

# BMJ Open Implementation and perceived impact of the SWAN model of end-of-life and bereavement care: a realist evaluation

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## ABSTRACT

**Objectives** To evaluate the End-of-Life and Bereavement Care model (SWAN) from conception to current use.

**Design** A realist evaluation was conducted to understand what works for whom and in what circumstances. The programme theory, derived from a scoping review, comprised: person and family centred care, institutional approaches and infrastructure. Data were collected across three stages (May 2021 to December 2021): semi-structured, online interviews and analysis of routinely collected local and national data.

**Setting** Stage 1: Greater Manchester area of England where the SWAN model was developed and implemented. Stage 2: Midlands. Stage 3: National data.

**Participants** Twenty-three participants were interviewed: Trust SWAN leads, end-of-life care nurses, board members, bereavement services, faith leadership, quality improvement, medicine, nursing, patient transport, mortuary, police and coroners.

**Results** Results from all three stages were integrated within themes, linked to the mechanisms, context and outcomes for the SWAN model. The mechanisms are: SWAN is a values-based model, promoting person/family-centred care and emphasising personhood after death. Key features are: memory-making, normalisation of death and 'one chance' to get things right. SWAN is an enablement and empowerment model for all involved. The branding is recognisable and raises the profile of end-of-life and bereavement care. The contextual factors for successful implementation and sustainability include leadership, organisational support, teamwork and integrated working, education and engagement and investment in resources and facilities. The outcomes are perceived to be: a consistent approach to end-of-life and bereavement care; a person/family-centred approach to care; empowered and creative staff; an organisational culture that prioritises end-of-life and bereavement care.

**Conclusion** The SWAN model is agile and has transferred to different settings and circumstances. This realist evaluation revealed the mechanisms of the SWAN model, the contextual factors supporting implementation and perceived outcomes for patients, families, staff and the organisation.

## INTRODUCTION

Death, dying and bereavement are a natural part of life, and yet in technologically

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Purposive sampling was used to include staff from different disciplines and settings.
- ⇒ Data were triangulated from different sources across the three project stages.
- ⇒ The interviews were conducted at only two different organisations in England but contextual information is provided to aid transferability.
- ⇒ This study only included organisations where the SWAN model has been successfully implemented.
- ⇒ The study did not include data directly collected from patients and families.

developed countries of the world, death and dying increasingly take place in a clinical or institutional setting. Experiences of death, dying and bereavement have far reaching consequences for individuals and society.<sup>1</sup> Many people have rarely if ever seen a dead person until it is somebody close to them, and Walter<sup>2</sup> suggests that this has led to support for the dying and bereaved being delegated to professionals. Up to one-third of the non-elective hospital inpatients at any one time may be in the last year of life<sup>3</sup> and in the UK, hospital remains the most common place of death.<sup>4</sup> However, providing care to the dying and bereaved poses multiple challenges to health professionals, including: complex attitudes to death and dying, uncertainty about clinical roles and responsibilities and difficulties in coordination and communication, which can all impact on the quality of care provided to patients.<sup>5</sup> Institutional and organisational cultures are also thought to influence end-of-life care, with some acute clinical settings being more equipped for curative rather than palliative care.<sup>6</sup>

Improving care of people at the end-of-life and those who are bereaved is a key policy priority within the UK<sup>7</sup> and worldwide,<sup>8,9</sup> and this includes those bereaved by both expected and unexpected deaths. Palliative care has recently been integrated into the WHO's

**Table 1** The SWAN model of care

The SWAN model of care for individuals expected to die	The SWAN model of care for individuals who have sudden/unexpected death
Aim of the swan: To promote dignity, respect and compassion at the end-of-life.	Aim of the swan: To promote dignity, respect and compassion following death.
<b>Sign</b> —is the patient believed to be entering the dying phase of life—start the individual plan of care and support for the dying person.	<b>Sign</b> —ensure the provision of private space is identified.
<b>Words</b> —sensitively communicate with the patient and those important to the patient and family.	<b>Words</b> —sensitively communicate with the family.
<b>Actions</b> —step outside the box and facilitate what is important to the patient and family.	<b>Actions</b> —step outside the box and facilitate what is important to the family.
<b>Needs</b> —are the needs of the patient and family being met, documented and reviewed regularly.	<b>Needs</b> —are the needs of the family being met, documented and reviewed regularly.
The Swan symbol is placed on the door or curtain of the bay/room, swan room, swan suite and mortuary in which the patient/family are being cared for or supported.	
Permission to act and break the rules that do not exist.	

definition of Universal Health Coverage.<sup>10</sup> Care of the dying and grieving is complex and does not fall under the remit of any single profession. Research examining the changing needs for end-of-life care in an ageing population recognises that a paradigm shift is required, from the provision of palliative services to a palliative approach to care, operationalised through integration into systems and models of care across institutional and organisational boundaries.<sup>11</sup>

### The SWAN model development and context

From the early 2000s, an integrated care pathway, the Liverpool Care of the Dying Pathway, was embedded in UK policy but then withdrawn in 2014 after mounting controversy,<sup>12</sup> with recommendations for personalised end-of-life care plans instead.<sup>13</sup> Since then, alternative guidelines have been published.<sup>7 14 15</sup> In addition, there is the Gold Standards framework for training primary healthcare providers to identify and plan care for people at end-of-life.<sup>16</sup> However, in many care settings, the lack of an overall model led to a vacuum for end-of-life care.

In a two times per day to enhance the provision of end-of-life and bereavement care, the SWAN model of care (see definition [table 1](#)) was developed in Greater Manchester, in the north of England, in 2012. This values-based model of care incorporates both expected and unexpected deaths, and focuses on enabling a flexible compassionate workforce to provide end-of-life and bereavement care across a variety of settings. The SWAN model meets the criteria for being a complex intervention as it comprises several interlinked components, is dependent on personnel delivering the model, and delivery is adjusted to different contexts and settings.<sup>17</sup>

The model's development was based at one National Health Service (NHS) healthcare organisation ('Trust'), comprising several hospitals and was implemented across the local community too, involving services such as the coroners and police force for unexpected deaths. The model's development and implementation was led by a designated senior nurse with a multidisciplinary team.

A small team of end-of-life care and bereavement nurses were employed to enable the wider workforce to deliver the SWAN model of care across the hospitals and community. Since inception of the SWAN model, it has been expanded and adopted by other NHS Trusts in the UK. However, despite anecdotal support for the model, there has been no formal evaluation of its use in clinical practice. In general, evaluation of end-of-life and bereavement care is considered ethically challenging<sup>18</sup> and robust evaluations of hospital based end-of-life and bereavement services are scarce.<sup>19</sup> This paper presents findings from a realist evaluation of the SWAN model.

### Aim and objectives

The study aim was to evaluate the End-of-Life and Bereavement Care model (SWAN) from conception to current use. The study objectives were:

1. To explore the conception, development and implementation of the SWAN model.
2. To investigate how the model was introduced across an organisation and community, and the wider implementation into other organisations.
3. To evaluate perceived impact of the SWAN model in different circumstances from the perspective of those using the model (including the COVID-19 pandemic).
4. To explore the emotional, personal, professional and practical experiences of staff using the model.

### METHOD

A realist evaluation aims to discover: 'what works, for whom in what circumstances and in what respects and how?'<sup>20</sup> Applied to the SWAN model, the focus was:

- ▶ Mechanism: what is it about the SWAN model that brings about change?
- ▶ Context: for what and for whom and in what circumstances will the SWAN model work?
- ▶ Outcome pattern: what are the intended and unintended consequences of the SWAN model?

The features of the evaluation were: the programme (SWAN model); the theory (end of life/bereavement care existing literature); the mechanisms for evaluation.

### Mechanisms for evaluation

The mechanisms for evaluation were derived from the literature during a scoping review at the design stage of the study. The scope included research that explores the mechanisms of bereavement interventions, the impact of care before and at the time of death on outcomes related to family and staff and the contextual conditions that facilitate or impede the provision of such care. Outcomes from the review are published elsewhere.<sup>19</sup> This review highlighted limitations in the quality and quantity of research available in relation to evaluating services and interventions at the end-of-life. However, from the literature identified, there are key mechanisms that appear to be of value, with three themes identified: person and family centred care, institutional approaches and infrastructure; these formed the programme theory for the evaluation.

### Patient and public involvement

A Steering Group was appointed to provide governance to the research project, which included patient and public involvement (PPI), providing independent advice, subject and lived experience/expertise, oversight, monitoring of progress and supporting the investigators in the delivery of the project. The PPI representative had access to all project progress documents, input in the design of the study, data analysis and dissemination strategy. The PPI representative reviewed and commented on the final report prior to release.

### Evaluation design

Data were collected across three stages from May 2021 to December 2021; see [table 1](#) for the stages, settings, purpose, data collection methods and participants.

### Settings

The Stage 1 data collection took place at a NHS organisation with several hospital sites ('Trust') in an urban area in the north of England (Manchester) where the SWAN model was originally developed and implemented. The Stage 2 setting was purposively selected as a Trust in a different area of England, where the SWAN model had been implemented for a minimum of 4 years, and there was an emergency department so that there were deaths in different circumstances. This Stage 2 Trust comprised of two hospital sites in a largely rural area in the Midlands. The Stage 2 data collection aimed to explore whether the mechanisms, context and outcomes identified at the Stage 1 Trust were apparent in a different setting too. The Stage 3 data comprised routinely collected national data, and local audit data from the Stage 1 Trust, as detailed in [table 2](#).

### Data collection

At Stages 1 and 2, data were collected through online semi-structured interviews with participants, purposively selected for their experience with the SWAN model, and to ensure inclusion of varied disciplines. Participants were approached by email, participant information sheets were provided and all participants signed written consent forms. Stage 1 topic guides (see online supplemental material 1) were developed by the project team,

Stage and setting	Purpose and participants/sources	Data collection method
Stage 1 phase 1 NHS Trust in Greater Manchester and community, where the SWAN model was first developed and implemented	To examine mechanisms, context and outcomes, through exploring the creation and implementation of the SWAN model with the architect/leaders of change, including senior nursing staff, a lead chaplain, a senior coroner and police chief.	Semi-structured interviews (n=8)
Stage 1 phase 2 (setting as phase 1)	To examine mechanisms, context and outcomes, through exploring implementation and adoption of the SWAN model with a range of staff involved: SWAN nurses; palliative care team staff; faith leader, quality improvement, medicine, nursing, patient transport, mortuary, police, coroner.	Semi-structured interviews (n=10)
Stage 2 A Trust in the Midlands that had implemented the SWAN model in 2015	To examine mechanisms, context and outcomes, through exploring the implementation of the SWAN model in an outside organisation with key implementers: Trust SWAN lead, an end-of-life care nurse, a chaplain, a Trust Board member and a bereavement service manager.	Semi-structured interviews (n=5)
Stage 3: National and local (Stage 1 NHS Trust)	To explore context and outcomes of the SWAN model through analysis of routinely collected national and local audit data. The data comprised: National: <ul style="list-style-type: none"> <li>▶ Care Quality Commission reports (2015–2020) on End-of-Life Care in England.</li> <li>▶ The 2019 Healthcare Quality Improvement Partnership national care at the end-of-life audit data.</li> </ul> Local (Stage 1 Trust) 2017–2020 audits <ul style="list-style-type: none"> <li>▶ Time of death to mortuary elapsed time.</li> <li>▶ The presence or absence of a care plan for end-of-life where end-of-life was expected and not sudden.</li> </ul>	

NHS, National Health Service.

based on the scoping review and mechanisms identified, and piloted prior to use. The Stage 2 topic guide was adapted from the Stage 1 guides, to reflect initial themes from the Stage 1 data analysis, with the aim of investigating whether the mechanisms, context and outcomes were apparent at the Stage 2 site. Interviews were audio-recorded and professionally transcribed.

Stage 3 comprised analysis of routinely collected data, as listed in [table 1](#). The Care Quality Commission (CQC) monitors care standards in England producing periodic reports. The Stage 1 Trust local audit data pertained to best practice at end-of-life targets: the presence of end-of-life care plans, and mortuary transfer time within a 6-hour maximum time frame. Previous delays to mortuary transfer reduced opportunities for tissue donation due to non-compliance with national guidelines,<sup>21</sup> which removed choice from families about this option. Families may perceive the consenting to tissue and organ donation as fulfilling their loved one's known preferences and giving meaning to their life.<sup>22</sup>

### Data analysis and synthesis of findings

The interview data were analysed thematically, using Braun and Clarke's<sup>23</sup> six-phase method. Following familiarisation with all the Stage 1, phase 1 interview data (phase 1 'familiarisation'), coding commenced (phase 2 'generating initial codes') by developing a deductive coding framework, drawing from the scoping review. As this framework was applied to each transcript, the framework was further developed by adding inductive codes from the data. This iterative process continued throughout the coding process. Two researchers reviewed the data set and codes to identify candidate themes and subthemes, with their contributing codes (Phase 3 'Searching for themes'). At Stage 2, the coding framework was used to code the transcripts; while most Stage 2 data could be coded with existing codes, there were some additional inductive codes added. The coding was then considered against the Stage 1 themes, which were reviewed and refined (Phase 4 'Reviewing themes' and 'Phase 5 Defining and naming themes'). Credibility of the results was enhanced by reviewing the original interview transcripts to make sure that all themes were grounded in the data or explained by the researchers' interpretive scheme.

The Stage 3 CQC reports for England (2015–2020) were searched for the term SWAN; there were 142 citations, relating to six NHS Trusts across England, with multiple hospital sites. The qualitative comments related to end-of-life care in these Trusts' reports were extracted and content analysed and then merged with the themes from the Braun and Clarke analysis of Stages 1 and 2 interview data. During the report production (Phase 6), all these data contributed to the final version of the themes and subthemes.

The Stage 3 quantitative data (Healthcare Quality Improvement Partnership (HQIP) and local audit data) were analysed using descriptive statistics such as

difference in time elapsed, frequency and performance against national benchmarks, such as the best practice indicator for tissue donation. Data synthesis was achieved through the convergence of the data sets (qualitative and quantitative).<sup>24</sup> To enhance the quality of the findings,<sup>25</sup> integration of findings were applied through triangulation, where the Stage 3 quantitative results were reviewed against the themes from the qualitative data sets (Stage 1, Stage 2, Stage 3 CQC reports), to produce the final, integrated report, with overall themes aligned with mechanisms, context and outcomes for the SWAN model.

### RESULTS

The integrated findings are presented for the mechanisms, context and outcomes. The data extracts are identified as: S1P1\_1–S1P1\_8 (Stage 1, Phase 1 participants); S1P2\_1–S1P1\_10 (Stage 1, Phase 2 participants), S2\_1–S2\_5 (Stage 2 participants) and Stage 3 with data source, for example, S3\_CQC. [Table 3](#) summarises key findings, related to the realist evaluation questions and the programme theory of person-centred care, institutional approaches and infrastructure. The results are presented with data extracts from all three stages of the evaluation.

#### Mechanism: what is it about the SWAN model that brings about change?

Data from Stages 1 and 2 interviewees, and the Stage 3 CQC report analysis, highlighted the SWAN model as values-based, including compassion, kindness, respect, dignity and discretion. At the Stage 2 Trust, the SWAN model drew positive responses from staff, comparing it favourably with the Liverpool Care Pathway, which preceded it:

Where there was a reluctance in the Liverpool Care Pathway, people are generally more accepting of this, this is the right thing. (S2\_1)

Participants perceived SWAN to represent a person/family-centred approach to care, with an emphasis on personhood continuing after death too:

That philosophy of actually, the patient continues to be the patient and should be treated with care and dignity. (S1P2\_5)

Participants viewed important aspects of the model as normalisation of death, and 'one chance': 'You only have one opportunity to make a difference when somebody dies' (S1P1\_8). The SWAN model includes the key principles of 'Break the rules that don't exist' and 'Permission to act'. These form the basis for the SWAN model as: 'an enablement model' (S1P1\_6), empowering staff to act in the best way for people at, and after, end-of-life, without constraints. The SWAN symbol was agreed through local consultation and is an acronym for: Signs, Words, Actions and Needs (see [table 1](#)). The SWAN model branding, which is used for all the resources and facilities, signified dying and bereavement and raised the profile of the

**Table 3** Realist evaluation questions and key findings related to the programme theory

Realist evaluation questions	Key findings	Programme theory component
Mechanism: what is it about the SWAN model that brings about change?	SWAN is a values-based model, promoting person/family-centred care and emphasising personhood after death.	Person/family-centred care
	Key features of SWAN are: memory-making, normalisation of death and 'one chance' to get things right for individuals.	Person/family-centred care
	SWAN is an enablement and empowerment model for all involved.	Institutional approaches
	SWAN branding is recognisable and raises the profile of end-of-life and bereavement care.	Institutional approaches
	Swan is an agile and transferable model.	Institutional approaches
Context: for what and for whom and in what circumstances will the SWAN model work?	SWAN enables person/family-centred care in different settings and circumstances, including after disasters (Manchester bombing) and during the COVID-19 pandemic.	Person/family-centred care Institutional approaches
	To implement and sustain the SWAN model the following circumstances are necessary:	
	Leadership and high-level organisational support.	Institutional approaches
	Teamwork and integrated working within and across organisations.	Infrastructure
	Workforce resourcing, education and engagement.	Infrastructure
	SWAN resources and facilities that enable staff to act for people at end-of-life and afterwards.	Infrastructure
Outcome pattern: what are the intended and unintended consequences of the SWAN model?	Consistent standards for end-of-life and bereavement care within and across organisations and settings.	Institutional approaches
	Person/family-centred care at end-of-life and after death.	Person/family-centred care
	Empowered and creative staff who take pride in delivering SWAN.	Infrastructure
	Organisational culture that prioritises end-of-life and bereavement care.	Institutional approaches
	Staff resistance.	Not applicable

changes. The Stage 3 CQC reports data confirmed the SWAN model as an entity/brand; SWAN was recognisable to CQC inspectors and used by staff to describe a model of care. The SWAN model is agile and can be adapted and transferred to different circumstances and settings, based on the values and principles, and without the constraints of guidelines.

### Context: for what and for whom and in what circumstances will the SWAN model work?

#### SWAN is transferable to different settings and circumstances

While the SWAN model was developed and first implemented at the Stage 1 NHS Trust in 2012, where it remains embedded, it has since transferred to many other Trusts, mainly through informal networking. At the Stage 2 Trust, participants revealed that, after reviewing several models of care, the SWAN model was selected and implemented in 2015. The Stage 3 CQC report analysis revealed citations of SWAN relating to six NHS Trusts, which incorporated numerous hospitals, demonstrating wide application across England.

Participants from Stages 1 and 2 Trusts reported transfer of the SWAN model into their local community settings, including care homes. Participants believed that

the SWAN model is adaptable to differing settings and circumstances:

Whatever situation that you're in, whether you're stood in a mortuary, whether you're out in the community or whether you're in an acute setting. For me, it's transferable across all those areas. (S1P1\_3)

Two specific examples are, at the Stage 1 Trust, supporting families after the 2017 Manchester Arena bombing, and, at both the Stage 1 and 2 Trusts, adaptations during the COVID-19 pandemic. Several Stage 1 participants recalled how after the Manchester Arena bombing, the model lead and bereavement nurses worked with the coroner and police to provide individualised care using SWAN model principles, including mementoes and offering choices in their care. The established relationships with coroners ensured families could spend time with their loved ones and touch them, recognising that: 'This is their last time with their loved one' (S1P1\_4).

At the Stage 1 Trust, during the COVID-19 pandemic, participants believed that the SWAN model: 'Enabled us in a huge way because we had a model that was recognised and well known' (S1P2\_6). They explained

how staff focused on what *could* be done, adapting ways of working to the new circumstances. A new health-care worker role of ‘Cygnet’ enabled individualised one-to-one care: fulfilling last wishes, bridging communication between the person and family, supporting mementoes and ensuring no one died alone. At the Stage 2 Trust, participants considered that they still delivered person/family-centred care through focusing on how they could meet individual needs within the current regulations.

#### Leadership and high-level organisational support

To implement and sustain the SWAN model, leadership and high-level organisational support are necessary contextual factors. Stage 1 participants discussed how the SWAN model lead built relationships at senior level, worked outside traditional boundaries and was supported by senior Trust staff, including the Chief Executive and Chief Nurse:

I know [model lead] worked very closely with the Chief Nurse at the time who was a huge supporter of the work and was quite a positively formidable force in the organisation. (S1P2\_2)

At the Stage 2 Trust, there was a SWAN lead but participants considered that high-level organisational support has ‘ebbed and flowed’ with senior staff changes (S2\_5). The Stage 2 participants explained that end-of-life care was managed through a steering group with implicit rather than explicit Board support; without high level support ‘Sometimes, we would struggle to implement things’ (S2\_2). The Stage 3 CQC data revealed high level recognition for the model at some Trusts, for example:

The SWAN initiative was given emphasis and importance at the trust in being central to its development of end-of-life care services. (S3\_CQC)

#### Teamwork and integrated working within and across organisations

A further essential contextual requirement for the SWAN model’s implementation and sustainability was perceived to be teamwork and integrated working: ‘It’s a real team approach: there’s no way that one person, in one organisation, can do it alone: it has to be everybody’s business’ (S2\_2). Participants reflected that staff from across the organisation and beyond together delivered the SWAN model, working: ‘with other people we’d never worked with before’ (S1P1\_3). Relationships developed with voluntary organisations, faith groups, the police and coroners: ‘It’s about that integrated model around death’ (S1P1\_4). The Stage 3 national CQC data also referred to integrated working:

Collaboration with multiple local healthcare stakeholders to implement a comprehensive end-of-life plan. (S3\_CQC)

#### Workforce resourcing, education and engagement

Stage 1 and 2 participants explained how specialist teams of skilled and knowledgeable bereavement/end of life nurses facilitated the wider workforce to deliver the SWAN model. The Stage 3 national CQC analysis also indicated dedicated staff resourcing for the SWAN model, such as bereavement nurses and educationalists.

Stage 1 and 2 participants emphasised the need for education of the workforce, for implementation and on an ongoing basis, due to staff turnover. They explained that there are regular, multidisciplinary SWAN bereavement study days and coaching in practice. The importance of staff engagement was highlighted: ‘It’s got to be owned by every single person that works in the organisation’ (S2\_2). The Stage 3 national CQC report analysis identified inclusion of the wider workforce, for example, the domestic, portering, chaplaincy and mortuary staff, and referred to workforce engagement too:

There was an overriding culture of passion and enthusiasm among staff in all areas to deliver care within the principles of the SWAN scheme [model]. (S3\_CQC)

Both Stage 1 and 2 participants described how volunteers play an important role, particularly supporting the SWAN model resources. In addition, developing SWAN champions among the Trust staff built local expertise, empowering the wider workforce to take ownership.

At the Stage 2 Trust, some wards implemented the model better than others and so ‘it was about finding out how they were managing to achieve it where others weren’t’ (S2\_2). A key factor for success was the engagement and commitment of the ward leader and whole ward team. Staff in some areas found end-of-life conversations difficult, often for personal reasons and so: ‘it was about recognising areas that were struggling and individuals that were struggling and spending time with them’ (S2\_2).

#### SWAN resources and facilities

At the Stage 1 Trust, participants emphasised the importance of investing in resources for the SWAN model:

Unless we equip staff with the tools to be able to do what we ask, I don’t believe it can happen in the way that we want it to. (S1P1\_6)

At both the Stage 1 and Stage 2 Trusts, the participants explained that funding is mainly through charitable sources, legacies and community engagement. Participants discussed how resources for families promote comfort and reduce stress, support memory-making and different faiths. The Stage 1 and 2 Trusts have branded SWAN property bags for the person’s belongings. The Stage 3 CQC data also referred to dedicated SWAN resources on each ward.

Stage 1 and 2 participants discussed the bereavement facilities for families, including comfortable SWAN visiting rooms in the mortuary and memorial gardens.

At the Stage 2 Trust, side rooms were converted into relaxing ‘SWAN rooms’, with comforting resources for individuals and families. The participants explained how continuing improvements result from staff creativity, community engagement and patient/family feedback: ‘it’s still ongoing, there’ll always be things that they can add to it’ (S1P2\_1). Therefore, while the resources and facilities are necessary for implementation, they are also outcomes of embedding the SWAN model.

### Outcome pattern: what are the intended and unintended consequences of the SWAN model?

While much of the data illuminating the outcomes are based on perceptions from the Stage 1 and Stage 2 participants, there was also relevant data from the Stage 3 analysis of routinely collected data. Most subsections report on the intended consequences of the SWAN model. However, there was some staff resistance, which, while not intended, could be expected when implementing any new programme.

#### Consistent standards for end-of-life and bereavement care within and across organisations and settings

The Stage 1 participants considered implementation of the SWAN model leads to a consistent approach:

It’s equitable, doesn’t matter who you are, what age you are, what faith you are, everybody receives that outstanding end-of-life care. (S1P2\_7)

At the Stage 1 Trust, there is now a bereavement care nurse based in the coroner’s office to facilitate the SWAN model so that families in the community ‘get the same service tailored to their needs as they would if it was a bereavement from the hospital’ (S1P1\_8). The Stage 1 and 2 participants described that the roll out of the SWAN model across community and care homes in their localities promoted consistency across care environments. Stage 3 analysis of the Stage 1 Trust’s audit data showed more people had end-of-life care plans since the SWAN model implementation. The Stage 3 CQC reports also referred to consistency:

The trust’s end-of-life-individualised SWAN care plans were being used consistently throughout the hospital (S3\_CQC)

However, at the Stage 2 Trust, participants considered that the lack of resourcing and staff turnover led to complete consistency being aspirational.

#### Person/family-centred care at end of life and after death

The Stage 3 HQIP National Audit of Care at the End-of-Life revealed little difference between the average scores for non-SWAN and SWAN implemented hospitals, perhaps highlighting the difficulty of measuring end-of-life care quality. The qualitative data, from the CQC reports and the Stages 1 and 2 interviews provided perceptions of how person/family-centred care was achieved. The Stage 3 CQC reports analysis indicated that

the SWAN model promotes early recognition of dying, enabling staff to support the person and family. At the Stage 2 Trust, participants reported that family feedback confirms appreciation for the SWAN model; in comparison with the previous LCP: ‘families are more involved in the discussions about their loved ones’ (S2\_1).

The Stage 1 and 2 participants perceived that the SWAN model promoted more person/family-centred care approaches before and after death, for example, creating a homely environment with music and photographs, and individualised mouthcare using favourite flavours. They believed that memory-making is an important component: ‘Capturing those moments and those memories is so significant for people’ (S1P1\_3). Examples from Stage 1 and 2 participants included reuniting families and taking photographs, and ensuring people see their pets for the last time. Mementoes include handprints, footprints, locks of hair and prints of lip kisses. The participants believed that memories are also about spending time together, before and after death, as ‘you can never get those times back again’ (S1P2\_9).

The Stage 1 and 2 participants described how individualised care after death includes favourite clothing, leaving meaningful items with the person, meeting faith needs and making the person ‘comfy and cosy’ (S1P1\_6) on a bed, rather than a trolley, with bedding in their favourite colour. Patients are transferred to the mortuary in their beds, rather than the traditional metal box. Stage 3 local audit data analysis demonstrated that transfer to the mortuary is now consistently achieved within a maximum of 6 hours, across the Stage 1 Trust, thus enabling families the option of tissue donation, denied to them otherwise.

#### Empowered and creative staff who take pride in delivering SWAN

Stage 1 and 2 participants perceived the SWAN model as: ‘an enablement model’ (S1P1\_6), empowering staff to act in the best way for people at, and after, end-of-life, and to empower families, so they have some control. Staff at the Stage 1 and 2 Trusts displayed satisfaction and pride:

They couldn’t wait to show off what they were doing about end-of-life care, about their relatives’ rooms. (S1P2\_5)

The participants reported that staff are confident to take initiative, fulfilling last wishes, such as weddings, early birthday celebrations or pets visiting. During the COVID-19 pandemic, there were still emergency weddings: ‘the boost that gave the nursing team during a pandemic’ (S2\_2).

#### Organisational culture that prioritises end-of-life and bereavement care

The Stage 1 participants reflected that prior to the SWAN model being developed and implemented: ‘End of life care wasn’t really very high on the agenda’ (S1P1\_5). Stage 1 and 2 participants perceived that end-of-life and bereavement care are now a high priority in their Trusts and everybody’s business: ‘we’ve got a hospital that is full

of people who are passionate about good end-of-life care' (S1P2\_5). They reported a more open culture of talking about death and dying: 'there's not this fear around death any more' (S1P2\_10). The Stage 3 CQC data, mirrored these findings:

Through the SWAN model of care, the hospital wanted to promote a culture that end-of-life care was everybody's business which involved talking about it more and for all staff to contribute to its implementation. (S3\_CQC)

A further perceived impact is the valuing of all staff roles for supporting end-of-life and bereavement care, and 'the proactive, celebrating of good practices' (S1P1\_5). Participants reported that a culture of feedback and improvement, along with integrated working, leads to quick resolution of concerns. There were perceptions that systems for dealing with the administrative and legal aspects following death are now more efficient, which were considered to reduce time and stress for families. At both Stage 1 and 2 Trusts, the bereavement teams debrief staff, reviewing how end-of-life care can be improved, supporting reflection and learning. In addition there was a culture of support for staff with death and dying, including after the death of a colleague; one participant reflected the support was: 'everything to us at the time' (S1P2\_3).

#### Staff resistance

Stage 1 and 2 participants reflected that there was some resistance to the SWAN model during implementation, and some still remains. Some staff, particularly palliative care teams, felt threatened by the SWAN model, which they saw as encroaching on their domain:

I think people were quite protective—myself probably being one of them as well: 'Well, actually, we do a lot of that' [...] I think people took that as a bit of a criticism. They didn't know what they didn't know. (S1P1\_5)

In addition, the SWAN model did not align with some staff's views about how care should be delivered; they believed:

It's too pink and fluffy. 'We only need to control symptoms.' But actually, the memories that will live on with the family are the pink and fluffy things. (S1P1\_6)

At the Stage 2 Trust, the Trust SWAN lead expressed her shock at some of the staff resistance, but also reflected that for some staff, death and dying is a difficult topic.

## DISCUSSION

The study aim was to evaluate the End-of-Life and Bereavement Care model (SWAN) from conception to current use using a realist approach to discover: What works for whom and in what circumstances? A key requirement of realist evaluation is to identify the different layers of

social reality which make up and surround programmes. The programme theory developed from the scoping review indicated that person/family-centred care, institutional approaches and infrastructure are important for end-of-life and bereavement care, and these components were reflected in the integrated results. The SWAN model's mechanisms include its branding and agility, that it is value-based and normalises death, promotes person/family-centred care, including memorialisation and the 'one chance' to get things right, and empowers and enables all involved. The SWAN model has transferred to varied settings and circumstances. The contextual factors for implementing the SWAN model are leadership and high level organisational support, teamwork and integrated working, workforce resourcing, education and engagement and availability of resources and facilities to enable the SWAN model delivery. The outcomes are: consistency in standards for end-of-life and bereavement care, person/family-centred care at end-of-life and afterwards, empowered and creative staff and an organisational culture that prioritises end-of-life and bereavement care. As an unintended consequence staff resistance to the model was found, though any change can engender such responses. These principal results are next discussed in relation to other studies.

The SWAN model mechanisms appear to work due to being values and principles based, which frees the workforce to deliver person/family-centred care that is based on the individuals' needs rather than being constrained by policies or guidelines. The values of dignity, respect and compassion are central to the SWAN model; previous research has confirmed that patients and families appreciate compassionate support before and after death.<sup>26</sup> One of the principles, as shown in [table 1](#), is to 'break the rules that don't exist' in order to meet the person and family's individual needs. Similarly, in a realistic evaluation of a coordinated end-of-life care service, Efstathiou *et al*<sup>27</sup> found that the service's success and acceptability was partly due to how it challenged traditional ways of working. However, the staff resistance to the SWAN model encountered was perceived to arise partly because some staff could not understand the values base of the model, and it threatened their established ways of working.

The contextual factors that enabled implementation and embedding of the SWAN model were found to align across the different data sources. The need for consistent, senior Trust support for the SWAN model was an important contextual factor, not only to support changes in practice but to ensure end of life care remains a priority and continued funding and resources are available to support delivery. Hospital-wide leadership has been previously identified as important for implementing new bereavement and end-of-life care services.<sup>28</sup> However, the Stage 2 Trust had sometimes lacked this senior level support, which had affected delivery of the SWAN model.

The SWAN model development, implementation and delivery was characterised by collaborative working, involving different disciplines and departments across the



organisation, and community. Transdisciplinary working is considered to be an important factor in the success of end-of-life care services in different settings.<sup>29</sup> At the Stage 1 Trust, following the Manchester Arena bombing in 2017, the established interpersonal relationships across sectors facilitated agility and adaptations to how the SWAN model was used to provide person/family-centred care for the victims and their families. SWAN nurses were cited by the bereaved families as offering valued support and by council workers who felt reassured that families were being cared for while they did their aftermath work.<sup>30</sup> Indeed the implementation of the SWAN model is one of the recommendations of the first official report and it has continued in use in the coroner and police service for sudden and unexplained deaths.

The importance of workforce education for the delivery of end of life and bereavement services has been previously recognised.<sup>27 28</sup> Across the data sources it was clear that education and engaging the whole workforce with the SWAN model's principles were necessary on an ongoing basis, to overcome the common issue of a workforce that is not confident in death, dying and bereavement.<sup>31</sup> Having the appropriate resources and facilities to deliver the SWAN model based on the values and principles were also essential contextual factors. Many of these resources and facilities seem unique to the SWAN model and their continuing development stemmed from the empowerment of the staff who embraced the SWAN model's values.

Data from all three stages of the evaluation indicated that the SWAN model provided an institutional approach to end-of-life and bereavement care, resulting in consistent standards across organisations and other local settings too. However, to achieve this consistency, the contextual factors, discussed previously, were important. In particular, Stage 2 data illustrated how a lack of senior Trust support could affect achievement of consistent standards. Person/family-centred care was an important outcome, based on the programme theory, and supports a systematic review that found acute care nurses provide vital patient-centred and family-centred care at the end-of-life and during the bereavement period.<sup>32</sup> Participants at both the Stage 1 and 2 Trusts reported the embedding of memory-making activities; these types of interventions were found to be valued by bereaved families in previous qualitative research.<sup>19</sup> The SWAN model of care improved the overall attention to end-of-life and bereavement care, as demonstrated through the qualitative findings as well as routinely collected data such as end-of-life care plans as well as timely mortuary transfer, which then enabled potential tissue donation, as desired by families, in accordance with their loved ones' preferences.

For the workforce, the SWAN model promotes empowerment and engenders satisfaction and pride about the care they are providing. Similarly, Walsh *et al*<sup>28</sup> reported staff pride, when a new bereavement service was implemented across a hospital. Data from all three stages of the evaluation indicated the impact of the SWAN model on

organisational culture, with death and dying now seen as a high priority and everyone's business. This institution-wide approach to prioritising end of life and bereavement care has been found to be highly valued by staff in clinical settings where death occurs.<sup>33</sup> A further outcome was support provided for staff affected by death and bereavement, personally or professionally. Previous research has highlighted the importance of providing support for staff, particularly where there are unexpected or traumatic deaths.<sup>34</sup>

### Meaning of the study: possible explanations and implications for clinicians and policymakers

The scoping review indicated there is limited knowledge and understanding of end-of-life care interventions. However, the evaluation results indicate that the SWAN model architects had effectively implemented a best practice model to deliver person/family-centred care, based on available evidence, including bereavement care and memorialising.<sup>35</sup> The values and principles basis for the SWAN model, rather than sets of guidelines, with an emphasis on normalisation of death and delivery of end-of-life and bereavement care by the whole workforce, appears to be a successful model. The SWAN model has grown organically, being implemented in different NHS organisations, the community and the care home sector. This evaluation indicates that for the model to be successfully implemented, there needs to be consistent senior level commitment and leadership, workforce engagement and education, teamwork and integrated working and appropriate investment in roles and resources. The SWAN model is currently being used in varied organisations across England. Consistent standards of end-of-life and bereavement care could be achieved nationally if the SWAN model was integrated into healthcare policy.

### Strengths and limitations

Previous evaluations of end-of-life and bereavement care are scarce and are predominantly survey-based<sup>19</sup>; in contrast this evaluation, using a realistic approach, included qualitative interview data as well as analyses of routinely collected qualitative and quantitative data. The use of a mixed method realist evaluation captured the nuances of what it is about the SWAN model that brings about change and the context ('for whom' and 'in what circumstances') SWAN works. The interview data were gathered from only two NHS Trusts, though national data from audits and reports were also analysed. The evaluation included organisations that have successfully implemented the SWAN model; it did not include organisations that have attempted to implement the SWAN model without success. The evaluation also did not include data directly collected from patients or families.

### Unanswered questions and future research

This evaluation focused in depth on the Trust where the SWAN model was first developed and implemented, and a second Trust that had since implemented and embedded

the model. The Stage 3 national data confirmed that SWAN has been implemented at other Trusts across England too, with comparable outcomes. An evaluation of the use of the SWAN model at national level is recommended to gain a greater understanding of the concepts and mechanisms to support national implementation. We also recommend the inclusion of direct patient and family data in future studies. Further research could evaluate the SWAN model's implementation in different settings and circumstances, such as care homes and the community, including the unique role of the coronial bereavement nurse. In addition, future research could investigate why the model has not worked in other organisations and the challenges associated with failed implementation attempts.

## CONCLUSION

This realist evaluation has demonstrated the mechanisms (what it is about SWAN that brings about change), the context ('for whom' and 'in what circumstances' will SWAN work?) and the outcomes of the SWAN model's implementation. The evaluation has revealed that, with successful implementation, the outcomes include consistent delivery of person/family-centred care at end-of-life and afterwards, staff satisfaction and pride, and the development of an organisational culture that prioritises care for the dying and bereaved.

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## **The implementation and perceived impact of the SWAN model of end-of-life and bereavement care: a realist evaluation**

### **Stage 1 Phase 1 Stakeholder interviews topic guide**

Open questions will be asked on the following topics, with follow-up probes for examples and further detail/depth

- Background (conception) of SWAN: how, when, where, why?
- The initial SWAN development: your role/involvement, views, experiences
- How SWAN was implemented initially: infrastructure, documents, resources, views about process
- Views about initial impact of SWAN: on working practices for end of life/bereavement care, organisational culture, staff/patient/family experiences
- How SWAN has evolved since initial conception and why
- Views about most important aspects of SWAN and why
- Any other thoughts about SWAN

### **Stage 1 Phase 2 Implementer interviews topic guide**

Open questions will be asked on the following topics, with follow-up probes for examples and further detail/depth

- Your first encounter with the Swan model:
  - When and where
  - How did you learn about the Swan model and from who?
  - What were your initial responses to the model?
- Implementation of the Swan model:
  - How was the Swan model implemented?
    - How were people prepared?
    - Resources and facilities
  - What are your views about how the Swan model was implemented?
  - Have there been any barriers/hurdles to the Swan model implementation?  
Explore what and if still present
  - What were your first experiences of using the Swan model?
  - How did the Swan model differ from how you (or others) previously worked?  
What changed - examples

- Who were you working with during implementation of the Swan model? Did you work with different people than previously?
- Experiences of the Swan model:
  - What do you feel are the key elements of the Swan model?
  - What are your views about how using the SWAN model has impacted on (probe for examples):
    - patient/family experiences
    - staff experiences: emotional, personal, professional and practical, including working practices for end of life/bereavement care,
    - organisational culture.
- Have there been any changes or developments to how the Swan model is used since first implemented? How did these happen and why? Examples (probe: Covid 19)
- Any other thoughts about SWAN

## Stage 2 - other organisations

Open questions will be asked on the following topics, with follow-up probes for examples and further detail/depth

Your first encounter with the Swan model:

- When and where
- How did you learn about the Swan model and from who?
- What were your initial responses to the model?

Implementation of the Swan model:

- Was there high level support for implementation? Explore response
- Who led the implementation? Are they still leading Swan?
- Were there new staff appointed to support the implementation?
- Explore response (roles, how they came about)
- How were staff prepared?
- What resources and facilities were developed to support Swan implementation?
- Have there been any barriers/hurdles to the Swan model implementation?
- Explore what and if still present
- What were your first experiences of using the Swan model?
- How did the Swan model differ from how you (or others) previously worked?
- What changed – examples

- Who were you working with during implementation of the Swan model? Did you work with different people than previously?

Views about the Swan model and impact:

- What do you feel are the key elements of the Swan model?
- What are your views about how using the SWAN model has impacted on
- (probe for examples):
  - patient/family experiences
  - staff experiences: emotional, personal, professional and practical,
  - including working practices for end of life/bereavement care, organisational culture.

Have there been any changes or developments to how the Swan model is used since first implemented? How did these happen and why? Examples (probe: Covid 19)

What will ensure sustainability of this model within your organisation?

What are the specific resources required to ensure continuity?

Any other thoughts about SWAN