 'quarterback'. A quarterback is a position in American and Canadian football. Quarterbacks are members of the offensive team and are considered the leader of the offensive team. In this context Penderson et al (2014) consider patient navigators leader of patients care co-ordination. Natale-Pereira et al (2011) found patient

navigators assist patients with identifying a primary care "patient-centred medical home". The patient-centred medical home is a care delivery model whereby patient treatment is coordinated through a patient's primary care physician to ensure they receive the necessary care when and where they need it, in a manner they can understand. Patient Navigators assist with facilitating appointments as needed including transportation needs. They also facilitate ancillary care, procurement of medications, and equipment (Natale-Pereira et al 2011). Four studies included in a systematic review (two were randomised controlled trials (RCTs), one was a quasi-experimental pre-post-test design study and one was a cohort study) looking at care coordination undertaken by Ranaghan (2016) et al showed that a patient navigator had benefit for patient coordination, timely access to healthcare services and patient satisfaction. One Of the randomised controlled studies reported a mean satisfaction score of 4.3 for navigated patients and 2.9 for non-navigated patients; P < 0.001. The second randomised controlled study showed an odds ratio 1.29; 95% confidence interval 0.92-1.82 for navigated versus non-navigated patients. The quasi-experimental pre-test-post-test study showed navigated patient satisfaction with a mean = 11.45 (standard deviation [SD], 3.69) in comparison with the non-navigated patient (mean, 14.95; SD, 1.69) (F = 11.85; P = 0.000). The cohort study demonstrated a mean satisfaction score of 90.7 for navigated patients and 85.5 for non-navigated patients; P = 0.03. The four studies showed no clinically significant results; however, Ranaghan et al (2016) found the patient navigator role may promote relationships among the healthcare team, reduce barriers to patient-centred care and enhance patient satisfaction. Wessex Academic Health Science Network (2018) found care navigators work in a problem solving capacity that often requires a quick response to meet the needs of people at crisis point. They coordinate input with other teams such as hospital discharge staff, district nurses, and local area coordinators. Care navigators provide people with advice, equipment, and adaptations to their homes to support selfmanagement in their own homes (Wessex Academic Health Science Network 2018). However, a major challenge for care navigators was how to achieve service user selfmanagement without creating a long-term dependency on the care navigator (Wessex Academic Health Science Network 2018). Care navigators believed taking a collaborative approach to their work made their role successful with colleagues stating they relied on care navigation services and that they *"wouldn't survive"* if the service was withdrawn (Wessex Academic Health Science Network 2018). It was reported that care navigators were directly educating health professionals' about the availability of services, voluntary services and local assets in the community (Wessex Academic Health Science Network 2018). This was considered beneficial to the wider health and social care system and would impact positively on health professionals' activity with people (Wessex Academic Health Science Network 2018).

### 2.14 Descriptive theme: Educational support

A literature review of 45 articles undertaken by Wells et al (2008) using the the keywords 'navigator' or 'navigation' and 'cancer,' in the PubMed database and from reference searches that were published or in press through October 2007, found there is evidence for some degree of efficacy for patient navigation in increasing participation in cancer screening and adherence to diagnostic follow-up care following an abnormality. Interventions found included patient navigation with or without co-interventions including health education, counselling, gastrointestinal suite improvement intervention and free cancer screening (Wells 2008). There is less evidence regarding efficacy of patient navigation in reducing either late stage cancer diagnosis or delays in initiation of cancer treatment or improving outcomes during cancer survivorship (Wells et al 2008). Wells et al (2008) report methodological limitations in most studies reviewed, such as lack of control groups, small sample sizes, and contamination with other interventions. Horner et al (2013) found many patients saw the patient navigator as a source of further education, supplementing the information they had been given by other health care professionals. This was apparent in areas such as explaining the medical terminology provided at diagnosis and during treatment (Horner et al, 2013), encouraging compliance with treatment programmes (Kelly et al, 2013) and further dissemination and clarification of information (Robinson & Watters, 2010). Repetition of information giving by patient navigators to reinforce the education provided increased patient understanding (Korber et al 2011) enabling them to make appropriate choices about their care pathway and treatment options (Hacking et al 2013). Within the mental health care setting patient navigators were able to provide specific educational input in relation to the use of appropriate interaction skills and health and wellness which Kelly et al (2013) suggest played an important role in participants in a patient navigator programme making more strategic use of emergency resources and a greater compliance with treatment regimes. Campbell et al (2010) found that a year after the introduction of patient navigators into a community cancer centre levels of patient satisfaction in relation to all aspects of cancer care had improved with education being identified as a specific area of this improvement. Natale-Pereira et al (2011) found patient navigators educate patients regarding screening guidelines appropriate for their status, identify providers and/or programs to perform screenings as needed and can educate patients regarding early signs and symptoms of cancer through information giving. Macredie et al (2014) found in a questerview study that 72% (N=18) patients felt they had a better understanding of their condition and 52% (N=13) felt more confident and in control of managing their condition with input from a care navigator. The educational input of a care navigator gave patients an increase in confidence to self-manage (Macredie et al 2014). Confidence building was important to address to enable patients to access care, socialise and negotiate with organisations delivering health and social care services (Macredie et al 2014). Wessex Academic Health Science Network (2018) found the care navigator would educate patients about community activities or social services by providing patients with information about what was available locally.

## 2.15 Descriptive theme: Information giving

Penderson and Hack (2010) reported the importance of timely and accurate information giving to patients by patient navigators through repetition, clarification, reinforcement and validation of detail. Robinson and Watters (2010) and Korber et al (2011) consider information giving as essential components of the patient navigator's role in improving the hospital experience of women with breast cancer. A focus group study carried out by Harding and McCrone (2013) found that young women undergoing breast diagnostic investigations who did not have access to a patient navigator were dissatisfied with the information they were given. This led to a loss of trust in the care providers, who they felt did not acknowledge their need for information, leaving them feeling unprepared for the ensuing diagnostic procedures. Harding and McCrone (2013) recommend that women must be given information to help them navigate the care system and obtain referrals for breast care services and conclude that patient navigators are well positioned to fill this gap in care provision. A qualitative, descriptive, grounded theory guided study found older women with breast cancer remembered the patient navigator as being particularly helpful in guiding them through the cancer care trajectory especially in relation to providing information and answering their questions (Pieters et al, 2011). While it cannot be assumed that, the needs of these two groups of women are the same it would be logical to suggest that the need for consistent information is the same and is best delivered by a patient navigator. Lubetkin et al (2010) worked with a group of general practitioners in a health promotion setting who had limited awareness of the role of the patient navigator. After receiving information about the patient navigator role the general practitioners thought there could be a role for patient navigators in following up, advising and supporting patients who had attended information giving sessions about smoking cessation (Lubetkin, 2010). Cancer Care Nova Scotia (CCNS) (2002) developed and implemented a Patient Navigation Service in partnership with three District Health Authorities. CCNS (2002) describes patient navigation as a client centred outcome-focused case management approach. Patient navigation is put in place to help health professionals, patients and their families and district health leaders deal more effectively with cancer and the cancer system. The patient navigators play a part within the cancer care team in the district health authorities by educating

and preparing patients so they are ready for their treatment visits. The navigators also provide liaison between community-based professionals and provincial cancer care programs. A report released by Our Healthier South East London (2016), stated care navigators should hold detailed knowledge of local resources and how to access them as the need to signpost patients to local resources was critical. The report stated care navigators require knowledge about social care, housing, benefits information and mental health services with this knowledge being underpinned by a broad general understanding of the National Health Service structure. The report positions that care navigators have a demystifying role through the avoidance of the use of professional 'jargon'. It goes on to state care navigators should recognise the importance of effective recording of information, use of databases, production and analysis of reports, production of minutes and action plans, and the need to pass the right information to the right agencies in a timely manner (Our Healthier South East London, 2016). Macredie et al (2014) asked patients how they would like information and support to be provided. The overall response received was that paid professionals should provide it. However, carers were happy to receive information from volunteers (Macredie et al, 2014). Macredie et al (2014) contemplated this may be due to where the initial support is pursued and/or an indication that if someone is regarded as already having knowledge and embarked on self-care they are a good source of support and information. Anderson and Larke (2009) found that patient navigators were active in linking mental health care service users with primary care services. The patient navigators provided information making positive associations with primary care interventions while undertaking patient assessment.

#### 2.16 Descriptive theme: Patient assessment

Anderson and Larke (2009) sort to evaluate if a community supported navigator model could help solve some of the challenges for mental health and substance use clients and service providers in their local community. On introduction, the navigator service was embedded in a local family mental health service organisation based in North America. The navigators provided low barrier access, comprehensive assessment, collaborative service planning, and linkage and referral facilitation for any individual or family who requested assistance (Anderson and Larke 2009). The navigator service served as an information resource for any community service provider or family physician needing to assist a client and collected data on local service needs (Anderson and Larke 2009). Analysis of quantitative data demonstrated that the navigator service model was effective in improving service access, assessment and linkage for citizens with mental health and addictions concerns (Anderson and Larke 2009). Anderson and Larke (2009) also found the navigator service was successful at connecting community services to provide a more effective network of care. Key navigator functions included connecting clients to primary care providers, supporting needs assessment and service planning for patients of local family physicians (Anderson and Larke 2009). Pendersen & Hack (2010) identified the value of the patient navigator in the oncology setting in relation to needs assessment and Korber et al (2011) identified a more specific area in terms of symptom management through ongoing assessment of needs and effectiveness of suggested interventions. Natale-Pereira et al (2011) found patient navigators undertaking patient assessment could determine eligibility for Medicaid, Medicare, and other public programs in North America. Patient navigators could procure forms and assist with completion, monitor eligibility renewal dates as needed, and follow up and assist with renewal to ensure insurance continuity. They could assist with identifying and advocating for patients for coverage of required services and assist patients with selecting and applying for health insurance by providing practical support. Carter et al (2017) in their environmental scan of health and social system navigation services in an urban Canadian community describe The Guided Care Model, a nurse-led interdisciplinary model of primary care designed to improve the quality of life and resource use for medically complex older patients through navigation. Navigators undertake a home assessment of the patient and caregiver on referral to the service, encouraging self-management. Navigators provide support to patients and carers following assessment by coordinating providers of care, smoothing patient transitions by communication with hospitals and emergency departments, and educating and supporting caregivers (Carter et al 2017).

## 2.17 Descriptive theme: Practical support

Within the reviewed North American literature (Kelly 2015, Carter 2018), much of the practical support found was provided by patient navigators in supporting service users navigate their way through financial costs and/or insurance cover required for the treatment of cancer. Providing support with financial issues is something care navigators in the United Kingdom could also become involved in by supporting service users with personal budgets introduced as part of the Better Care Fund (previously referred to as the Integration Transformation Fund) to provide person-centred integrated care. The aim of the Better Care Fund (BCF) is to get the National Health Service and local authorities to work together, as equal partners, with shared objectives. Delivery plans produced are owned by Health and Wellbeing Boards, representing a single, local plan for the integration of health and social care in all parts of the country. From April 2015, under the Care Act 2014, all adults in England who have been assessed as eligible for support from social services (including carers of adults) are required to have a personal budget. The Care Act 2014 statutory guidance states that a personal budget must always be sufficient to meet the service users' care and support needs. The amount awarded must include the cost to the local authority of meeting the person's needs that the local authority is under a duty to meet. Local authorities are required to make people aware that direct payments are available and to promote their use. However, even with no health care costs at point of delivery, financial issues can cause concern for patients which patient navigators are able to provide practical support. Penderson and Hack (2010) identified financial issues concerning patients included transport costs, parking and childcare. Repeat studies (Pendersen et al, 2014) showed financial issues are still a concern which patients need help in resolving. Natale-Pereira et al (2011) found patient navigators provided practical support in a number of ways. Patient navigators organised and/or delivered translation services and supported patients at medical visits. They assisted patients and physicians with communication at these visits, and coordinated the medical visits, looking after the patients' needs and expectations. Patient navigators also identified and supported patients to

access community resources that provided support to the patient and their significant others. Yusuf (2017) undertook a care navigator 2-year pilot project funded by the Merton Clinical Commission Group with the vision to build a more supportive, inclusive and resilient community. The main aim of the project was to connect people to activities, services and support in the community, ensuring individual wishes, goals and preferences were met. Yusuf (2017) states people were unaware of the statutory and non-statutory services available to provide support and meet their needs in the local area. Yusuf (2017) also states that people may be reluctant to independently access these services without any endorsements from family, friends or professionals. The Community Navigation Service connected 363 people (March 2016 - July 2017) across the Holistic Assessment Rapid Investigation Team and General Practitioner Practice. The Community Navigation Service received 181 referrals with 105 connections/referrals made to over 25 different organisations/services. When interviewed as part of the evaluation, 92% of patients said without the intervention from the Community Navigation Service they would not have come across the services/activities on their own. Carter et al (2017) in their environmental scan of health and social system navigation, asked navigators what activities they performed to understand the breadth and frequency of the work navigators were doing. The activities were organised into seven categories: administrative functions (e.g., conducting meetings and managing paperwork); navigating (e.g., advocating, developing linkages, and identifying services); coordinating (e.g., housing and community programs); making referrals (e.g., appointment reminders); working with other agencies (e.g., communicating with relevant agencies); client and family assessment (e.g., mental health, strengths based assessments); assisting clients and families (e.g., employment or legal issues); and client and family interventions (e.g., home visits, screening and motivational interviewing) (Carter et al 2017). Using a 5-point ordinal scale, participants were asked to report the frequency of navigation-related activities (1 = never, 2 = monthly; 3 = less than monthly; 4 = weekly; 5 = daily). Means were reported for the six most frequently reported these included building professional relationships ( $\mu = 4.38$ ), managing paperwork ( $\mu = 4.34$ ), communicating with relevant agencies or organisations ( $\mu = 4.26$ ),

advocating for clients ( $\mu$  = 4.21), providing emotional support ( $\mu$  = 4.20), and engaging and building relationships with clients ( $\mu$  = 4.08) (Carter et al 2017). Carter et al (2018) undertook a literature review of 34 patient navigator papers, most of which were descriptive with the majority originating in the United States of America. Most of the studies involved studies of individual navigators (lay person or nurse) and were developed to meet the needs of specific patient populations (Carter et al 2018). The authors make make an important contribution to care navigator literature by highlighting navigation models that address both health and social service navigation. The emergence and development of system navigation signals an important shift in the recognition that health care and social care are inextricably linked especially to address the social determinants of health (Carter et al 2018). The aim of most models found was to provide general support to facilitate access to health care through linking and connecting or removal of obstacles or barriers (Carter et al 2018). Peart et al (2018) undertook a scoping review that identified 20 studies that used patient navigation to facilitate access, and connect vulnerable patients without regular primary care, to a primary care provider. All except three studies used a person to connect the patient to a provider; the remaining three used a navigation process. Most programmes described components that could be included in a framework of patient navigation, and 17 of the 20 studies included factors inherent to patient-centred care in their design, implementation or analysis (Peart 2018).

# 2.18 Conclusion of the literature review

This review demonstrates the complex needs of patients entering the health and social care systems. Irrespective of the care environment there are common themes that have been identified that are valuable in supporting patients, carers and significant others through their health and social care journey. While some patients involvement may be brief, others have a longer relationship with the health and social care system. The consistency to be found by having one supportive individual guide patients and significant others through the care trajectory can only improve their experience of health and social care (Natalie-Pereira 2011).

Paskett et al (2011) found in their literature review of thirty-three articles published from November 2007 through July 2010 that there is some degree of evidence that patient navigation is increasing cancer screening rates, there is less recent evidence concerning the benefit of patient navigation with regard to diagnostic follow up and a paucity of research focusing on patient navigation in cancer survivorship. Paskett et al (2011) found methodological limitations in patient navigator studies, including small sample sizes and a lack of control groups. Paskett et al (2011) state that as patient navigation programs continue to develop across North America and beyond, further research will be required to determine the efficacy of cancer patient navigation across all aspects of the cancer care continuum.

As contemporary knowledge about care navigators is limited in a time of expansion of the role within health and social care in the United Kingdom (Tierney et al 2019) I chose to undertake an interpretive phenomenological study. My original contribution to care navigator knowledge is to find out the way in which care navigators make sense of their experience of their role and the extent to which these experiences impact on individual perceptions. In the next chapter, I present the methodology and method used to enable my study.

# **Chapter Three: Methodology and Method**

# 3. Introduction

In chapter two, I explored existing literature to find out what has already been identified about care navigator lifeworld to contextualise my study findings and consolidate what is already known. The lifeworld of the care navigator refers to the fundamental concept that lifeworld is the world of lived experience inhabited by us as conscious beings, and incorporating the way in which phenomena (events, objects, emotions) appear to us in our conscious experience or everyday life (Brooks 2015).

Undertaking the scoping review identified knowledge gaps that guided my appreciation of how my study contributes to further understanding and knowledge of the lifeworld of the care navigator. Undertaking the literature review permitted me to frame my study question subsequently prompting evaluation of my findings that consequently determined their relevance and usability. My review of the relevant available literature established that there is a restricted amount of published literature available regarding care navigators working in the United Kingdom (Macredie et al 2014). This made finding published peer-reviewed original research articles to inform my study inspiring but very challenging. Given the subject choice and nature of my research, I chose to take a qualitative research approach to the study. I chose this approach because qualitative' methods are used to answer questions about experience, meaning and perspective usually from the standpoint of the participant with the findings not often used for counting or measuring

(Hammarberg et al 2016). This directed my choice to undertake the study in the participants' natural setting to support my attempt to make sense of, and interpret the phenomena to understand care navigators lifeworld experience from their personal perspective (Hammarberg et al 2016). To empower this I chose to take an interpretative phenomenological analysis (IPA) approach to the study (Brooks 2015). I considered this best choice as using IPA allowed me to offer detailed examinations of the participants' interpreted personal lifeworld experience (Brooks 2015). I was able to produce an account of the participants' lived experience in its own terms rather than one prescribed by pre-existing theoretical preconceptions while recognising that this is an interpretative endeavour as humans are sense-making organisms (Smith and Osborn 2015). IPA is unequivocally idiographic in its commitment to examining the detailed experience of each participant in turn, prior to the move to more general claims (Smith and Osborn 2015). I found IPA particularly useful in examining the lived experience of care navigators, which was complex, ambiguous, and at times emotionally laden (Smith and Osborn 2015).

This chapter addresses a number of methodological principles. I start by introducing the research methodology and study design, including the underpinning epistemological stance and ontological position. I then present my chosen methodology with a number of discussions regarding the theoretical underpinnings, the rationale for selecting this approach, the limitations associated with this approach and the consideration of other approaches. The procedures that followed are outlined and discussed in relation to ethical considerations and guality in gualitative research.

#### 3.1 Applied research

For the purpose of my study, I chose to undertake an applied research approach as this type of research solves everyday problems that impact on life, work, health and well-being, addressing real world issues (Cherry 2020). It is directed primarily towards a specific practical aim or objective such as understanding the lifeworld experience of the study participants (Frascati

Manual, 2015). I chose to use an interpretive phenomenological analysis approach to the study as undertaking an action research approach would have created social change in the participants lifeworld using a process of knowledge building (Cordeiro and Soares 2018) and this was not an aim of the study. Taking a interpretative phenomenological analysis approach to the study allowed me to have theoretical commitment to the study participants as cognitive, linguistic, affective and physical beings and assume a chain of connection between the participants talk, thinking and emotional state (Smith and Osborn 2003). I understood that this chain of connection was complicated as study participants may struggle to express what they are thinking and feeling and that they may not wish to self-disclose, with me having to interpret participants mental and emotional state from what they say (Smith and Osborn (2003). This emphasis on sense-making of study participants and me, means having cognition as a central analytic concern, suggesting an interesting theoretical alliance (Smith and Osborn 2003).

In undertaking the study, I aspired to gain an understanding of the lifeworld experiences of the participants' as care navigators by exploring and illuminating the way in which they make sense of their experience of their role. I also sought to enquire how these experiences influence the participants individual perception (Smith and Osborn 2015) while working within an Inner London Borough. I sought to yield findings that would be useful in the world of contemporary health and social care by providing insight into care navigators role and how they function by interpreting their lifeworld experience (Smith and Osborn 2015). The interpretive analysis illuminates what is presented grounded in close examination of what the participant has said (Smith and Osborn 2015). Although the findings of applied research cannot be customarily generalised, my study findings provide great insight into the presently under explored identity of the care navigator role. The new knowledge generated by my study can be employed to advise on the care navigator role with the findings are emerging from the lifeworld of the participants' taking part in the study. The

participants' lifeworld experience, as I found much of the existing published care navigator literature focuses on patient and service user outcomes.

# 3.2 Research approach

Saunders, Lewis and Thornhill (2019 p.153) state that '*researchers can follow an abductive, deductive or inductive approach to research*". In abductive research the researcher collects data to explore a phenomenon, identify themes and explain patterns, to generate a new or modify an existing theory that is subsequently tested through additional data collection. In deductive research, the researcher develops a hypothesis and then designs the research to tests a theory. As I explore care navigator lifeworld experience I chose to use an inductive approach to my research, where I first collect the data and then, from the data analysis, develop knowledge of the participants lifeworld experience (Saunders, Lewis and Thornhill 2019).

# 3.3 Interpretivist research philosophy

To ensure I integrate human interest in to the study by interpreting elements of my review I followed an interpretivist research philosophy because as Myers (2008 p.38) states *"interpretive researchers assume that access to reality (given or socially constructed) is only through social constructions such as language, consciousness, shared meanings, and instruments"*. Collins (2010 p.38) positions Interpretivism as *"associated with the philosophical position of idealism, and is used to group together diverse approaches, including social constructivism, phenomenology and hermeneutics; approaches that reject the objectivist view that meaning resides within the <i>world independently of consciousness*". By operating an interpretivist approach to my research I

performed as a social actor having the capacity to shape my world in reflecting on my situation in the study, allowing me to appreciate variances found in the lifeworld experience of the participants' (Saunders et al 2012). Wilson (2012) views human beings as being cognitively gifted and exquisitely social, who evolve to live as social actors in complex hierarchical groups. Hogan (1982 pp. 55-89) sees social actors as striving for social acceptance and social status, to attain this, actors form alliances and shifting coalitions with each other. They jockey for position in different social arenas by working in groups through cooperation, competition, persuasion, guile, deception, reputation, and, when other strategies seem wanting, brute force. Human beings feel a strong need to belong to groups and have evolved adaptive mechanisms and systems to enact, monitor, develop, and refine the behaviours they exhibit in groups to process the feedback they receive from other group members regarding their social action (the meaning of social life) from the viewpoint of the study social actors [participants'] I took a naturalistic inquiry methodological approach to understanding the social world from which I interpreted the experiences and actions of the participants' in their societal and cultural context.

## 3.4 Naturalistic inquiry

Naturalistic inquiry is a paradigm of inquiry with two major features: a low degree of manipulation or control of the variables prior to the inquiry and a low degree of constraints imposed on the outcomes of the inquiry (Jacobs 1985). Using this form of inquiry prompted meanings to emerge at the end of the study process, while analysing and interpreting the findings and during the writing up process. This approach supports the interpretivist phenomenological methodology to the study as phenomenology seeks to understand the world through directly experiencing the phenomena (Littlejohn and Foss 2009). Undertaking an interpretivist approach to the study endorses the epistemological assumption that knowledge about the world is acquired through social constructions such as language, consciousness, and shared meanings. This permitted the study

to focus on the participants' making sense of their lifeworld experiences when they occurred and on the meanings they assigned to them using social constructivism as a lens. Social constructivism emphasizes the importance of culture and context in understanding what occurs in society and constructing knowledge based on this understanding (McMahon 1997). Social constructivists believe that reality is constructed not discovered through human activity with members of society together inventing the properties of the world (Kukla 2000). Individuals create meaning through their interactions with each other and with the environment they live in. There are two strands of thought found in interpretive research based on this epistemological assumption: one is based on language and its meaning; the other is related to phenomenology and hermeneutics (Klein & Myers 2001).

### 3.5 Phenomenology, hermeneutics and interpretative phenomenological analysis

Interpretative phenomenological analysis is an integrative hermeneutic phenomenology (Findlay 2011) [figure 8] with an emphasis on the convergence and divergence of experiences, as well as examining detailed and nuanced analysis of the lived experience of a small number participants (Smith et al 2009). I chose this qualitative research methodology for the study for two primary reasons: to observe how the participants' make sense of their lifeworld experience, and to provide detailed interpretation of the account to understand the experience (Smith et al 2009). I found this methodology essential when studying the participating care navigator's existential experience (Findlay 2011) as hermeneutic or existential phenomenology emphasises an understanding and meaning of "being" based on interpretive sciences, which focuses on ontological questions (Santiago Team al 2020).



Figure 7: The three influences of interpretative phenomenological analysis (Charlick et al 2016 [adapted from Smith et al 2009])

# 3.6 Introducing phenomenology

Phenomenology has evolved into the qualitative research methodology of choice towards the end of the twentieth century largely due to a seismic shift from deductive quantitative research to inductive research (Tuffour 2017). Phenomenology has gained growing interest from nursing, education, psychology, and social work when observing everyday experience in the domain of public and professional practice (Henriksson et al 2012). Smith et al (2012) leaders in the use of interpretative phenomenological analysis posit there are four leading phenomenological philosophers Husserl, Heideggar, Merleau-Ponty and Sartre that exemplify that phenomenology is a pluralist endeavour recognising more than one ultimate principle.

Phenomenology has transitioned from descriptive phenomenology, which seeks to provide a 'pure' description of people's experiences, to hermeneutic phenomenology that provides a 'interpretation'

of such experiences (Matua and Van Der Wal 2015). A review of selected peer-reviewed research and discussion papers published between January 1990 and December 2013 by Matua and Van Der Wal (2015) found that most studies following the 'descriptive approach' to research illuminated poorly understood aspects of experiences. Whereas when the 'interpretive/hermeneutic approach' was followed, contextual features of an experience in relation to other influences such as culture, gender, employment or wellbeing of people or groups experiencing the phenomenon was examined. A interpretive/hermeneutic approach is followed in the study to allow a deeper understanding of the participants experience (Matua and Van Der Wal 2015).

### 3.7 Hermeneutic phenomenology

Hermeneutic phenomenology, is also known as interpretive phenomenology, emerges from the work of Martin Heidegger (1889–1976) a German philosopher (Neubauer et al 2019). Heidegger's philosophical inquiry began in alignment with Edmund Husserl's (1859 – 1938) work the principal founder of phenomenology (Neubauer et al 2019). Heidegger later challenged the key aspects of Husserl's transcendental phenomenology (Neubauer et al 2019). Heidegger was interested in the nature of being and temporality within an ontological focus, while Husserl's interest was in the nature of knowledge within an epistemological focus (Reiners 2012). Heidegger's focus on hermeneutic phenomenology, human experience and how it is lived, moves away from Husserl's focus on 'acts of attending, perceiving, recalling and thinking about the world and on human beings as knowers of phenomenon (Laverty 2003). Heidegger saw human beings as actors in the world and focused on the relationship between an individual and their lifeworld (Neubauer et al 2019). Lifeworld referred to Heidegger's idea that 'individuals' realities are invariably influenced by the world in which they live (Lopez and Willis 2004). Because of this individual's have an understanding of themselves within the world, even if they are not constantly, explicitly or consciously aware of that understanding (Staiti 2012). Heidegger believed an individual's conscious experience of a phenomenon is not separate from the world or the individual's personal

history (Neubauer et al 2019). An individual's consciousness is a formation of their historically lived experiences including their individual history and the culture in which they were raised (Lopez and Willis 2004). Individual's cannot step out of their lifeworld, they cannot experience a phenomenon without referring back to their individual background understandings (Neubauer et al 2019). Hermeneutic phenomenology seeks 'to understand the deeper layers of human experience that lay obscured beneath surface awareness and how the individual's lifeworld, the world as they pre-reflectively experience it, influences this experience (Bynum and Varpio 2018). Hermeneutic phenomenology studies individuals' narratives to understand their lifeworld experience of their daily lives (Neubauer et al 2019). Hermeneutic phenomenology is rooted in interpretation going beyond a descriptive understanding by interpreting experiences and phenomena via the individual's lifeworld (Neubauer et al 2019). If an individual's experience is informed by their lifeworld, and if all experiences must be interpreted via their background, hermeneutic phenomenology must go beyond description of the phenomenon, to the interpretation of the phenomenon (Neubauer et al 2019).

Hermeneutic phenomenology studies the meanings of an individual's being in the world, as their experience is interpreted through their lifeworld, and how these meanings and interpretations influence the choices that the individual makes (Laverty 2003). A researcher undertaking a hermeneutic phenomenological inquiry cannot rid of themselves of their lifeworld with their past experiences and knowledge being valuable guides to the inquiry (Neubauer et al 2019). The researcher's own education and knowledge base can lead them to consider a phenomenon or experience worthy of investigation (Neubauer et al 2019). The researcher undertaking a hermeneutic phenomenological inquiry should openly acknowledge their preconceptions, and reflect on how their subjectivity is part of the analysis process (Neubauer et al 2019). Hermeneutic phenomenological interpretation is not bound to a single set of rule-bound analytical techniques; it is an interpretive process involving the interplay of multiple analysis activities (Bynum and Varpio 2018).

## 3.8 Ontological and epistemological positioning

Interpretive phenomenological analysis adopts an interpretive ontological approach, not viewing reality as objective nor as a methodological approach at the positivist end of the ontological continuum (Vicary 2017). The epistemological stance rests on the person's subjective account of experience (Vicary 2017). The study's epistemological stance is informed by the constructivism paradigm of investigative thinking. This allowed me to journey with participants into a space of interpreted reality that is as personal and individual as each of the participants and as diverse as the multiplicity of lived experiences that were found (Borland 2019). As the study participants live in the world of their personal reality each interprets that reality in their own way, this allowed me to interpret the diverse and complex socially constructed collective experience without the presumption of universality (Borland 2019). By being aware and recognising that my own interpretations of lived experience can influence interpretation of the study findings, I acknowledged my personal subjectivity throughout the investigative process (Borland 2019). Interpretative phenomenological analysis theoretical underpinnings stem from the phenomenology which originated with Husserl's attempts to construct a philosophical science of consciousness, with hermeneutics (the theory of interpretation), and with symbolic-interactionism, which posits that the meanings an individual ascribes to events are of central concern but are only accessible through an interpretative process (Biggerstaff and Thompson 2008). Interpretative phenomenological analysis acknowledges that the researcher's engagement with the participant's text as an interpretative element, it assumes an epistemological stance whereby, through careful and explicit interpretative methodology, it becomes possible to access an individual's cognitive inner world (Biggerstaff and Thompson 2008).

### 3.9 Phenomenological philosophy

Phenomenology is characterised as a 'movement' with phenomenological philosophy emerging at the end of the nineteenth century, being developed by Edmund Husserl (1859–1938) who is often considered the founder of phenomenology (Davidson 2013). Phenomenology attempts to unite philosophy, science and lifeworld and attaches importance to rich contextualised descriptions, based on experience (Davidson 2013). Husserl's work was primarily epistemological (Husserl 1982) with him believing it was possible to separate the experiencing subject from what is experienced in the world (Davidson 2013).

Husserl studied consciousness and how phenomena in the world is constituted by the human consciousness to describe how phenomena appear to the subject and how experience is established (Davidson 2013). He believed it was not possible to isolate the objects from the subject experiencing them (Davidson 2013). Husserl insisted that it is philosophically unacceptable to take the validity of the natural attitude for granted (Davidson 2013). We should not let preconceived theories form our experience but rather let our experience determine our theories (Davidson 2013). Husserl introduced the concept of 'phenomenological reduction' and the term 'epoché' (Davidson 2013). Reduction prepares individuals for a critical attitude to what is indubitably given, before interpreting beliefs rush in, suspending acceptance of the natural attitude and bracket its validity, this known as epoché (Davidson 2013). Husserl believed that through different stages of reduction it was possible to reach a more fundamental understanding of the phenomena he though it was possible to reach a state with a 'transcendal I' from where the consciousness itself could be grasped (Davidson 2013).

Although Husserl thought that transcendental reduction was possible, his successors, Heidegger, Merleau-Ponty, and Sartre thought this could be only partially achieved as individuals could never truly bracket off all presuppositions (Davidson 2013). Some phenomenologists believe it is possible to reach an understanding of phenomena without the need for interpretation (descriptive phenomenology), while others have rejected this (Davidson 2013). This difference in option is mirrored in the disagreement about whether interpretation has a place in the analysis or whether the analysis must depend solely on description when undertaking qualitative research (Davidson 2013).

Postmodernism has little regard for the philosophical contribution of Husserl (Schrag 1991). The most generous attitude toward Husserl within postmodernity is that his transcendental phenomenology may have had its day but has now outworn its usefulness (Schrag 1991). The majority of Husserl's followers, including Heidegger, developed phenomenology in less essentialist directions and stated that interpretation could not be avoided and that descriptions always involved interpretation (Davidson 2013).

Heidegger introduced the existential turn in phenomenology with the aim of 'Being' to understand existence' (Davidson 2013). Heidegger believed 'Being' always presupposes the being of something with the investigation of 'Being' requiring a choice of thematised 'Being' for analysis (Davidson 2013). This requires analysing one's own 'Being' in a circular process where the formulation of the investigative method also articulates the kind of 'Being' to be investigated (Stolorow 2006). Heidegger uses the word 'Dasein' about this kind of 'Being': "*This entity [dieses Seiende] which each of us is himself and which includes inquiring as one of the possibilities of its Being, we shall denote as "Dasein."* (Heidegger 1962, p. 27).

"*Understanding of 'Being' is itself a definite characteristic of Dasein's Being*" (Heidegger 1962, p. 32). Dasein is not another name for the human being (man) or subject but is an expression for a definite structure which makes our understanding of 'Being' possible (Figal 2009). Heidegger considered his method of investigating our own understanding to be a phenomenological one aimed at illuminating the fundamental structures of our own understanding of our 'Being'

(Davidson 2013) believing "Only as phenomenology is ontology possible" (Heidegger, p. 60) with our 'Being' often disguised in our understanding of it and we must find ways of "passage through whatever is prevalently covering it up" (Heidegger, p. 61). It must be unconcealed by means of interpretation of that understanding: "Phenomenological interpretation must make it possible for Dasein itself to disclose things primordially; it must, as it were, let Dasein interpret itself" (Heidegger 1962, p. 179).

Phenomenology relies on description, to Heidegger this description inevitably involves interpretation leading the development of phenomenology in a hermeneutic direction (Davidson 2013). This interpretation brings forward the development of understanding: "In interpretation, understanding does not become something different, It becomes itself" (Heidegger 1962, p. 188). It is concerned with "the working-out of possibilities projected in understanding" (Heidegger, 1962 p. 189). Through his concern with the ontological foundation of experiencing and understanding Heidegger displaces the concept of understanding (Davidson 2013). Understanding is a way of being situated in time and space (Davidson 2013). A main issue of concern for Heidegger was time and temporality as our experience and our existence are always understood in a temporal context between past, present, and future (Davidson 2013). Dasein is a process in a threefold temporal context and directedness: toward the future (ahead of itself), its factual being (thrownness), and its being lost in daily preoccupations (Davidson 2013). Heidegger refers to our preoccupation with this three-fold structure as 'care' (Sorge) (Davidson 2013). This term signifies the "formally existential totality of Dasein's ontological structural whole" (Heidegger 1962 p. 237). Each element of care has its basis in temporality and the meaning of care is temporality, revealing itself as the meaning of authentic care (Davidson 2013). Dasein's existentiality is always more than it is at a given time-point, It being fundamentally temporal and "being-toward-death" (Davidson 2013). Individual understanding is based upon our situated position in the world, referred to as our 'thrownness' (Heidegger 1962), interwoven in a historical world shared with others where we can never free ourselves from preconceptions which we are not aware of

(Davidson 2013). Individuals understand things from certain framework conditions that cannot be objectified or explained completely (Davidson 2013). Individuals see things in their appearing, meaning a phenomenon is not clearly showing itself but that it makes itself known, announcing itself without showing itself (Davidson 2013). Later phenomenologists Merelau-Ponty and Sartre built upon Heidegger's view of Dasein as being-in-the-world, an entity whose essence is its existence (Kelly 2016). Merelau-Ponty develops Heidegger's notion of Dasein as being-in-the-world, emphasising the being of Dasein as its bodily comportment and declares the body an essentially intentional part of the subject (Kelly 2016). In his view, Merleau-Ponty wants to make the body itself intentional, intertwining time and the subject (Kelly 2016). Sartre's contribution to the phenomenology of time lies in his understanding of how consciousness relates to the world (Kelly 2016). This fundamental mode of transcendence Husserl labeled 'absolute time-constituting consciousness', Heidegger, 'Dasein', and Sartre termed 'for-itself' (Kelly 2016). Sartre's theory presents an unlikely union of Husserl's and Heidegger's differing views of consciousness mode of intentionality and its fundamental self-transcending nature in its mode of temporality (Kelly 2016).

### 3.10 Husserl (1859 – 1938)

Husserl believed phenomenological inquiry requires experience to be explored in its own terms in the way that it occurs (Smith et al 2009). Husserl was concerned with finding a means by which someone might come to precisely identify their own experience of a given phenomenon with a depth and rigour that stimulated them to identify the essential qualities of that experience (Smith et al 2009). He reasoned that these essential qualities of the experience could go beyond the particular circumstances of their appearance, allowing an illustration of the experience to others (Smith et al 2009). Husserl's phenomenology involved stepping outside of our natural attitude (everyday experience) in order to scrutinise that experience (Smith et al 2009). Husserl supposed phenomenological inquiry emphasises what is experienced in the consciousness of the individual (Smith et al 2009). He raises the term 'intentionally' to describe the relationship between the consciousness process and the object of attention for that process (Smith et al 2009). So, in

phenomenological terms, experience or consciousness is always consciousness of something, seeing is seeing of something, remembering is remembering of something, judging is judging of something (Smith et al 2009). That experience of something could have been simulated by a perception of a 'real' object in the world, or through an act of memory or imagination (Smith et al 2009). Husserl developed a 'phenomenological method' to identify the core structures and features of human experience (Smith et al 2009). He suggested we need to 'bracket' our 'taken for granted world' in order to focus on our perception of the world (Smith et al 2009). This 'putting in brackets' closes the phenomenological field the world as it exists for the subject in simple absoluteness; its place, however is taken by the world as given in consciousness (perceived, remembered, judged, thought, valued) (Husserl, 1927:para 3) (Smith et al 2009). This bracketing does not mean the taken for granted world disappears as Husserl defines a process of 'reductions' each reduction offers a different way of thinking and reasoning about the phenomenon experience (Smith et al 2009). This sequence of reductions takes the inquirer away their own assumptions and preconceptions and allows the essence of the phenomenon experience to be found (Smith et al 2009). Husserl was critical of scientific world reminding us that our lifeworld (everyday life) provides the experiential grounding for the objective or scientific world (Smith et al 2009). He believed the scientific world is a second order knowledge system that depends on first order personal experience to further scientific account (Smith et al 2009). Therefore when conducting phenomenological inquiry, scientific constructs need to be 'bracketed' because they act as a screen from experience (Smith et al 2009). Husserl's work encouraged me to focus on the process of reflection on the lived experience of life. This tactic supported me in finding the essence of the participant's experience as care navigators in their lifeworld.

### 3.11 Heidegger (1889 – 1976)

Heidegger was a student of Husserl's acknowledging an intellectual debt to Husserl, he stressed his difference from him in his approach to phenomenology (Smith et al 2009). He set out the early stages of the hermeneutic and existential emphases in phenomenological philosophy (Smith et al 2009). Heidegger believed Husserl's 'descriptive approach' to phenomenology was too theoretical and questioned the possibility of any knowledge outside of an interpretative stance, whilst grounding his stance in the lived world (Smith et al 2009). Husserl was predominantly concerned with the individual psychological processes, such as perception, awareness and consciousness (Smith et al 2009). Whereas Heidegger's 'interpretive/hermeneutic approach' is concerned with the ontological question of existence itself (Smith et al 2009). This being the practical activities and relationships in which involved and through which our world is made meaningful (Smith et al 2009). The key ideas I took from Heidegger are human beings can be conceived as being 'thrown into' a world of objects, relationships, and language (Smith et al 2009). Our being-in-the-world is always perspectival, always temporal, and always 'in-relation-to' something. Meaning that the interpretation of people's meaning-making activities is central to phenomenological inquiry (Smith et al 2009).

### 3.12 Merleau-Ponty (1908 – 1961)

Merleau-Ponty advocates that humans see themselves as different from everything else in the world (Smith et al 2009). This is because our sense of self is holistic and is engaged in looking at the world, rather than being subsumed within it (Smith et al 2009). Merleau-Ponty holds Husserl's view of science, as providing second-order knowledge derived from a first-order experiential base (Smith et al 2009). He believed empirical science failed to conceptualise the mechanisms of perception and judgement adequately (Smith et al 2009). He believes our perception of 'other' always develops from our own embodied perspective (Smith et al 2009). Meaning that our relations to others begin from a position of difference (Smith et al 2009). While we can observe and experience empathy for another, however we can never wholly share another's experience, because their experience belongs to their own embodied position in the world (Smith et al 2009). From Merleau-Ponty I took that the body shapes the fundamental character of our knowing about
the world and this is critical. Merleau-Ponty supposed that practical activities and relations, the physical and perceptual affordances of the body in the world are thus more significant than abstract or logical ones (Anderson, 2003).

### 3.13 Sartre (1905 - 1980)

Sartre accentuated that we are caught up in projects in the world (Smith et al 2009). He thought our self-consciousness is an action-orientated, meaning making, self-consciousness that engages with the world we inhabit (Smith et al 2009). Sartre stresses the developmental, processual aspect of human being (Smith et al 2009). He stated 'existence comes before essence' (1948:26) indicating that the self is not a pre-existing unity to be discovered but rather an ongoing project to be developed (Smith et al 2009). I take from Sartre that we are better able to conceive of our experiences as contingent upon the presence and absence of our relationships to other people.

# 3.14 Summary of consideration of various phenomenological theorists

Husserl, Heidegger, Merleau-Ponty and Sartre are foremost figures in phenomenological philosophy. Husserl recognised the importance and relevance of a focus on experience and its perception (Smith et al 2009). Heidegger, Merleau-Ponty and Sartre develop Husserl's work each by viewing of the person as embedded and immersed in a world of objects and relationships, language and culture, problems and concerns (Smith et al 2009). They build upon his descriptive commitments and transcendental interests to provide a more interpretative focus on understanding the perspectival directness of our involvement in the lived world (Smith et al 2009). This being personal to each of us, related to our relationship to the world and others (Smith et al 2009). There is a growing interest in phenomenology has contributed to the spread of the approach with little consensus of what constitutes the methodology (Tuffour 2017). Debates about the appropriate

ways to undertake phenomenological research continue (Tuffour 2017). Tuffour (2017) states two broad categories can be identified: descriptive and hermeneutic.

# 3.15 Hermeneutics

Descriptive phenomenology focuses on the essence or structure of experiences in the way it occurs to our conscious (Neubauer et al 2019). Descriptions of the experiences are strictly connected to the data without influence of any external theory. This approach is based on Husserl's phenomenology philosophy which involves the principles of epoché, "suspension of judgment", intentional analysis and eidetic reduction. It is compulsory for the researcher to adopt a phenomenological attitude and bracket or put aside past knowledge or presuppositions (Finlay 2011). Opposed to descriptive phenomenology is the hermeneutic or interpretative approach that is based on the principles that reduction is impossible and therefore personal opinions are endorsed in favour of interpretation of experiences (Tuffour 2017). Thus, research findings are immersed with philosophical, theoretical, literary and interpretative lenses ensuing to an aspect of human experience grounded on unrestricted imagination and metaphorical sensibility (Tuffour 2017). Allen (1995) contends that there is no clear distinction between descriptive phenomenology and hermeneutic phenomenology, he describes phenomenology as foundationalist, as it seeks a correct answer or valid interpretation of texts not dependent on the biographical, social or historical position of the interpreter. Hermeneutic phenomenology is described as non-foundationalist, as it focuses on meaning that arises from the interpretive interaction between historically produced texts and the reader (Laverty 2003). Finlay (2011) identifies four contemporary phenomenological approaches that do not fit the Husserlian and Heideggerian or the descriptive-hermeneutic divide: lifeworld approaches; first person accounts; reflexive, relational approaches; and Interpretative Phenomenological Analysis (IPA). Lifeworld is descriptive or hermeneutic phenomenology research used to explore how everyday experience demonstrates itself in the lifeworld of individuals. This approach is used to find the intentional relationship between the conscious,

social, perceptual, and practical experiences by analysing time, space, and the taken-for granted presentation of experience (Finlay 2011). Researchers use their own subjective experiences in first-person approach with the use of interpret descriptive or hermeneutic approaches to examine the quality and essences of a phenomenon (Tuffour 2017). The approach uses the ideals of Husserl who believes that access to the world is through consciousness as experienced from the first-person perspective. This approach combines concrete narrative descriptions of momentous events with theoretical discussion and/or literary flourish thus, catapulting personal reflection to a detailed and deep analysis that embellishes experiences (Finlay 2011). Data and/or meanings are seen to surface out of the context or dialogue in reflexive-relational approaches between the researcher and the participant. The participant is regarded as co-researcher in the embodied dialogical encounter. Researcher reflexivity and researcher-participant (inter-)subjectivity is celebrated (Finlay 2011). Interpretative phenomenological analysis is committed to explore, describe, interpret, and situate the participants' sense making of their experiences (Larkin et al 2006). The main theoretical underpinnings of interpretative phenomenological analysis are phenomenology, hermeneutics, and idiography (Smith et al 2009).

### 3.16 The Hermeneutic circle

Hermeneutics the art and science of interpretation or meaning, is a key theoretical underpinning of interpretative phenomenological analysis. In this context, meaning is considered fluid and is continuously open to new insight, revision, interpretation, and reinterpretation (Henriksson 2012). Ricoeur, an eminent French philosopher of the twentieth century, linked phenomenology and hermeneutics by explaining that experience and meaning are closely intertwined. He believed meaning to be indispensable to experience with hermeneutics experience and language being coemergent. Language is an expressive force of experience not only used for descriptive purposes (Tuffour 2017). Experience reveals itself only when it is expressed in poetic, figurative and rhythmic language (Tuffour 2017). Thus, through interactive and textual interpretation,

hermeneutic theorists utilize their subjective expressions to reconstruct original meanings during textual interpretation. Hermeneutic phenomenology, therefore, embraces the literary and poetic aesthetic application of language that emanates from the process and product of research (Henriksson Team al 2012). Heidegger believes that our being in the world presents us with a fundamental interpretative situation that compels us to ask questions about our world (Henriksson et al 2012), therefore Heidegger's concept of appearance of being captures the essence of interpretation well in interpretative phenomenological analysis. This presents the notion that there is a phenomenon out there ready to be explored requiring the detective work of the researcher to bring it to light using prior experience, assumptions or preconceptions to make sense of the experience once it is revealed (Smith et al 2009). Undertaking interpretative phenomenological analysis required me to employ close interpretation of participant's narratives when I was not necessarily aware of my preconceptions beforehand (Smith Team al 2019). However the complex and dynamic way the relationship between interpretation and fore-understanding is explored may reveal a more robust and cyclical reflexive bracketing (Smith et al 2009). While undertaking the study I engaged in 'double hermeneutic' with me making sense of the participants' sense making (Smith et al 2019). While doing so I undertook the central role of analysis and interpretation of the participants' experiences (Smith et al 2009). This prompted me to spontaneously probe experience surface meanings by reading in between the lines for deeper interpretation (Finlay 2011). The dynamism of interpretation and reflection resonates superbly with the hermeneutic circle model dealing with the dynamic relationship between the 'part' the encounter with the participants' in the study and the 'whole' my drawing of knowledge and experience at numerous levels for a holistic analytical interpretation (Smith et al 2009).

### 3.17 Idiography

Interpretative phenomenological analysis is idiographic in nature with its commitment to the detailed analysis of particular or unique events (Shinebourne, 2011). As I wanted to delve deep

into each individual case, an ideographic approach to my study fitted (Smith and Osborn, 2015). Using an interpretative phenomenological analysis approach within the study allowed a very specific focus on how the participants' experience has been understood from their perspective in their lifeworld. This was achieved by ensuring each participants' narrative received detailed and nuanced analysis, valuing each on its own merits before moving to the general cross-case analysis for convergence and divergence between narratives (Smith et al 2009). I adhered to this idiographic approach throughout the analytic process to ensure the meticulous detailed examination of the convergence and divergence between the participants' experiences. Interpretative phenomenological analysis allowed for great potential of understanding and interpreting of the participants' experiences (Eatough and Smith 2006 and Shinebourne and Smith 2010). However, having taken an interpretative phenomenological analysis approach within the study there are methodological limitations were needed to be considered.

### 3.18 Criticisms of interpretative phenomenological analysis

As with all methodologies interpretative phenomenological analysis has been criticized, Giorgi (2010 p.7) describes it as *'being riddled with ambiguities as well* 

*as lacking standardization*'. Hefferon and Gil-Rodriguez (2011) believe it to be mostly descriptive and not sufficiently interpretative. Willig (2008) believes like many phenomenological studies interpretative phenomenological analysis provides unsatisfactory recognition to the integral role of language. However she accepts that meaning making takes place in the context of narratives. Smith et al (2009) believe while the primary purpose of interpretative phenomenological analysis is to gain insight into experience, it will always be entwined with language. Willig (2008) considers phenomenological research is only appropriate to use with eloquent individuals as phenomenology as a research approach relies on the accounts of participants and the experiences of researchers. Tuffour (2017) suggests this criticism can be considered elitist by suggesting only those having access to the right level of fluency are allowed to describe their experiences. Interpretative phenomenological analysis focuses on perceptions making it problematic and limiting to our understanding, because phenomenological research seeks to understand the lived experiences but does not explain why they occur (Tuffour 2017). Willig (2008) believes research inquiry should seek to understand the experiences of its participants and also explore the conditions that triggered the experiences which are located in past events, histories or social-cultural domain. Smith et al (2009) counteract this by arguing that interpretative phenomenological analysis uses hermeneutic, idiographic and contextual analysis to understand the cultural position of the experiences people have. Interpretative phenomenological analysis is primarily a subjective research approach, so two analysts working with the same narrative may provide very different interpretations (Brocki and Wearden 2006).

### 3.19 Rationale for adopting interpretative phenomenological analysis

In reviewing my own epistemological stance, that my values are inherent throughout all phases of the study process, interpretative phenomenological analysis was the most appropriate methodological approach to use to undertake the study (Smith 2004). When comparing interpretative phenomenological analysis' epistemological stance alongside other qualitative methodologies, I believe that interpretative phenomenological analysis was not purely a 'best fit' but echos my own beliefs and expectations for the study. I asked three questions as suggested by Willig (2012) when determining interpretative phenomenological analysis as the approach for the study: What type of knowledge does interpretative phenomenological analysis hope to create? What are interpretative phenomenological analysis assumptions about the world it studies? And what is the relationship between the researcher and the knowledge generated? Interpretative phenomenological analysis adopts a 'constructivism-interpretivism' stance to generate a detailed understanding of experiences from the viewpoint of the participants (Ponterotto, 2005). By engaging with the findings I was able to gain an insight into the participants' lifeworld thus

producing emperical knowledge about what and how the participants' think (Willig, 2008). In order for the participants' experience to be understood I interpreted the findings, this being influenced by my experiences and beliefs, described by Gadamer (1990) as a 'fusion of horizons'. As this influence is embraced in interpretative phenomenological analysis the knowledge generated can be considered to be reflexive (Willig, 2008).

By using interpretative phenomenological analysis I recognised each participant brought their own subjectivity to their lifeworld experience and that each experience was unique to the participant who perceived it (Brook 2015). This is in direct contrast to the positivist epistemological position that presumes an objective reality can be captured (Ponterotto, 2005). Willig (2008) argues that interpretative phenomenological analysis in its recognition that a person's interpretation is inevitably affected by social interaction and processes thus adopts a 'symbolic interactionist' perspective (Dionysiou 2013). Interpretative phenomenological analysis positions itself within an interpretative phenomenological stance towards its analysis as meaning is understood through interpretations made by the researcher (Tuffour 2017). This highlighted the importance of my incorporating a reflexive attitude towards the findings. Willig (2008) believes that interpretative phenomenological analysis does not advise the researcher on how to include their reflexivity or how their conceptions may impact on the analysis. Ponterotto (2005) considers that the constructivism-interpretivism approach demands that meaning behind a phenomenon lies hidden but can be found through reflection that occurs through discussion between the researcher and the participant as observed in interpretative phenomenological analysis. I believe that the study supports participants' to be 'heard' through the bottom-up inductive approach thus giving 'voice' to the participants with this being a fundamental element of interpretative phenomenological analysis (Larkin & Thompson 2012).

# 3.20 Positionality

As interpretative phenomenological analysis works with a 'double hermeneutic' where the researcher endeavours to understand the participant's own understanding of the phenomenon (Smith et al, 2009), the researcher is the main data collection instrument. Because of this my socio-cultural background and subjectivity influenced the study findings as far as the participant background affected the findings (Bourke, 2014). This confirms that the study was a collective space where the participants' and my identities are expressed through our perceptions and therefore have impact on the quality of the work. Positionality therefore represents a space in which objectivism and subjectivism meet (Freire, 2000 p50) and where objectivity can never truly be achieved. Smith and Osborn (2015) believe interpretative phenomenological analysis is designed to create an insider's perspective, therefore, I had to position myself within the lifeworld of the participants'. This dichotomy required me to consider how I could step back from the insider position to interpret the findings more broadly described by Ritchie et al (2009) as an 'outsider'' taking an 'insider's perspective.

A significant amount of the discussion has concentrated on the insider/outsider status dichotomy (Moore 2015). An example of this can be found in the work of Foster (2009) who conducted a research study regarding cancer as an insider and deliberated that she was able to connect to her participants in a way that was unique. While Foster (2009) did deliberate against insider status, she concluded that research conducted by insiders is valid, legitimate, and rigorous as qualitative researchers recognise the fluidity and multilayered complexity of human experience.

I considered myself to be an 'insider' while undertaking the study as I had previous experience of working with care navigators in clinical practice as the lead of an inpatient unit and community based intermediate care service. I also had experience of developing and delivering a training programme for care navigators working across three Greater London Boroughs. This did not

include the Borough in which the study participants worked. I also worked on developing the Health Education England publication Care Navigation: A Competency Framework (Health Education England 2016) as a professional adviser in my capacity as an associate professor of health and social care vocational education. This was of significance when I was sampling participants for my study as I wanted to generate a purposive, fairly homogeneous sample as required when undertaking interpretative phenomenological analysis. This ensured the study holds relevance and personal significance to respondents, and enabled me to capture detail on a specific group of individuals who had experienced the phenomenon of being a care navigator (Noon, 2018).

### 3.21 Sampling

Various sample sizes have been used for interpretative phenomenological analysis with the specificity of the sample dependent upon the phenomena under investigation (Noon 2018). Smith et al (2009, p.48) emphasise that sampling in interpretive phenomenological analysis must be theoretically consistent with the qualitative paradigm this means that samples should be selected purposefully. Suri (2011) states purposive sampling allows the researcher to access key informants within the phenomenon. It permits the selection of a sample that is homogeneous, which is important for capturing the understanding (Wagstaff and Williams, 2014) embedded in care navigators lifeworld experience. A purposeful homogeneous population sample accessible to me was chosen for the study. This being five care navigators working in the third sector in two sectors of an Inner London Borough *[table 5]*. I considered five paticipants' a adequate sample as larger samples can become unwieldy and as Smith et al (2009, p56) suggest in interpretative phenomenological analysis research, *"there is no right answer to the question of …sample size"*. Access to the participants' was neogoiated with their employing organisation and with each care navigator. Clarke (2010) stipulated that four to ten participants is advised for professional doctorates.

### 3.22 Sampling Technique

Criterion sampling in which participants meet predefined criteria is used within phenomenology. The participant's experience with the phenomenon under study is the main criterion used (Moser and Korstjens 2018). To meet this criterion the participant sample consisted of people working in a paid role in the third sector with the job title care navigator based in primary care within the nominated London Borough.

# 3.23 Recruitment

I identified participants by approaching the care navigator's line manager the 'workplace gatekeeper'. Potential participants' were invited to join the study with the use of an invitation letter containing information about the study which supported informed consent *[Appendix 5]*. Those who wanted to partake in the study of their own free will, were requested to sign a participant consent form, stating they made an informed choice to participate in the study. Informed consent to participate in the study was obtained as Health Research Authority guidance.

No financial incentives to participate were used, as this could be perceived as coercion or inducement, and may have ramifications for those who may feel disadvantaged or advantaged by this (Bradbury and Alcock 2010). Participants' were informed that they were free to withdraw themselves or their data from the study at any stage (Bradbury and Alcock 2010). Participants' where informed they would not be required to provide a reason for withdrawal and would not be penalised for withdrawing (Bradbury and Alcock 2010). Participants' were given pseudonym throughtout the study (Bradbury and Alcock 2010).

As my study involved observation of human subjects I ensured that the benefits of undertaking the study outweighed the risk of harm (Bradbury and Alcock 2010). To acknowledge and respect the human dignity of participants' an ethical framework was adhered to during the study process

(Bradbury and Alcock 2010). Ethical frameworks often change to reflect evolving social context that includes research, moral imperatives and ethical principles, and the law (Bradbury and Alcock 2010). To offset this current Health Research Authority was referred to during the study to advise and guide ethical requirements.

Ethical approval to undertake the study (Bradbury and Alcock 2010) was sort from and granted by the London South Bank University Health and Social Care School Ethics Panel and the study conformed to the principles set out in The LSBU Code of Practice. Ethics approval was also sort from and granted by The Health Research Authority *[Appendix 1,2,3,4]*.

I honoured the Gillon (1994) ethical principles throughout the study; Do good (beneficence), Do no harm (non-malficence), Protect participant anonymity and confidentiality, Avoid using deceptive practices (veracity) and Give participants the right to withdraw from the study (autonomy) when collecting data.

# 3.24 Sources of data

A semi-structured interview schedule containing open-ended, non-directive questions to encourage free narrative and detailed responses was used during the study as required in interpretative phenomenological analysis (Smith and Osborn 2008) to capture the data source. The interviews were held at the participants availability which due to work commitments was limited to a one and a half hour session. A 'prompt sheet' with main themes for discussion with the participants' was used (Moser and Korstjens 2018). The 'interview schedule' was merely a basis for a conversation: it was not intended to be prescriptive and certainly not limiting to the expressed experience of the participant (Moser and Korstjens 2018). The participants' took the lead during the conversation (Biggerstaff and Thompson, 2008) allowing them to express their thoughts, understanding and experience without being directed or prompted by myself to promote credibility and trustworthiness. The interview was recorded with consent from the participant and later transcribed verbatim by me (Moser and Korsjens 2018).

# 3.25 Credibility and trustworthiness

Interpretative phenomenological analysis shares the aims of hermeneutic phenomenology with the aim of capturing individual experiences (Tuffour 2017). This required me to recognise myself as the researcher within the research and analytic process (Tuffour 2017). My analysis was a product of the interactions between the participants' and myself, with it being considered to be both phenomenological (participants' accounts) and interpretative (my interpretation of participants' accounts) (Tuffour 2017). These interpretations are based on my own conceptions, beliefs, expectations and experiences (Smith et al.1999). In this respect, the use of interpretative phenomenological analysis required reflexivity from myself as I was expected to explicitly present my own perspectives in the findings, thus illuminating the analysis (Willig, 2008).

My interpretation of participants' accounts in this study are influenced by my own lifeworld experience and exposure to care navigators. I had the preceding experience of developing and delivering an education programme for care navigators and being involved in the development of Care Navigation: A Competency Framework led by Dr Jacqueline Simms, Darzi Fellow in Clinical Leadership for Health Education England. There is also possible cross contamination from my experience of undertaking the systematic literature review. However by undertaking an interpretative phenomenological analysis approach my own assumptions and explanations were a necessary precondition for my making sense of participants' thoughts and feelings (Willig, 2008).

As the participants' and myself are living, experiencing human beings, it was necessary for me to reflect on how that would impact the research rigor and reflexivity when gathering my findings and analysing them (Tuffour 2017). For the purpose of the study the gathering of the findings involved

me engaging with other people's language, and their interpretation of the experiences they had (Tuffour 2017).

# 3.26 Rigor and reflexivity

The methodological rigor of interpretive research was a major concern that I had to approach. Klein and Myers (1999) propose a set of principles that explore the role of hermeneutics, anthropology and phenomenology in eliciting knowledge from interpretive studies. They recommend researchers not to apply the principles automatically but reflect how and if they are useful to their project. The hermeneutic principle is a fundamental meta-principle, and the other six principles are in its dependency. Klein and Myers (1999) define the principles as the principle of hermeneutic circle; the principle of contextualisation; the principle of interaction between the researcher and the subjects; the principle of abstraction and generalisation; the principle of dialogical reasoning; the principle of multiple interpretations; and the principle of suspicion.

The fundamental meta-principle of the hermeneutic circle, suggests that human understanding is achieved by iterating between the interdependent meaning of the parts and the whole they form (Cardoso and Ramos 2012). The parts and the whole can be at numerous levels as in this study: the different levels of observations (researcher and participants') and our shared understanding, the historical and social aspects of the participants' with the whole perspective of the context, and the conceivable relation with the literature reviewed (Cardoso and Ramos 2012). The principle of contextualisation observes that an explanation of the situation under investigation, the lifeworld experience of the participants', requires a critical understanding of the social and historical aspects (Neubauer et al 2019).

The principle of interaction between the participants' and me required critical reflection of how the findings were socially constructed through the interaction between us (Neubauer et al 2019). However, the principle of abstraction and generalisation required that I relate the idiographic details revealed by the findings interpretation to theoretical and general level concepts (Cardoso and Ramos 2012). The principle of dialogical reasoning advises that there should be understanding given to potential contradictions between the theoretical framework guiding the study and the actual findings (Cardoso and Ramos 2012). The sixth principle emphasises the possible differences in interpretations of the events under study among the participants', and the principle of suspicion recommends I should also be aware of possible biases and distortions in the narratives collected from the participants' (Klein and Myers 1999).

Reflexivity required me to reflect on my thoughts, actions, assumptions and expectations throughout the study (Lambert et al 2010) *[Appendix 7]*. This required me to be aware of my influence on the study findings by bringing my thoughts and actions to a conscious level (Jootun et al 2009). Finlay (1998) and Smith (2006) consider that reflexivity enables the researcher to provide a rationale for their decisions, and if required alter the research process to generate relevant findings. Darawsheh (2014) belives it is not clear if reflexivity is a criterion, strategy or tool of rigour in qualitative studies. She posits reflexivity is an introspective process in which the researcher becomes aware of and more 'transparent' when presenting their subjective influence on the research process.

Reflexivity allowed me to advance my awareness of my personal qualities and characteristics that influenced the research process (Attia and Edge 2017). This facilitated me to further explore participants' interviews (Jootun et al 2009, Finlay 1998, and Smith 2006) and control my subjectivity so not to overly assert my interpretation on the interviews (Jootun et al 2009, McCabe and Holmes 2009, Lambert et al 2010). I did not employ relexivity to bracket my subjectivity or increase my objectivity (Lambert et al 2010) but utilised it to increase the credibility of the study to generate relevant findings (Findlay 1998, Smith 2006, Jootun et al 2009). With this I support Findlay and Ballingers (2006) belief that subjectivity should be celebrated when undertaking

analysis of findings and not viewed as 'contamination' to be elimiated as proposed by Thurston (2010).

### 3.27 Findings analysis

Interpretative phenomenological analysis does not have one 'prescribed method' for working with findings, it involves the close reading and re-reading of the text (Smith et al. 1999). Data analysis has been described as an 'iterative' and 'inductive' cycle (Smith 2007) that draws upon a number of strategies.

During the initial stage of data analysis I read and re-read the transcripts I produced of the participants interviews to enable full immersion in the process I order to get as 'close' to the data as possible (Noon 2018). I annotated the text on each reading with my initial ideas in a wide margin I created on the transcript [see appendix 7] (Noon 2018). I made notes of any thoughts, observations and reflections that occured to me while reading the semi structured interview transcript while undertaking line by line analysis of the experiential claims, concerns and understandings of the participant (Larkin, Watts and Clifton 2006). These notes included any recurring phrases, my questions and own emotions, and descriptions of, or comments on, the language used. These notes were used to document points I observed while engaging with the text (Smith et al. 1999). This allowed me analytic focus that directed my attention to the participants attempt to make sense of their experience (Smith et al 1999). To produce a deeper, interpretive analysis I reflected not only what was said, but also how it was said, and what that told me about the experience (Noon 2018). The use of coding helped to ensure that the participants individual voice emerged from their interview rather than pre-existing thoughts I found while undertaking the study scoping literature review (Noon 2018).

After reading and re-reading the verbatim interview transcript and annotation I returned to the beginning of the transcript to document any emerging themes (Noon 2018). I drew emergent

themes from the detailed and comprehensive annotations made earlier rather than the transcript itself (Noon 2018) computer aided analysis supported this process (see 3.28). Similar themes began to emerge during initial note taking with these initial annotations developing into concise phrases which reflected the essence of what was found in the transcript during the secondary stage reading (Noon 2018). These emergent themes were a little more advanced allowing theoretical connections to be made, while remaining grounded in the particularity of the participant's initial response (Noon 2018).

To connect emergent themes; the conceptual similarities (Smith and Osborn 2008), I used a separate piece of paper, listing emergent themes in chronological order, based on the sequence they appeared in the transcript (Noon 2018). Clustering themes together prompted the emergence of superordinate concepts that held hierarchical relationships with one another, while others were dropped entirely from the process as having a weak evidence base (Noon 2018). The clustered emergent themes became sub-themes (Noon 2018). As I had drifted from using the exact words of participants at this stage of analysis, I referred back to the transcript to ensure connections were consistent with the raw data to ensure that I stayed true to the essence of the participant's lifeworld experience (Noon 2018).

Sub-themes were then situated into the superordinate themes using a table format to provide a composite portrayal of experience (Denovan & Macaskill 2012). The table placed the sub-themes within their respective superordinate theme, along with relevant data extract or quote beside each theme to retain the voice of each individual participant (Noon 2018).

I then moved onto the next transcript repeating the process (Noon 2018). Early interpretive phenomenological analysis literature notes that the researcher may elect to draw upon themes from the first case to aid their subsequent analysis (Smith et al 1999). However later discussions have placed a greater emphasis on approaching each case "on its own terms, to do justice to its

own individuality" (Smith et al 2009, p. 100). During this process, I considered my analysis would be influenced by the findings from previous accounts and my own lifeworld experience (Noon 2018).

After all the transcripts had been analysed a final table of superordinate themes and their respective sub-themes was produced (Noon 2018). During this iterative process I re-read the original transcripts to identify emergent themes in the experiential material, emphasizing both convergence and divergence, commonality and nuance, across the transcripts (Eatough and Smith 2008). If I found material that did not appear to fit an emerging theme, I revisited all the transcripts to observe if I had missed or misunderstood something posited as a contrasting theme (Biggerstaff and Thompson 2008) and if necessary I amended them to support the decision on which themes to prioritise, and which to abandon (Noon 2018).

Smith and Osborn (2008) suggest that themes should not be selected purely on their prevalence within the data, but also on the richness of the passages which highlight said themes, and how the themes assist in illuminating other aspects of the account. I decided that at least two participants must have discussed a topic for it to be considered along with my analysis of the level of pertinence placed upon the topic by the participants' (Noon 2018).

I found the Smith et al (2009) interpretative phenomenological analysis seven-step guide adapted by Charlick et al (2016) valuable when undertaking the data analysis *[figure 9]*. The use of this guide supported my data analysis process as I found this challenging as the route through data analysis in interpretive phenomenological analysis is not linear (Charlick et al 2015). I found the experience to be conceptually demanding and intense, drawing on my intuition and creativity as there is no clear right or wrong way to conduct this type of analysis as perceived by Smith, Flowers, and Larkin (2009).



Figure 8: The seven-steps of IPA data analysis (Charlick et al 2016 [adapted from Smith et al 2009])

# 3.28 Computer aided analysis

To enhance and support my analysis of the study findings I used the computer assisted data analysis programme (CAQDAS) Nvivo version 11 (2015). The programme assisted me in my analysis of the findings by retrieving specific words and text strings in the primary findings. Text mining *[Appendix 6]* helped with visualizing the findings by displaying frequencies, co-occurences, or other connections found in the transcripts (Green and Thorogood 2018).

Text mining provided a visable means of checking the veracity of interview analysis. For example, the number of instances a concept appears is given, as well as a visual representation as to how that term links to related concepts (Prior et al 2011). I support Ryan and Bernards (2003) belief

that text mining can alert the researcher to hidden themes when exploring or mapping the experience findings that the researcher may have missed by ignoring the value of underestimated themes. Text mining enabled me to find the nine subordinate themes that emerged from the superordinate themes, both found in the study interpretative narrative.

Using Nvivo 11 allowed my analysis to be more thorough and systematic than if I had done it by hand. With the whole findings set coded, searches for segments relating to codes produced all relevant findings, rather than just those excerpts that I had noticed. This facilitated analysis that had greater transparency, as there is a record of how coding schemes were developed and how theoretical concepts emerged through recorded memos during the interpretative phenomenological analysis process (Green and Thorogood, 2018).

### 3.29 Validity

There is an ongoing debate surrounding the means in which qualitative research can be assessed to ensure its quality (Elliott, Fischer & Rennie, 1999; Yardley, 2000). Yardley (2000) considers this is a contentious topic due to the uniqueness of this methodological approach. She considers that unlike quantitative methods, the ways in which to assess validity within qualitative research are not well established and are challenging to define. She suggests that this could be because of the rich diversity of qualitative methodologies available and their accompanying epistemologies. She asserts that due to the unwillingness of qualitative researchers to employ universally agreed methods, assumptions and objectives, a cloud of confusion and scepticism envelops their work.

A number of guiding principles are available that attempt to factor how qualitative research should be assessed for validity. Yardley (2008) states that by simply following guidelines you cannot guarantee good quality research. Yardley offers four core principles for assessing quality within qualitative research that I follow within the study. The first principle is 'sensitivity to context' this is followed in three ways within the study, through sensitivity to existing theory, to the socio-cultural context of the study and to the participants (Yardley 2000). The use of interpretative phenomenological analysis in the study establishes sensitivity to context as it explores the idiographic, the specific focus on how the participants' experience has been understood from their perspective in their lifeworld. The research was born from a gap in the existing literature, which was discovered through an extensive systematic review of material available.

I sought to use a purposeful homogeneous sample for the study to ensure a non-probability sample was selected based on characteristics of the participant population and the objective of the study (Palinkas et al 2015). I aimed to observe sensitivity to context by attempting to make participants' feel as comfortable as possible by conducting interviews at a time and location convenient to them and by endeavouring to convey an appreciation of their lifeworld context to encourage them to feel at ease discussing their experiences (Moser and Korsjeno 2018). The interview schedule comprised open-ended questions with the sole intention of stimulating the participant to lead the interaction to discuss their lifeworld experience consequently demonstrating sensitivity to context (Moser and Korsjeno 2018). I endeavoured to maintain sensitivity to context throughout the analysis process by giving attention to detail when analysing the findings. This should be observed by the reader via the inclusion of verbatim extracts from the participant's interviews in the study findings. In support of this, the study findings are offered in relation to the existing literature within the findings and discussion chapters. The second principle is 'commitment and rigor' this is recognised in the study via engagement with and immersion in the findings being found and analysed in a thorough and attentive manner (Yardley 2000).

I endeavoured to maintain the third principle 'transparency and coherence' throughout the entire study process (Yardley 2000). Transparency is measured in how clearly the reader views what has been conducted and the rationale behind this, with coherence being seen as whether the research makes sense as a whole and if it follows the theoretical stance underpinning it (Yardley 2000). To realise this I provide a comprehensive account of the study design and process followed. I conveyed my understanding of the theoretical and epistemological standpoint of interpretative phenomenological analysis and assumed a hermeneutic phenomenological approach during the write-up stage of the study. Interpretive phenomenological analysis adopts an interpretive ontological approach, not viewing reality as objective nor as a methodological approach at the positivist end of the ontological continuum (Vicary 2017). The epistemological stance rests on the person's subjective account of experience (Vicary 2017). The study's epistemological stance is informed by the constructivism paradigm of investigative thinking (Borland 2019). I aimed to demonstrate transparency by identifying my own position in relation to the findings throughout the study and by sharing my epistemological stance and how my own experiences and perceptions affected the study and findings. This is essential to upholding quality in the study (Meyrick 2006). I trust that the study meets the requirement of the fourth principle 'impact and importance' that is measured by assessing how useful research is in informing the reader (Yardley 2000). I hope the study informs the reader of my interpretation of the participants' understanding of their lifeworld experience.

This chapter has addressed a number of methodological principles and provided my chosen research methodology and study design, including the underpinning epistemological stance and ontological position. In the next chapter I present the participant lifeworld findings.

# **Chapter 4 Findings**

# 4. Introduction

In the previous chapter, I addressed a number of methodological principles. I introduced my chosen research methodology and study design, including the underpinning epistemological stance and ontological position (Jackson 2013). I presented my chosen methodology with a number of discussions regarding the theoretical underpinnings, the rationale for selecting this approach, the limitations associated with this approach and the consideration of other approaches (Jackson 2013).

In this chapter, I offer my interpretation of the participants' lifeworld experience by presenting the emergent themes drawn out during the interpretative analytic process (Vaismoradi et al 2016). I use this process to get close to the participants' lifeworld by taking 'an insiders perspective' (Conrad 1987). I do this by trying to make sense of the participants' trying to make sense of their lifeworld (Brooks 2015). To achieve this the findings presented are drawn directly from the interpretative analytic process described in the methodology chapter with my aim to capture how the participants' make sense of their role by giving meaning to their experiences and the extent to which these experiences impact on individual perception (Sutton and Austin 2015). Smith et al (2009 p108) state that there is not a single right way to write up an interpretive phenomenological analysis, analysis. They state writing is a creative process, and authors have a voice in the findings just as the participants do and this is heard in the construction of the account (Smith et al p108). Three superordinate themes emerged (Jeong and Othman 2016) during my interpretative analysis, compassionate carer, holistic assessor and engagement enabler. I found these themes interrelated across all five participants' lifeworld experience. Nine subordinate themes emerged (Jeong and Othman 2016) from the superordinate themes. Person centred, active listener, and explorer emerging from compassionate carer, active observer, home visit, and prevention and isolation from holistic assessor, with direct to groups, attend groups and local community from

engagement enabler. While the analysis for the most part focuses its attention on the 'essence' of the participants' experience and presents the experiences of the participants' I have also sought to preserve the idiographic nature of interpretative phenomenological analysis (Neubauer et al 2019). I offer insight into how the participants' in the context of their lifeworld, make sense of this world and their personal perception of social identity within it (Smith and Osborn 2015). In this respect, the participants' introduce themselves by articulating their personal perception of role in the context of the phenomena was not classified into pre-defined categories, but considered on its own terms through an inductive bottom-up process during the analytic process of the interview transcripts (Vaismoradi et al 2016).

I interviewed five care navigators *[table 5]* each bringing their unique interpretation of their lifeworld experience to the study. Jenny and Edward held a number of years of care navigator experience. Mary, Gary and Natalie had a number of months of care navigator experience, when the interviews took place. The participants interviewed reflected the Boroughs diverse population. Like much of Inner London, the local population of the Borough in which the participants practice is richly diverse (The Joint Strategic Needs Assessment 2020). It is difficult to have a complete and accurate picture of the ethnicity of the rapidly changing population (The Joint Strategic Needs Assessment 2020). Census information suggests that 63% of the population is White British, , the next largest ethnicity being the broad 'Black' group at 26% (The Joint Strategic Needs Assessment 2020) The proportions of ethnic groups varies widely across the borough with some parts being highly diverse. Within the broad 'Black' ethnic group most adults and children are 'Black African', however among the older people most are 'Black Caribbean (The Joint Strategic Needs Assessment 2020).

The Participants					
Pseudonym	Age Group	Gender	Care Navigator Lifeworld	Previous Lifeworld	Personal Perception
Jenny	20-25	Female	Jenny	Jenny has	ʻl support
			manages the	worked as a	people to lead
			care	care	independent
			navigator	navigator for	lives by
			team and	a number of	problem
			'loves the	years.	solving, I can
			<i>job'</i> . She		help them with
			supports and		anything from
			provides		completing
			guidance and		paperwork for a
			advice for		mobility scooter
			junior care		to
			navigators.		accompanying
					them on public
					transport and
					attending a
					group with
					them on their
					first visit'.

Mary	30-35	Female	Mary is new	Mary has a	ʻl Pick up
-			to the role of	long history of	, unresolved
			care	working with	issues and
			navigator and	the public in a	open up issues
			finds the role	role with the	for older people
			'very	local	not following
			enjoyable'.	authority.	the 'because
					your old forget
					about it',
					finding new
					things for the
					older person'.

Edward	20-25	Male	Edward has	Edward	'l Listen to
			worked as	originally	people, find out
			care	started in the	from them what
			navigator for	care	is missing,
			a while and	navigator role	helping them to
			'enjoys being	as a	find ways of
			out in the	volunteer.	getting there,
			community		encouraging
			meeting		them to see
			people'.		that, without
					pushing on to
					the person they
					could do with
					that. I try to
					socially engage
					people to the
					community. I
					am passionate
					about my local
					community and
					the benefits
					that come from
					that. I hope that
					by doing that if
					someone's
					health
					deteriorates
					someone will
					notice'.

Gary	20-25	Male	Gary is new	Gary	'l Bring
			to role of care	previously	positivity into
			navigator and	worked in	people's lives,
			is 'enjoying it	voluntary	slightly non-
			so far'. He	sector youth	judgemental or
			has a history	services.	clinical attitude
			of working in		to improve
			the charity		someone's life,
			sector with		positive things
			the		not covered by
			vulnerable.		statutory
					clinical and
					social services
					to support
					people in living
					decent lives. I
					wouldn't
					compare it to
					homeopathy,
					as I'm not
					supporting
					homeopathy
					but we offer an
					alternative to
					statutory
					clinical and
					social services,
					a bit like
					homeopathy
					offers an
					alternative to
					traditional
					medicine'.

Natalie	30-35	Female	Natalie is	Natalie	'I Enable and
			new to care	previously	empower
			navigation	worked within	people,
			with a history	the National	preventing
			of working in	Health	isolation by
			a healthcare	Service as a	reaching the
			professional	health care	disempowered.
			role in the	professional.	Hard to say
			past. She		really, I think I
			finds the role		explained it by
			'quite		the case study'.
			liberating'		
			after working		
			within the		
			statutory		
			healthcare		
			sector for a		
			number of		
			years.		

Table 5: Meet the participants

The superordinate and subordinate themes (Jeong and Othman 2016) found in the participants' interviews are explored and presented in turn. For the purpose of presentation, the themes were separated during the analysis process, although in the participants' lifeworld they are interrelated *[figure 10]* as found through the interpretation of participant transcripts. Each theme should be considered in relation to the holistic experience and the hermeneutic circle as conceptualised by Gadamer (1990). Gadamer (2003, p307) suggests the complex relationship between the interpreter (researcher) and the interpreted (participants) is one that cannot be separate, he termed this a "*fusion of horizons*". Gadamer (1975) explains the hermeneutic circle is an iterative process through which a new understanding of a whole reality is developed by means of exploring

the detail of existence. He views understanding as linguistically mediated, through conversations with others in which reality is explored and an agreement is reached that represents a new understanding. To discern this new understanding, extracts from the interview transcripts are included presenting the phenomenological core from which my interpretation of the participant lifeworld experience is made, starting with the superordinate theme compassionate carer.



Figure 9: Superordinate and subordinate themes (interrelated)

# 4.1 Superordinate theme: Compassionate carer

The superordinate theme 'compassionate carer' captures the importance the participants' gave to being 'person centred', a 'listener', and an 'explorer' in their lifeworld experience. This theme was reflected in the literature review descriptive themes of communication and practical support (Natalie-Pereira et al 2011). Various definitions of compassionate care exist, uniting a range of fundamentals (Bivins et al 2017). These fundamentals usually consist of a number of elements (Bivins et al 2017). These elements include a cognitive [explorer] element: understanding what is important to the other by exploring their perspective. Volitional and affective [person centred] elements: choosing to act to try to alleviate the other's disquiet by actively imagining what the

other is going through. Altruistic and moral [listener] elements: reacting to the other's needs selflessly by showing compassion to the other by listening to their experiences of pain or distress (Gilbert 2013, Von Dietze and Orb 2000).

### 4.2 Subordinate theme: Person centred

All five participants' expressed in their own unique way that they are person centred. They portrayed this in a number of ways; when recounting how they had supported service users, when describing their role and when explaining the formal and informal training they received to undertake the role. The Health Foundation (2016) describe person-centred care as supporting people to develop the knowledge, skills and confidence to make informed decisions about their own health and health care. I interpret this from the participants' interview transcripts with service users having their care coordinated and tailored to their individual needs by the care navigator. The participants' always treated service users with dignity, compassion and respect. Natalie described her care navigator role as being 'creative' when solving service user problems in a new way by taking risks and ignoring doubt and facing fears:

'I care navigate person centred complex pathways by providing creative support to access services'. (Natalie)

A 'complex pathway' would require the co-ordination of a number of different inputs for the service user. By using the term 'creative support' Natalie refers to approaching each service user in a unique way for the benefit of the individual. Bujold et al (2017) believe service users with complex care needs often suffer from combinations of multiple chronic conditions, mental health problems, drug interactions and social vulnerability. They face interactional issues and unmet decisional needs regarding possible options in a cascade of interrelated decisions involving different stakeholders; themselves, their families, their caregivers, their healthcare practitioners (Bujold et al 2017). This 'complex care pathway' is where the care navigator is best situated to co-ordinate person centred care. Edward explains what being person centred means to him: 'You see the actual person rather than their problems, how to address their issues or difficulties, remember who the person is. Person centred can just be used as buzz words if not truly believed or practised'. (Edward)

The National Institute for Health and Care Excellence (NICE) (2019) state older people with multiple chronic conditions are likely to have a wide range of care needs. Those with social care needs may need support with personal care and other practical assistance. They go on to describe how older people may not know what social care support they are entitled to or what their funding options are. This may lead to their needs being left unmet because they are not claiming support. NICE (2019) believe a person-centred, integrated approach to providing services across the statutory, private and voluntary sectors is fundamental to delivering high-quality care to older people with multiple long-term conditions. They advocate that older people should receive a care and support needs assessment to ensure that all their health and social care needs are identified to enable them to access the support they need to maintain their independence and improve their quality of life. This assessment should take into account the person's strengths, needs and preferences, to enable health and social care practitioners to work together to meet the person's needs. Gary expounds the formal person centred training he received from his employer to undertake the care navigator role:

### 'We had person centred assessment training with AgeUK'. (Gary)

Prior training is not the only requirement when undertaking a person centred assessment as Mary pronounces the challenges experienced when endeavouring to remain person centred during an assessment due to limitations experienced in her lifeworld:

'Time limitation is a problem, I would like more time with the service users to undertake a more indepth assessment. We could miss out on certain things. We don't build up a long term relationship with the service user that can have positive and negative on the relationship. Service users can self-refer and come back to the Care Navigation Service, as sometimes people's issues are only half resolved'. (Mary)

Despite limitations experienced in their lifeworld, the participants told me how they approached their role. Jenny describes her experience of being person centred as a care navigator in her lifeworld:

'I love the job, I enjoy working with people, being person centred, you've got to keep open minded as you can experience some upsetting situations'. She considers to be person centred 'It's better meeting the individual in person to observe the person you are assessing while asking open questions'. Jenny illuminates the care navigator:

'Listens for clues regarding the person for instance if the older person mentions a fall, the care navigator will reflect on how they can support the older person to avoid further falls" (Jenny)

# 4.3 Subordinate theme: Listener

As Jenny, other participants expressed that listening to service users was a foremost component of their lifeworld. Jenny comments that through listening to the service users:

'Junior Care Navigators will refer back for advice.' (Jenny)

The participants conveyed they gave more time to listen to service users than was usual in a health and social care interaction. Edward's explains he perceives his role is to:

'Listen to people, find out from them what is missing, helping them to find ways of getting there, encouraging them to see that, without pushing on to the person they could do with that'. He believes the care navigator role is 'about people engaging with services and being socially engaged, listen to them and value them, good for confidence and self-worth'. (Edward) Hunsaker et al (2008) believe people can be placed in one of four categories when listening, nonlistener, marginal listener, evaluative listener, and active listener. Each category requires a particular depth of concentration and sensitivity from the listener, to produce effective communication. Gary considers care navigators as active listeners:

'We actually listen, we use a soft skills approach, a different approach than speaking to a doctor or speaking to a social worker. People who are nervous are often relieved when assessed by a Care Navigator, all services and suggestions are optional. Soft skills are used positively in the short

*term*'. (Gary)

Natalie explicates how it is not only with service users that listening is an active part of the care navigator role. She relates how she supports members of the health and social care multidisciplinary team she works with:

'I work 2 days a week in a GP practice in a care navigator role supporting staff in the practice to undertake care navigation within their roles. I attend a multidisciplinary team meeting in the North of the Borough, listening to their needs and advising on care navigation issues'. (Natalie)

Mary expresses her active listening skills are utilised while exploring service users' lives: 'At the home visit I explore and find out about the person's life, what they feel is missing from their life, what they enjoy doing, I talk and listen to them about social groups, exercise classes and other services and benefits available'. (Mary)

### 4.4 Subordinate theme: Explorer

As Mary alludes, exploration of the service users' lives allows the care navigators to develop an understanding of what is important to the service user by exploring their perspective. This underpins the approach to being person centred in meeting service users' needs and creating individualised outcome focused plans. 'Exploring' people's lives can be *'enjoyable'* but can also give rise to limitations and frustrations within the participant lifeworld, Mary voices her lifeworld experience in her care navigator role:

'I find the role very enjoyable, it's very interesting and focused on making people's lives better through exploring their needs through conversation with no particular agenda'. She goes on to explain her preparation for the role 'I undertook some shadowing visits and had sessions with team colleagues about what groups and services are offered in Southwark and administration processes, including the person centred exploring and solving tools we use in our home visits. I was able to call on my previous counselling skills'. (Mary)

Mary makes the insightful comment '*I* was able to call on my previous counselling skills' this indicates that undertaking an assessment exploring a service users' needs may require the care navigator to hold counselling skills such as listening and observing, capturing and understanding the verbal and nonverbal information communicated to aid relationship building between the care navigator and service user. This is demonstrated further as Gary explicates how difficult 'exploring' can be:

'Engaging with people, they are often unsure what they have been referred for from the doctor. They think I may be snooping, ensuring they are taking their medication, that they are doing what the doctor told them to do, they can be very wary. They may live with a family member or spouse, so it can sometimes be difficult talking to someone, they may find it difficult to talk about being isolated or depression. It can be difficult to see what is really going on for that person. They are adamant they don't want anything because the husband or wife does not want any input, which can be quite limiting on what I can do'. (Gary)

Natalie shares some of her lifeworld experience of 'exploring' people's lives while undertaking complex assessment:

'There are a lot of situations you come across, people with multiple needs with high level complex needs to people who only need a referral to a befriender, I prefer to meet people in their own home as they can have whole other story to tell from the one presented by the referral, 8 out of 9 times. I had one lady referred by women's aid for befriending as she had had to move to be rehoused by the council, she had a complex web of needs, she was paying 2 rents, had experienced domestic abuse and financial problems'. (Natalie)

### 4.5 Superordinate theme: Holistic assessor

This superordinate theme was found in the participants experience in the assessment of service users' and the skills required to do this. This was observed in the literature review descriptive themes, patient assessment and educational support. The holistic assessment undertaken by the participants' on a one to one basis with a service user allows the development of an outcomes based individualised plan. Nicholas et al (2003) suggest outcomes-focused holistic assessments support person-centred care, an effective working partnership and offer best value. Nicholas et al (2003) uphold there are three sets of outcomes; maintenance; with a focus on maintaining health and well-being, change; with a focus on improving health and well-being, and process; with a focus on the way that services are delivered to allow quality delivery. The participants' utilise an outcomes focus when undertaking service users' assessments in their lifeworld. Glendinning et al (2008) believe implementing outcomes focused assessment in the real world is multifaceted. They

believe there are a number of issues that need to be addressed including; a 'whole systems' approach to outcomes based assessment, further debate about the discourse of 'outcomes' and how they are prioritised, and the need to think 'outside of the box' rather than work within traditional services boundaries. These issues are portrayed in the participants' interviews with how they approach solutions in their lifeworld. Jenny describes the assessment process:

'Clients can decline assistance. Assessment is person centred focused on what the individual wants, what their interests are, then a match can be made with community groups and/or services available in the borough. There is no allegiance with statutory health and social care services, the assessment is all about the individual's well-being, there's no hidden agenda'.

(Jenny)

All of the participants interviewed described assessment of service users' as observing the whole person, taking into account physical, mental and social factors, rather than just the symptoms of a disease. This holistic assessment process took many forms including face to face preferably in peoples own homes or if not possible or desired by the service user in a health or social care centre or over the telephone. This last option being the least preferred by the participants' as they could not observe the service user in their lifeworld. Jenny explains:

'I love the job, I enjoy working with people, being person centred, you've got to keep open minded as you can experience some upsetting situations. We also undertake phone-based navigation, this can be difficult as it's the opposite to face to face person centred assessment.

(Jenny)

Interpretation of the interviews establish that care navigators are active observers when performing visits to service users' own homes. The holistic assessment focuses on safeguarding, prevention, and alleviating isolation in the older population. Gary explains:
'Typically the referrals are for people with social isolation and malnutrition problems. I arrange to meet people in their own homes, often with very little information about them for the first home visit. We give short term support of up to 6 visits, there can be more if someone has very complex needs. A large part of my role is to help people with social engagement mainly older people and safe guarding issues'. (Gary)

Nolan et al (2016) 'Senses Framework' model best interprets what the participants' holistic assessment observes. The model promotes well-being of the service user, carers, and staff who work with them. All should experience a sense of security; feeling safe within relationships, belonging; to feel part of things, continuity; to experience links and consistency, purpose; to have personal goals, achievement; to make progress towards a desired goal or goals, and significance to feel that they matter.

# 4.6 Subordinate theme: Observer

The participants' considered observation of the service user in their lifeworld significant. This allows the care navigator to observe the service user non-verbal's and the authentic home situation. This allows a mental note to be made of any relatives or carers who are also at home and the physical setting in which the service user resides. Examples of the type and success of observation was offered in a number of interviews, Jenny believes:

# 'It's better meeting the individual in person to observe the person you are assessing while asking open questions'. (Jenny)

It is thought-provoking Jenny relates the asking of open questions as open questions stimulate longer answers. They usually begin with tell me what, why, or how. An open question allows the service user and/or significant others to express their knowledge, opinion or feelings, Mary explains:

# 'I observe and ask questions about their housing, health and social care needs, and utilities. I involve family members if they are present'. (Mary)

Edward describes how he views himself as an observer in his life world:

'I guess I'm observant, nosey, it helps to direct people to services'. (Edward)

Natalie describes the difficulty of not being able to follow up on service users directed to services to observe the outcome:

'I find monitoring the effectiveness of what I do and outcomes quite important but this is difficult to achieve, as we do not follow people up after our intervention. We should follow up six months later to observe the persons quality of life and what services they may now require. For us it's hard to gage what's has improved for the older person'.

Jenny also raises the challenges post service user observation in her lifeworld:

'Not knowing the impact you have on people's lives as there is no follow up on outcomes. Seeing people in situations where accepting help is difficult can be upsetting'. She goes on to say 'There are external limitations to the role, it can take you to 6 months for someone to be allocated a friend on the befriending service, mainly due to people's needs. There is no capacity in the system for us to monitor individuals referred to the service. It would be good to observe if by our intervention we were keeping people at the functioning level. It would be good to be able to measure the impact of

our input'. (Jenny)

Jenny provides an example of an outcome after undertaking a home visit:

'In one case we did a home assessment on an older person, who had not been going out. They declined us referring them to various groups available, but they did start going out on their own following our assessment'. She determined 'so the home visit was a catalyst to a later positive outcome'. (Jenny)

Interpretation of Jenny's and other participants' interviews illustrates the importance the participants place on the ability to undertake a home visit.

# 4.7 Subordinate theme: Home visit

All the participants consider undertaking a home visit the most appropriate form of undertaking a service user assessment. Home visits are claimed to be a central element of general practice (Kao et al, 2009). The participants' collectively expressed how you could observe things in the home and the service user's body language during a home visit that you would not be able to do by undertaking an assessment over the telephone or in a health or social care centre. However, there are safety issues to consider when undertaking a home visit, Jenny explains:

'There are risks in undertaking home based assessment visits on your own. We text in and out to the office. We often receive little information before undertaking a home visit, things like whether the older person has a dog. We see people aged 50 and above in the service, most will have experienced long-term isolation prior to their referral, with little or no support network'. (Jenny) Mary illuminates on a home assessment activities:

'There is no hidden agenda, it's not limited, and the person can set the agenda for the home visit'. (Mary)

Edward enlightens on how his experience has led him to believe home assessment is better when assessing service user needs:

'Undertaking home visits showed me the importance of undertaking them, I learned a lot. If you visit a home that has a strong smell of urine, it could indicate the older person has an infection and increase the problems experienced with dementia, that's something you could not pick up by making a phone call assessment'. (Edward)

Gary expands on the support role a care navigator can give following an assessment visit: 'I arrange to meet people in their own homes, often with very little information about them for the first home visit. We give short-term support of up to six visits, there can be more if someone has very complex needs'. He went on 'My manager shadowed me on the first few home visits that was a nice process'. (Gary)

Natalie describes how she receives requests to undertake a home assessment visit and her role as a care navigator:

'I work within a multidisciplinary team linking them to agencies to develop role and development of services. I provide care navigation in a number of different ways, I undertake home visits with people who have been pre-referred by the person directly, by a family member or friend. I work 2 days a week in a GP practice in a Care Navigator role supporting staff in the practice to undertake care navigation within their roles'. She explained 'I think it's more comfortable to see people at home for their interview. More often as not the role is far more than signposting'. (Natalie)

As the care navigator role *'is far more than signposting'*, Mary illuminates on the problems experienced when undertaking home visit assessments:

'Time limitation is a problem, I would like more time with the service users to undertake a more indepth assessment. We could miss out on certain things. We don't build up a long term relationship with the service user that can have positive and negative impact on the relationship. Service users can self-refer and come back to the Care Navigation Service, as sometimes people's issues are only half resolved'. (Mary)

As service users' can self-refer and return to the service if required, Jenny clarifies the process for home visits:

'Care navigators receive referrals through the care navigator programme. Once a referral is received, an appointment is made to see the person on a home visit. The visit focuses on prevention and isolation for housebound people who are not accessing community services. The person is assessed using a [structured] person centred open questions on a rated scale [approach]'. (Jenny)

# 4.8 Subordinate theme: Prevention and isolation

As revealed by Jenny prevention and isolation were the foremost reasons care navigators gave for their invitation into service users lives. Service users who have more knowledge, skills and confidence to manage their health and health care are more likely to engage in positive health behaviours and to have better health outcomes (Hibbard and Gilburt, 2014). However when attempting to achieve this participants' expressed the limitations that they and service users' experience. Natalie describes her role as a care navigator role as:

'Enabling and empowering people, preventing isolation by reaching the disempowered'. (Natalie)

Like Natalie, Gary offers insight into his care navigator lifeworld prevention and isolation experience:

'I try and create realistic expectations. When people are used to talking to the GP or a Social Worker they are pleasantly surprised by my approach, there's no pressure and it's not rushed. Doing what you actually can do and being able to do it in the time available can be difficult with a large number of people to get too'. He goes on to say 'I give professional input but like a family member a concerned nephew. Key to being a Care Navigator is to drive positivity to give a leg up. Sometimes people don't want anything and want to be left alone, you can tailor services to people'. (Gary)

Mary explains how she approaches service users' concerning prevention and isolation:

'There are two approaches of care navigation, social isolation and prevention of malnutrition. I phone people and explain who I am and what my role is and who made the referral to the Care Navigation service. I then arrange to visit the individual at home'. (Mary)

Edward comments on his lifeworld experience of visiting service users regarding prevention and isolation:

'When I first started in the role I thought people would be very demanding, but generally people are just happy to have someone to talk too, people like contact, it can be eye opening, people like human contact, feeling valued'. (Edward)

Jenny illuminates on how statutory services utilise the care navigator service regarding prevention and isolation:

'Social services will refer to us following care package assessments or safeguarding issues for example shopping and telecare referrals'. (Jenny)

These examples of how the participants' work with service users referred with social isolation and prevention needs, illuminate the way care navigators enable individuals to lead independent lives.

# 4.9 Superordinate theme: Engagement enabler

This superordinate theme observes the role of the care navigator in enabling service users to engage in the local community by leading independent lives on their own terms. It also observes how the participants see themselves and their role in the local community by directing service users to services and attending community based groups. This theme was found in the literature review descriptive themes, Co-ordination (continuity) and information giving. Throughout the interview process, all participants eloquently voiced their role as enabling service users to make their own decisions about their lives with or without support and input from the local community statutory and voluntary sector. NHS England (2017) state over 40% of people want to be more involved in decisions about their care. Similarly, 40% of people living with long-term conditions want more support to manage their health and wellbeing on a day-to-day basis (NHS England,

2017). Care navigators are best placed to enable service users to be involved in their care and direct them to appropriate services.

# 4.10 Subordinate theme: Direct to services

All the participants described their role in directing service users to services available in the community to support independent lives. They also raised their lifeworld experience of the limitations and frustrations felt by service users in the community.

Directing services users to services is of particular importance with the introduction of personal health budgets that are intended to improve personal outcomes and experience by giving more choice and control over care received. NHS England (2017) believe service users who might benefit from a personal health budget should experience a methodical, coordinated approach to their care and support. This is a role undertaken by the care navigator. Natalie describes her lifeworld experience of directing service users to community-based services:

'It's varied definitely, it's not here's a leaflet about services and groups available, see you later'. (Natalie)

Mary echoes Natalie's lifeworld experience and describes her way of working to maintain service users' independence:

'I discuss the services available such as befriending, taxi card and dial a ride. I check what benefits someone may be entitled to and make referrals to the appropriate services, the referrals can be quick or take a long time to be processed and accepted'. (Mary) Edward provides his lifeworld experience of maintaining service users' independence by describing his role:

'Is to connect people to services to remain safe and independent. Helping people to remain at home in sustainable ways. To support people with home adjustments by referrals to groups, organisations, services and benefits. He goes on to say 'Sometimes it feels that there are no services they need, a few people have slipped through the net, sometimes there's not a great deal you can do about that'. 'The services can be target based, getting people through quicker decreases the quality of the work we do. The short term aspect is difficult, someone may have not be out in 20 years for a reason, sign posting them to services and groups is not going to change that due to fear, anxiety, confidence, they are out of their comfort zone. We need long term help out in the community'. (Edward)

Adding to Edward's experience of confines in maintaining service users' independence Gary points out the limitations experienced within his lifeworld:

'Limitations yeah, I think limited by lack of or cost of services, the Care Navigator signposts to services and makes referrals, people asking for same things, housework, that can be costly, meal delivery, there's no meals on wheels deliveries anymore and people have to pay now for services like Wiltshire Home Food that is not freshly prepared. There's often frustration felt for processes taking so long, there's so many people with few people doing the Care Navigator role, it can be up to 2 months to be seen after receiving a referral, things can be forgotten or changed, with social isolation you need to grab the iron while it's hot, yeah timescales can be disappointing'. (Gary)

Jenny eludes to the limitations experienced in her lifeworld:

'Stretched' statutory health and social care services, too many older people experience problems accessing services. If we can help someone with their social issues it can have a positive impact 152 | P a g e on their health issues. People often highlight their own health problems when undergoing a home assessment. The service has GP practice based Care Navigators who signpost patients to services by developing 'wellbeing' plans. They undertake person centred signposting and referring to other services. GPs will ask the Care Navigator to refer to other community-based services like home visiting dentists. Working in GP practices assists with the collecting of evidence of Care Navigators impact receiving GP feedback, discussing benefits with GP hub knowing about what's happening with the service'. (Jenny)

A wellbeing plan can be useful for service users to help them to think about ways in which they can deal with their needs. It provides a framework for service users' to use to gain more control over their life. A wellbeing plan will include details of groups the service user can attend.

#### 4.11 Subordinate theme: Attend groups

Attending groups with service users is a part of the care navigator role the participants were clearly proud of, particularly in situations where individuals were apprehensive about attending alone or had no other significant other to attend with them. Jenny the team manager explains:

'We can attend groups with people the first time they attend if they find it difficult to attend alone'. She goes on to discuss the various groups available 'There are a number of groups available such as the Age-UK 'menders club'. The Menders Club is part of the Men's Shed Association. It is a creative space established by the men who attend. Its purpose is to provide a space for men over

50 to come together to meet up, to talk and share or learn skills in a Workshop environment. Menders was started by Age UK, following demand from local older people and with the support of a generous grant from the Big Lottery Funds Awards for All. By providing this safe space, Menders help address many issues facing older people, such as reducing isolation and improving health and wellbeing'. (Jenny) To maintain credible local connections to groups Edward believes:

'You've just got to keep up with the changing services available, visit somewhere, like a group with an older person, get to know about the groups available for older people'. (Edward)

# 4.12 Subordinate theme: Local community

All the participants mentioned the importance of being a part of the local community in which they are based. This required them to be aware of what the local community had to offer service users and gave them a personal feeling of being part of and a strong bond to the local community. Edward described his connection to the local community:

'I try to socially engage people to the community. I am passionate about my local community and the benefits that come from that'. He believes 'There's been a decrease in pubs and social centres, there's a strong community feeling with the role'. He goes on 'I enjoy, love, being out in the community meeting people, making people feel safe, love the Borough, being out in the community'. He gave an example of a success story despite local community limitations 'We need long term help out in the community. One of my service users was a sociable lady with a great personality, would ensure all her clothes match, shoes, handbag, sunglasses. I went to visit her with a colleague because she had not been out since her husband passed away. We referred her to the local group, when I contacted them to find out how she was doing they told me she was out on her second outing, she now goes out to the centre and has a lot going on in her life. There can be problems with public transport due to a poor transport system, there are limitations, service users tell me dial a ride can be unreliable. First thing you need to think about when assessing a person is how are they going access the services or groups you refer then too'. (Edward)

Gary explains his lifeworld view of the role of the care navigator in the local community:

'I guess being a Care Navigator is like being a borderline Care Co-ordinator beyond isolation, housing, and medical issues. We know what's there in the community, sometimes people cannot access services because of problems with hearing, poor IT skills, or the general skills required to access services or just being tired, I can support them with their needs to access appropriate services'. (Gary)

Gary's view illuminates how care navigators' work across a number of statutory service boundaries to engage the service user with the required services. This involves the care navigator in working in partnership with a number of health and social care providers. Natalie describes working with others in the local community and the problems experienced:

'I undertake partnerships visits with other services, like the community mental health team, it often requires two or more services to meet the individual's needs. I think we make a real difference working together, leaving the older person satisfied. Sometimes the service is not quite right or not available due to service and funding cuts'. (Natalie)

Natalie gave an example of the 'funding cuts' affecting the service:

'lack of mental health support, there's an increase in mental health problems but the services required to meet the demand are not there. When I arrived, there were lots of needs, a lot of complex pathways that were lost in the system, people with problems that had no CPN [community psychiatric nurse], it was a real challenge as there were no services to support these people'. (Natalie) Jenny describes the logistics of being based in the local community:

'The Care Navigation service is Borough wide based in different locations, this can have an impact on information governance when sharing information. I've found undertaking the role a very positive experience; you can direct people to access other local services/teams/people to enhance their well-being'. (Jenny)

The participants expressed frustration at not being able to measure the impact they have in the local community. Jenny expresses her concerns:

'It would be good if an 'in-depth' study could be undertaken into the long-term outcomes of Care Navigator input and if we could follow up services users long-term'. (Jenny)

Natalie expresses her concerns about not monitoring impact of the care navigator role:

'There is no capacity in the system for us to monitor individuals referred to the service. It would be good to observe if by our intervention we were keeping people at the functioning level. It would be good to be able to measure the impact of our input'. (Natalie)

Edward also raises the issue of impact monitoring:

'I really enjoy my role I believe it makes a difference but I don't always see the impact. A colleague of mine showed me some case studies that showed the impact of care navigation, I look at those when I need too, I think it's important not to get hung up on outcomes, it's about people engaging with services and being socially engaged, listen to them and value them, good for confidence and self-worth'. (Edward)

#### 4.13 Care navigator identity

The construct of identity viewed at individual and collective levels of analysis has become increasingly popular in research studies (Alvesson et al, 2008). The construct of the participants' individual identity in this study is constituted through comparison and interactions with other people and groups, meaning that how others relate to the participants' is crucial in how they see themselves (Alvesson et al 2015).

Jenny compares her role to General Practitioner surgery receptionists:

'They are training receptionists in some GP practices to undertake Care Navigator duties. Being a Care Navigator is a full time role that has the freedom from not being sat in statutory health and social care services'. (Jenny)

How the participants' see themselves is interwoven throughout the three superordinate and nine subordinate themes that emerged via interpretative analysis of the participants' lifeworld experience. Lifeworld experience as perceived by the participants' allows for an appreciation of the participants' individual and collective identity. This individual and collective identity forms the foundation of the participants' practice as a care navigator. Identity within health and social care practice is significant, particularly when new roles are introduced to allow the roles to embed in practice and be recognised by service users and colleagues (Gilburt 2016).

The introduction of new roles represent a significant challenge to traditional roles and modes of service delivery in health and social care practice as new roles threaten existing professional jurisdictions and identities (Nancarrow and Borthwick, 2005; Sanders and Harrison, 2008). The care navigator role was first introduced to London as part of workforce transformation via a number of health and social care initiatives. Workforce changes within health and social care generate challenge as it works against pre-existing, dynamic, professional systems (Hyde et al., 2005; Young et al., 2001). Transformation workforce changes have a number of implications for

traditional workforce boundaries. This is seen when non-registered workers such as healthcare assistants and support workers perform tasks previously undertaken by registered professionals (Cooper 2001, Buchan and Dal Poz 2002). As the role of the care navigator does not require registration with a regulation body, it is imperative for the participants' to have a collective as well as an individual identity when working with service users and colleagues (Gilburt 2016). This allows service users and colleagues to differentiate the role of the care navigator from other members of the health and social care team (Gilburt 2016). Being able to differentiate the role and the participants' professional identity is important when wishing to recruit and retain staff to health and social care services. Jenny explains:

'Staff retention can be poor as a large number of care navigators use the role and experience as a spring board into other jobs or careers, mainly due to the poor pay scales. Care Navigators tend to fall into the 20-40 age bracket'. (Jenny)

Adams et al (2006) and Crossley and Vivekananda-Schmidt (2009) define professional identity, as the attitudes, beliefs, knowledge, skills, and values, that are shared with others within a professional group. Together these affect how people interrelate, compare and differentiate themselves from professional groups in the work place. Plack (2006), when studying physical therapy students found identity development is achieved within practice through interactions and socialisation and observation of professional roles and functions. Deppoliti (2008) observing nurses believes there are 'several passage points' while new graduates build their professional identity with several elements such as professional relationships, responsibility, and continued learning contributing to their professional identity. This is reflected in how the study participants form their professional identity from their lifeworld experience of professional relationships, responsibility, and continued learning. Their professional, individual and collective role identity is linked throughout the superordinate themes, compassionate carer, holistic assessor and enabler.

Sluss and Ashforth (2007) contend that the question of identity should be one of 'who are "we"?', rather than 'who am "I"?' At the interpersonal level, relational identity is how role holders enact their respective roles vis-à-vis each other. Role-based and person-based identities of two individuals in a role relationship interactively influence the relational identity (Sluss and Ashforth 2007). The participants' relational identity is captured in their interviews when describing their working relationship with others in their lifeworld. Through interpretation this relational identity strongly influences the role-based care navigator identity of the participants.

This role-based identity is formed by the goals, values, beliefs, norms, interaction styles and time horizons associated with the participants care navigator role through the interpretation of their lifeworld experience (Ashforth 2001). This role-based identity forms the foundation on which participants in the study make sense of their individual lifeworld experiences (Brooks 2015). The participants person-based identity is the personal qualities that bear on the enactment of the role-based identity, meaning that no two-role enactments are identical, except in extremely strong situations (Ashforth 2001). This person-based identity influences how lifeworld experience impacts on the participants' individual perceptions of role.

The participants' role-based identity comprises the knowledge they hold as an individual and as a collective (King et al 2018). The extent to which a profession uses the capacity to exercise influence in this regard is its ability to enact occupational closure (King et al 2018). Occupational closure is based upon a distinctive knowledge base held by a profession (King et al 2018). The knowledge base on which occupational closure relies must simultaneously be articulated or codified and indeterminate (Kirkpatrick and Ackroyd, 2003). The knowledge base of the study participants is articulated through interpretation of their interviews and expressed through the subordinate themes found. The subordinate themes being, person centred, active listener, and explorer from compassionate carer, active observer, home visit, and prevention and isolation from holistic assessor, with direct to groups, attend groups and local community from enabler. The participants hold both practical and theoretical knowledge of their local community and what is

available for service users in their community to maintain independence. Natalie provides some examples of practical and theoretical knowledge she holds from training:

'I received no formal in-house training; we can access free training on the council website. I have received training about safeguarding, malnutrition, self-assessment checklists and different members of the community team, recording information, different services available, dementia training, fire safety and first aid'. (Natalie)

Indeterminacy of knowledge held by a profession prevents others claiming jurisdiction over a distinctive professional domain (King et al 2018). The knowledge that the participants' hold such as identifying and accessing systems and support for services users that are available to them within health and social care and beyond, ensures they hold a distinctive professional domain. This knowledge is found in the participants' interviews in how they support service users in making positive choices to promote good health, emotional wellbeing and maintain independence. The participants' provide non-medical referral options to community services that compliment medical treatments. The participants' also offer support to obtain advice for issues such as housing, benefits or debt management. This indeterminacy of participants' knowledge greatly influences their professional identity within their lifeworld.

Professional identity has generally been associated with the expectations that professions have of how professionals perform their roles, with the '*internalising of professionalism*' being the ultimate aim of developing such an identity (Olckers et al. 2007, p. 2). In health and social care responsibilities of role are tied to certain professional identities, and conceptualisation of professional identity is frequently linked to single-professions, so that people performing those roles have identities such as 'doctor', 'nurse', 'midwife' or 'social worker' (Joynes 2016). In the United Kingdom these roles require registration with a professional regulatory body. These bodies perform four duties;

- Set standards of competence and conduct that health and social care professionals must meet in order to be registered and practise
- Check the quality of education and training courses to make sure they give students the skills and knowledge to practise safely and competently.
- Maintain a register that everyone can search.
- Investigate complaints about people on the register and decide if they should be allowed to continue to practise or should be struck off the register, because of problems with their conduct or their competence.

The Professional Standards Authority (2016) state there is a lack of literature on regulation's role in professional identity. There is no professional regulatory body for the care navigator role, however, examples of professionalism in the participants' conduct and competence were found throughout the participants interviews during interpretation, such as communication skills, work ethic, and flexibility. Edward explains how his communication skills, work ethic and flexibility influences his lifeworld:

'I've attended workshops on unconscious bias, safety on home visits, that's important as I work with people, I went on a home visit with a colleague because I knew the individual, he was a lovely guy but could be quite intense, shouting. There's been a decrease in pubs and social centres, there's a strong community feeling with the role'. (Edward)

A couple of the participants conveyed that not being regulated by a professional regulatory body allowed them a freedom to work with individuals that was not available to the regulated health and social care team members. Natalie explains how her role allows her the freedom to say she does not something unlike her previous role as a registered health professional: 'I like challenges, limitations, broad area, communicating, supporting, dementia, outcomes measures. Given my previous role [registered health professional] I am allowed to know what I do not know'. (Natalie)

Franco and Tavares (2013) believe professional identity can be one of many 'societal identities an individual holds'. Societal identities are developed through 'affiliations with organisations, leisure activities, occupations, culture or ethnicity' (Gignac, 2015). The participants' societal identities are interrelated to the organisation they work for ethos, which is, '*to empower older people to make choices and take control of their lives and support, with the overall aim being to improve life for them, especially those who are vulnerable and frail' (Age UK, 2020).* Natalie sums up her role engaging this ethos:

#### 'Enabling and empowering people, preventing isolation by reaching the disempowered'. (Natalie)

To comprehend how the participants' experience their professional identity is best defined by Schein's professional identity definition found in Ibarra (1999, pp.764-5), with professional identity being a '*relatively stable and enduring constellation of attributes, values, motives, and experiences in terms of which people define themselves in a professional role*'. The participants 'attributes, values, motives, and experiences' are found throughout the interpretation of their interviews. As a collective the participants' attributes are those of compassionate carer, holistic assessor and enabler. Their values and motives are their being person centred, active listener, explorer and active observer. They actively demonstrate these when undertaking home visits to prevent isolation by directing people to groups, and attending them with services users if required. The foundation of the participants' lifeworld experiences is initiated while performing these 'attributes, values, motives' in their local community. Mary explains her attributes, values and motives by:

'Picking up unresolved issues and opening up issues for older people not following the because your old forget about it, finding new things for the older person'. (Mary)

In the case of the participants' it is key to differentiate between professional identity and professionalism as care navigators are not currently required to register with a professional regulation body and therefore are not bound in practice to follow standards of professional behaviour, competence and ethics as directed by the regulation body. There is a lot of corresponding literature regarding professional identity and professionalism, for example Wilson et al. (2013, p.370) perceptively explains professional identity in medicine as '*how an individual conceives of him- or herself as a doctor, whereas professionalism involves being and displaying the behaviour of a professional*'. This display of professionalism is established in the participants' interviews while performing their care navigator work in their lifeworld. Gary describes his professional approach to his role as:

'Bringing positivity into people's lives, slightly non-judgemental or clinical attitude to improve someone's life, positive things not covered by statutory clinical and social services to support people in living decent lives'. (Gary)

This individual and collective professionalism and knowledge base supports the foundations of the participants' work role identity.

The study participants' work role identity, supported by their professional identity and knowledge base expedites their work-based self-concept. Participants' self-concept is constructed through a combination of organisational, occupational, and other identities that shapes the role they adopt and the corresponding ways they behave when performing their work. Identities, in general, refer to "*who the individual thinks he or she is and who is announced to the world in word and action*" (Charon, 1992, p. 85). Identities are significant because they "*suggest what to do, think and even* 

*feel*" (Ashforth & Kreiner, 1999, p. 417) and in the case of the participants' what corresponding care navigator role they assume (Katz & Kahn, 1966). Gary explains his sense of work role identity when working with colleagues in the community:

'I'm slightly disappointed because I' supposed to be based with 4 GP practices, but they appear to be not interested in non-clinical people hanging around, office space is limited but I could see more people effectively if I was actually based in the surgery'. (Gary)

A number of research studies advise identity is linked with organisational commitment, loyalty, and the display of cooperative and supportive behaviours (Walsh and Gordon 2008). Commitment, loyalty, and the display of cooperative and supportive behaviours are interpreted throughout the participants' interviews. This provides an understanding of how the participants think of themselves in the context of their work. This is important because it influences the roles they adopt and their corresponding behaviours when acting on behalf of their organisation (Golden-Biddle & Rao, 1997). As found with participants' professional identity, they display the organisations ethos throughout their lifeworld experience by empowering older people to make choices and take control of their lives. Social identity theory holds that individuals create their self-concepts, in part, when they classify themselves into distinct social groups (Trepte and Loy 2017). Each social group offers a particular member-identity, which members can choose to incorporate into their own individual identities. Social groups can include demographically based ones as well as organisational ones, such as clubs, religious groups, places of employment, or occupations (Bhattacharya, Rao, & Glynn, 1995; Turner, 1982). Interpretation of the participants' interviews found that they are a distinct social group that view themselves collectively as care navigators. All participants hold a very clear idea of what their role is as an individual and as a collective. As Natalie explains:

'I work to link adults aged 50 and above with isolation and malnutrition problems to access services that promote their independence and support them to keep their independence. I work within a multidisciplinary team linking them to agencies to develop role and development of services. I provide care navigation in a number of different ways, I undertake home visits with people who have been pre-referred by the person directly, by a family member or friend. I work 2 days a week in a GP practice in a Care Navigator role supporting staff in the practice to undertake care navigation within their roles. I attend a multidisciplinary team meeting in the North of the Borough advising on care navigation issues'. (Natalie)

#### 4.14 Summary of findings

The importance of being a compassionate carer by undertaking holistic assessments of service users enabling them to make their own choices to lead independent lives was the theme running throughout the participants' lifeworld. To maintain this at the centre of all they do the participants' place a great importance on knowing and being part of the local community. This includes knowing what the local community has to offer service users and playing a part in the community they serve.

The interviews provide examples of how participants come up against a number of limitations in their role. This is often the result of the lack of services available in the local community provided by or funded by the local health and social care system. This has an impact on the participants' lifeworld having an effect on how they undertake their role. Collectively the participants' would like some real evidence of the impact of their work. This includes the monitoring of service users on an ongoing basis, with long-term outcomes being observed along with the impact of the role in the local community and health and social care sector. Overall it is evident the participants' enjoy their role and appreciate their input into changing individuals lives and feel it is a privileged to do so. Through the interpretive phenomenological analysis process the study provides an insight into how the participants identify themselves in the context of their lifeworld experience with the

participants' professional and work role identity being formed by the three superordinate themes that emerged during interpretative analysis, compassionate carer, holistic assessor and enabler.

In this chapter, I offered the experience through my interpretation of the participating care navigators' lifeworld by presenting the emergent themes drawn out during the interpretative analytic process. Three superordinate themes emerged during my interpretative analysis, compassionate carer, holistic assessor and enabler. I found these themes interrelated across all five-care navigator's lifeworld experiences. Nine subordinate themes emerged from the superordinate themes. Person centred, active listener, and explorer emerging from compassionate carer, active observer, home visit, and prevention and isolation from holistic assessor, with direct to groups, attend groups and local community from enabler. Interpretive analysis of these themes provides insight into their individual and collective role identity as care navigators.

literature supporting this subject. I discuss how my findings illuminate previous research and how existing literature supports my interpretation of these findings.

#### **Chapter 5: Discussion**

## 5. Introduction

In the last chapter, I offered the experience through my interpretation of the participants' lifeworld by presenting the emergent themes drawn out during the interpretative analytic process. In this chapter I consider the study findings in relation to participants' lifeworld experience and published literature in this subject. I discuss the way in which the participants make sense of their experience of role and the extent to which these experiences influence individual and collective perception of identity with use of participants' own words to support discussion. I discuss how my findings connect with previous research and how existing literature supports the findings. I employ pertinent literature to conceptualise my findings to understand in detail how the participants' experience being a care navigator from their perspective within their lifeworld and how they make sense of their experience and attach meaning to life events (Smith et al. 2009). Van Manen (1997) offers for reflection four lifeworld existentials of lived body, lived time, lived space, and lived human relations. These existentials underpin the process of how participants' make sense of their experience of role and influence their individual perceptions. Lived body refers to the physical body or bodily presence in daily life, for the participants' that involves how they feel, reveal, conceal, and share through their lived body. As they are always present in the world, it is through their lived body that they communicate, feel, interact, and experience the world. The existential of lived time can be understood as time the participants experience it. This is a subjective understanding of time and refers to the ways in which the participants experience the world on a temporal level. How the participants' feel can influence how they experience time and moments. Conversely, constraints, freedoms, and demands placed by time can also affect how the participants feel. The third lifeworld existential, lived space can be understood as the subjective experience of the spaces the participants' find themselves in. Lived space explores both the way in which the space participants find themselves and the way it affects the way they feel. Conversely, the way participants' feel can affect the way they experience a particular space.

Lastly, the existential lived human relations refers to the relations participants' make and/or maintain with others in their lifeworld. Although each of the four-lifeworld existentials focus on different themes, they are interwoven and interact with one another in the participants' lifeworld. Van Manen (1997) suggests that experiences can be understood as corresponding to these four lifeworld existentials. These lifeworld existentials proved valuable when exploring the phenomenon under investigation the participants' experience of role though the emergent pattern of three superordinate themes, compassionate carer, holistic assessor, and engagement enabler and nine subordinate themes; person centred, active listener, explorer, active observer, home visit, prevention and isolation, direct to groups, attend groups, and local community.

#### 5.1 Compassionate carer

A scoping review undertaken by Sinclair et al (2016) of 44 studies found six themes emerged from studies that explored perceptions of compassionate care, these being: nature of compassion, development of compassion, interpersonal factors related to compassion, action and practical compassion, barriers and enablers of compassion, and outcomes of compassion. The review identified the limited empirical understanding of compassion in healthcare and highlighted the lack of patient and family voices in compassion research (Sinclair 2016). The scoping review concluded that a deeper understanding of the key behaviours and attitudes that lead to improved patient-reported outcomes through compassionate care is necessary.

Davidson and Williams (2009) defined compassion as mercy and sympathy along with action and caress. Compassion is more than just the necessary care it includes empathy, respect, and recognition of personal characteristics (Davidson and Williams 2009). Although it may be difficult to understand the complexity of the term 'compassionate carer' given the need for further research into the area (Sinclair 2016), the study participants express compassion through their own words throughout their individual interviews by their expression of kindness, caring, and the willingness to

help others. Sinclair et al (2016) found compassion was extolled as a cornerstone of quality healthcare by patients, families, clinicians and policy makers. Cole-king and Gilbert (2011) believe the delivery of compassionate care by the health and social care workforce enhances their personal performance with staff eliciting better patient information to inform treatment plans leading to an associated increase in patient satisfaction. It is evident from interpretation of the participant interviews that being a compassionate carer is central to their role and their experience of their lifeworld. This compassion in practice supports the building of relationships with the service users in the short time available to develop a needs plan to enable positive outcomes for the individual.

The participants' interviews provide evidence on the prominence service users place on the nature and quality of the relationship they have with their care navigator. The significance of positive human gualities in health and social care workers is found in a number of studies (Beresford et al 2005, 2006; Nolan et al 2006; Andrews et al 2009). Interpretation of the interviews finds the importance of the individual and care navigator relationship is not an add-on but that a good relationship ensures success of the alliance to enable better outcomes as observed in work by Horvath & Symonds (1991) and Howe (1998). In a study by Van der Cingel (2011) patients were asked to provide the associations and situations that came to mind when they thought about compassion. The study found seven dimensions associated with compassion were identified: attentiveness, listening, confronting, involvement, helping, presence, and understanding (Van Der Cingel 2011). These dimensions emerge through the interpretation of the participants lifeworld experience. Bradshaw (2011) and Gilbert (2013) express compassion as incorporating a number of features, including a cognitive element; found in the participant interviews as understanding what is important to the individual service user. A volitional element as perceived in the participants' lifeworld experience when acting to alleviate an individual's disquiet. Effective and altruistic elements, heard in the participants' interviews of imaging what the individual is going through and reacting to the individuals needs selflessly. To react appropriately to service users'

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needs. Patients and family caregivers have described the inherent qualities of compassion (Sinclair et al 2016). These qualities' respect, dignity, care, and kindness are found throughout the interpretation of participants understanding of their lifeworld experience. In their scoping review of compassion Sinclair et al (2016) found studies that identified barriers to providing compassionate care. Barriers where found in the domains of the clinician, the healthcare system and education. These barriers are referred to throughout the participants' interviews. Problems experienced in their lifeworld include referral to clinicians, services and general inequalities and shortfalls of the health and social care system. The participants' raise the issue of a health and social care system wide lack of education regarding the role of the care navigator and their expertise in working with and supporting the local population. Dutton et al (2006) believe barriers can be overcome by creating a compassionate working environment. By doing this a positive impact is found in people's commitment to an organization; how they view their colleagues, and in turn help them to deal with suffering and distress they face in their job. The confirmation the participants' create a compassionate working environment is heard in their lifeworld experience of how they work together as a collective and with the wider health and social care workforce. Participants' describe how they received support on joining the care navigator team and how they go on to support others in the role by drawing on previous lifeworld experience. This enhances the communal experience of role and supports the collective and individual identity as care navigators. This communal experience supports Bivins et al (2017 p 1025) view on the delivery of compassionate care 'In the complex environment of modern health services, caring-for patients, for staff and for the organisations that enfold them-must be a shared responsibility, since no single individual or professional group can ensure the delivery of compassionate care'. This 'shared responsibility' in the conveyance of compassionate care stimulates identity correlated to group membership with the motivation on social identity rather than personal identity. This imitates social identity theory (Tajfel & Turner, 1986) where it is contended that being associated with a certain group influences how you think and behave. This social identity is influential in the participants' gaining their collective sense of their care navigator 'role' in their lifeworld. Hymans (2008) introduces the

concept of 'role' in which expected patterns of behaviour are associated. He argues that '*It is important for people working in the same professional role to construe certain experiences, events and other people in similar ways. This commonality of construing ensures successful and similar outcomes*' The participants' communal sense of social identity is shaped by a sense of agency; the subjective awareness of initiating, executing, and controlling their own volitional actions in their lifeworld and feelings of empowerment as seen in the work of Beauchamp & Thomas (2009) in their cooperative approach to the conveyance of compassionate woven throughout their communal characteristics. Way and Tracy (2012) identify three components of compassion that allow a distinction from empathy. These components are found in the participants' interviews as they describe how they recognize suffering, relate to the service users' suffering, and then re-act to this suffering by empowering the service user to grow into becoming independent.

As well as displaying compassion for the service user, the participant's, exhibit four defining attributes of empathy (Wiseman 1996). Through interpretation of their interviews the participants', see the world as others see it, and are non-judgemental. They show understanding of another's feelings and communicate the understanding through their interactions with service users. The participants' motivate the service users' journey to independence by undertaking a holistic assessment of needs observing the whole person, taking into account physical, mental and social factors, rather than just the symptoms of a disease.

#### 5.2 Holistic assessor

Concern regarding assessment in community based health and social care has been present for a number of decades with assessment procedures being service-led not user centred (Miller, 2010). This approach often saw individuals' being forced to use inflexible, traditionally delivered services, with little attempt made to meet individual need. Means et al (2008) proposes that there is a gap in the way in which assessment and care management systems are implemented which restricts the

development of the interpersonal skills required of the assessor. A study undertaken by Means et al (2008) discovered the introduction of a care navigator role bridges this gap by the care navigator being able to perform quality assessments focused on the specific needs of the individual. A literature review undertaken by Miller and Cameron (2010) identified a challenge in resolving the tension between standardisation and flexibility when developing assessment tools. Through interview interpretation participants' ability and skill in assessing service users' with a predetermined assessment tool was seen as valuable by them but being able to work outside of it should the need arise to meet a service users' specific needs was considered necessary. In their interviews, the participants' refer to their approach to assessment in their lifeworld with this interpreted as a holistic outcome-focused assessment. A number of authors identify outcomefocused assessment as restoring relationship-based approaches to practice, ensuring that the needs of the individual and carers are the main consideration of the assessment process rather than being determined by service priorities (Nicholas & Qureshi, 2004; Andrews et al., 2009; Miller et al., 2009).

The participants' raise concern about ability to meet an individual's needs due the lack of or limitations of services within the community as observed in literature (Qureshi & Nicholas, 2001; Andrews et al., 2009; Miller et al., 2009). The main areas of concern experienced as being the lack of accessible community mental health services and the length of time waited for external agencies to undertake assessment following care navigator referral. The participants' also spoke of their frustration of restricted access to services due to prescribed service user eligibility criteria. Miller and Cameron (2010) found these limitations a continuing challenge for staff undertaking assessments due to the need to balance an individual's needs with organizational requirements for rationing. Abendstern et al (2008) highlight this as an existent issue of conflict for staff who have to frame decisions about support needs against fixed agency criteria, supporting the lifeworld experience of the participants'.

The participants' raise their concern that their input with service users is often missed when evaluation of outcome-focused interventions are made. Miller (2010) notes that tension emerges when outcomes-based interactions are used for evaluations, particularly when they are firmly focused on evidencing the value of the service, or where the performance management agenda overrides value-based practice in the organisation. This is not found in the interpretation of the participants' commitment to ensuring service users' receive a person focused holistic outcomebased assessment. This commitment comes from a shared sense of social identity as social groups whether large demographic categories or small task oriented teams such as the participants' provide their members with a shared identity that prescribes and evaluates who they are, what they should believe and how they should behave (Hogg 2016). Cook and Miller (2010) consider that service-led evaluations often focus on the impact of the service intervention only, with no attention being paid to the role or person, [such as the care navigator] or informal support have played in an individual achieving their outcomes. Although there is no formal collection of data regarding the participants' impact on service user outcomes it is possible through interpretation of their interviews that their person focused holistic outcome-based assessments enable individuals to lead an independent life.

#### 5.3 Engagement enabler

The participants' interviews articulate their unique individual and communal skill for performing holistic outcome-based assessments that moves the focus from matching service users' needs to services to justly identifying what matters to the individual and working out what role the individual will have in achieving their outcome as appreciated by Miller et al (2009). This cooperative approach to assessment empowers service users and enables them to take control of their own life choices by the participants', recognizing, supporting, and emphasizing the individuals' personal capacity as accredited in a concept analysis undertaken by Hudon et al (2011) concerning enablement.

Hudon et al (2011) describe the origins of enablement being found in the concept of empowerment, this being a complex concept deriving from various literary fields. The participants' lifeworld experience demonstrate how they empower service users to make their own life choices. The term empowerment comes from the Latin verb for power 'potere' meaning 'to be able' with the prefix 'em' meaning 'cause to be or provide with'. The participants' provide service users with the opportunities available to be able to make their own life decisions, observing the genuine meaning of empowerment. Rappaport (1987) defines empowerment as a process by which a person gains more power over their life. This definition expresses the process the participants' follow in their world of daily practice, enabling service users to maintain independence by proposing suitable interventions. Wallerstein (2006) proposes that interventions, such as those found in the participants' lifeworld experience, support the development of individual empowerment and as such lead to positive outcomes. The participants' tell of their consideration of the person as a whole, taking a holistic approach to the individual, looking at their health condition, psychological condition, social condition (family, work, and finances), and knowledge of understanding, opinions, feelings and life expectations. This consideration of the person as a whole is explored in work by Loukanova et al (2007), Toofany (2007) and Virtanen et al (2007) who consider active listening, good communication, collaboration, and continuity all add to the egalitarian therapeutic relationship as captured in all the participants' lifeworld experience. Participants' tell of their part in enabling the service user by emphasising the individuals personal strengths, reinforcing their belief in their own skills and competence, while guiding the service user in understanding their situation as observed in the work by Loukanova et al (2007), Toofany (2007) and Virtanen et al (2007). Enabling the service user to see a positive vision for the future, assisting the process of transformation of thoughts by changing self-image, and giving hope and meaning to events and life is heard throughout the participants' lifeworld experience as found in work by Virtanen et al (2007). The normative enabling behaviour found in the participants' interviews is interrelated to their professional, work and social identity of role. Norms map social identity and are cognitively

represented as group prototypes that describe and prescribe identity-defining behaviour (Hogg & Smith 2007). In the case of the participants' lifeworld, their prototypes are compassionate carer, holistic assessor, and engagement enabler.

#### 5.4 Care navigator identity

Through interpretive phenomenological analysis, the study provides an insight into participants identity in the context of their lifeworld experience with their professional and work role identity formed by the three superordinate themes, compassionate carer, holistic assessor, and engagement enabler, found during analysis of their transcripts. Valaitis et al (2017) in their scoping review 'Implementation and maintenance of patient navigation programs linking primary care with community-based health and social services' of 34 papers, mostly originating in the United States (n = 29) with the remainder from the United Kingdom, Canada and Australia, reports on Five papers that specifically addressed issues related to role clarity of navigators. Valatis et al (2017) highlight the value of care navigators role clarification in relation to the importance of patients' roles as partners in their care, including the setting of clear boundaries such as not to provide any clinical advice as found in the interpretive phenomenological analysis of the study participants lifeworld experience. Peart et al (2018) in a scoping review of twenty studies reporting on patient navigators facilitating access to primary care, found only Three studies that provided detail about the role and responsibilities of the navigator. Carter et al (2018) in their scoping review of 34 papers reporting on care navigation models and roles, found Twelve papers that reported on lay person care navigation models. These papers reported on non-professionals trained to perform specific activities related to system navigation functions (Carter et al 2018) this being similar but not fully same as the study participants lifeworld experience. Carter et al (2018) found In four of the models, the navigator was described as a community health worker (CHW) or a certified CHW which suggests a formalised training program and role. Ten papers described six navigation models that were led by nurses. Two of the models utilized Advanced Practice Nurses and four models utilized Registered Nurse (Carter et al 2018). Six papers described navigation provided by

teams comprised of health professionals and laypersons with three papers describing navigation services provided by teams of health professionals (Carter et al 2018). The evidence provided does not report on non-professional care navigators identity within the papers reviewed. This new empirical knowledge is provided in the study, through the use of interpretive phenomenological analysis of the participants lifeworld experience.

#### 5.5 Summary of discussion

The study participants' have a clear understanding of their individual and collective identity in their lifeworld through interpretation of their lifeworld experience. This identity has enabled the participants' to be evidently differentiated from other members of the multidisciplinary health and social care team in their lifeworld work environment. Their professional and work role identity is formed individually and collectively by the role they undertake in their lifeworld on a daily basis. These roles are compassionate carer, holistic assessor, and enabler. The participants' work across traditional statutory health and social care boundaries to enable service users to maintain independence. This is achieved through being person centred, an active listener, explorer, and active observer when undertaking assessment and home visits for prevention of isolation. The participants' direct service users to groups and support attendance and interaction with these groups. By doing this the participants' enable service users engagement with the local community. To maintain and support their identity the participants' hold a unique knowledge base of their local community and the groups and services available to the service user population. In this chapter, I considered the study findings in relation to participants' lifeworld experience and published literature in this subject. I discussed the way in which the participants make sense of their experience of role and the extent to which these experiences influence individual and collective perception of identity with use of participants' own words to support discussion.

In the next chapter, I present my conclusions from the study and discuss conceivable limitations. I also consider how the findings translate into recommendations for future practice, policy and research in the care navigator domain.

#### Chapter 6: Contribution to knowledge and practice, limitations and recommendations

#### 6. Introduction

In the last chapter, I considered the study findings in relation to participants' lifeworld experience and published literature in the subject. I discussed the way in which the participants make sense of their experience of role and the extent to which these experiences influence individual and collective perception of identity with use of participants' own words to support discussion. In this chapter, I present the conclusions from the study and discuss conceivable limitations. I also consider how the findings contribute to new knowledge about care navigator identity and their relationship with the wider health and social care workforce and service delivery. I translate the findings into recommendations for future practice, policy and research in the care navigator domain.

## 6.1 Revisiting the research aims and objectives

Guided by the subjectivist ontological paradigms intrinsic to interpretative phenomenological analysis (Smith, Flowers and Larkin, 2009), the study aimed to gain an understanding of the way in which participants' made sense of their experience of care navigator role and the extent to which these experiences influence individual perception. My interpretation of the participants' experience was steered by the work of Gadamer (2004), he identifies that language acts as the medium for understanding and as a means of sharing the complexities of human experience. By using a qualitative approach to the study as a meaningful method, I discovered the participants' experience of role in their lifeworld. My use of semi-structured interviews allowed the participants to explore their experiences, and upheld their status as the experiential expert in the role of care navigator (Smith et al 2009). The study produced 'participant-generated' meanings to be uncovered, which according to Willig (2008), allows for the possibility of new and unanticipated categories of meanings to emerge, this being achieved by interpretative phenomenological

analysis. By using interpretative phenomenological analysis I believe I met my aim to capture and preserve the complexities and characteristics of experience, in contrast to my using quantitative methods for the study, where the aim of investigation is to achieve a single 'real' or true account of a phenomena. The study took the epistemological assumption that whilst an individual's account of their experience can reflect their internal world in a meaningful way, this insight is mediated by my own assumptions and conceptions as the 'insider-outsider' researcher (Smith et al. 2009), thus my own experience of care navigators may have influenced the interpretative phenomenological analysis process. I hold experience of developing and delivering an education programme for care navigators, not for the participants' involved in the study but a group of National Health Service employed care navigators working in three London Boroughs. I had the experience in being involved in the development of Care Navigation: A Competency for Health Education England. I also hold experience of undertaking a systematic literature review prior to commencing the participant interviews. My interpretation of the participants' understanding and individual perception was found in the language of their interviews, allowing the sharing of my interpretation of their interpretation of their lifeworld experience. Because of this, I consider the study to have met its aims and objectives by providing an understanding through interpretative phenomenological analysis the way in which the participants' make sense of their experience of role and the extent to which these experiences influence individual perception of individual and therefore collective identity. My interpretation of their lifeworld experience interviews explores how the participants' make sense of their role and my discussion examines the extent to which these experiences influence individual perceptions of identity. The contextual background of health and social care and systematic literature review explore the dominant discourse at the time of the study surrounding care navigators, and the reported experiences associated with care navigators. The findings through interpretative phenomenological analysis provide robust and credible evidence of the key features of the role of the care navigator as it is understood by the participants' working within the third sector in two sectors of a London Borough in the United Kingdom. This provides empirical knowledge about care navigators not previously available.
While undertaking the interpretative phenomenological analysis I endeavoured to maintain the phenomenological, hermeneutic and idiographic theoretical principles (Smith and Osborne 2008). I did this by the use of reflexivity, where I reflected on my thoughts, actions, assumptions and expectations throughout the study by the use of a hand written diary (Lambert et al 2010). This made me aware of my influence on the study findings by bringing my thoughts and actions to a conscious level (Jootun et al 2009). By the use of reflexivity I was able to provide a rationale for my decisions at the time, and if required alter the research process to generate relevant findings (Findlay 1998, and Smith 2006). By meeting the aims and objectives, the study provides an original contribution to the care navigator empirical evidence base by providing insight into the lifeworld experience of a group of care navigators.

# 6.2 Original contribution to knowledge and practice

### 6.2.1 Knowledge

A scoping review of literature undertaken prior to the study found little about care navigator experience of role in the United Kingdom. The mainstream of published literature is concerned with the impact of the role for service user and/or health and social care service outcomes. Studies undertaken in North America provided the majority of published work (Carter 2018), where roles such as the care navigator are delivered in a different health and social care system to that of the United Kingdom. This lack of literature and empirical evidence may be due to the want of identity care navigators hold in practice. This study provides new knowledge regarding care navigator identity within the health and social care workforce. This unique identity is formed from the participants' lifeworld experience and is found through interpretation of the participants' interviews. The study provides both individual and collective role identity influenced by the superordinate and subordinate themes found throughout the interpretative phenomenological analysis. This gives care navigators a defined role, separate from others within the multidisciplinary health and social care workforce. The study highlights the participants' commitment and resilience when building and shaping the care navigator role in the interminably changing world of health and social care service delivery within the United Kingdom.

The study provides new knowledge about the role care navigators perform, this being compassionate carer, holistic assessor and engagement enabler. To meet the needs of their role identity care navigators are person centred, active listeners, and explorers. Care navigators are active observers who undertake assessments and home visits with service users for prevention of isolation. They direct service users to groups and attend groups with service users to engage the service user with their local community.

# 6.2.2 Practice

Care navigation is an emerging idea in the United Kingdom with a growing evidence base demonstrating benefits for patients and carers (Health Education England 2016) as such this study provides empirical evidence to inform health and social care workforce planning, policy and procedure. This can be used by statutory and non-statutory organisations requiring evidence about what role the care navigator can play in the local health and social care system. The study findings can be used to support the introduction of the care navigator role into the health and social care workforce thus having impact on skill mix as suggested in work by Sibbald et al (2004). Sibbald et al (2004) consider changing workforce skill-mix is one strategy for improving the effectiveness and efficiency of health care. Introduction of the care navigator role can provide enhancement of career by up-skilling current health and social care support staff to become care navigators. It can be introduced as a substitution role by expanding the breath of a job to work across professional and/or service boundaries. Tasks traditionally undertaken by members of the multidisciplinary team can be delegated to the skilled care navigator. In this scenario, the

introduction of the care navigator role can be seen as an innovation within the workforce. The study provides evidence that the role of the care navigator should feature in local health and social care workforce planning. It is an ideal role to bring together health and social care and housing services together both in workforce planning and service delivery, creating 'one system' for service users to navigate with support.

The study offers empirical evidence that although The Department of Health and Social Care (DHSC) perceive health and social care as one system [figure 1] the participants' and users of the system do not. Service users require support to use the complex health and social care system with needs that require input from health and social care and housing services. The study provides empirical evidence that the role of the care navigator is central in maintaining service users' independence and enabling engagement with the local community. Tierney et al (2019) state there is a policy steer to engage patients in social prescribing, using some form of care navigator to help with this. Results from a cross-sectional study of NHS clinical commissioning groups undertaken by Tierney et al (2019) highlights that, although the care navigator role is being provided, its implementation is heterogeneous. The study findings should raise awareness and recognition of the role and support its introduction into the United Kingdom health and social care and housing system as Health Education England (2016) state care navigators play a crucial part in helping people get the right support, at the right time, to help manage a wide range of needs. This study provides empirical evidence to support this statement. The study adds an original contribution to knowledge and practice by hearing and interpreting the voice of the participants' performing the role of a care navigator within the United Kingdom. In achieving this the study has both strengths and limitations.

## 6.3 Strengths

The strength of the study lies in the flexible and versatile nature of interpretative phenomenological analysis in facilitating an understanding of the participants' subjective lifeworld experience. By taking this approach to the study, the findings provide interesting and detailed insights into the lifeworld of the participants' providing original empirical evidence that informs both knowledge and practice. The study findings emerge from the interpretation of the participants' lifeworld experience rather than being imposed by the investigator. To achieve this I was careful to keep descriptions as faithful as possible to the experiential raw data by utilising the participants' as experts while exploring their lived lifeworld experience.

### 6.4 Limitations

When reading the transcripts I endeavoured to suspend my presuppositions to focus on what was offered in the transcript data. This involved the use of "bracketing" (Husserl, 1999) the suspense of my critical judgement and refusal of critical engagement that would bring my own assumptions and experience (Spinelli, 2002). The concept of bracketing is to some extent contentious and gives way to a more interpretative process as analysis proceeds. This interpretative process prompted me to take a reflective and reflexive approach to the study. I aimed for transparency by identifying my position to the study, outlining the procedures and by presenting transcript extracts to allow the reader to reflect on my interpretation and contemplate potential alternatives. I fully concede that the transcript extracts presented could be considered to lack depth as they are presented primarily out of context (Potter and Hepburn 2005). However, those presented allow the reader to hear the voice of the participants' and their lived lifeworld experience. Using interpretive phenomenological analysis allowed the participants' to *'think, talk and be heard'* predisposed by the use of the small homogenous sample (Reid et al, 2005). Using the small homogenous sample confirms that the findings are not at first read generalisable. However, in an attempt to allow the reader potential transferability of findings I provide the participants' positions that form the setting so it can be fully

understood. All the participants' were employed in the third sector and worked across two sectors of a London Borough when the study took place. This has impact on the lifeworld experiences of the participants' and therefore the study findings. Care navigators working in a different sector and/or setting would have different lifeworld experiences to share. As the participants' selfselected to take part in the study, this should be considered when interpreting the study findings. It is possible that the participants' who took part in the study are more engaged and therefore more motivated in delivering their role, this can influence their interpretation of their lifeworld experience. Depending on the reader's interpretation of the findings, this could affect the transferability of the findings into real world policy, practice and research.

Unforeseen external factors presented challenges while undertaking the study. The Global COVID-19 pandemic and consequent national lockdowns and closure of the university campus had an adverse effect during the revision period of the study as access to university resources was majorly restricted. The university also experienced a criminal cyberattack during this period, leading to the closedown of a number of key IT systems until they could be safely restored.

### 6.5 Study impact

The impact the study findings have can occur in many ways, through knowledge exchange, to the introduction of new policies and processes. The study provides empirical evidence on the role and identity of the care navigator that can inform statutory, non-statutory and third sector services policy development. My primary criterion for impact is empirical research excellence. To prompt this I make recommendations for policy and practice and future research. To enable this I provide my plan for dissemination of the study findings.

# 6.6 Recommendations for policy and practice

In the current economic environment health and social care, budgets are highly constrained in the amounts that can be spent. The General Practice Forward View (2016) states the forward view cannot be delivered without sufficient recruitment and workforce expansion. To ensure workforce funding is spent for optimum gain the study provides through empirical evidence understanding of care navigator identity and what role the care navigator undertakes. By doing this, it is recommended the study findings be used to inform future health and social care policy and guidance with particular reference to workforce policy direction. To support this, recommendations for future research are necessary.

### 6.7 Recommendations for future research

As raised by the study participants' it is recommended research into how care navigators' impact on whole system and service user's outcomes is required. Further methodological work to robustly capture role impact is required, including cost benefit analysis of the role. This will be methodologically challenging but beneficial to conduct long-term studies that quantify the impact of care navigators on the Commissioning for Quality and Innovation (CQUIN) framework indicators. CQUIN supports improvements in the quality of services and the creation of new, improved patterns of care (NHS, 2020). Further exploration of the wider health and social care multidisciplinary teams understanding of the care navigator role is recommended. This should include the structures and processes of the health and social care teams to ensure the role is correctly utilised and supported in practice. Work is required to find out what brings people into the care navigator role and what is required to retain them. Additional investigation needs to be undertaken to identify what skills and competencies are required to deliver the role. This would advise on care navigator training and education needs not currently available or accessible. To enable these recommendations to be acted upon a study findings dissemination plan was required.

# 6.8 Dissemination of findings

There are a number of key audiences to be targeted when disseminating the study findings. These include statutory and non-statutory organisations such as the National Health Service, social care services, charities, social enterprises and the third sector. Care navigators, service users, the public and colleagues in academia.

To ensure that the study informs knowledge and practice and maximises the benefit to care navigators and service users' the World Health Organization (2014) dissemination strategy will be deployed to translate knowledge into practice *[figure 12]*.



Figure 10: Steps in developing a dissemination strategy (World Health Organization, 2014)

Research is utmost effectively disseminated using multiple vehicles (Edwards 2015) therefore in addition to giving written feedback to the participants'; I will undertake the process found in *[table 6]* to produce a dissemination action plan. The best routes for research dissemination is just one of the key lessons I have learned during my journey through the study.

Dissemination Action Plan	
Steps in developing a dissemination strategy	Action Plan
Review past dissemination efforts	Review previous available thesis dissemination plans
Devise dissemination objectives	To disseminated the finding re care navigator identity and role.
Determine audiences	Health and social care statutory and non- statutory organisations
Develop messages	<ol> <li>Care navigators identity</li> <li>Three superordinate themes</li> <li>Nine subordinate themes</li> </ol>
Decide on dissemination approaches	<ul> <li>Publishing project findings in peer- reviewed professional journals and publications</li> <li>Publishing on social media</li> <li>Presenting at local and national conferences</li> <li>Presenting findings to local community groups and other local stakeholders</li> </ul>
Determine dissemination channels	<ul> <li>Oral presentation</li> <li>Poster presentation</li> <li>Roundtable presentation</li> <li>Written presentation</li> </ul>
Review available resources	<ul> <li>Review costs for:</li> <li>Translation of materials</li> <li>Specialized skills such as graphic design, etc.</li> </ul>
Consider timing and windows of opportunity	Ensure one form of dissemination achieved within one year of thesis completion
Evaluate efforts	Evaluate success of dissemination plan six months post commencement

Table 6: Dissemination action plan

(World Health Organisation 2014)

## 6.9 Lessons learned

I have been on a long learning journey while undertaking the study. The research process from concept to delivery of a completed study is one that has provided many learning opportunities along the way. I have learnt how to register a research proposal and was thrilled to receive an email from the London South Bank University Research Board of Study stating that my application was considered exemplar, with permission being requested for it to be viewed by other students *[appendix 2].* 

I have learnt how long and arduous the process is to obtain ethical approval to undertake research within the National Health Service, that in the end I did not require as I undertook my study in the third sector. After a search of care navigator jobs advertisements in London, I found the majority of posts were located in the third sector. I learnt about interpretative phenomenological analysis while undertaking the study and its emphasis on convergence and divergence of experiences, as well as it being the correct choice for examining detailed and nuanced analysis of the lived experience of the study participants'.

# 6.10 Summary of thesis

This study provides new empirical evidence regarding care navigator role and identity within the health and social care workforce. This unique identity is formed through the participants' lifeworld experience and was understood through interpretation of participants' interview transcripts. Through the study findings care navigator identity emerges, defining the role, making it distinct from others within the multidisciplinary health and social care workforce. Through interpretive phenomenology analysis, three superordinate themes emerged from participant interview transcripts, compassionate carer, holistic assessor and engagement enabler. Nine subordinate themes emerged from these superordinate themes. Person centred, active listener, and explorer emerging from compassionate carer, active observer, home visit, and prevention and isolation

from holistic assessor, with direct to groups, attend groups and local community from engagement enabler.

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## Appendices

## Appendix 1 Research Degree registration GUIDANCE NOTES ON THE COMPLETION OF THE RES2 APPLICATION TO REGISTER FOR A RESEARCH DEGREE Section 1 - The Applicant

## Please complete fully.

Collaborating establishment - if an establishment is collaborating in the research (eg by providing a maintenance award, supplying equipment, providing a supervisor/or an adviser), allowing access to the establishment staff or facilities}, that establishment should be identified in the relevant box.

## Section 2 - The Programme Of Research

Section 2.2 *the aim and objectives of the investigation:* in this section, you are asked to briefly describe the main aim or goal of your research and the key objectives (up to seven) whose completion will enable the aim to be met.

Section 2.3 *the research proposal.* This is the most important section of the form. In it, you are asked to set out in detail what research you will be doing throughout the period of registration, how you plan to do it and why you think that this is the best way to conduct your research. The proposal should include the following probably, but not necessarily, in this order

- 1) **Introduction including Statement of the real-world problem** in brief (a paragraph or two);
- 2) **Literature review** which draws on key and recent published work in your field, explaining the gap in academic knowledge to be addressed by your research;
- 3) **Research question(s)/aim(s)** with a clear explanation of how they relate to the gap in knowledge and, if there are multiple questions/aims, how they inter-relate;
- 4) **Research objectives** these should provide a series of explicit and measurable objectives around which the research methods can be designed and assessed. These are not the general aims of the research, but the key detailed questions which would need to be answered so that the research question as a whole can be answered.
- 5) **Methodology**, drawing on research methods' literature as appropriate and setting out the methods to be used in meeting the research objectives, you should explain your research paradigm and strategy, what data you will collect, how and where you will collect the data, and describe the techniques that you will use to process and verify the data that you have collected. The methods should be appropriate for the\_aim(s) and objectives of the project. Any ethical issues should be identified.
- 6) **Original Contribution to knowledge** summarise how you believe your research will advance knowledge in the field and contribute to new knowledge.

7) **Timescale**- - the proposal must state what you will be doing at each stage of the project. The first months and the first year should be charted in more detail than the later years. However, your plan must link with the research questions described in your aim(s) and objectives and the tasks described in your methodology. For part-time students, the timescale will be longer and can be less precise than might be the case for a full-time student. The timescale should be presented in diagrammatic form in the form of a GANTT chart or similar.

## Please note

*feasibility* - You should ensure that your proposal is feasible and realistic. Make sure that the tasks that you are setting yourself are not too great.

*references* - the proposal should demonstrate that the student is familiar with recent published research and other scholarly activity related to the proposal. It is through the inclusion of up-to-date references that an awareness of the current state of knowledge in the chosen discipline can be demonstrated. References are exactly that and should therefore be discussed within the text of the plan of work. The London South Bank University guide to referencing should be followed.

*length* - This section should not exceed a maximum of 4 sides of A4 in Times New Roman or Arial font point 12, excluding the list of references and gantt chart. Single line spacing is acceptable. The Research Board of Study will not review applications submitted where the proposed plan of work is larger than the maximum number of A4 sheets.

## 2.5 Research Ethics

Section 2.5 Research for awards of the University must conform to the **Code of Practice** laid down by LSBU's Research Ethics Committee (REC). It is important to obtain any necessary ethical approvals before starting research.

It is impossible to give a detailed guide to ethical approval here. The Code of Practice should be consulted. Briefly, however, approval is generally required when the research involves human participants, and sometimes you will need to obtain approval from an <u>external body</u> <u>such as an</u> NHS REC first (your supervisor should be able to advise you on this). You **will** need ethical approval if you want to take samples or measurements from people, or to administer substances to them, or to take part as an investigator in a clinical trial. You **are likely** to need ethical approval to interview people or to conduct surveys. Work which is purely laboratory or library-based is unlikely to require ethical approval.

## Transferring registration from another University:

If a student is transferring registration from another University, some of the work may already have been completed. This should be made clear in the plan of work. The timetable for example might specify those tasks which have been completed. In these cases, students can apply for the registration to be backdated to the point at which the work was commenced at the prior University.

Section 2.6 *Relationship with any collaborating establishment* - in section 1 you were asked to identify those establishments, if any, collaborating in the research. {eg by providing a maintenance award, supplying equipment, providing a supervisors (or an advisers), allowing access to the establishment staff or facilities}, that establishment should be identified in the relevant box and the nature of your relationship with each collaborating organisation or person identified.

## Section 3 - Research Skills Development Self Audit

In your supervisory meetings you will have already discussed what research skills development skills you have already gained to a competent level and these should be recorded in Section 4 under the appropriate headings, e.g. communicating with people on a variety of levels, at meetings, on the telephone etc. would be recorded under 4.5.

## Section 4 – Research Skills Development Programme

Having previously completed the self audit you and your supervisor will have devised a suitable development plan to enable you to develop weak or non-existent skills under the relevant headings; this development plan should be recorded in this section.

## Section 5 - The supervision of the programme of work

It is most commonly the case that students are supervised in their research by a team of supervisors rather than an individual. University regulations stipulate that the supervisory team, either individually or collectively, normally have successfully supervised two students to completion of a PhD.

The University recognises that, either as a result of contacts made by the supervisor or the student, there may be a wish to collaborate in the supervision with another academic institution or research centre. This is acceptable although if the experience of successful supervision is provided by non-London South Bank University staff, the University may require the external supervisor to be formally contracted by the school to ensure the adequate and on-going participation of the external supervisor. This is not necessary if the external is merely involved in an advisory capacity. It is important that Form RES 9 is completed for a supervisor in this situation, or is a new research supervisor at London South Bank University.

## Section 6 - Types of registration

Section 6.1: Type of degree sought:

Section 6.2: You should include in this box the date you commenced your research i.e. date of enrolment; unless this predates the submission of your registration form by six months (full-time) or nine months (part-time).

Students transferring registration from another University can apply for registration to be backdated to the point on which they commenced their research at the transferring University.

## Section 7: Declaration

You should read the statement and sign and date it before uploading the document to the review folder assigned to you in the Connections Tool (My LSBU).

## Checklist:

- Ensure that all the boxes on the form have been completed.
- Ask members of your supervisory team who are new supervisors at London South Bank University or external supervisors to complete a RES9 CV form to supplement your RES 2.
- Signed and dated the declaration.
- Obtained signatures from your supervisory team and Dean or Director of Postgraduate Research, or Research Lead.

## Section 8: Recommendation of the Review Panel.

## London South Bank University

# APPLICATION TO REGISTER FOR A RESEARCH DEGREE

#### Data Protection Act 1998

RES 2

The data collected on this form will only be used for the purpose of student and course administration as required by the University and will be retained securely on your file.

Surname:			Student No:			
Johnson		3100196				
First Name(s):	-	rt-Time:	School: School of Health and Social Care			
Richard	Part-Tir	ne				
Telephone:		Telephone:				
Email:		Emoile				
			Email:			
Details of any scholarship held or		Details of any collaboration (contact name & address)				
financial support:		Not applicable				
Not applicable						
			nts should additionally supply a letter of n the collaborating partner.			
			n no condectating particle.			
2. PROGRAMME OF RESEARCH						
2.1 Title of the proposed investigation (12 words maximum):						
'Exploring Care Navigators experience of role'						

2.2 Aim, objectives and desired outcome of the investigation (please be specific): **Aims:** 

- To explore how care navigators make sense of their experience of their role
- To examine the extent to which these experiences impact on individual perceptions **Objectives:**
- Explore dominant discourse surrounding care navigators;
- Explore the reported experiences associated with care navigators within the literature;

• Provide robust and credible evidence of the key features of care navigation as it is understood by care navigators working within two sectors of a London Borough in the United Kingdom.

2.3 Proposed plan of work, including its relationship to previous published academic work with up to twelve references. Please keep within a maximum of four sides (not including the 12 references or GANTT Chart) of A4 in font 12 (Arial or Times New Roman) otherwise the application will be returned.

## 1) Introduction

Transforming Primary Care (DH 2014) states that there are now over 4.4 million aged 75 in England and that by 2026 there will be more than 6.3 million. More than a quarter of these people who have a long term condition say they are not well cared for by the NHS, and two-fifths expect their care to get worse over the coming years. People are frustrated by using different services that do not speak to each other, and feel that their conditions are treated in insolation.

The Five Year Forward View (NHS England 2014), highlights the importance of integrated care in bringing services together so patients receive holistic co-ordinated care. It describes a number of models of care that can play a role in integrating services across different care settings, including multispecialty community providers and primary and acute care systems. The Care Act (2014) also necessitates an integrated approach with planning of care across a person's whole care needs, not separate ones for health and social care. From September 2014 people with the most complex health and social care needs were placed on the Proactive Care Programme, receiving personalised, joined up care and support. People have a personalised, proactive care and support plan supported by a care navigator who provides advice and helps them to navigate the health and social care system. The care navigator role, usually based in a multidisciplinary team identifies available services, signposts and supports access and acting as link workers, facilitates appropriate service integration (Anderson and Larke 2009).

To expedite integrated care policy into practice in London The Transforming Primary Care in London: A Strategic Commissioning Framework (NHS 2015) was developed by clinicians, commissioners, patients and other partners across London, presenting an ambitious and attractive vision of general practice that operates without borders, and in partnership with the wider health and social care system. To meet the needs addressed in the framework it discusses implications for the workforce and the introduction of new roles; including care co-ordinators and navigators supporting new ways of working within general practice and across the wider care team.

Our Healthier South East London (OHSEL) (NHS 2016) undertook a project to understand the various models of care co-ordination and navigation that exist in South London. They found a diverse number of roles and job titles for staff undertaking care co-ordinator/navigator duties, that include care management, signposting, health advice and administrative management of care plans and co-ordination of multiple agencies for those with complex care needs, including mental health. As the diverse number of roles and job titles are not formally recognised they do not currently require registration with a health or social care professional body.

As local and national policy endorses a shift toward preventative, integrated care, the need for the care navigator role becomes paramount in supporting service users and their significant others. Despite a growing number of reports providing evidence of the effectiveness of embedding prevention in older peoples services, the evidence base remains 'fragmented and underdeveloped' (Allan and Glasby, 2013) with ambiguity around which models (processes or structures) demonstrate improved outcomes. To understand the impact of care navigation, and to build a programme theory to develop the evidence base of the role of the care navigator in preventative and integrated care; it is essential that different care navigation models, implemented in practice are observed.

The research study will look at the subjective state of care navigation taking an insider perspective using an interpretive approach recognising negotiation between researcher and researched to produce an insider perspective of care navigation so researcher and care navigator are present.

The term care navigator will be used throughout the study to describe all navigator and coordinator roles, as this is the job title used for the role within the practice area of the subjects being studied.

## 2) Literature Review

A systematic literature review was conducted from published journals and online databases (CINAHL, Pubmed, Proquest, Ovid, Medline and Science direct) from January 2011 to January 2016 to learn about the role of the care navigator and to identify a gap in what is known about the phenomenon with the literature not subsequently being used to inform data collection in a rigid way (Smith, Flowers and Larkin, 2009). Search strings were designed to include terms for navigator titles, roles, and responsibilities. Terms included: 'care navigator' 'patient navigator', 'system navigator', 'care facilitator', 'transitional care', 'post-discharge support', 'care coordinator', 'service coordination', 'patient advocacy', and 'transitional care'.

There is currently limited published literature regarding the role of the care navigator in the United Kingdom. The literature that is available focuses on patient and carer perspectives on the nature, effectiveness and impact of care navigation systems, rather than the role of the care navigator found originates from North America and concentrates on the role of the care navigator in cancer care. This focuses on the application of care navigation in supporting patients transitioning to community care, reaching marginalised groups and improvement in patient compliance.

Care navigation in North America is on the whole provided by trained healthcare professionals, with evidence supporting the view that care navigation has a beneficial effect on overcoming barriers to accessing appropriate health care. Care navigation models in the United Kingdom address similar issues to that found in North America, relating to complex health and social care systems, however the way in which health and social care is commissioned, designed, and delivered differ between the two health economies. Models in the United Kingdom usually deliver early intervention and prevention, maintain the well-being of people with long term conditions, therefore reducing the reliance on acute and secondary health care services. However the North American literature found does give an insight into the general role and actitivities of care navigators. The researcher intends to contribute to the growing care navigation evidence base in the United Kingdom, by exploring the role of the care navigator within two inner London boroughs. The systematic literature review found the following 'themes'

- Information Giving
- Continuity/Co-ordination
- Communication
- Educational Support
- Patient Assessment
- Practical Support

The systematic literature review demonstrates the complex needs of patients entering the health and social care system, irrespective of the care environment there are common themes that have been identified that are valuable in supporting patients, carers and significant others on their journey through health and social care services. While some patient's involvement may be brief, others have a longer relationship with health and social care services, and the consistency of one supportive individual through the care trajectory can only improve the patient experience. The review supports the researcher in understanding and critically analysing previous care navigator research and how the intended study relates to this research. It also reveals the contribution the study will make in exploring the role of the care navigator in a United Kingdom setting and provides evidence that may help explain study findings.

## 3) Research Question Aims

As the majority of published literature found explores and describes the care navigator role in North America, the researcher intends to explore the role within two London Boroughs in the United Kingdom.

In order to develop an understanding of the experiences of care navigators the study aims to explore and explicate:

- The way in which care navigators make sense of their experience of their role
- The extent to which these experiences impact on individual perceptions

## 4) Research Objectives

Guided by the subjectivist ontological paradigms intrinsic to interpretative phenomenological analysis (Smith, Flowers & Larkin, 2009), the study will draw upon the philosophical assumptions of IPA, to represent, interrogate, juxtapose, and construct the experience of care navigation by focusing on the voices of care navigators.

The objectives of this study are to:

- Explore dominant discourse surrounding care navigators;
- Explore the reported experiences associated with care navigators within the literature;

• Provide robust and credible evidence of the key features of care navigation as it is understood by care navigators working within two London Boroughs in the United Kingdom.

## 5) Methodology

## Rationale for Qualitative Study

Smith, Flowers and Larkin (2009), believe qualitative research is involved in exploring, describing and interpreting the personal and social experiences of individuals from a relatively small sample pool. Qualitative research explores the understanding of the subjective experiences of the individual, and the meanings they attach to those experiences. Qualitative methods aim to capture and preserve the complexities and characteristics of experience, in contrast to quantitative methods, where the aim of investigation is to achieve a single 'real' or true account of a phenomena.

The researcher will use a qualitative approach to the study as a meaningful method through which to discover the role of the care navigator. The use of semi-structured interviews will allow the participants to explore their experiences, and upholds their status as the experiential expert in the role of care navigator (Smith et al 2009). The aim of the study is for 'participant-generated' meanings to be uncovered, which according to Willig (2008), allows for the possibility of new and unanticipated categories of meanings to emerge, this will be achieved via interpretative phenomenological analysis.

The study will ensue on the epistemological assumption that whilst an individual's account of their experience can reflect their internal world in a meaningful way, this insight is mediated by the researcher's own assumptions and conceptions (Smith et al. 2009), thus the researcher's own experience of care navigators may have influence when interpreting study findings.

# Interpretative Phenomenological Analysis Sample

Various sample sizes have been used for Interpretative phenomenological analysis, a typical purposive population sample accessible to the researcher will consist of care navigators working in two London Boroughs as large samples can become unwieldy (Smith et al. 2009). Access to the participants will be neogoiated with the care navigators and their employing organisation.

## Sources of Data

A semi-structured interview schedule containing open-ended, non-directive questions to encourage free narrative and detailed responses as required for Interpretative phenomenological analysis (Smith and Osborn 2008) will be used as the data source with a 'prompt sheet' with a few main themes for discussion with the participants. The 'interview schedule' is merely a basis for a conversation: it is not intended to be prescriptive and certainly not limiting to the expressed experience of the participant. It is intended that the interviewee take the lead during the conversation (Biggerstaff and Thompson, 2008) allowing them to express their thoughts, understanding and experience without being directed or prompted by the researcher exploring the way in which care navigators make sense of their experience of their role.

## **Data Analysis Strategies**

Interpretative phenomenological analysis involves the close reading and re-reading of the text (Smith et al. 2009). Biggerstaff and Thompson (2008) describe the IPA as a cyclical process where the researcher proceeds through several iterative stages:

- Stage 1: first encounter with the text
- Stage 2: preliminary themes identified
- Stage 3: grouping themes together as clusters
- Stage 4: tabulating themes in a summary table

#### Ethics and Human Subjects Issues

Ethics approval for the research will be sought for the following reasons:

• To protect the rights and welfare of participants and minimise the risk of physical and mental discomfort, harm and/or danger from research procedures

• To protect the rights of the researcher to carry out any legitimate investigation as well as the reputation of the University for research sponsored by it

• To minimise the likelihood of claims of negligence against individual researchers, the University and any collaborating persons or organisations.

#### Anonymity and Confidentiality

Each participant is entitled to anonymity and confidentiality on ethical grounds and in terms of the protection of their personal and sensitive data under the Data Protection Act (1998). Each participant will therefore have the freedom to decide to share or withhold information. Maintaining anonymity and confidentiality protects the access, control and dissemination of personal information; this also assists to protect mental or psychological integrity. To maintain participant anonymity and confidentiality pseudonyms will be used.

#### **Time Line**



#### References

Allan, K. and Glasby, J. (2013) 'The Billion Dollar Question': Embedding Prevention in Older People's Services – Ten 'High-Impact' Changes. British Journal of Social Work, 43, 904 – 924.

Anderson, J. E. and Larke, S. C. (2009) The Sooke Navigator project: using community resources and research to improve local service for mental health and addiction, Mental Health in Family Medicine, 6, 21-8

Biggerstaff, D. L. & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. Qualitative Research in Psychology, 5: 214 – 224.

Department of Health (2014) Transforming Primary Care; Safe, proactive, personalised care for those who need it most. London: The Stationary Office.

Great Britain (1998) Data Protection Act. London: Stationery Office

Great Britain (2014) Care Act (c.23) Part 1 – Care and support: General responsibilities of local authorities. London: Stationery Office

NHS England (2015) Transforming Primary Care in London: A Strategic Commissioning Framework. London: NHS.

NHS England (2016) Care Navigator Project: initial report on findings from stakeholder event held in February 2016. London: NHS.

NHS England, Care Quality Commission, Health Education England, Monitor, Public Health England, Trust Development Authority (2014). NHS five year forward view. London: NHS England

Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, Method and Research. London: Sage.

Smith, J.A. and Osborn, M. (2008). Interpretative phenomenological analysis. In Smith, J.A. (editor) Qualitative psychology: a practical guide to research methods (2nd edition). London: Sage.

Willig, C. (2008). Introducing Qualitative Research in Psychology (2nd Ed.). Maidenhead: Open University Press.

- 2.4 Details of resources required for the investigation (including funding, space and specialised equipment):
- Appropriate venue to undertake interviews
- Audio equipment to capture interviews
- Stationary
- 2.5 Research Ethics please state whether you consider ethical approval to be an issue for the topic. (If so, then contact should be made with the LSBU Research Ethics Committee).

Ethical approval will be sought by the research from:

- School of Health and Social Care Research Ethics Committee
- East London and The City Research Ethics Committee
- 2.6 Collaborative engagement please state whether or not the proposal will involve any collaborative activity and, if so, where, of what nature, and with whom.

**3. RESEARCH SKILLS DEVELOPMENT SELF AUDIT** Candidates should list relevant experience in the following categories. A maximum of two sides of A4 paper can be attached

In completing this section, please refer to the *Research Development Planner Handbook*, for an explanation of the information required in each section.

3.1 Research Skills (i..e. knowledge of research methodology) I am able to:

- understand relevant research methodologies and techniques and their appropriate application within own research area.
- justify the principles and experimental techniques used in own research.

3.2 Research Environment (i.e. context & demands of research programme) I am able to:

- balance work-life issues.
- use support and advisory resources when necessary to avoid undue pressure and to enhance personal well-being.
- consider the needs of others.

3.3. Research Management (i.e. organization and approach) I am able to:

- prepare and plan project to meet objectives and, with support, is able to adapt if necessary.
- manages own time effectively to complete research project; adheres to clear plan.
- adapt approach when required to; seeks guidance and recognises risks.

3.3 Personal Effectiveness

I am able to:

- isolate basic themes of own research; formulate basic research questions and hypotheses.
- manage own time effectively to complete research project; adheres to clear plan.
- adapts approach when required to; seeks guidance and recognises risks.

## 3.4 Communication Skills

I am able to:

- construct coherent arguments and articulate ideas clearly to a range of audiences, formally and informally, through a variety of techniques.
- actively engage in knowledge exchange and debate with colleagues, sometimes between disciplines/research areas.
- appreciate the skills of rhetoric.
- develop skills in a range of communication means, e.g.face-to-face interaction using interactive technologies, and/or textual and visual media, where useful/necessary.
- use audio-visual aids effectively in presentations.

## 3.6 Networking/Teamworking

I am able to:

- understand own behaviours and impact on others when working in and contributing to the success of formal and informal teams.
- appreciate contributions of other team members including non-academic members. Thank people for their contribution.
- engages in debate and invite challenge.
- recognise implications of own research for real life contexts.
- learn the value to academia of engaging in dialogue with those who use the outputs of research.
- develop and maintain co-operative networks and working relationships with supervisors, colleagues and peers, within the institution and the wider research community.
- use personal and/or online networks effectively for feedback, advice, critical appraisal of work and for responding to opportunities.
- engage with learned societies and public bodies.

3.7 Career Management

I am able to:

- demonstrate an insight into the transferable nature of research skills to other work environments and the range of career opportunities within and outside academia.
- understand and take advantage of a broad range of employment and professional development opportunities within and outside academia, including work experience and internships.

## 3.8 Project Specific Skills

I am able to:

- be sensitive to and respectful of individual differences.
- develop awareness of diversity and difference within working environment.
- understand equality and diversity requirements of institution.

## 4. RESEARCH SKILLS DÉVELOPMENT PROGRAMME

Your programme of research skills development should be agreed with your supervisory team and listed here.

4.1 Research skills

I would like to:

• develop detailed and thorough knowledge/understanding of own and related subject areas – and becomes familiar with associated areas in other disciplines/research areas.

• demonstrates link between own research and real world affairs.

<ul> <li>have deep and holistic understanding of strategic direction and intellectual developments of discipline/research area and its inter-relatedness with other disciplines/research areas. Use this knowledge to enrich own discipline/research area.</li> </ul>
<ul> <li>contribute to the integrity and future vibrancy of the discipline/research area.</li> </ul>
4.2 Research environment I would like to:
<ul> <li>build strong networks to acquire resources and influence change through knowledge exchange.</li> <li>turn ideas into real ventures which enrich research and transfer knowledge and expertise to</li> </ul>
<ul><li>wider audiences internally and externally.</li><li>stimulate, create and build extensive relationships in business/commercial context.</li></ul>
<ul> <li>establishe recognised reputation for enterprise and knowledge exchange.</li> <li>provide strategic leadership and support to others relating to enterprise.</li> </ul>
4.3 Research management
I would like to:
<ul> <li>ensure research contributes to the discipline/research area and own research agenda institution and also to wider aims of all stakeholders, the public and the business sector.</li> <li>use range of project management strategies.</li> </ul>
<ul> <li>clarify priorities; sets expectations, keeps project on track.</li> </ul>
4.4 Personal effectiveness
I would like to:
<ul> <li>recognise, create and confidently act on opportunities with the potential to develop own career within or outside academia.</li> </ul>
<ul> <li>understand the complexity of the academic job market; able to advise others effectively and in a sensitive manner.</li> </ul>
<ul> <li>actively create and champion opportunities for others within and outside academia.</li> </ul>
<ul> <li>be responsive to collaborative opportunities across disciplines/research areas and with non-</li> </ul>
academic organisations. 4.5 Communication skills
I would like to:
<ul> <li>publishes and is involved in editing/may be editor of nationalpublication.</li> </ul>
•actively seek collaborative and/or interdisciplinary partners; is lead author on co-authored
outputs.
<ul> <li>support and enables less experienced researchers to publish.</li> </ul>
peer reviews publications.     4.6 Networking/teamworking
I would like to:
lead networks.
<ul> <li>have national, international and policy-making network connections with academic and non-</li> </ul>
academic bodies and organisations, and in public and private research and development areas.
<ul> <li>have influential connections with significant bodies and organisations; has high impact on</li> </ul>
society through academic and non-academic bodies and organisations.
4.7 Career management
I would like to:
have an established and growing reputation in own and, possibly, other disciplines/research
areas; increasing research esteem.
<ul> <li>conduct peer review internally and acts as reviewer for projects and journals.</li> <li>support the development of the reputations of less experienced researchers.</li> </ul>
4.8 Project specific skills
I would like to:
<ul> <li>lead others in a range of environments to solve problems in a creative and innovative manner.</li> </ul>

• build	strong networks to acquire resources and influence change through knowledge exchange.
• turn	ideas into real ventures which enrich research and transfer knowledge and expertise to
wider	audiences internally and externally.

• recognise potential for new products and novel applications of research for commercial and/or social benefit.

• be skilled at developing relationships in business/commercial context; commercially and socially aware.

• educate, advise and guide less experienced researchers.

5. DETAILS OF SUPERVISORY TEAM NB Candidates will usually have a director of studies and one additional supervisor. A third supervisory team member may be required in some circumstances.

Director of Studies (First Supervisor)	):		Second Sup	ervisor:	
Name:			Name:		
Title: Professor			Title: Doctor		
Post held: Chair of Healthcare & Wo Modelling	rkforce		Post held: A	ssociate Professor	<sup>-</sup> in Midwifery
Place of work: LSBU HSC			Place of wor	k: LSBU HSC	
Third Supervisor (if applicable):				y other person(s)	who will act in an
Name:			advisory cap	pacity:	
Title:					
Post held:					
Place of work:					
<u>Currentiaente currentianes (te be</u>		Direc	tor of	and Cup on visor	Ord Currentie or
Supervisory experience (to be completed by the Director of Studies)		Stud	ctor of ies (1 <sup>st</sup> ervisor)	2 <sup>nd</sup> Supervisor	3 <sup>rd</sup> Supervisor
Number of students currently being supervised at <b>LSBU</b>		0		1	
Number of stduents currently being		0		1	
supervised Externally	MDbil	0 (2	profdee)		
Successfully completed	MPhil PhD	3	profdoc)	1	
6. MODE OF STUDY: P/T		0			
6.1 Research degree sought: (Tick one box)	hD	)		Professional Doctorate	
6.2 Date of Enrolment: February 2012					
Approved start date (for office use only)	:				

## 6.3 Part-time Students: 20

Please state average number of hours study proposed in each week (minimum 16):

7. DECLARATION				
I wish to apply for registration of my proposed research project on the basis of the information given in this application. I confirm that the particulars given are correct. I understand that I must prepare				
and defend my thesis in English. I understand that my rec	gistration may	only conti	nue after the	
submission of approval form ongoing progression panels. I	My supervisor	rs have see	n my RES 2	
prior to submission.				
Pharma				
Signed (Applicant): Date: 14/09/2016				
8. PANEL REPORT				
	Please tick			
	boxes below	N		
Thesis Title: agreed				
Aims: appropriate				
Research Question: appropriate				
Research Question. appropriate				
Original Contribution: statement of original				
contribution to knowledge				
5				
Literature: appropriate				
Research Methods: approriate for the study				
Recommendation:	PhD	MPhil	W/D	
			11/0	
	Prof Doct	W/D exit	with relevant	
		Masters		
The Panel Report must be signed by the attending Panel rev	viewers	L		
Signed:Name:		Date:		
Signed:Name:		. Date:		
Signed: Name:		Date <sup>.</sup>		
			•••••	

#### Appendix 2

#### **Research Degree registration approval**

From: Sent: 19 October 2016 08:37 To: Johnson, Richard 14 Cc: Subject: Richard Johnson - RES2 - 3100196

Dear Richard

#### **Registration of your Research Proposal**

We write to advise your Application to Register for a Research Degree (RES2) was reviewed by the Research Board of Study at its meeting on 4<sup>th</sup> October 2016 and was <u>Approved</u>.

The Board considers your application an exemplar submission and would like to request your permission for it to be viewed by other students. If you are agreeable we would ask you to remove any self identifiers from your original documents and forward a pdf copy to Mr John Harper.

Kind regards

Chair, Research Board of Study

#### **Research Degrees Support Officer**

for Engineering (ENG) & Business (BUS) | Research, Enterprise and Innovation

London South Bank University | Clarence Centre for Enterprise and Innovation

6 St George's Circus, London SE1 6FE

Tel: | Email



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## Appendix 3

#### London South Bank University ethical approval London South Bank

University

School of Health and Social Care 103 Borough Road London SE1 0AA T: 020 7815 7815 F: 020 7815 8099 www.lsbu.ac.uk

Associate Professor School of Health & Social Care T: 020 7815 8368 F: 020 7815 8490 Email: benwelmj@lsbu.ac.uk

Mr Richard JOHNSON

31st January 2017

Dear Richard

#### HSCSEP/17/01 – Exploring Care Navigators experience of role

I am writing to confirm that the School Ethics Panel of the School of Health and Social Care, London South Bank University has considered the above study. A feedback sheet providing detailed comments from the Committee is attached to this letter and explains the decision of the Committee. Your application has been approved subject to some conditions.

#### The Ethics Committee approved study HSCSEP/17/01 subject to the following:

- 1. Revise the participant information sheet as below.
- 2. Revise consent form as below.
- 3. Provide a copy of the letter of invitation.
- 4. Provide written evidence of permission from Care Navigators Gatekeepers in both trusts.
- 5. Provide written evidence from R&D Departments in both trusts that they do not require this study to go for NHS Ethics Approval.

You must respond to the numbered conditions listed above, more details are provided in the feedback sheet attached. You do not need to resubmit the application form or proposal, just send an e-mail or letter giving your responses to these conditions and providing a copy of any of the revised and additional documents requested. You should send this to the Chair of the School Ethics Panel at hscsep@lsbu.ac.uk for approval. These changes will be dealt with by Chairs action. You may not begin the study until you have received a letter from the Chair of the School Ethics Panel confirming that the changes have been approved.

Yours sincerely

Associate Professor Chair of School Ethics Panel School of Health and Social Care



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#### Feedback from School Ethics Committee Panel (To be read in conjunction with Ethics Committee letter)

#### ID Number: HSCSEP/17/01 Applicant Name: Mr Richard Johnson

#### Study Title: Exploring Care Navigators experience of role

		Location of change
Point number	Point to respond to	(document, page, para)
Application Form:	Satisfactory	
Proposal:	Satisfactory	
As to the population under study:	As these are members of staff in NHS trust you will nee letters from both trusts that give gatekeeper permission t interview their staff (managers for example). You will need evidence of permission from R&D Departments at both trusts stating that this study does no require NHS Ethics Approval.	
Methods Issues:	Please supply a letter of invitation that will be used to recruit participants.	
Within Information Sheet:	You should include a statement that the interview will be audio recorded. A statement saying electronic data will be on a pass-word protected computer.	
Within theConsent Form:	There is a typo in the section regarding audio recording Please state who will obtain consent and when it will be obtained.	
Other things to consider (do not need a reply):		

Appendix 4 NHS ethical approval

> **NHS** Health Research Authority

> > Email: hra.approval@nhs.net

Mr Richard Johnson Associate Professor School of Health & Social Care London South Bank University 103 Borough Road SE1 0AA

04 August 2017

Dear Mr Johnson

Letter of <u>HRA Approval</u>

Study title: IRAS project ID: Sponsor 'Exploring Care Navigators experience of role' 226187 London South Bank University

I am pleased to confirm that **<u>HRA Approval</u>** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

*Appendix B* provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read Appendix B carefully**, in particular the following sections:

- *Participating NHS organisations in England* this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- Confirmation of capacity and capability this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment *criteria*) this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact detailand further information about working with the research management function for each organisation can be accessed from <u>www.hra.nhs.uk/hra-approval</u>.

## Appendices

The HRA Approval letter contains the following appendices:

- A List of documents reviewed during HRA assessment
- B Summary of HRA assessment

#### After HRA Approval

The attached document *"After HRA Approval – guidance for sponsors and investigators"* gives detailed guidance on reporting expectations for studies with HRA Approval, including:

- Working with organisations hosting the research
- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

#### Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <a href="http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/">http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/</a>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

#### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <u>http://www.hra.nhs.uk/about-the-hra/governance/guality-assurance/</u>.

#### HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <a href="http://www.hra.nhs.uk/hra-training/">http://www.hra.nhs.uk/hra-training/</a>

Your IRAS project ID is 226187. Please quote this on all correspondence.

Yours sincerely

Assessor

Email: hra.approval@nhs.net

Copy to:

, South Bank University, Sponsor Representative Barts Health NHS Trust, Lead NHS R&D contact , London South Bank University, Academic Supervisor

## Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

Document	Version	Date
Covering letter on headed paper [University Ethics letter]		26 April 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only)		26 April 2017
HRA Schedule of Events [Validated SoE]		02 August 2017
HRA Statement of Activities [Validated SoA]		02 August 2017
IRAS Application Form [IRAS_Form_14072017]		14 July 2017
Letter from sponsor		26 April 2017
Letters of invitation to participant [Letter of Invitation]	Version 1	10 July 2017
Participant consent form [Participant Consent Form]	Version 1	10 July 2017
Participant information sheet (PIS) [Participant Information Sheet]	Version 1	10 July 2017
Research protocol or project proposal [HRA Qualitative Protocol ]	Version 1	10 July 2017
Summary CV for Chief Investigator (CI)		26 April 2017
Summary CV for supervisor (student research)		26 April 2017
## Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England. please refer to the. *participating NHS organisations. capacity and capability* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections in this appendix.

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name:		
Tel:		
Email:		

## HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	The IRAS application has not been signed by the Academic Supervisor or the Sponsor, confirmation has been received from both (letter from sponsor and e-mails) that they are happy to act in this capacity.
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The statement of activities and schedule of events will act as agreement of an NHS organisation to participate. Although formal confirmation of capacity and capability is not expected of all or some organisations

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			participating in this study (see <i>Confirmation of Capacity and Capability</i> section for full details), and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this Appendix B
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	No external application for funding has been made. The statement of activities confirms that there will be no funding available to sites from the sponsor.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	The applicant will be transcribing the interviews; the audio will be deleted immediately following transcription.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion	Not Applicable	No comments

Section	HRA Assessment Criteria	Compliant with Standards	Comments
	received for applicable studies		
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

## Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will be recruiting sites - staff interviews may take place at site

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at <u>hra.approval@nhs.net</u>. The HRA will work with these organisations to achieve a consistent approach to information provision.

## **Confirmation of Capacity and Capability**

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

The HRA has determined that participating NHS organisations in England are **not expected to formally confirm their capacity and capability to host this research**, because of their limited involvement in this staff only study.

- The HRA has informed the relevant research management offices that you intend to undertake the research at their organisation. However, you should still support and liaise with these organisations as necessary.
- Following issue of the HRA Approval letter, and subject to the two conditions below, it is expected that these organisations will become participating NHS organisations 35 days) after issue of this Letter of HRA Approval (no later than 08/09/2017):

- You may not include the NHS organisation if they provide justification to the sponsor and the HRA as to why the organisation cannot participate
- You may not include the NHS organisation if they request additional time to confirm, until they notify you that the considerations have been satisfactorily completed..
- You may include NHS organisations in this study in advance of the deadline above where the organisation confirms by email to the CI and sponsor that the research may proceed.
- The document "<u>Collaborative working between sponsors and NHS organisations in England</u> for HRA Approval studies, where no formal confirmation of capacity and capability is <u>expected</u>" provides further information for the sponsor and NHS organisations on working with NHS organisations in England where no formal confirmation of capacity and capability is expectations, and the processes involved in adding new organisations. Further study specific details are provided the *Participating NHS Organisations* and *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* sections of this Appendix.

## Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

No PI or LC is expected at site.

GCP training is <u>not</u> a generic training expectation, in line with the <u>HRA statement on training</u> <u>expectations</u>.

## HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

A Letter of Access (or equivalent) would be expected for any external NHS/research staff undertaking staff interviews at the participating NHS sites.

## Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.



Research

**Participant Invitation** 

February 2017

Richard Johnson MSc BSc (Hons) DipDN RGN S.F.H.E.A. FAcadMEd Associate Professor in Vocational Learning School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

Dear

This is an invitation to consider participating in a study I am conducting as part of my Doctoral degree in the School of Health and Social Care at London South Bank University. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part; this can be found in the attached Participant Information Sheet.

Participation in this study is voluntary. It will involve an interview of approximately 60 minutes in length to take place in a mutually agreed upon location. You may decline to answer any of the interview questions if you so wish. Further, you may decide to withdraw from this study at any time without any negative consequences.

With your permission, the interview will be audio recorded to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

All information you provide is considered completely confidential. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. All primary data sources will be kept securely for 10 years as London South Bank University policy; including publication of the study in case of challenge in validity. All primary sources will be disposed of in a secure manner as directed by the study requirements.

There are no known or anticipated risks to you as a participant in this study.

If you have any questions regarding this study, or would like additional information to assist you in reaching a decision about participation, please contact me at:

- Telephone: +44 (0)20 7815 8372
- Email: johnsr19@lsbu.ac.uk

I would like to assure you that this study has been reviewed and received ethics clearance through the Research Ethics Review Board at London South Bank University and the Research and Development Department at your employing organisation.

I hope that the results of my study will be of benefit to those organizations directly involved in the study, other organizations not directly involved in the study, as well as to the broader research community.

I very much look forward to speaking with you and thank you in advance for your assistance in this study.

Yours Sincerely,

P omoo

Associate Professor in Vocational Learning School of Health & Social Care London South Bank University



Research

Participant Information Sheet

February 2017

Richard Johnson MSc BSc (Hons) DipDN RGN S.F.H.E.A. FAcadMEd Associate Professor in Vocational Learning School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

#### **Exploring Care Navigators Experience of Role**

I am a student at London South Bank University, currently studying for my Doctoral degree in professional practice. As part of this I am conducting some research regarding Care Navigators experience of role, which you are being invited to take part in. Before you decide whether or not to take part, it is important for you to understand why the research study is being done and what it will involve. Please take the time to read the following information carefully. If you would like more information on any aspect of the study please contact me using my contact details found at the top of this information sheet. Please take your time to decide whether or not you wish to take part in the study.

#### The purpose of the study:

#### Aims:

- To explore how care navigators make sense of their experience of their role
- To examine the extent to which these experiences impact on individual perceptions

#### **Objectives:**

- Explore dominant discourse surrounding care navigators
- Explore the reported experiences associated with care navigators within the literature
- Provide robust and credible evidence of the key features of care navigation as it is understood by care navigators working within two London Boroughs in the United Kingdom

#### Why have you been asked to participate

You have been asked to participate in the intended study as you are working as a Care Navigator in one of the London Boroughs in which the research is being undertaken. Between 8 and 10 Care Navigators will be involved in the study.

#### The voluntary nature of participation

It is up to you to decide whether or not you take part in the study. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are free to withdraw at any time and without giving a reason by informing the Researcher you wish to withdraw.

#### What happens if you take part and opt in

You will be invited to take part in an audio recorded interview where you will be asked questions related to your experiences as a Care Navigator.

For example, I will ask you about your job and what your role involves. You will not be expected to answer any questions that you do not wish to.

#### Possible disadvantages/risks to participation:

- There are no known risks or disadvantages of taking part, I will strive to maintain your confidentiality throughout the research process
- If you take part in the face-to-face interview, I will send you the transcript of the interview before the analysis to allow you to ensure that you have not been misrepresented.

#### Possible benefits to participation:

- Contribute towards the advancement of Care Navigator knowledge
- Take an active part in developing the Care Navigator role
- To do something interesting
- Exercise one's autonomy by taking an active role in research

#### Data collection and confidentiality

All the information collected about you and other participants will be kept strictly confidential (subject to legal limitations).

Data generated by the study will be retained in accordance with London South Bank University's Code of Practice. All data generated in the course of the research will be kept securely in paper or electronic form for a period of 10 years after the completion of a research project on a pass-word protected computer.

If you choose to take part in the research you are entitled to anonymity and confidentiality on ethical grounds and in terms of the protection of your personal and sensitive data under the Data Protection Act (1998). You will therefore have the freedom to decide to share or withhold information. Maintaining your anonymity and confidentiality protects the access, control and dissemination of personal information; this also assists to protect mental or psychological integrity.

To maintain your anonymity and confidentiality a pseudonym will be used.

The researcher is a registered nurse (adult) on the Nursing and Midwifery Council professional register and as such will follow The NMC Code of professional standards for nurses and midwives (NMC 2015), while undertaking the study.

The Code is structured around four broad themes: prioritising people; practising effectively; preserving safety; and promoting professionalism and trust. The revised Code includes greater focus on compassionate care, team work, record keeping, delegation and trust, accountability, co-operating with investigations and audits and raising concerns.

The Code sets out the processes to follow to raise a concern and the legislation in place to protect individuals who raise concerns. The researcher has a professional duty to put the interests of people in your care first and to act to protect them if they consider them to be at risk. This may include raising any concerns with your employing organisation.

#### What will happen to the results of the research study on completion

When the study has finished, all of the data gathered will be subjected to analysis and will be submitted for an award of a doctoral thesis. It is expected that the results of this study will be published in a professional journal. Any information that could potentially identify you will not be included in any publication.

#### Who is organising the research

Richard Johnson Associate Professor in Vocational Learning School of Health & Social Care London South Bank University

#### Who has reviewed the study

The study will follow the following best practice ethical guidelines:

- 1. Department of Health (2005) Research Governance Framework for Health and Social Care
- 2. London South Bank University (2011) Code of Practice for Research Involving Human Participants
- 3. London South Bank University (2014) Safeguarding Good Scientific Practice
- 4. Nursing and Midwifery Council (2015) The Code
- 5. The Royal College of Nursing (2009) Research Ethics
- 6. The Royal College of Nursing (2011) Informed Consent in Health and Social Care Research

Approval has been given to undertake the study by the Research Governance and Ethics Committee within the School of Health and Social Care at London South Bank University, and the research and development departments of Bart's Health Care NHS Trust and East London NHS Foundation Trust.

#### Who to contact for further information

If you experience any problems due to taking part in the study, I would be happy to discuss these with you. However, contact details for other people involved in the research are available and they can also help with any problems or complaints.

#### Researcher:

Richard Johnson Associate Professor in Vocational Learning School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

#### **Research Supervisors:**

Associate Professor in Midwifery School of Health & Social Care London South Bank University 3 Borough Road, London, SE1 0AA Telephone:

Professor Healthcare & Workforce Modelling School of Health & Social Care London South Bank University 3 Borough Road, London, SE1 0AA Telephone:

If you have any concerns about the way in which the study has been conducted, you should contact the School Ethics Coordinator:

Associate Professor Allied Health Sciences School of Health & Social Care London South Bank University 3 Borough Road, London, SE1 0AA Telephone:

Thank you for taking the time to read this information sheet.

Research

#### Research Project Consent Form Full title of Project:

Exploring Care Navigators Experience of Role

#### Ethics approval registration Number: HSCSEP-17-01

Name:

**Richard Johnson** 

#### **Researcher Position:**

Associate Professor

#### Contact details of Researcher:

School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

Taking part (please tick the box that applies)	Yes	No
Consent obtained by the researcher prior to commencement of the interview Date:		
I confirm that I have read and understood the information sheet/project brief and/or the student has explained the above study. I have had the opportunity to ask questions.		
I understand that my participation is voluntary and that I am free to withdraw at any time, without providing a reason.		
Use of my information (please tick the box that applies)	Yes	No
I understand my personal details such as phone number and address will not be revealed to people outside the project.		
I understand that my data/words may be quoted in publications, reports, posters, web pages, and other research outputs.		
I agree for the data I provide to be stored (after it has been anonymised) in a specialist data centre and I understand it may be used for future research.		
I agree to the interview being audio recorded.		
I agree to the use of anonymised quotes in publications.		
I agree to assign the copyright I hold in any materials related to this project to <b>Richard Johnson</b> ( <b>Researcher</b> )		
I agree to take part in the above study.		

Name of Participant

Date

Date

Signature

Richard Johnson Name of Researcher

Signature

February 2017





Research

Participant Debriefing Sheet

February 2017

MSc BSc (Hons) DipDN RGN S.F.H.E.A. FAcadMEd Associate Professor in Vocational Learning School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

Debriefing for 'Exploring Care Navigators experience of role'

Transforming Primary Care (DH 2014) states that there are now over 4.4 million people aged 75 in England and that by 2026 there will be more than 6.3 million. More than a quarter of these people who have a long term condition say they are not well cared for by the NHS, and two-fifths expect their care to get worse over the coming years. People are frustrated by using different services that do not speak to each other, and feel that their conditions are treated in insolation.

The Five Year Forward View (NHS England 2014), highlights the importance of integrated care in bringing services together so patients receive holistic co-ordinated care. It describes a number of models of care that can play a role in integrating services across different care settings, including multispecialty community providers and primary and acute care systems. The Care Act (2014) also necessitates an integrated approach with planning of care across a person's whole care needs, not separate ones for health and social care. From September 2014 people with the most complex health and social care needs were placed on the Proactive Care Programme, receiving personalised, joined up care and support. People have a personalised, proactive care and support plan supported by a care navigator who provides advice and helps them to navigate the health and social care system. The care navigator role, usually based in a multidisciplinary team identifies available services, signposts and supports access and acting as link workers, facilitates appropriate service integration (Anderson and Larke 2009).

To expedite integrated care policy into practice in London The Transforming Primary Care in London: A Strategic Commissioning Framework (NHS 2015) was developed by clinicians, commissioners, patients and other partners across London, presenting an ambitious and attractive vision of general practice that operates without borders, and in partnership with the wider health and social care system. To meet the needs addressed in the framework it discusses implications for the workforce and the introduction of new roles; including care co-ordinators and navigators supporting new ways of working within general practice and across the wider care team.

As local and national policy endorses a shift toward preventative, integrated care, the need for the care navigator role becomes paramount in supporting service users and their significant others. Despite a growing number of reports providing evidence of the effectiveness of embedding prevention in older peoples services, the evidence base remains 'fragmented and underdeveloped' (Allan and Glasby, 2013) with ambiguity around which models (processes or structures) demonstrate improved outcomes. To understand the impact of care navigation, and to build a programme theory to develop the evidence base of the role of the care navigator in preventative and integrated care; it is essential that different care navigation models, implemented in practice are observed.

The research study will look at the state of care navigation taking an insider perspective using an interpretive approach recognising negotiation between researcher and researched to produce an insider perspective of care navigation so researcher and care navigator are present.

Please contact Richard Johnson at the following e-mail address: <u>johnsr19@lsbu.ac.uk</u> if you have any questions regarding this study.

#### THANK YOU AGAIN FOR YOUR CO-OPERATION

#### References

Allan, K. and Glasby, J. (2013) 'The Billion Dollar Question': Embedding Prevention in Older People's Services – Ten 'High-Impact' Changes. British Journal of Social Work, 43, 904 – 924.

Anderson, J. E. and Larke, S. C. (2009) The Sooke Navigator project: using community resources and research to improve local service for mental health and addiction, Mental Health in Family Medicine, 6, 21-8.

Department of Health (2014) Transforming Primary Care; Safe, proactive, personalised care for those who need it most. London: The Stationary Office.

Great Britain (2014) Care Act (c.23) Part 1 – Care and support: General responsibilities of local authorities. London: Stationery Office.

NHS England, Care Quality Commission, Health Education England, Monitor, Public Health England, Trust Development Authority (2014). NHS five year forward view. London: NHS England.

NHS England (2015) Transforming Primary Care in London: A Strategic Commissioning Framework. London: NHS England.



Role Research

**Participant Interview Schedule Sheet** 

Richard Johnson MSc BSc (Hons) DipDN RGN S.F.H.E.A. FAcadMEd Associate Professor in Vocational Learning School of Health & Social Care London South Bank University 103 Borough Road, London, SE1 0AA Telephone: +44 (0)20 7815 8372 Email: johnsr19@lsbu.ac.uk

February 2017

#### 'Exploring Care Navigators experience of role'

Thank you for agreeing to be interviewed about your experience of being a Care Navigator.

Please answer as openly as you can, but do not feel obliged to answer any question you would rather not.

- 1. Can you please describe your role as a Care Navigator to me?
- 2. Can you please describe your experiences of being a Care Navigator?
- 3. Do you experience challenges in your role?
- 4. Do you experience limitations in your role?
- 5. Did you receive any preparation for your Care Navigator role?
- 6. What, if any, formal training have you received to become a Care Navigator?
- 7. What do you see your role as a Care Navigator to be?
- 8. Is there any formal training you would like to receive?

Is there anything that we haven't covered that you feel is important concerning your experience of being a Care Navigator?

# Thank you very much for your time and effort It is very much appreciated

## Appendix 6 Nvivo word search examples





Word	Length	Count	Weighted Percentage	Similar Words
	1.0		(%)	
assessment	10	22	0.73	assessed, assessing, assessment,
				assessments
care	4	83	2.77	care
community	9	26	0.87	communicating, community
experiences	11	30	1.00	experience, experiences
groups	6	20	0.67	group, groups
home	4	32	1.07	home, homes
interviewer	11	52	1.73	interview, interviewer
like	4	34	1.13	like
navigators	10	75	2.50	navigate, navigation, navigator, navigators
needs	5	20	0.67	need, needed, needs
older	5	26	0.87	older
people	6	95	3.17	people, peoples
person	6	47	1.57	person, personality, persons
receive	7	25	0.83	receive, received, receiving
role	4	64	2.13	role, roles
services	8	73	2.43	service, services
social	6	24	0.80	social, socially
support	7	29	0.97	support, supported, supporting
training	8	30	1.00	training
visit	5	33	1.10	visit, visiting, visits
working	7	25	0.83	work, worked, working

Original transcript	Notes
Me: Can you describe your role as a Care Navigator to me?	Aware of supporting role
Jenny: 'I support people to lead independent lives by problem	in helping people lead
solving, I can help them with anything from completing paperwork for	independent lives
a mobility scooter to accompanying them on public transport and	Assists individual to
attending a group with them on their first visit'.	problem solve
	Can accompany to
	attend groups

Notes	Emergent Themes
Aware of supporting role in helping	Supports people with prevention and isolation
people lead independent lives	problems/concerns to lead independent life
Assists individual to problem solve	Assists people by taking a person centred approach to individual problems/concerns
Can accompany to attend groups	Practically enables people to engage with local community

# Appendix 8

## Example of personal reflection

## **Personal Reflection Diary Extract**

'As a registered nurse who has experience of working as a discharge coordinator and had worked with and delivered an education programme designed for care navigators, I had to be aware what I was bringing to the interpretative analytic process. I had to ensure the care navigators voices were heard by moving between the emic, from within the social group (from the perspective of the subject) and etic, from outside (from the perspective of the observer)'. As the researcher I am central as observations made during analysis are necessarily the product of interpretation (Willig 2008).