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Social Return on Investment: A Mixed Methods Approach to Assessing the Value of Adult Hospice Services in North Wales

Hughes, Nicole

Award date:
2021

Awarding institution:
Bangor University

Link to publication

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Social Return on Investment: A Mixed Methods Approach to Assessing the Value of Adult Hospice Services in North Wales

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A thesis submitted in fulfilment of a Doctor of Philosophy Degree

Funded by the Knowledge Economy Skills Scholarship (KESS)

Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

AUTHORS DECLARATION

‘Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw’r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o’r blaen ar gyfer unrhyw radd, ac nid yw’n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deuol cymeradwy.’

Rwy’n cadarnhau fy mod yn cyflwyno’r gwaith gyda chytundeb fy Ngrichwyliwr (Goruchwylwyr)’

‘I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.’

I confirm that I am submitting the work with the agreement of my Supervisor(s)’

There is concern that potential funders know

“*the price of everything, and the value of nothing*”

Lady Windermere’s Fan (1893), Oscar Wilde

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ACKNOWLEDGEMENTS

Writing a PhD can feel like a lonely venture, and often it is, but in many ways this was a team effort. My first thank you goes to Professor Jane Noyes, who has mentored me throughout this PhD, read through endless drafts, answered innumerable queries and asked questions that forced me to sharpen my argument and defend my thesis. Next, thanks go to Dr Julia Wardaugh and Dr Lindsey Eckley, both of whom provided continued guidance and support despite their departure from Bangor University.

I have so many people to thank who were generous with their time and always on hand to provide their expertise. First, Dr Carys Jones who alongside being a friend, provided invaluable expertise, feedback and belief in my academic abilities when my own was wavering. Dr Ned Hartfiel, who again provided expertise and feedback on draft chapters and Dr Alison Orrell who, despite her busy schedule, made the time to provide me with a crash course in statistics. Gratitude is also due for the chair of my supervisory committee, Dr Dianne Seddon, who provided helpful comments and encouragement when necessary.

The biggest thanks of all, however, must go to Trystan Pritchard and the hospice consortium who are relentless in ensuring that they provide the best possible care for those who need it. I was inspired every day by the staff and volunteers within your organisations and the positive impact they have on the lives of service users. I would also like to register my gratitude to the many patients and family-caregivers whose time was invaluable, yet still agreed to participate in this study. I hope this thesis does justice to the positive comments you provided, and truly conveys the value of hospice care. I will be forever grateful to you all for this opportunity.

Special thanks must also be given to Bangor University for providing the opportunity to undertake a Knowledge Economy Skills Scholarship (KESS) and to the Social Value Network who provided a supportive space to learn from others.

Finally, but by no means least, I wish to express heartfelt thanks to my family for their enduring encouragement and words of wisdom such as “just write something”. My

appreciation also extends to all of my friends for supporting me throughout this journey and putting up with my disappearing act and cancellation of plans for months on end. To Jack, thank you for your endless support and patience, and for putting your life on hold whilst I completed this PhD. You never once doubted that I would complete this study.

I would like to dedicate this thesis to ‘Uncle Bobby’ [Robert Henry Hughes] who sadly lost his battle with cancer in 2017.

ABSTRACT

BACKGROUND

In the UK, there is increasing pressure on third sector hospice services to demonstrate their value amidst considerable financial and economic austerity. With competition for limited statutory funding continuing to rise, it is necessary for hospices to demonstrate that they represent good value for money. Traditional economic evaluation methods such as cost-utility and cost-effectiveness analysis have frequently been used to evidence value; however, there has been a shift towards the use of alternative health economic measurement techniques [1]. In particular, the Social Return on Investment (SROI) methodology, which has the ability to account for wider socio-economic outcomes, thus ensuring a broader representation of value [2], has been promoted by the Cabinet Office [3]. In this KESS studentship, an evaluative SROI analysis of the inpatient and day therapy units of four North Wales hospice sites (A-D) was conducted to assess their social value.

METHODS

This thesis reports five empirical studies: I) a partial economic analysis was conducted through the application of a step-down costing methodology; II) a three-stage, mixed-studies, systematic literature review to determine the aspects of hospice care that patients and family-caregivers valued; III) a qualitative study using semi-structured interviews and focus groups was undertaken to explore stakeholder experiences, ascertain values, and identify outcomes to be used as quality indicators; IV) patient outcome data were collected via the Integrated Palliative Outcome Scale (IPOS); V) findings from the aforementioned studies were used to calculate the final SROI ratio.

FINDINGS

I) Due to structural differences in care models, the costs for Site D were calculated separately. The mean total cost of palliative care provision was £1,512,841 per year for Sites A–C and £1,034,927 per year for Site D. The average cost per patient admission to the inpatient unit was £446 (Sites A–C). The unit cost per at home visit was estimated as £190 per patient (Site D). The average cost per

patient visit to the day therapy unit was £292 (Sites A–C) and £178 (Site D). Based on an occupancy rate of 80%, the mean unit cost for the inpatient unit and day therapy units was £407 and £169 respectively.

II) Thirty-four studies highlighted that an amalgamation of hospice service components were valued by patients and family-caregivers. These generally remained consistent across studies; however, the overarching synthesis demonstrated disparities between what people valued and why.

III) Seven principal outcomes were identified: improvements in relationships, physical and psychological symptomology, mobility, informedness, social isolation, and autonomy.

IV) Within the inpatient unit, ‘poor mobility’, ‘appetite loss’, and ‘weakness’ were recognised as prevalent issues. Psychosocial items of care were generally well managed although there was limited data pertaining to this. Within the day therapy unit, ‘breathlessness, ‘patient anxiety’, ‘family anxiety’, ‘weakness’, and ‘pain’ were identified as prevalent issues. In contrast to the inpatient unit, psychosocial items of care were often presented as severe.

V) The inpatient unit returned a base case ratio of £2.77:£1, whilst the day therapy unit returned a base case ratio of £11.85:£1.

CONCLUSION

Prior to this study, the SROI methodology had not previously been applied and completed within a palliative setting, and thus this thesis presents a novel approach. By taking this approach, important findings have been unearthed which have assisted in the construction of recommendations to guide future policy, practice, education, and research. As a result of substantial stakeholder involvement, these recommendations have been informed by stakeholder values and are thus representative of the population they seek to assist. Finally, the findings have emphasised the need for continued collaboration between academia and the third sector to generate and implement evidence-based practice.

Publications

Hughes, N., Noyes, J., Jones, C., & Pritchard, T. (2018). The value of hospices in North Wales: a collaboration between academia and third sector organisations. *BMJ Supportive & Palliative Care*, 8, A90. https://doi.org/10.1136/bmjspcare-2018-hospiceabs.249

Hughes, N., Noyes, J., Eckley, L., & Pritchard, T. (2019). What do patients and family-caregivers value from hospice care? A systematic mixed studies review. *BMC Palliative Care,* 18(18), 18-31. https://doi.org/10.1186/s12904-019-0401-1.

Presentations

Hughes N. What do patients, carers and family members value from hospice services?, 2016, Hospice UK National Conference: People, Partnerships and Potential, Liverpool, UK.

Hughes N. What do patients, carers and family members value from hospice services?, 2017, The European Industrial Doctoral School (E.I.D.S.), Bangor, UK.

Hughes N. How do we engage with our stakeholders?, 2017, North Wales Social Value Network Meeting, Rhyl, UK.

Hughes N., Noyes, J., Jones C., & Pritchard, T. The value of hospices in North Wales: a collaboration between academia and third sector organisations, 2018, Hospice UK National Conference: Transforming Palliative Care, Telford, UK.

GLOSSARY OF TERMS

Apportion: To divide up and share out.

Attribution: An assessment of how much of an outcome was as a result of other organisations.

Attrition (Drop-off): The deterioration of an outcome over time.

Baseline: A benchmark against which future progress can be assessed.

Blended value: Value created through an amalgamation of economic, environmental, and social factors.

Capital costs: Costs incurred when purchasing land, buildings, construction, and equipment or through the rendering of services.

CERQual: Confidence in Evidence from Reviews of Qualitative research

Cost allocation: The distribution of costs or expenditure across specific programmes, products, or businesses.

Cost–benefit analysis: An analysis which compares the costs and consequences of an intervention in monetary terms.

Cost-effectiveness analysis: An analysis in which the costs of an intervention are measured in monetary units and the outcomes are measured in health-related units.

Cost–utility analysis: An analysis where the costs of an intervention are measured in monetary terms and the outcomes are measured in quality adjusted life years (QALYs).

Cost drivers: Factors that consequently lead to a change in the cost of an activity.

Deadweight: An assessment of the proportion of an outcome that would have occurred in the absence of an intervention.

Displacement: An assessment of how much of an outcome supplanted other outcomes.

Duration: The period over which something lasts.

Epistemology: A theory of knowledge

Extra-welfarism: An approach to welfare economics in which maximising individual utility is rejected in favour of adopting other sources of valuation such as health state, freedom of choice, and quality of relationships between individuals.

Financial proxy: The monetary representation of the value of an outcome.

Fixed costs: Costs that are independent of the level of goods or services produced.

Hedonic pricing: The hedonic price method uses the value of a surrogate good or service to measure the price of a non-market good. This method takes into account how different characteristics and external factors affect the price.

ICECAP-Supportive Care Measure: A self-complete questionnaire developed to rate quality towards the end of life.

Impact: The difference between the outcome for participants following an intervention and the outcome for participants without the intervention.

Impact map: A document which shows the relationship between inputs, outputs, and outcomes.

Income: The money generated by an organisation through sales, donations, contracts, or grants.

Indicator: Measures that provide an insight into the expected quantity of an outcome.

Inputs: Stakeholder contributions which ensure an intervention is possible. These can be financial or non-financial.

Inter-rater reliability: The extent to which two or more raters agree.

Intervention: A procedure designed to produce change or improvement amongst individuals or populations.

IPOS: A 17-item multidimensional tool that can be completed by patients (self-reported), caregivers, or staff (proxy-reported) to assess symptomology.

Knowledge Economy Skills Scholarship (KESS): A major pan-wales operation supported by European Social Funds through the Welsh Government.

Monetise: The act of assigning a financial value to something.

Nurse-led model of care: A service model in which nurses are responsible for the overall coordination and management without having direct supervision.

Opportunity cost: The foregone value of benefits that would have been derived by choosing the next best use of resources.

Outcome: The changes resulting from an activity.

Outputs: The activities that stem from the use of resources.

Pro-rata: Proportionate allocation.

Proxy: An individual authorised to act on behalf of another party.

Psychosocial: The interrelation of social and psychological factors.

Qualitative: Observational data that seeks to measure the characteristics of a phenomenon.

Quantitative: Numerical data that seeks to quantify a phenomenon.

Scope: The parameters within which a study operates and the extent to which a topic will be explored.

Replacement cost method: This is the method of replacement value, which suggests that hours should be valued at the hourly market value.

Sensitivity analysis: An analysis in which the value of an independent variable is amended to view its effect on a dependent variable to determine research uncertainty.

Social Return on Investment: An outcomes-based measurement tool that assists organisations in understanding and quantifying the social, environmental, and economic value they generate.

Social value: The quantification of the relative importance that people place on the changes they experience in their lives.

Soft outcome: Outcomes that are often intangible and thus harder to observe or measure.

Stakeholders: Parties that are affected by the activity of an organisation.

Statistical significance: The determination that a result is not likely to occur through chance but is instead attributable to a specific cause**.**

Subjective well-being: Personal perception and experience of well-being.

Sustainability: The ability to be maintained at a constant rate without becoming depleted.

Thematic analysis: A method of analysing primary qualitative data.

Thematic Synthesis: Thematic synthesis is a method used combine, aggregate, integrate, and synthesize primary research findings.

Theory of change: A tool used by organisations to plan how they will create change, assess their effectiveness, and communicate with stakeholders.

Utility: In health economics, utility is the measure of preference for a particular health state or outcome.

Validity: How accurately a result has been measured and therefore how likely it is to be true and free of systematic error.

Variable costs: Costs that vary in relation to the level of goods or services produced.

Welfare economics: A branch of economics which seeks to determine the effect of resource distribution on social welfare.

Willingness to pay: The maximum amount of money that a stakeholder is willing to pay for a product, service, or outcome.

Welfarism: An approach to welfare economics which seeks to maximise individual utility.

Chapter 1 : Introduction

Chapter Summary

This chapter starts by providing definitional clarity regarding palliative care before proceeding to discuss the current policy context from a UK and Welsh specific perspective and the challenges surrounding palliative care research. Following this, the aims of this thesis are defined and the rationale for commissioning the research is outlined. Subsequently, the justification for applying the Social Return on Investment (SROI) methodology is provided, followed by a brief overview of the hospice study sites. To conclude, an outline of the thesis is provided.

Introduction

The research presented in this thesis focuses on the value of hospice care and services delivered to adults with palliative care needs and their families. For definitional clarity, hospice care is a service delivery system that provides palliative care to any person diagnosed with a terminal illness. Hospice care, which is often location specific; either delivered in a dedicated facility or within the patient's home [4], offers an alternate, patient-centred model of care which focuses on optimizing quality of life for patients in their last months of life and their families by minimizing physical, psychological, social and spiritual suffering [5]. Despite this, the terms 'hospice' and 'palliative care' continues to be synonymous with terminal care which has been proven to hinder timely referrals [6]. In this thesis, the palliative care definition provided by the World Health Organisation [7] as outlined in *Figure 1.1* has been applied. Notably, this thesis will employ the terms 'hospice care' and 'palliative care' interchangeably.

The World Health Organisation (WHO)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of patient care

- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life and may also positively influence the course of illness.
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Figure 1:1: The World Health Organisation (WHO) definition of palliative care [7]

Palliative care for non-malignant diseases

Each year, hospices provide care for 225,000 people in the UK who have been diagnosed with a terminal or life-limiting illness [8]. In 2019, 530,841 deaths were registered in England and Wales. Most of these deaths occurred in a hospital (242,472), followed by at home (128,918), in a care home (116,698), in a hospice (29,456), or elsewhere (13,297) [9]. Although a number of publications have unearthed the inequalities associated with access to hospice care, it remains synonymous with a cancer diagnosis [10]. The 1995 Calman–Hine report [11] presented a policy framework for the commissioning of cancer services, which subsequently led to the development of national service frameworks for other conditions [12] such as congestive heart failure, dementia, motor neurone disease and chronic obstructive pulmonary disease. Despite these recommendations, inequities continue to exist, with funding for non-cancer conditions remaining limited [13]. The 'End of Life Care Strategy 2008' [14] published by the Department of Health recognised the need for palliative interventions to encompass a wider patient population, which is likely to require additional resources. Despite the strategy's introduction, disparities continue to exist, with just 7.7% of all deaths in hospice inpatient units within England and Wales stemming from non-cancer conditions between 2008 and 2012 [9]. Furthermore, in 2012, it was found that 17.8% of people with cancer diagnoses died in hospices, whereas only 0.8% of people with non-malignant diagnoses died in hospices' [15].

Types of palliative care services

Palliative care services provided by the NHS and third sector organisations typically comprise an inpatient unit, a day therapy unit, and an at home service [16]; however, these core services will differ in terms of processes, services, capacity, and length of service provision. A brief summary of the three service models is provided below:

Day therapy

Day therapy services provide multidisciplinary out-of-home support for patients with a palliative diagnosis. Through participation in supervised activities, patients are able to access a range of support networks on a regular basis, which helps ensure that they are able to remain at home [17]. Day therapy has also been thought to aid family-caregivers and reduce emergency hospital admissions due to recurrent access to short bouts of respite [18]. The service includes, but is not limited to, the provision of medical and nursing care, complementary therapies, and peer support.

At home care

Recent decades have marked a growing individual preference to die at home, with approximately two thirds of ill patients choosing home as their desired place of death [19]. Despite this, the reality is that very few patients fulfil their preference and instead die in an alternative setting [20]. In response, there has been a sustained international effort to ensure that patient preferences are met [21]. Within the UK, at home services have become well established and seek to assist patients to die at home by providing a support network for patients and their families. Evidence suggests that commissioning at home services has resulted in increased incidences of home deaths [22], improved quality of life [23], and pain and symptom management [24]. It is worth noting, however, that the way in which services operate is not uniform [25] and that a single model of at home service does not exist [26]. Whilst some units offer 24/7 care, others may put the onus on out-of-hours and emergency services [25].

Inpatient unit

Inpatient units provide assessment and symptom management for palliative patients in addition to respite for their family-caregivers. Each patient’s length of stay is largely determined by their diagnosis and condition as well as the hospice's capacity [16]. Although inpatient care is often associated with advanced stages of illness, many patients are admitted for short periods of time to alleviate specific problems and return home following treatment [16].

Hospice governance and funding

The development of hospice and palliative care services has been largely underpinned by the third sector and thus is primarily reliant upon funds raised through charitable activities and fundraising. Informed by the Welsh Funding Formula, statutory contributions remain limited as the formula is linked to spending decisions made in England [27]. The formula is not inexplicably linked to any fundamental welfare or equity rationale and instead correlates population size with fiscal need, thus overlooking the actual need of UK countries [28]. Despite calls for alternative funding arrangements, the use of the Barnett funding formula remains, which results in high levels of uncertainty [29]. These challenges have been further perpetuated by the emergence of the Covid-19 pandemic, which has caused an almost complete cessation of fundraising activities. In England and Wales, hospices are governed by trustees and regulated by the Charity Commission and hence are subject to the regulatory requirements of the Charities Act 2011 [30]. To ensure legislative compliance, all charitable organisations whose income exceeds £250,000 are required to prepare and publish their financial statements, which ensures accountability as it permits public scrutiny [30]. The Welsh Government's strategy entitled 'A Strategic Direction for Palliative Care Services in Wales' [31] sought to provide a strategy which meets the needs of people in Wales. This strategy recognises that hospices and their supporting services must be able to operate in a stable and sustainable financial environment [31].

Policy context

Globally, there has been a shift towards ensuring sustainability, and this has been reflected in the 2030 Agenda for Sustainable Development [32]. The vision presented is based on five values (People, Planet, Prosperity, Peace and Partnership) and 17 Sustainable Development Goals (SDGs) which seek to reform economic, social, and environmental processes to maintain future viability. Notably, the third goal, entitled 'Good Health and Well-Being', addresses multiple facets of health care; however, there is no specific mention of palliative care [33], which reinforces the fact that it is frequently neglected as an important domain of the health system [34]. Due to palliative care's position as an economic, social justice, and human rights issue, it is still necessary to demonstrate its long-term value [33]. Whilst focus must be maintained on achieving SDGs on a global scale, the economics of palliative care cannot be overlooked and must also be integrated into legislation pertaining to improved policy and health outcomes [33].

Despite their leading role in the provision of palliative care, hospice services across the UK are facing substantial financial and economic austerity, which has been further exacerbated by the recent Covid-19 pandemic [35]. These pressures, which undermine hospice capacity to meet increasing demand for care [36], have heightened pressure to evidence the value of hospice services and activities. This drive for financial sustainability has also aligned with the emergence of the Public Services (Social Value) Act 2012 [37], which encourages organisations to consider and evidence their social value. This Act has allowed voluntary organisations to demonstrate their capabilities for and achievements in delivering additional social value through the delivery of their services. In view of the inherent confusion surrounding the concept of social value [38], for the purpose of this thesis, social value is a burgeoning concept which can be broadly defined as the sum of the positive and negative, intended and unintended changes experienced by stakeholders as a result of the service [39]. In healthcare a positive change for patients could be a reduction in pain, however, an unintended consequence of this could be increased drowsiness. The Social Return on Investment (SROI) methodology, which is a transition from a traditional focus on the gross domestic product (GDP), has been heavily promoted by the Cabinet Office to measure progress and encompass an organisation's wider social value [40] and will be discussed further later in this chapter.

In a Welsh-specific context, the introduction of three key pieces of legislation has transformed the legislative landscape considerably: the Social Services and Well-being (Wales) Act 2014, the Well-being of Future Generation (Wales) Act 2015, and the Prudent Healthcare Principles 2015. The Social Services and Well-being (Wales) Act 2014 provides the legal framework necessary to reform care and support services across Wales and places well-being at the forefront of the policy agenda [41]. The definition of well-being is intentionally broad to encompass a number of specific considerations; however, it can generally be defined as the prevention of and protection from abuse, harm, and neglect, in addition to the physical, mental, and emotional health of an individual [42]. Through the imposition of duties upon local authorities, health boards, and ministers, the Act seeks to encourage collaboration in an effort to promote well-being and develop service integration [41]. The onus on public bodies to take responsibility for their decisions has been heightened by The Well-Being of Future Generations Act which, through the application of seven well-being goals, aims to improve the social, economic, environmental, and cultural well-being of Wales [43]. This is to be achieved by transcending the rigid traditional care models and instead employing flexible approaches with a greater emphasis on multi-agency co-operation in tandem with rational and logical planning [44]. The Prudent Healthcare Principles (2015) are central to the Welsh Government's ambition for sustained improvements in healthcare and inform the majority of policy and discussions [45]. Currently, healthcare delivery is often misaligned due to the complex and dynamic governance systems that exist and because of the disconnect between local authorities, the NHS, and other healthcare agencies [46]. Introduced in 2016, The Prudent model promotes an alternative ethos within which cooperation, joint ownership, and stakeholder engagement are central [47]. Evidence suggests that co-production results in more cost-effective processes, more appropriate levels of treatment and ultimately improved patient outcomes [48]. In order to achieve this however, a cultural shift is required which the Prudent Healthcare Principles seek to achieve [48]. There is a necessity for Health Boards to focus on delivering outcomes and experiences that patients value whilst simultaneously ensuring individuals are able to migrate between health services efficiently [49]. The collection of data regarding patient preferences, experiences and outcomes is therefore pivotal in guaranteeing organisations deliver a service that addresses patient needs (3). As part of this shifting dynamic, medical professionals must engage with the public to ensure they are fully informed and involved in the decision making process, subsequently ensuring a patient centric approach to health care delivery [49]. This strongly aligns with the SROI methodology utilised within this thesis as it is heavily underpinned by stakeholder engagement. Palliative care has often been overlooked from the global health dialogue however, following the publication of the United Nations Sustainable Development Goals (2015) [32], an opportunity has arisen for palliative care to emerge at the forefront of the global health agenda [50]. The 2030 Agenda for Sustainable Development, comprised of 17 Sustainable Development Goals (SDGs), provides a detailed strategy which seeks to stimulate action in areas of critical importance and shift the world on to a sustainable and resilient path [32]. The Sustainable Development Goals replaced the unsuccessful Millennium Development Goals (MDGs) that were adopted by 193 countries in 2000 and made little reference to improving quality of life, palliation of symptoms or palliative interventions [50].

The alignment of palliative care with the 2030 Agenda may not be immediately obvious however, under closer inspection, it’s apparent that several points of congruence exist. Although the Sustainable Development Goals contain just one explicitly health-oriented goal, as opposed to three of the eight Millennium Development Goals, many of the goals make reference to factors such as poverty, hunger and education which are key determinants of health and well-being [32]. This shift in understanding of what constitutes health represents a positive step in facilitating multi-agency collaboration for those whose activities impact health but are often beyond the purview of the traditional health sector [49]. By embracing a broader and more multifaceted vision for health and development, the aim is to encourage innovation from the government, private sector and civil society resulting in better delivery of global health care.

Table 1.1 provides an overview of each piece of legislation’s main principles and the contribution this thesis makes to achieving them. Collectively, they have placed an emphasis on the delivery of sustainable, outcome-focused services, and therefore the ability of organisations to prove that they are achieving this is paramount.

Table 1:1: Summary of legislative principles applicable to this research study

Name	Main Values/Principles*
Public Services (Social Value) Act 2012	All public bodies in England and Wales must consider how their services might improve the economic, social, and environmental well-being of the relevant area
Social Services and Well-being (Wales) Act 2014	Voice and control Prevention and early intervention Well-being Co-production
Well-being of Future Generations (Wales) Act 2015	A prosperous Wales A more equal Wales A healthier Wales A Wales of cohesive communities A Wales of vibrant culture with a thriving Welsh language
Prudent Healthcare Principles 2015	Achieve health and well-being through co-production Effective use of all skills and resources Reduce inappropriate variation using evidence-based practices consistently and transparently
2030 Agenda for Sustainable Development	Good health and well-being Quality education Industry, innovation, and infrastructure

*Legislation may contain more than just the principles listed however, only those which map on to the objectives of this thesis have been included.

Research challenges in palliative care research

Palliative care is a rapidly expanding field which is facing increased demand due to an ageing population, but despite its importance, research within this field is challenging. Whilst these challenges can be attributed to a variety of factors, difficulties pertaining to the study population are consistently cited within the existing literature [51]. Palliative care patients are inherently difficult to recruit, retain, and measure due to the nature of their illness and their vulnerable population status [52]. Patients are likely to experience rapid deterioration in health and symptom fluctuation and therefore difficulties exist regarding reliable data collection. Furthermore, a palliative diagnosis imposes a substantial psychological burden on a person, and such distress may heavily inhibit their willingness to participate [53]. Notably, questions regarding the ethical validity of palliative care research remain because there are concerns pertaining to the involvement of those at the end of life.

It is necessary for researchers to obtain informed consent from participants, but because of some patients' diagnosis, both their mental and their physical capacity are often hindered [54]. Informed consent relies on an individual being presented with comprehensible information that enables them to evaluate the risks and benefits and, subsequently, to make a well-reasoned, autonomous decision [55]. Given that cognitive impairment is commonly associated with palliative diagnoses, acquiring informed consent is difficult. Even for individuals who are initially able to comply, there is a possibility that their illness will lead to reduced mental capacity during the study and hence a redaction of their informed consent.

Further challenges exist as there is a requirement to consider the needs of the family as well as the individual, which may impact willingness to participate and detract from patient autonomy [56]. A family member's inclination to protect an individual from distress can result in gatekeeping, through which decisions are made on behalf of potential participants despite the fact that they have the capacity to consent themselves [55]. Gatekeeping can also extend to healthcare professionals, research ethics committees, hospice management, and the researcher themselves, with a rationale that is congruent with that used by families [57]. By preventing willing participants from contributing to research studies, population representation is stifled and selection bias arises [58].

As discussed previously, the demand for palliative care continues to rise but funding remains a concern. Palliative care services are heavily reliant on statutory funding streams and third sector fundraising, and with these becoming increasingly constrained, financial uncertainty remains. Palliative care services must therefore demonstrate their worth and hence justify receipt of funding; however, doing so requires fiscal support, thus creating an impasse. Money is a central to research, and currently there is a lack of national strategy that is directing funding towards palliative care research [59]. In a 2013 study, 149 UK funding organisations were identified; they had a combined budget of £260 million [60]. Of this, only £3.37 million (1.3%) was allocated to palliative and end of life care research [60]. Failure to allocate a sufficient research budget encumbers research design and innovation whilst halting the potential for practice development [61].

Staff shortages stemming from limited funding of services have also resulted in increased workloads across palliative care settings [62]. Although staff are often willing to participate in research, they lack the time to do so as the additional burden would diminish their ability to perform their primary caring role [62]. Evidence suggests, however, that researching practice change results in improved patient outcomes [63]. Regarding patients and family-caregivers who do enroll, a lack of research infrastructure and training negatively impacts their effectiveness [60]. Inadequate education regarding research methods and governance issues results in a lack of staff confidence and inevitably leads to poor engagement, which produces substandard research [60].

Aim

A) This thesis was conducted as part of a Knowledge Economy Skills Scholarship[1] (KESS) [64] to answer the overarching research question 'What is the social value of hospice care?'. In order to do so, the following research questions are addressed: What is the per patient unit cost associated with each of the hospices for (1) a day therapy visit, (2) an inpatient bed day, and (3) an at home visit?

B) What do patients and family-caregivers value about adult hospice care in the UK?

C) What are the key benefits and outcomes experienced by patients and family-caregivers who access the hospice day therapy unit, inpatient unit, or at home service?

D) To what extent are patients exhibiting changes in their physical and psychosocial outcomes post-hospice intervention?

Choice of SROI methodology

Historically, organisations have demonstrated their value through the implementation of methodologies such as cost–benefit analysis (CBA), cost-effectiveness analysis (CEA), and cost–utility analysis (CUA); however, issues exist regarding their ability to account for wider socio-economic facets of value [1]. Given the changing legislative landscape, which seeks to place emphasis on sustainability and quality service delivery whilst ensuring that social,

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[1] This project was supported by KESS, a Welsh operation which is endorsed by the Welsh Government's European Social Fund. Their objective is to promote collaboration on research projects between local businesses and students in higher education to facilitate the acquisition of postgraduate qualifications [64]. Each of the four company partners have invested a cash contribution to this project.

economic, and environmental issues are addressed, a social impact measurement tool which can accurately equate such factors is required.

The Social Return on Investment (SROI) methodology, which has been heavily promoted by the Cabinet Office, seeks to achieve this ambition by departing from traditional methodologies and accounting for the wider value that organisations generate [40]. Instead of placing emphasis solely on fiscal metrics, SROI analysis prioritises stakeholder engagement and allows stakeholders to define the outcomes that matter to them, allowing for the capture of subjective well-being [65]. The evidence obtained through stakeholder engagement will be used to map outcomes, by employing a theory of change. A theory of change (or impact map) details how the change was created [66]. This process starts with the initial investment (inputs) and the activities carried out (outputs), before being mapped onto the changes (outcomes) experienced by stakeholders as a result of an activity or intervention. Within the health sector, such an approach is beneficial as outcomes are often intangible, leading to difficulties in identification and measurement [67]. This is especially relevant in palliative care research. Despite the drive for organisations to capture their social value, due to an absence of a dedicated indexed database pertaining to SROI studies, identifying literature in which the SROI framework has been applied remains challenging. Nevertheless, it can be concluded with some degree of certainty that a limited number of SROI studies have been conducted within the field of palliative and/or hospice care. For transparency, a Nottinghamshire hospice [68] advertised the commencement of an SROI project prior to 2016; however, despite continued attempts to contact the hospice, further details could not be obtained. There are various instances in which third sector organisations have adopted the methodology, but not within an academic context, thus limiting its development and validity [1] *(Chapter 2).*

Novelty and contribution of the thesis

To the best of my knowledge, the a completed SROI within a hospice care setting has not previously been conducted. Although a Nottinghamshire hospice commenced an SROI project prior to 2016, there is no evidence to suggest it was completed. This thesis therefore offers a novel opportunity to achieve the following:

- Increase the evidence base for use of the SROI methodology within a palliative care setting by performing an evaluative SROI analysis of the core hospice services: day therapy unit, inpatient unit, and the at home service.
- Improve limited knowledge about the cost of hospice care provision.
- Provide a deeper understanding of the facets of hospice care that both patients and family-caregivers value.
- Support evidence-based decision-making that concerns the use of public resources to deliver and improve hospice care.

KESS research partners and hospice study sites

Prior to the commissioning of this research, the hospice consortium, which consists of four hospice study sites, was formed to revolutionise the delivery of palliative care in North Wales. To ensure anonymity, each hospice study site was assigned a letter (*Table 1.2).* The hospice consortium contributed financially to the KESS studentship so that an SROI analysis could be done and findings could be unearthed which will inform future planning and decision-making in addition to providing evidence that can be used when dealing with funding applications with the local health board. This consortium, whose services at the time of writing encompassed an estimated population of 698,400 persons [69], pooled their varying levels of resources, expertise, and experiences with the aim of becoming more research active. At the design, inception, and negotiation stages of this KESS study, each hospice agreed to provide access to the data required to conduct an evaluative SROI analysis; however, Site D was subsequently excluded due to its inability to provide the necessary qualitative and quantitative data. Nevertheless, to inform the current evidence base, any data obtained is presented in the subsequent chapters. Whilst the three remaining hospice study sites had many organisational similarities, Site A, in an attempt to ensure financial viability had moved away from the traditional model of care within which a nurse is responsible for the overall co-ordination and management of the facility [70]. It should be noted that Site A closed intermittently throughout this research study for expansion and restructuring. Within the original scope of this research, three hospice services were included: the day therapy unit, the inpatient unit, and the at home service; however, due to the exclusion of Site D, the at home service was subsequently excluded from the SROI analysis.

Table 1:2*:* Key for anonymising each hospice site

Setting	Hospice Study Sites			
	Site A*	**Site B**	**Site C**	**Site D**
	Inpatient Unit (8 beds)	Inpatient Unit (12 beds)	Inpatient Unit (12 beds)	At Home Service
	Day Therapy Unit (15 spaces)	Day Therapy Unit (10 spaces)	Day Therapy Unit (15 spaces)	Day Therapy Unit (10 spaces)

*Operates a nurse-led model of care

Research prioritisation and transition from MRes to PhD

Initially, this project began as a Master of Research (MRes) and thus the scope of the research was constrained by the time frame and expectations of the MRes. Whilst the choice of using the SROI methodology was pre-determined by the hospice consortium to evidence its value, due to time restrictions, ethical approval could only be obtained for interviews with hospice personnel initially (ethical procedures described further in *Chapter 4),* so proxy perspectives had to be gleaned on behalf of patients and family-caregivers, an approach which is supported by the wider literature [71]. As the project progressed, there was an opportunity to apply for additional KESS funding and to upgrade to a Doctorate of Philosophy (PhD), which consequently afforded more time to attain ethical approvals from NHS REC 4 (17/WA/0399) to conduct interviews with patients and family-caregivers.

Organisation of the thesis

This thesis is divided into eight sections, of which, five (*Chapter*s *3 – 7*) feed into the SROI analysis to determine the value of hospice care in North Wales. The five empirical studies will be presented as standalone studies which align with each stage of the SROI analysis to heighten readability and, individually, contribute to improving the current evidence base. The introduction contributes to the first stage of the SROI process as it outlines its scope and identifies stakeholders. Next, the methodology chapter provides an overview of the SROI methodology, which is the overarching methodology employed within this thesis. *Chapter* 3 presents the first data collection phase as the 'mapping inputs' stage of the SROI methodology commences, with input costs for the inpatient unit, day therapy unit, and at home services determined. The systematic evidence synthesis in *Chapter* 4 was employed to understand the attributes of hospice care that matter to patients and their family-caregivers. This informed the development of topic guides and established the foundation for the coding framework, both of which are utilised in the subsequent chapter. The use of qualitative research using interviews and focus groups in *Chapter 5* unearthed outcomes experienced by patients and family-caregivers which were mapped against the Integrated Palliative Care Outcome Scale (IPOS) in *Chapter 6* to determine change over time. Finally, the data obtained through the aforementioned chapters informs the closing SROI analysis in *Chapter 7*. The final section of this thesis reports a critical analysis of the findings and establishes the implications of the research for policy, practice, and future research.

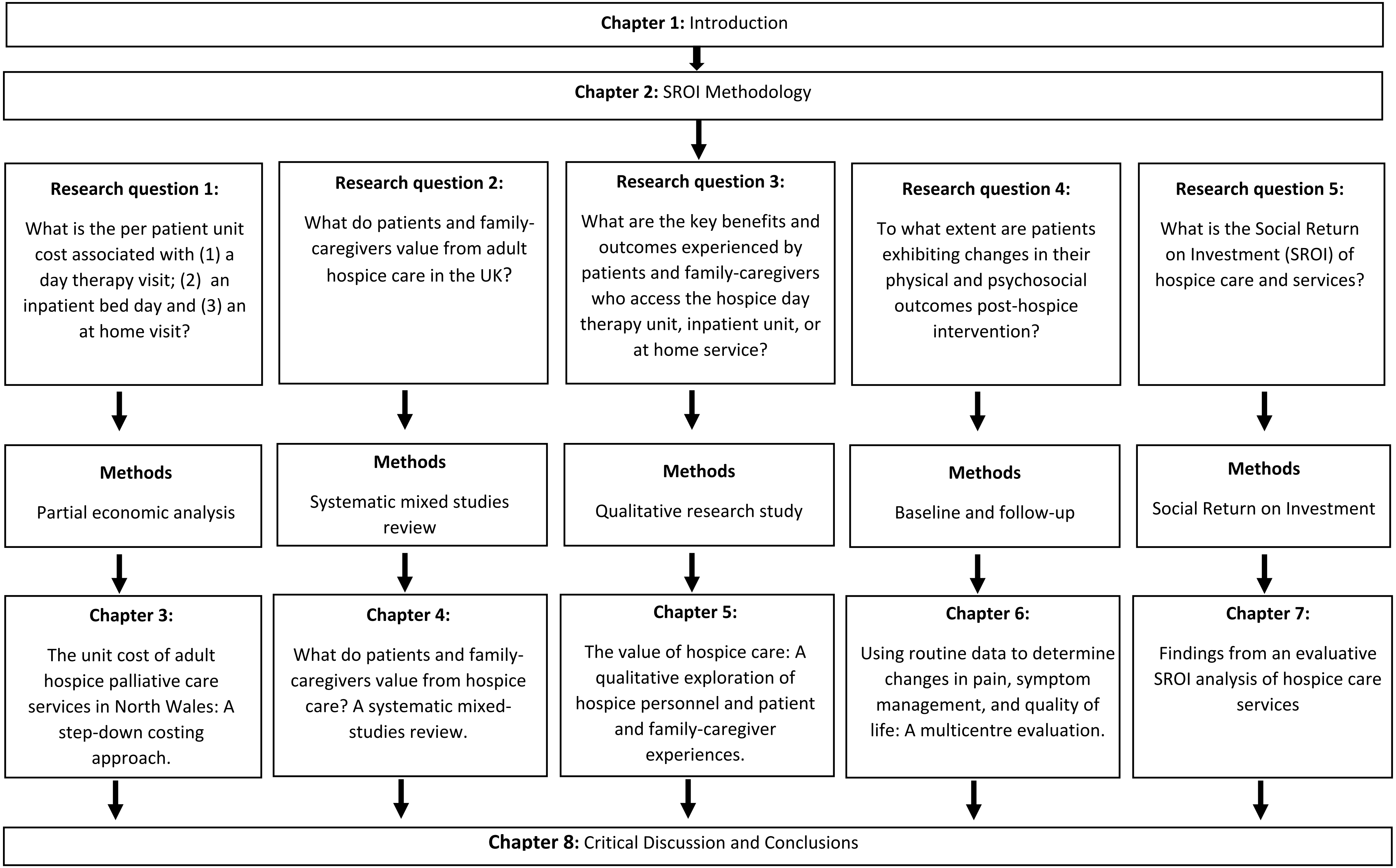


Figure 1:2: Structure and layout of the thesis

Chapter 2 : Social Return on Investment (SROI) Methodology

Chapter Summary

In this chapter, the Social Return on Investment (SROI) methodology will be outlined as the overarching methodology utilised in this thesis to determine value. This includes an exploration of its epistemological positioning, its theoretical background, and an examination of the six stages involved. To avoid repetition, however, the conceptualisation of each stage will be presented across *Chapter*s *3–7* and presented as standalone studies.

Introduction

An evaluative SROI approach was applied in this thesis to establish the social value of hospice care across a one-year period. Whilst the SROI methodology is arguably the most established and widely known methodology for capturing social value [72, 73], the data collection processes and valuation techniques involved have been criticised due to their lack of standardisation [2]. There is, however, a general consensus that best practice requires a combination of qualitative and quantitative approaches [1]. It has been suggested that the development of the methodology, which has largely been driven by the third sector, has been hindered by its limited application within academia [74]. The value of SROI analysis to decision-makers is the engagement of stakeholders and the development of a theory of change to explain and value what matters to people. The application of monetary values to outcomes that matter to stakeholders ensures ease of communication between third sector organisations and funders, trustees, and the general population.

Methods

Economic methods and paradigms

Partitioned into one of two branches, economic analyses can be categorized as either normative or positive [75]. Whilst positive economics posits that descriptive statements ought to be objective and verifiable, in contrast, normative economics is subjective and focused on value judgements to ascertain the desirability of outcomes [75]. Unlike positive economics, which can be addressed through reference to analysis and empirical evidence, normative economics comprises of ethical precepts and values to which a definitive answer may not exist [76]. Instead, answers are obtained through continuous discussion and debate [76]. Notably, the SROI methodology has faced criticisms as opponents believe that there exists an absence of a clear, principled, normative approach [77]. Although, in response to this criticism, Social Value UK, a national network, has argued that there is a normative position underpinning the principles of social value [78]. Within the following sections two normative approaches, extra-welfarism and welfarism are discussed further.

Welfarism

Economic evaluation stems from Paretian welfare economics which, in part, stipulates that individuals are the best judges of their own well-being [79]; although it has been argued that this is not strictly a requirement of the Welfarist approach [80]. Furthermore, welfarism proposes that if one person can be made better off without another being made worse, there is a global improvement in welfare. This is known as a Pareto improvement. Pareto efficiency is reached when no further Pareto improvements can be made. At Pareto efficient points, any further increase in utility can only be obtained by reducing another individual's utility [81]. This view, however, is considered useless in policy terms since few policies benefit certain individuals without affecting others [81]. The compensation principle was therefore proposed, which asserts that a global improvement will occur if those who gain from a change could hypothetically compensate those who have been adversely affected [79]. Cost-benefit analysis, where benefits are often based upon individuals' willingness-to-pay, directly utilises the compensation principle to assess the benefit of an intervention [81]. There are, however, two fundamental limitations of applying willingness to pay in healthcare. First, willingness to pay is somewhat associated with an individual's ability to pay (wealth) [82]; therefore, there is the potential to skew resource allocation towards those more affluent. Secondly, many people are uncomfortable with valuing length and quality of life in monetary terms.

Extra-welfarism

Extra-welfarism, which is referred to as a form of non-welfarist approach, is ostensibly based in Sen's notions of functioning and capabilities [81]; considering outcomes equitably, rather than accepting an approach in which choices are heavily influenced by the ability to pay. The goal in extra-welfarism is to maximise health output which rejects the welfarism goal of maximising societal utility. Quality of life measurement is consistent with this framework, and cost-effectiveness and cost-utility analysis are used in the extra-welfarism paradigm [83]. *Table 2.1* presents a comparative summary of welfarism and extra-welfarism.

Table 2:1: Summary of four main differences between welfarism and extra-welfarism

	Welfarist	Extra-welfarist
Relevant outcomes	Welfarism considers overall well-being and incorporates both health and non-health benefits [84].	Postulates health rather than utility maximization [84].
Source of valuation of relevant outcomes	The affected group of individuals is the primary source of valuation [84].	Any stakeholder can be considered an appropriate source of valuation [84].
Weighting of outcomes	Sometimes permitted in a social welfare function [84].	Weighting is important as a means of incorporating equity. Need not be preference based [84].
Interpersonal comparability of relevant outcomes	Normally considered impossible in the relevant evaluative space [84].	Comparisons between individuals on a range of well-being measures can be made [84].
Example	Cost-benefit analysis	Cost-effectiveness analysis

Choice of methodological perspective

Typically, economic analyses can be categorised into four types: cost-minimisation, cost–utility, cost-effectiveness and cost–benefit analysis, each of which are described in T*able 2.2*. Cost-effectiveness analysis, which is considered extra-welfarist, quantifies the value of interventions, typically using an intervention and control group study design, in terms of costs per unit of health benefit achieved [81]. Whilst cost-effectiveness analysis is a well-established method, it was not a plausible option to use in this study as the use of a control group would prove problematic; the most viable approach would involve comparisons of the outcomes of hospice patients and hospital patients. Given the position of the NHS as a hospice stakeholder, such comparisons would not be feasible.

Social Return on Investment (SROI) analysis is a form of cost–benefit analysis that adopts a triple bottom line approach [85] to account for the social value generated by each hospice site. Historically, SROI analysis, which has its roots in welfarism [3], has been heavily utilised within a range of third sector organisations [86] [87] but its use remains limited within the health and social care field. Given that the SROI methodology complies with the National Institute for Health and Care Excellence's (NICE) public health guidelines and cost–benefit analysis has been approved as an appropriate analytical tool by NICE [88], SROI analysis presents a suitable approach for this evaluation.

Table 2:2: Description of the four types of economic evaluation

Cost-minimisation analysis	Cost-minimisation analysis is an evaluative methodology which looks to assess the lowest cost input having first evidenced that the outcomes for competing alternatives are equivalent [89].
Cost-effectiveness analysis	Cost-effectiveness analysis combines data on the costs and outcomes (effects) of two or more interventions in order to identify courses of action that yield the greatest results for the least resources [90].
Cost-utility analysis	Cost-utility analysis is a form of cost-effectiveness analysis where the outcomes are measured in 'utility based' units, most commonly the quality adjusted life year (QALY) [91]. A QALY is a measure of utility combining both the quality and the quantity of the life lived [92].
Cost-benefit analysis	Allowing for cross-programme comparisons, cost-benefit analysis, which is underpinned by welfarism, is an evaluative tool whereby all costs and consequences of an intervention are compared in monetary terms. The benefits can be valued by their market price or by the price that individuals are willing to pay [93].

Epistemology

SROI analysis has been touted as a crucial development in the capture of third sector outcomes [94]; however, this approach is not without its criticisms as it is argued to lack a cohesive theoretical and epistemological perspective [95]. As an outcome-focused methodology, SROI analysis follows, in part, positivist principles *(Table 2.3)* [96] although positivism states that science should remain value-neutral [96], a notion which does not comply with SROI methodology. The substantial involvement of stakeholders in the SROI process is aligned with realism/social constructivism on the epistemological spectrum *(Figure 2.1)*. Furthermore, whilst the methodological approach to quantifying both costs and outcomes in monetary values aligns with cost-benefit analysis - a welfarist approach- the SROI methodology rejects the notion that decisions are based on the option that has the greatest social ranking in terms of net monetary value [97]. Instead, in alignment with an extra-welfarist approach [98], equity and the distribution of value is generated across stakeholder groups.

Table 2:3: Five principles of positivism [99]

Positivist principles
Research should aim to explain and predict.
Research should be proved only by empirical means and via human senses.
Inductive reasoning should be used to develop statements (hypotheses) which will be tested during the research process.
Science is not the same as common sense. Researchers should not allow common sense to bias the research findings.
Science should be judged by logic and remain value-neutral.

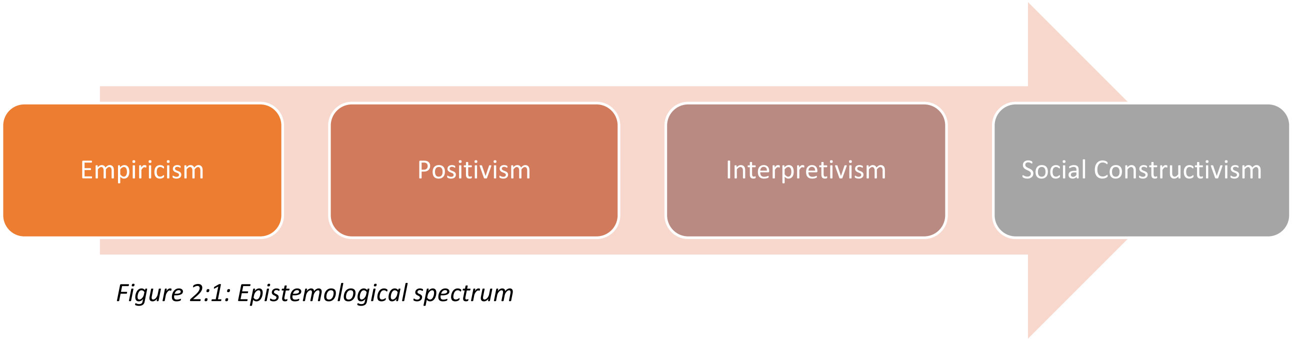


Figure 2:1: Epistemological spectrum

SROI study design

Two types of SROI analyses exist, forecast and evaluative analysis. Forecast analysis uses a range of data sources such as literature, stakeholder opinions, and results from evaluations of other initiatives to predict the amount of social value that will be generated should the intended outcomes materialise [100]. As a result, forecast analysis is useful during the initial planning stages of an initiative when outcome data is not yet available [101]. Like summative or impact evaluation, evaluative SROI analysis seeks to use primary data collected by a researcher and supplemented by routinely collected data held by the initiative organisers/funders to directly assess effectiveness and the value generated for stakeholders impacted by the initiative under evaluation [101]. This thesis uses evaluative SROI analysis to explore the social return on investment of hospice units in North Wales.

The principles of SROI

There are seven principles which underpin the conduct of SROI evaluations [101]. These principles are outlined in *Table 2.4* and their application within this PhD thesis is noted. Through the adherence of these principles, the rigour of the analysis is enhanced.

Table 2:4: Description of the SROI principles

Principle	Meaning	Application in the PhD
Involve stakeholders	Engaging with key stakeholders is vital for any SROI analysis. The identification of how changes are created is achieved through dialogue with key stakeholders	- Advisory group meetings to determine scope *(Chapter 1)* - Qualitative research with patients, family-caregivers, hospice personnel, and volunteers
Understand what changes	Understand what changes. Develop a story of change and gather evidence of positive and negative change.	- Systematic review to determine what patients and family-caregivers value from hospice care - Qualitative research with patients and family-caregivers - Embedding the outcome tool, collecting, and analysing the data
Value the things that matter	Apply financial proxies to derive monetary values for the changes that matter to stakeholders, which	- Step-down costing of inputs - Searching cost databases (e.g. PSSRU, British Household Panel

	are often not included in accounting and decision-making due to their intangible nature	Survey, GVE) for financial proxies for outcomes
Only include what is material	Use evidence to show what important changes are created as a result of activities. Deciding which stakeholders and outcomes have the most importance and significance	- Qualitative research with patients, family-caregivers, hospice personnel and volunteers. - Embedding, collecting and analysing outcome tool
Do not over-claim	Make comparisons of performance and impact using appropriate benchmarks, targets, and external standards to understand the particular impact of an activity	- Qualitative research with patients and family-caregivers - Systematic review - Desk-top research and review of similar projects, stakeholders, outcomes; checking what similar services are in the local area that could have contributed to the outcome - Duration of outcomes for hospice patients are capped and financial proxies pro-rated to reflect the patients average length of life
Be transparent	Demonstrate the basis of any information that could affect accuracy and honesty of findings. Explain all the evidence and assumptions clearly	- Reporting progress with thesis
Verify the result	Ensure independent verification of the account	- Advisory group meetings, presentation of findings to academic audiences, KESS administrators, and the hospice consortium, feedback on draft thesis chapters, peer review of published research

Stages of SROI methodology

Conforming to the stages set out in ‘A Guide to Social Return on Investment’ [101], the SROI analysis reported in this thesis consisted of six stages: 1) establish scope and identify stakeholders, 2) map outcomes, 3) evidence scope, 4) value outcomes, 5) calculate the SROI, and 6) report the findings (*Figure 2.2)* [101].

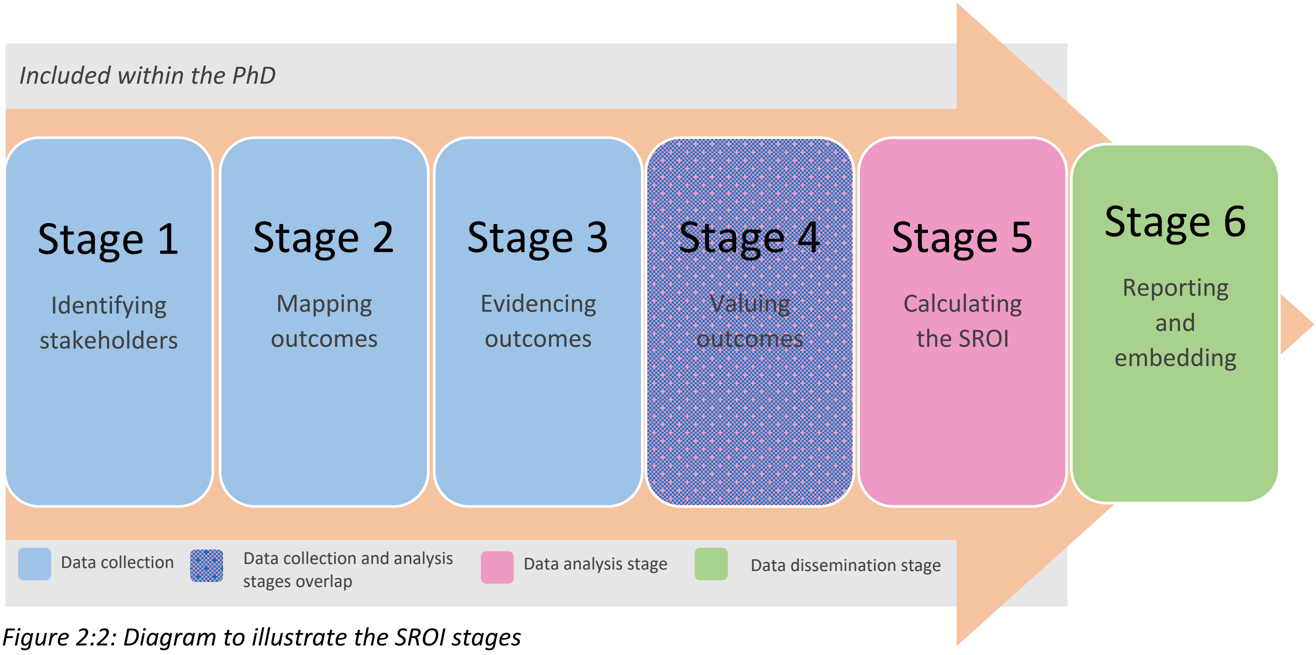


Figure 2:2: Diagram to illustrate the SROI stages

Stage 1*: Establishing scope and identifying stakeholders*

The hospice consortium has a vested interest in calculating its social return on investment to convey its impact to funders. The first stage of the SROI analysis involved setting clear boundaries regarding what the SROI analysis would encompass, as well as identifying which stakeholders would be involved and how. Stakeholders are defined as people or organisations that experience a change as a result of the service in question. The decision to include patients and their family-caregivers as the focus of this analysis was made by consensus with the hospice CEOs and key staff. This process was further explained in *Chapter 1*. Due to time constraints, a collaborative decision was made to focus on three core hospice services: 1) the inpatient unit, 2) the day therapy unit, and 3) the at home service. The operationalisation of the process of establishing the scope and identifying the key stakeholders is described in *Chapter* 7.

Stage 2: *Mapping outcomes*

The second stage of the SROI methodology sets out the story of how change was created. This process involves the development of an impact map *(Appendices 365-370)* which displays the relationship between the inputs, outputs, and outcomes [101]. In this thesis, the initial hospice investment was calculated in *Chapter 3* and the resultant outcomes were informed through a mixed-studies systematic review (*Chapter 4)* and a primary qualitative research study (*Chapter 5).* The mixed-studies systematic literature review was used to ascertain the value placed on adult hospice services. Subsequently, the findings from the review were fed into the primary qualitative research study, where they were further developed and tested with the stakeholders using semi-structured interviews and/or focus groups. In some instances, outcomes may be achieved through a chain of events, which can result in double counting the outcomes. This can be avoided by only including the final outcome in the chain (*Figure 2.3).*

Figure 2:3: Example chain of events

Stage 3: *Evidencing outcomes*

For the purposes of this SROI analysis, the third stage of the process used the Integrated Outcome Palliative Care Scale (IPOS) [102] to capture changes over time in the outcomes identified by stakeholders *(Chapter 6).* The responses from the patient self-reported version and the staff proxy-reported version of the 17-item tool were utilised in this SROI analysis. This stage of the analysis relied on routinely collected questionnaire data (*Chapter 6*); however, in the absence of a suitable outcome indicator for specific items, data from qualitative interviews *(Chapter 5)* was utilised to address this evidence gap, an approach which has been used in other SROI studies [103].

Stage 4: *Valuing outcomes and establishing impact*

Appropriate financial proxies (approximations) were used to apply a monetary value to the outcomes experienced by stakeholders. The process of choosing proxies is subjective, which is a heavily cited limitation of the SROI methodology [104]; although, in this thesis, the impact was minimised by ensuring transparency when reporting the sources of all financial proxies used. Whilst financial proxies can be obtained through various mediums, for example stated preference techniques such as willingness to pay [1] or revealed preference techniques such as hedonic pricing, the sensitive nature of palliative research dictated the approach used in this thesis. Instead the well-being valuation approach was employed whereby large databanks of social value proxies were utilised which helped to minimise patient burden. Social value databanks are created using consistent methodology from sources such as national surveys and the UK census [105].

Establishing impact (attribution, deadweight, displacement, drop-off)

The fourth stage of this process involves the calculation of the impact associated with the hospice services. Therefore as part of the analysis, assumptions are required to ensure that only the benefits directly attributable to the service are counted. The following considerations are required to calculate the impact and minimise the risk of over-claiming; deadweight, displacement, attribution, and attrition [101]. Deadweight is the proportion of change that stakeholders would have experienced over time, irrespective of their admission into the hospice. For palliative patients, this could be a decline in physical health which would be expected over time. This assumption is based on literature which describes how hospice patients' functional status generally declines after they are referred to a hospice [106]. Displacement is the proportion of potential change that is being displaced, for example attending hospice services may reduce the time that a patient is able to spend doing other activities which improve their quality of life, such as seeing family and friends [40]. This does not apply to every SROI analysis. Attribution is the proportion of the observed change that is due to the services under evaluation [40]. In SROI analysis, drop-off refers to the deterioration of an outcome after the first year [107]. For outcomes that last for more than one year, the influence of the organisation or service under evaluation on that outcome is weakened.

Stage 5: *Calculating the SROI*

The fifth stage reports the calculations made to estimate the social value generated by the service. This involved comparing the value of the investments in the hospice services to the value of the benefits created in a ratio *(Chapter 7).* The formula used is as follows:

SROI = net present value of benefits / value of inputs

Whilst the resultant figure is the social value achieved per £1 of investment, it should be noted that the utility of SROI analysis is not about the final figure but the underlying story of change. This story will assist in making the hospices more sustainable by increasing the hospice consortium's understanding of what matters to patients and their families and how changes in these outcomes are valued. To test the robustness of the results, multiple one-way sensitivity analyses were undertaken to test the assumptions made during the data collection and analyses stages. The percentages for deadweight, attribution, displacement, and drop-off were also adjusted within appropriate ranges to assess their impact on the base-case scenario.

Stage 6: *Reporting the findings*

In line with the KESS studentship, there is a focus on knowledge exchange and thus the findings on the social value generated by hospices have been written up as part of this PhD thesis and within an executive summary document which will be sent to the hospice board.

Reporting guidelines

The SROI assurance standard checklist was used to guide the reporting of this study *(Appendix 6.3).*

Quality appraisal

This SROI analysis was assessed for methodological strengths and weaknesses using Krlev et als [108] 12-point quality assessment framework *(Chapter 8).*

Chapter 3 : The economic cost of adult hospice palliative care services in North Wales: A step-down costing approach

ABSTRACT

INTRODUCTION

Hospice funding is heavily reliant on charitable donations as well as on statutory funding; however, the latter is becoming increasingly constrained, resulting in financial uncertainty. It is therefore necessary for hospices to demonstrate that they represent good value for money and to define an effective resource allocation model. Although the economic efficiency of UK palliative care has been examined to some extent, there is an absence of Wales-specific literature. Furthermore, the existing studies fail to assess the cost implications of alternative models of care delivery. This study will therefore broaden the existing evidence base by determining the per patient unit costs associated with (1) day therapy visits, (2) inpatient bed days and (3) at home visits for four North Wales hospices.

METHODS

A partial economic analysis of four hospices across North Wales was conducted. Annual cost data (January–December 2016) was collected from each hospice using standardised extraction forms and a step-down costing methodology was applied to calculate the estimated (a) cost per day therapy visit, (b) cost per inpatient bed day, and (c) cost per at home visit. Due to differences in operating capacities between sites, a univariate sensitivity analysis was utilised, standardising capacity rates at 80% for the inpatient and day therapy units.

RESULTS

The total number of bed days in the inpatient units across Sites A, B, and C was 8,384, and 4,112 home visits were completed by Site D. Across all four sites, 4,151 day therapy visits were facilitated. The mean total cost of palliative care provision (Sites A, B, and C) was £1,512,841, with a significant proportion of this spent on human resources (73%). Due to structural differences in care models, the mean total cost of palliative care at Site D was calculated independently and equated to £1,034,927.

Within the inpatient unit, the average cost per patient admission was £446 (Site A: £542; Site B: £400; Site C: £442). The unit cost of the at home service (Site D) was estimated as £190 per patient.

The average cost per patient visit to the day therapy unit was £292 (Site A: £191; Site B: £679; Site C: £160). The unit cost for a day therapy visit at Site D was £178. As the cost data provided for Site D consisted of estimates, the data was treated independently and was not used for comparative purposes.

Based on an occupancy rate of 80%, the mean unit cost for the inpatient unit was £406 and it was £179 for the day therapy unit. Excluding volunteer costs resulted in an 8% decrease in the unit costs of day therapy unit and a 2% decrease in the inpatient unit costs.

CONCLUSION

This study contributes to the limited literature base regarding the costs of palliative care in North Wales, but data limitations mean that further research would be beneficial. By highlighting variances in operating costs between sites, the focus has been placed on the significance of hospice occupancy rates and the associated financial impact. The mean costs of providing palliative care in both the day therapy and the inpatient units will be extracted for contribution to the SROI analysis.

Chapter contribution to the SROI analysis

This chapter presents a partial economic analysis, which contributes to the Social Return on Investment (SROI) methodology by measuring the financial and non-financial contributions (inputs) invested by stakeholders to make the delivery of certain services possible. Information on all resources associated with delivery of day therapy, inpatient, and at home services were collected from each hospice site and used in conjunction with utilisation data to obtain a greater understanding of resource consumption. This study will inform the mapping outcomes stage of the SROI analysis *(Figure 3.1).*

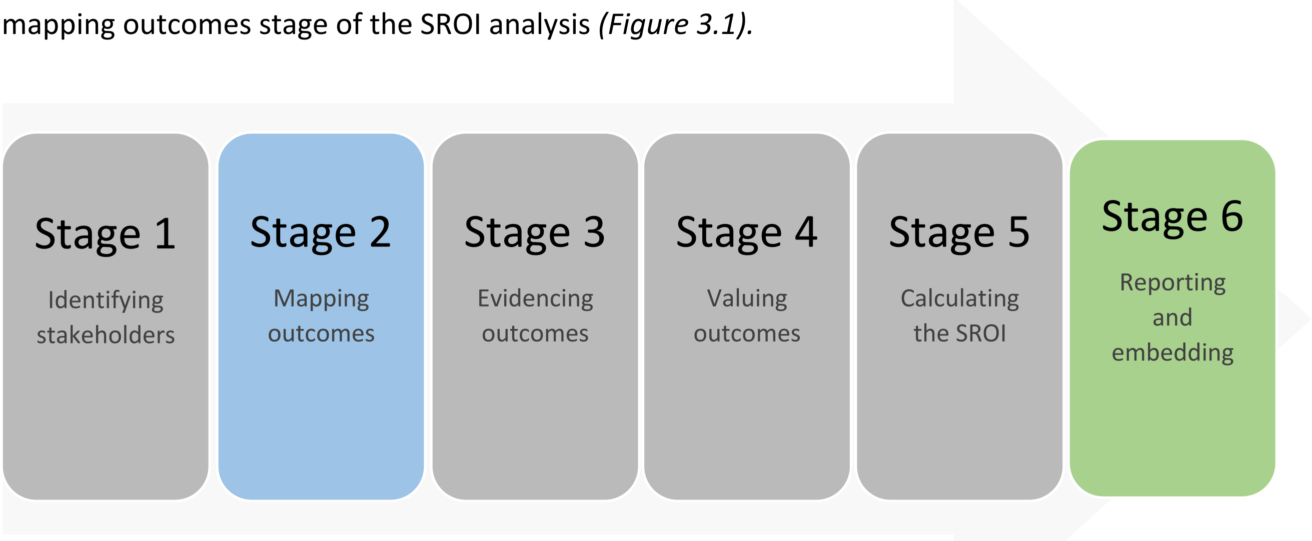


Figure 3:1: Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

Palliative care services vary throughout Wales and are currently provided across three principal settings: hospital, community/home based, and hospice facilities. Community and hospice-based palliative care services are developing in an ad hoc way, often responding to local demand and spearheaded by the voluntary sector [109]. Funding, however, continues to be a great concern within the third sector and remains inconsistent due to it being heavily reliant on the availability of resources in certain localities via charitable donations, along with statutory contributions from the Welsh Government. Both statutory and voluntary funding streams, however, are becoming increasingly constrained and uncertain [110]. These fiscal uncertainties and the lack of a clearly defined funding model have resulted in increased pressures, causing hospices to re-evaluate how their services are run. Over recent years, networks have been developing which bring together administrative, organisational, clinical, and practical facets of palliative care to ensure continuity between all partners [111]. Within the UK, the Leeds Palliative Care Network [112] and Together for

Short Lives [113] network are but two initiatives which seek to achieve such aims. Several studies have suggested that this contributes to integrated palliative care, in terms of both quality of life and costs [114]. Although networks continue to thrive, competition remains, as third sector organisations compete for the same funding [115]. When coupled with a lack of sustainability, this has the potential to place significant pressures on an already overstretched NHS service, as charitable hospice facilities may be forced to reduce their level of support in the community. Due to this increasingly competitive economic climate, it is essential for hospices to demonstrate that they represent good value for money, especially when competing for funding from the NHS and other potential investors. To support more informed resource allocation decisions, the identification and measurement of resources and their associated costs are essential. By developing an understanding of resource use, opportunities for effective resource control can be created. A working paper on the Commission into the Future of Hospice care [116] elucidated the hardships that hospices have faced in their attempt to produce evidence exploring their cost-effectiveness. Health economic research is essential in the drive for evidence-based provision of palliative care which offers value for money; however, this has been slow to develop in the field of palliative care [117]. A 2011 report from the UK Department of Health identified “a stunning lack of good data surrounding the costs for palliative care”[118], but with the ‘End of Life Care: Annual Statement of Progress’ report [119] calling for increased research, a growing evidence base may be on the horizon. There is some evidence to suggest that palliative care in the UK context is economically efficient (e.g. Hatziandreu and Archontakis [120]), but to the best of my knowledge there is currently no available evidence exploring the costs associated with the provision of hospice services in Wales specifically, and only a small proportion of studies have sought to assess the cost implications of alternative models of care delivery.

Aims and objectives

This study aimed to identify the financial investment associated with the delivery of services included within the boundaries of the Social Return on Investment (SROI) analysis. Accounting for both financial and non-financial inputs, the per patient unit costs associated with (1) a day therapy visit, (2) an inpatient bed day, and (3) an at home visit were determined and, in doing so, the cost-saving benefits of hospice palliative care were explored. This chapter sought to highlight the correlation between descriptive hospice characteristics and the obtained unit costs.

Methods

Setting and study population

Study hospices

The four hospice sites included in this research focus solely on adult end of life care and are representative of third sector palliative care settings across North Wales. All of the hospices are similar in the way they operate; however, some variances do exist *(Table 3.1),* ranging from minor variances such as the capacity of the hospice and bed occupancy rates to substantial differences in their models of care. This is demonstrated by the nurse-led model of care employed by Site A in which the service is primarily provided and overseen by a registered nursing team with extended nursing roles. The most substantial variance, however, is the way in which the sites are funded, as study Sites A, B, and C rely largely on charitable donations but also receive a contribution of approximately 20% from the Welsh Government. Site D, however, operates differently as it is involved in a partnership with the North West Wales NHS Trust, resulting in pooled resources between the charity and this Trust.

Table 3:1: The availability of services across hospices at the time of research

Hospice Characteristics	Site A*	Site B	Site C	Site D
Available services				
Inpatient Unit	✓	✓	✓	✗
Day Therapy	✓	✓	✓	✓
At Home Service	✗	✗	✗	✓
*Operates a nurse-led model of care.				

Design

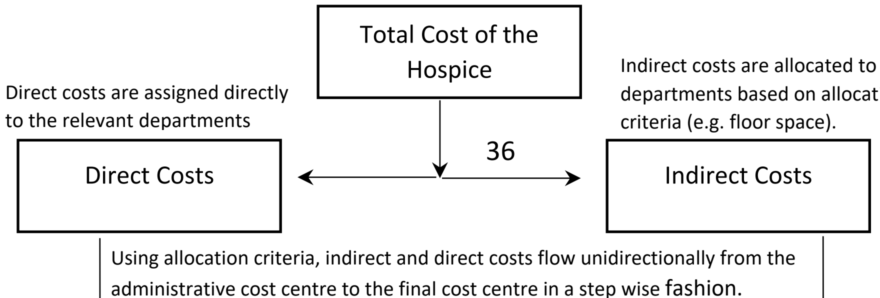
A partial economic analysis was performed as part of a multi-site comparative study of four hospices across North Wales. To help capture site-level differences, centre-specific information for both the unit costs and the resource volumes were accessed retrospectively. The estimated (a) cost per day therapy visit, (b) cost per inpatient bed day and (c) cost per at home visit were calculated using the step-down costing methodology [121]. Although the estimation of unit costs is context specific and reliant on available data, this study utilises the step down cost method, a six stage process which provides both a simple and practical approach to costing health care facilities. By identifying the resources required to operate a health care facility, the step down costing then assigns them to specific cost centres based on allocation criteria such as floor space, occupied bed days etc. Subsequently, these costs are filtered down until only the final cost centres remain.

Data collection

Using standardised extraction forms, annual data from each hospice (January–December 2016) was collected in cooperation with designated hospice personnel. The principal sources of data were obtained from central accounting and patient administrative system databases (CANASC), staff and volunteer rotas, and patient attendance records. Comprehensive information (anonymised) on personnel salaries per month, coupled with the hours worked, were obtained from the hospice payroll, and from here the working minutes were used to calculate full-time equivalents (FTE). Figures for annual expenditures such as drugs, utilities, laundry, maintenance, and catering provisions were collected by the finance departments directly from the central accounting system of each hospice. Anonymised patient-level data from each study site was accessed retrospectively from the administrative databases and paper registers to obtain data on age, sex, date of admission, date of death/discharge, diagnosis, and the number of admissions. Age categories were generated based on quintiles chosen according to the observed distribution of age in the data (21–24 years, 25–64 years, 65–74 years, 75–84, and ≥ 85 years), and entries within and across the paper registers and electronic databases were linked using unique patient identifiers.

Costing methodology

The unit cost of two patient-related services (day therapy and inpatient unit) were calculated using a top-down costing methodology known as step-down accounting [121]. This approach was used in lieu of the micro-costing methodology, as the level of detail required for a micro-costing approach was not feasible for this study due to limited resources. The costs associated with running the at home service and the day therapy services at Site D were excluded from the step-down costing methodology as Site D was unable to provide accurate costing data. Consequently, based on information obtained from the chief executive at Site D, best estimates were provided and are displayed in *Table 3.13*. The step-down allocation method is an approach to costing whereby all resources utilised in the operation of the inpatient and day therapy units were identified and grouped and their total enumerated. From here, the costs associated with each grouped resource were allotted to the appropriate departments, each of which falls under one of the following cost centres: administration (administration, building), supportive (pharmacy, catering, housekeeping, travel, and transport) and final patient services (day therapy, inpatient) cost centres. All costs which could be attributed directly to a cost centre were classified as direct costs, whereas costs which could not be attributed to a single cost centre were known as indirect costs, which needed appropriate cost drivers to disaggregate. By utilising a sequential process, this methodology assumes a unidirectional flow of resources which filters the costs through the departments until it reaches the inpatient and day therapy units in the final cost centre. Owing to the lack of detailed information held electronically at each of the research sites, the final unit costs were largely dictated by the level of aggregation of both the cost and the utilisation data, resulting in an estimated average cost per day therapy visit/bed day (including an overhead allocation) per facility. The study sites (A, B, and C) provided cost data for a 12-month period, which enabled any seasonal variances to be detected and costing was completed from the service provider's perspective, meaning that costs were only assessed if incurred by the service. All patient-related and other societal costs were excluded, as were costs related to fundraising, lottery, retail, and services not directly associated with the inpatient and day therapy units. The step-down allocation method is operationalised in *Figure 3.2.*



Step 1: Define the final services or cost objects to be costed

The purpose of the analysis was to filter the total hospice expense to the two final departments of interest (i.e. the inpatient and day therapy units).

Step 2: Define cost centres

The step-down approach to costing uses a multi-level cost allocation structure which incorporated four tiers of cost centres (*Table 3.2*):

- *Human Resources:* Human resources such as salaries and uniforms were routed through each of the cost centres listed below.
- *Administrative Cost Centre:* The second-tier cost centre, known as the administrative cost centre, included all departments and resources associated with the overall running of the hospice.
- *Supportive Cost Centre:* The third-tier cost centre encompassed the departments which provide support to the final cost centre. The cost of these departments varied proportionately in line with variations in patient volume.
- *Final Cost Centres:* The final-tier cost centres included the departments of interest which provided care directly to patients.

Table 3:2: The division of departments into cost centres

Cost Centre	**Resource Group**
Human Resources	Personnel salaries Volunteer time Uniforms
Administrative	Administrative costs Building costs Housekeeping Transport
Supportive	Pharmacy Catering
Final	Inpatient Day therapy

Step 3: Identify the full cost of each type of input/line item

In the third step, a comprehensive list of resources expended by each hospice in the delivery of services was produced, regardless of who paid for or funded the expense. The costs were extracted directly from hospices' central accounting systems. Two of the study sites could not supply the cost of medications as it was provided by the local health board. From here, further categorisation of the hospices' expenditure was achieved by grouping costs and assigning each resource to one of the following categories: human resources, administrative costs, transport costs, catering, housekeeping costs, or pharmacy *(Table 3.3),* but several resources required a more detailed explanation.

Table 3:3: Description of resources

Resource group	Description of resources

<table>
<tr><td rowspan="7">Human resources</td><td colspan="3">**Personnel salaries**
Personnel costs were based on the payroll of the respective hospice and accounted for irregular working hours, sick cover, and fringe benefits such as holiday and sick pay, NHS pension contributions, and National Insurance received as part of their employment. Interest lay not only in medical staff who worked in the two final cost centres (inpatient and day therapy units), but also in support staff such as housekeepers and kitchen personnel. Since the allocation of staffing costs can be allocated across all cost centres, the assignment of personnel costs warrants special attention and will therefore be applied directly to the final cost centres.</td></tr>
<tr><td>**Site A**</td><td>**Site B**</td><td>**Site C**</td></tr>
<tr><td>£999,097</td><td>£1,245,253</td><td>£1,046,575</td></tr>
<tr><td colspan="3">**Volunteer time**
To obtain a full, accurate picture, economic costs were estimated for all resources used to produce the outputs – including those for which there were no financial transactions, such as volunteer time. To capture the value of volunteer time, a financial proxy was utilised with one-month rotas provided by each hospice to determine this. The total hours worked for each hospice were calculated separately and multiplied by 52 weeks to provide an estimate of the hours worked in a one-year period. A financial value was assigned based on the cost of replacing volunteers with non-voluntary equivalents. Volunteers bring unique skills and approaches to working with patients and their families. Those working in non-vocational roles were assigned the 2016 national minimum wage for people age 25 and over (£7.20), whilst NHS Bands and online recruitment websites such as www.indeed.co.uk were used for vocational roles. Examples of vocational roles include chaplains and hairdressers whereas non-vocational roles encompassed administrative staff and other roles akin to a befriending service. For the cost of a specialised chaplain, NHS band 7 at £16.05 an hour pay was applied. Using job advertisements on indeed.com, the hourly wage of £9.50 [122] was applied to the volunteer hairdressers.</td></tr>
<tr><td>**Site A**</td><td>**Site B**</td><td>**Site C**</td></tr>
<tr><td>£61,452</td><td>£50,328</td><td>£34,777</td></tr>
<tr><td colspan="3">**Uniforms**
The cost of uniforms for both voluntary and non-voluntary staff was provided as a single aggregated total for 2016. It was surmised that all uniforms purchased were distributed during the year and that uniforms are replaced annually.</td></tr>
</table>

<table>
<tr><td rowspan="2"></td><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£569</td><td>£2,944</td><td>£1,739</td></tr>
<tr><td rowspan="6">Administrative costs</td><td colspan="3">Administrative costs
Administrative costs include the costs associated with office costs (stationary, phone, postage, etc.), management salaries, general expenses (e.g. flowers, sundry items) and audit fees.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£62,203</td><td>£394,103</td><td>£66,265</td></tr>
<tr><td colspan="3">Building costs
Costs corresponding to property management, encompass a wide range of expenditures, such as utilities (e.g. gas, water, electric, and waste management), building maintenance, and equipment purchases/hire. The cost of purchasing general equipment, medical equipment, and furniture such as tables, beds, and chairs was included under this heading. As the hospices were unable to provide a full inventory of fixed assets, it was not possible to calculate depreciation.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£101,385</td><td>£146,553</td><td>£126,347</td></tr>
<tr><td rowspan="3">Housekeeping</td><td colspan="3">Cleaning supplies and laundry
A large proportion of the housekeeping department's costs related to the laundry service it operated and the cleaning supplies it consumed.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£1,758</td><td>£13,612</td><td>£6,756</td></tr>
<tr><td rowspan="3">Transport</td><td colspan="3">Transport-related costs
These related to the transporting of patients to and from the day therapy and inpatient units. Factors such as the cost of fuel, tyres, servicing fees, insurance, repairs, and maintenance were also considered.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£12,835</td><td>£28,922</td><td>£3,052</td></tr>
<tr><td>Pharmacy</td><td colspan="3">Medicines and medical supplies
It was necessary to consider the cost of medical supplies such as aromatherapy oils and medications used in patient treatments. Difficulties arose when trying to attribute the exact resource use per patient, as exact supplies issued to patients were not computerised or stored in a way that could be easily accessed. For ease, each hospice</td></tr>
</table>

<table>
<tr><td rowspan="3"></td><td colspan="3">provided their total annual cost associated with medical supplies for 2016. As the cost of drugs reflects the expenditure made in the year and not the cost of drugs issued, there can be substantial differences in these figures due to factors such as bulk orders made near the end of the year which are not issued to patients during the year of interest and stock losses. An assumption was made that all medical supplies and medications purchased were used within this year.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£19,185</td><td>---</td><td>---</td></tr>
<tr><td rowspan="3">Catering costs</td><td colspan="3">Catering provisions
Costs associated with catering related to supplies and utensils that had to be purchased.</td></tr>
<tr><td>Site A</td><td>Site B</td><td>Site C</td></tr>
<tr><td>£23,935</td><td>£66,662</td><td>£22,220</td></tr>
</table>

Step 4: Assign inputs to cost centres

Once the full cost of each resource was calculated, many of them could be apportioned directly under one of the three cost centres (administrative, supportive, and final). The costs associated with catering, pharmacy, transport, and administration could be assigned directly to the appropriate cost centre; however, the same could not be assumed for human resources. It was decided that all costs associated with human resources would be allocated directly to the final cost centres. Rotas allowed for many hospice personnel costs to be allocated to the relevant final cost centre, but they did not account for personnel who worked across multiple departments, and therefore the remaining personnel were assigned to either the inpatient or the day therapy unit through the use of suitable allocation criteria. Allocation criteria are a set of rules devised to logically apportion costs to specific cost centres. The allocation criteria chosen for this study were based on personal knowledge of the study sites coupled with evidence from literature to determine the most suitable approach *(Table 3.4).* The best allocation criteria to use for determining the distribution of salaries of multi-departmental personnel were twofold: 1) the estimated percentage of time devoted to either the inpatient or the day therapy unit and 2) the proportion of inpatient bed days and day therapy equivalents. As the information provided for uniforms was not department-specific and instead was given as an annual total, it was impossible to assign it to a specific cost centre. The cost of uniforms, therefore, was determined using full-time equivalents (FTE) – a concept used to transform the hours worked by several part-time employees into the typical hours worked by a full-time employee.

Table 3:4: Allocation criteria used to assign costs directly to the final cost centres

Cost Centre	Allocation Criteria and Calculation	Source
Personnel costs	Hospice personnel were approached and asked to estimate the time spent in each cost centre *(Table 3.6).*	[123]
	Exceptions were catering, pharmacy and housekeeping cost centres as personnel costs were apportioned based on patient inpatient days and day therapy equivalents.	[124]
Uniforms	Cost of uniforms was apportioned across the inpatient and day therapy units using full-time equivalents (FTE) *(Table 3.5).*	[125]

Full-time equivalents (FTE)

To apportion the cost of uniforms between the inpatient unit and the day therapy unit, full-time equivalents (FTE) were used *(Table 3.5),* assuming that a full-time member of staff would work a total of 37 hours a week. The actual hours worked by each staff role over the year were divided by the maximum possible full-time hours worked over the same period to calculate FTEs. From here, the total FTE for every staff role was calculated across the two units and costs were apportioned based on each unit's proportion of the total. The rationale for using FTEs as an allocation criterion is based on the assumption that units with a greater number of employees will utilise a greater proportion of the uniforms.

Table 3:5*:* Combined full-time equivalents across the three study sites

	Site A		**Site B**		**Site C**	
	FTE	%	FTE	%	FTE	%

Inpatient Unit	23	85	40	93	39	93
Day Therapy Unit	4	15	3	7	3	7
Total	**27**	**100**	**43**	**100**	**42**	**100**

Estimated time spent in departments

Personnel at each hospice were approached and asked to apply a percentage to the time spent in each department, which served as the allocation criterion for this resource. Salaries were then pro-rated accordingly (*Table 3.6*). These percentages were further verified by the matron at each of the sites.

The proportion of inpatient bed days and day therapy equivalents

Using personal knowledge regarding the study sites, it was determined that the best criterion to utilise for the apportionment of costs associated with catering and housekeeping personnel was the proportion of inpatient bed days and day therapy equivalents *(Table 3.8*). The costs could then be split based on the volume each unit operated at, and these percentages were further verified by the matron at each study site.

Table 3:6*:* Revised personnel costs based on their estimated time spent across departments

	Site A			**Site B**			**Site C**		
Staff role	Revised cost based on % of time in department (£)		Total Cost (£)	Revised cost based on % of time in department (£)		Total Cost (£)	Revised cost based on % of time in department (£)		Total Cost (£)
	Day Therapy	Inpatient		Day Therapy	Inpatient		Day Therapy	Inpatient	
Advanced Nurse Practitioner	-	-	**-**	**21,737	-	****21,737**	-	34,288	**34,288**
Art Therapists	8,144 (100%)	-	**8,144**	**11,136	-	****11,136**	-	-	**-**
Bereavement Counsellor	5,772 (50%)	5,772 (50%)	**11,544**	-	-	**-**	-	-	**-**
Catering Team***	23,207 (36%)	41,258 (64%)	**64,465**	**10,584 (14%)	**65,019 (86%)	****75,603**	4,203 (7%)	55,827 (93%)	**60,030**
Chaplain	**Volunteer role**			**2,573 (75%)	**858 (25%)	****3,431**	11,025 (75%)	3,675 (25%)	**14,700**
Complementary Therapists	18,975 (100%)	-	**18,975**	-	-	**-**	8,010 (100)	-	**8,010**
Day Therapy Team	18,336 (100%)	-	**18,336**	**16,256 (100%)	-	****16,256**	-	-	**-**
Healthcare Support Worker	-	180,727 (100%)	**180,727**	-	**177,736 (100%)	****177,736**	9,696	133,836	**143,532**
Housekeeping***	5,955 (14%)	34,881 (82%)	**40,836**	**21,166 (28%)	**54,426 (72%)	****72,592**	1,893 (6%)	28,707 (91%)	**30,600**
Doctors (including locum)	-	42,379 (100%)	**42,379**	**10,439 (5%)	**198,341 (95%)	****208,780**	-	111,849 (100%)	**111,849**
Nursing Team (incl. Matron)	-	553,181 (100%)	**553,181**	**85,887 (14%)	**527,595 (86%)	****613,482**	62,013	442,728	**504,741**
Occupational Therapist	7,691 (50%)	7,690 (50%)	**15,381**	**6,401 (35%)	**11,887 (65%)	****18,288**	-	39,278 (100%)	**39,278**
Physiotherapist	15,251 (50%)	14,398 (50%)	**29,649**	**2,916 (50%)	**2,916 (50%)	****5,832**	-	51,388 (100%)	**51,388**
Social Worker	2,580 (20%)	12,900 (80%)	**15,480**	-	**17,380 (100%)	****17,380**	-	48,156 (100%)	**48,156**
Volunteers (Vocational)	-	-	**-**	-	-	**-**	7,371	-	**7,371**
Volunteers (Non-vocational)	**35,802*	**25,650*	**61,452***	**24,192*	**26,136*	****50,328***	13,658	13,748	**27,406**
Uniforms	85 (15%)	484 (85%)	**569**	206 (7%)	2,738 (93%)	**2,944**	122 (7%)	1,617 (93%)	**1,739**
Total	**141,798**	**919,320**	**1,061,118**	**213,493**	**1,085,032**	**1,298,525**	**117,991**	**965,097**	**1,083,088**

**Includes cost for volunteer time* ***Doesn't include NI or pension* ****Costs apportioned using patient volumes*

Step 5: Allocate all costs to the final cost centres

In the fifth step, suitable allocation criteria were employed once more to apportion the costs from the administrative and supportive cost centre to the final cost centre *(Table 3.7).* Personnel salaries had been assigned to the final cost centres in the previous step and were therefore excluded from the calculations. Assumptions were made to help account for those departments deemed to be more resource intensive than others thus to consume a greater portion of the budget. The inpatient unit, for example houses more patients annually and is operational 24 hours a day, 366 days a year (leap year), in contrast to the day therapy unit, which only operates 3–4 days a week, depending on the hospice. Therefore, a weighting based on a range of pre-determined rules was applied when allocating costs to departments deemed to utilise a greater proportion of resources *(Table 3.7).*

Table 3:7: Allocation criteria used to assign indirect and intermediate costs to the final cost centres

Cost Centre	Allocation Criteria and Calculation	Source
	Administrative Cost Centre	
Building costs	Surface area (m^2) with a weighting applied to the inpatient unit.	[126]
Housekeeping	Surface area (m^2) with a weighting applied to the inpatient unit.	[127]
Transport	Transport was allocated directly to the day therapy unit as transport was primarily utilised by day therapy patients.	[126]
	Supportive Cost Centre	
Catering	Cost apportioned according to the proportion of inpatient days and day therapy equivalents.	[124]
Pharmacy	Cost apportioned according to the proportion of inpatient days and day therapy equivalents.	[124]

Inpatient bed days and day therapy equivalents

The allocation of costs for both catering and pharmacy were determined by the number of inpatient bed days and day therapy equivalents respectively, as a proportion of the combined total of inpatient bed days and day therapy visits *(Table 3.8).* The rationale for allocating costs on this basis was based on the supposition that the costs associated with medical supplies, particularly drugs, and food provision will vary depending on patient volume and thus a higher patient volume in a particular unit will equate to higher costs.

Table 3:8: The proportion of inpatient bed days/day therapy visits in the final cost centres

	Site A		**Site B**		**Site C**	
	Inpatient	Day Therapy	Inpatient	Day Therapy	Inpatient	Day Therapy
Number of inpatient days and day therapy equivalents	1,982	1,093	3,809	627	2,603	991
The proportion of inpatient days/day therapy equivalents	64%	36%	86%	14%	72%	28%

Table 3:9: Allocation of the administrative cost centres to the supportive and final cost centres

Site A						
Cost centres	Direct totals from line items (£)	Administration		Building		Total expense of supportive departments
		%	Revised totals £	%	Revised totals £	
Administrative						
Administration	*62,203	100	*62,203			
Building	*101,385 +	10	6,220 =	100	**107,605**	
Supportive						
Housekeeping	*1,758 +	10	6,220 +	1	1,076 =	**9,054**
Transport	*12,835 +	5	3,110 +	0	0 =	15,945
Catering	*23,935 +	10	6,220 +	3	3,228=	33,383
Pharmacy	*19,185 +	15	9,330 +	0	0 =	28,515
Final						
Inpatient	*919,320 +	30	18,661 +	82	88,236 =	1,026,217
Day therapy	*141,798 +	20	12,441 +	14	15,065 =	169,304
Total	1,282,419	100	62,203	100	107,605	1,282,418

[a] *Differences in totals are as a result of rounding*

These expenses are obtained direct from each hospice

Allocation of the supportive cost centres to the final cost centre

	Site A									
Cost centres	*Revised totals (from previous step) (£)*	*Housekeeping*		*Transport*		*Catering*		*Pharmacy*		*Total expense of final departments*
		%	*Revised totals £*	*%*	*Revised totals £*	*%*	*Revised totals £*	*%*	*Revised totals £*	
Administrative-already allocated										
Supportive										
Housekeeping	9,054	100	**9,054**							
Transport	15,945 +	0	0 =	100	**15,945**					
Catering	33,383 +	3	274 +	0	0 =	100	**33,657**			
Pharmacy	28,515 +	0	0 +	0	0 +	0	0 =	100	**28,515**	
Final										
Inpatient	1,026,217 +	82	7,499 +	0	0 +	64	21,540 +	64	18,250 =	**1,073,506**
Day therapy	169,304 +	14	1,280 +	100	15,945 +	36	12,117 +	36	10,265 =	**208,911**
Total	1,282,418	99	9,053	100	15,945	100	33,657	100	28,515	1,282,417

[a] *Differences in totals are as a result of rounding*

Table 3:10: Allocation of the administrative cost centres to the supportive and final cost centres

Site B						
Cost centres	Direct totals from line items (£)	Administration		Building		Total expense of supportive departments
		%	Revised totals £	%	Revised totals £	
Administrative						
Administration	*394,103	100	**394,103**			
Building	*146,553 +	10	39,410 =	100	**185,963**	
Supportive						
Housekeeping	*13,612 +	5	19,705 +	0	0 =	**33,317**
Transport	*28,922 +	5	19,705 +	0	0 =	48,627
Catering	*66,662 +	10	39,410 +	0	0 =	106,072
Pharmacy	*0 +	15	59,115 +	0	0 =	59,115
Final						
Inpatient	*1,085,032 +	35	137,936 +	72	133,893 =	1,356,861
Day therapy	*213,493 +	20	78,821+	28	52,070 =	344,384
Total	1,948,377	100	394,103	100	185,963	1,948,376

[a] *Differences in totals are as a result of rounding*

**These expenses are obtained direct from each hospice*

Allocation of the supportive cost centres to the final cost centre

Site B

Cost centres	Revised totals (from previous step) (£)	Housekeeping		Transport		Catering		Pharmacy		Total expense of final departments
		%	Revised totals £	%	Revised totals £	%	Revised totals £	%	Revised totals £	
Administrative-already allocated										
Supportive										
Housekeeping	33,317	100	**33,317**							
Transport	48,627 +	0	0 =	100	**48,627**					
Catering	106,072 +	0	0 +	0	0 =	100	**106,072**			
Pharmacy	59,115 +	0	0 +	0	0 +	0	0 =	100	**59,115**	
Final										
Inpatient	1,356,861 +	72	23,988 +	0	0 +	86	91,222 +	86	50,839 =	**1,522,910**
Day therapy	344,384 +	28	9,329 +	100	48,627 +	14	14,850 +	14	8,276 =	**425,466**
Total	1,948,376	100	33,317	100	48,627	100	106,072	100	59,115	1,948,376

[a] *Differences in totals are as a result of rounding*

Table 3:11: Allocation of the administrative cost centres to the supportive and final cost centres

Site C						
Cost centres	Direct totals from line items (£)	Administration		Building		Total expense of supportive departments
		%	Revised totals £	%	Revised totals £	
Administrative						
Administration	*66,265	100	**66,265**			
Building	*126,347 +	10	6,627 =	100	**132,974**	
Supportive						
Housekeeping	*6,756 +	10	6,627 +	1	1,330 =	**14,713**
Transport	*3,052 +	5	3,313 +	0	0 =	6,365
Catering	*22,220 +	10	6,627 +	2	2,659 =	31,506
Pharmacy	*0 +	15	9,940 +	0	0 =	9,940
Final						
Inpatient	*965,097 +	30	19,880 +	91	121,006 =	1,105,983
Day therapy	*117,991 +	20	13,253 +	6	7,978 =	139,222
Total	1,307,728	100	66,267	100	132,973	1,307,729

[a] ***Differences in totals are as a result of rounding***

****These expenses are obtained direct from each hospice***

Allocation of the supportive cost centres to the final cost centre

Site C

Cost centres	Revised totals (from previous step) (£)	Housekeeping		Transport		Catering		Pharmacy		Total expense of final departments
		%	Revised totals £	*%*	Revised totals £	*%*	Revised totals £	*%*	Revised totals £	
Administrative-already allocated										
Supportive										
Housekeeping	*14,713*	*100*	**14,713**							
Transport	*6,365 +*	*0*	0 =	100	**6,365**					
Catering	*31,506 +*	*2*	297 +	0	0 =	100	**31,803**			
Pharmacy	*9,940 +*	*0*	0 +	0	0 +	0	=	100	**9,940**	
Final		*0*								
Inpatient	*1,105,983 +*	*91*	13,524 +	0	0 +	72	22,898 +	72	7,157 =	**1,149,562**
Day therapy	*139,222 +*	*6*	892 +	100	6,365 +	28	8,905 +	28	2,783 =	**158,167**
Total	*1,307,729*	*99*	14,713	100	6,365	100	31, 803	100	9,940	1,307,729

[a] Differences in totals are as a result of rounding

Allocation of estimated costs to Site D

Limitations regarding the availability and accessibility of data at Site D prevented the use of the step-down approach. The financial data provided by Site D was based on estimates supplied by the chief executive *(Table 3.12)*; however, the unit costs for both the day therapy and the at home service regarding Site D are standalone findings and cannot be used for comparative purposes so they will be excluded when determining the mean unit costs of the services later.

Table 3:12: Allocation of the costs to the final cost centre at Site D

Site D		
	At Home Service	**Day Therapy**
Item	**Cost**	**Cost**
Hospice personnel*	£731,428	£198,299
Administration	£10,000	£10,000
Catering provisions	£0	£8,320
Laundry and cleaning	£0	£1,040
Transport and travel	£18,000	13,000
Uniforms	£1,200	£800
Waste disposal	£0	£0
Property maintenance	£0	£10,000
Utilities	£0	£7,770
Furniture	£20,000	£5,000
Total	**£780,628**	**£254,299**

**This excludes volunteer costs.*

Step 6: Unit costs of final cost centre outputs

The unit costs of each output were calculated after calculating the total costs for Sites A, B, and C, and subsequent allocation to the final cost centres via the step-down methodology was made. Following this, the total costs of each of the final cost centres were divided by the total number of output units to provide a cost per unit. As the step-down costing methodology was not used for Site D due to insufficient information, the estimates provided by Site D were treated independently. Due to substantive variances in operating capacities across each study site, the unit costs per inpatient bed day and day therapy equivalents were not a true reflection of variation in costs between hospices.

Sensitivity analysis

When data is collected and assumptions are made within an economic evaluation framework, uncertainty naturally arises. The impact of this uncertainty is assessed by undertaking a sensitivity analysis. In this study, univariate sensitivity analyses were utilised which explored the effects of changing a single parameter's value whilst keeping the value of all others unchanged. Firstly, the capacity of the inpatient unit and the day therapy unit was standardised by adjusting capacity rates to 80% capacity. When adjusting capacity, however, the number of beds at each study site, along with the number of available spaces at the day therapy units, remained unadjusted. For adjusted capacities, costs were assumed to fluctuate minimally with patient utilisation (i.e. building and administration costs were not adjusted when determining standardised unit costs). In a recent study, 28% to 38% of costs per attendee were attributed to volunteer contribution [128]. Due to the potential for volunteer time to have a substantial impact on the unit cost of hospice services, a sensitivity analysis was conducted to determine the cost of hospice care inclusive and exclusive of volunteer contribution.

Data analysis

Data was tabulated and calculations were made using Microsoft Excel 2010 and descriptive statistics were used to characterise each hospice, providing basic profiles of patients in terms of their gender, age, diagnosis, and average length of stay.

Reporting

The Consolidated Health Economic Evaluation Reporting Standards checklist (CHEERS) [125] was used to assist with the reporting of economic evaluations. Whilst some of the checklist was not relevant, because only a partial economic analysis was conducted, it allowed the construction of a clearly defined reporting format.

Findings

Basic demographics and healthcare resource utilisation

Inpatient unit and at home service

The demographic characteristics of the patients admitted to an inpatient unit from 1st January to 31st December 2016 along with the hospice resource utilisation data are reported below *(Table 3.13).* During the period of interest, 538 patients (including readmissions) were admitted to one of the three inpatient facilities (Sites A, B, and C), 64% of whom were female. At admission the mean age of patients was 70 years (standard deviation 6). The distribution of patients across the study sites varied substantially. Site B, with 236 admissions, had the highest proportion of inpatient bed days (3,809 [45%]), followed by Site C, with 152 admissions over 2,603 (31%) bed days, and Site A with 150 admissions over 1,982 (24%) bed days. The mean length of stay within was 15 days (minimum 13 days, maximum 17 days).

Calculations for Site D have been presented separately because its home services are not directly comparable to the services of the inpatient unit. In total, there were 952 admissions (including readmissions) for Site D *(Table 3.13)*. Due to the structure of the home service provision of Site D, it was not limited by the restrictions of a bedded unit and was able to provide support for 4,112 home visits.

Table 3:13: Basic characteristics and activity statistics of the inpatient units (2016)

	Site A	**Site B**	**Site C**	Mean (Standard Deviation)	**Site D**
	Inpatient	Inpatient	Inpatient		Home service
Mean age (Years)	73	74	64	70 (6)	75
Female (%)	85 (53%)	123 (75%)	79 (65%)	-	469 (49%)
Male (%)	75 (47%)	42 (25%)	43 (35%)	-	483 (51%)
Cancer diagnosis (%)	109 (73%)	200 (85%)	130 (86%)	-	722 (76%)
Non-cancer diagnosis (%)	41 (27%)	36 (15%)	22 (14%)	-	231 (24%)
Number of beds	8	12	12	11 (2)	-
Annual number of admissions (*including readmissions*)	150	236	152	179 (49)	952
Bed days	1,982	3,809	2,603	2,798 (929)	4,112 (visits)
Bed occupancy rate (%)	68%	87%	59%	-	-
Mean length of stay (days)	13	16	17	15 (2)	4 (visits)
Average life expectancy (days)	-	102.86	-	-	-

Day therapy unit

The palliative day therapy units accommodated 4,151 visits in 2016 (*Table 3.14*), although large variances in admissions across the study sites were observed within this total. The largest proportion of patients attended the day therapy unit at Site D (1,440 visits; 35%). Site A had 1,093 (26%) visits, followed by Site C with 991 (24%) visits and Site B with 627 (15%). A cancer diagnosis was the reason for admission of 71% of the sampled patients. Using the age of patients at admission, the mean age of patients at Site A was 70 years; however, due to absences in the data provided by the other hospice sites, the mean age of patients at each site could not be determined. Most patients who visited the hospice facilities were female (53%). The mean number of visits across the study sites was eight visits (minimum 6, maximum 13).

Table 3:14: Basic characteristics and activity statistics of the day therapy units (2016)

	Site A	**Site B**	**Site C**	Mean (Standard Deviation)	**Site D**
	Day Therapy	Day Therapy	Day Therapy		Day Therapy
Age (mean)	70	-	-	-	-
Female (%)	75 (50%)	66 (61%)	58 (57%)	-	48 (44%)
Male (%)	75 (50%)	42 (39%)	43 (43%)	-	62 (56%)
Cancer diagnosis (%)	94 (63%)	92 (85%)	68 (67%)	-	80 (73%)
Non-cancer diagnosis (%)	56 (37%)	16 (15%)	33 (33%)	-	30 (27%)
Number of day therapy spaces	15	10	15	13 (3)	10
Annual number of patients	150	108	101	120 (27)	110
Number of readmitted patients	-	9	1	-	3
Day therapy visits	1,093	627	991	904 (245)	1,440
Occupancy rate	35%	40%	42%	-	74%
Mean no. visits	7	6	6	6 (1)	13
Average life expectancy (days)	-	290.66	-	-	-

Unit costs of final cost centre outputs

Estimated total cost

The mean total cost of providing care to palliative patients (Sites A, B, and C) in 2016 was £1,512,841, with a range of £1,282,417 (Site A) to £1,948,376 (Site B). Of the overall total cost, the highest proportion was spent on human resources (73%), followed by administration (22%). Costs related to housekeeping (<1%), pharmacy (1%), transport (1%), and catering (3%) contributed to less than 6% of the total health centre costs.

Cost of inpatient hospice bed day (or at home visit)

The average cost per patient admission to an inpatient facility was £446 (*Table 3.15*). Unit costs ranged from £400 at Site B to £542 at Site A. The unit cost of the at home service (Site D) was estimated as £190 per patient (*Table 3.15*). The low occupancy at which Site A operated meant that its average cost per inpatient bed day seemed to be the most resource intensive.

Table 3:15: Inpatient unit cost calculations

	Site A	**Site B**	**Site C**	**Average**	**Site D**
Final Cost Centre	Inpatient	Inpatient	Inpatient	Inpatient	At Home service
Total (£)	£1,073,506	£1,522,910	£1,149,562	£1,248,659	£780,628
Total number of bed days	1,982	3,809	2,603	2,798	4,112
Unit cost per inpatient bed day (£)	£542	£400	£442	£446*	£190

**The average was calculated by dividing the total cost for all three hospices by the total number of patients. If site averages were used, the resultant figure would be less accurate due to the magnification of rounding errors.*

Cost of day therapy visit

The estimated cost attributable to the provision of the day therapy services varied substantially across the study sites *(Table 3.16).* The cost assigned to day therapy services for all sites ranged from £160 at Site C to £679 at Site B, with a mean of £292, whilst the cost of day therapy services overall comprised less than a quarter of the total hospice cost. The substantial variances across hospices could be attributed to the number of visits, as fewer day therapy visits will equate to a higher per patient cost due to the hospices incurring semi-fixed costs such as staffing regardless of the number of patients attending the service. As the costs associated with Site D were based on estimates, these are treated independently and not used for comparative purposes. The unit cost of running the day therapy services at Site D was £178.

Table 3:16: Day therapy unit cost calculations

	Site A	**Site B**	**Site C**	**Average**	**Site D**
Final Cost Centre	Day Therapy	Day Therapy	Day Therapy	Day Therapy	Day Therapy
Total (£)	£208,911	£425,466	£158,167	£264,181	£254,299
Actual number of patient visits	1,093	627	991	904	1,440
Unit cost per day therapy visit (£)	£191	£679	£160	£292*	£178

**The average was calculated by dividing the total cost for all three hospices by the total number of patients. If site averages were used, the resultant figure would be less accurate due to the magnification of rounding errors.*

Sensitivity analyses

There were limitations to the data set that was received and assumptions had to be made, therefore it was appropriate to undertake univariate sensitivity analyses to test how varying the assumptions affected the base case scenario. In the sensitivity analyses, the occupancy rates for each unit were standardised at 80%. This was done because an analysis by Hospice UK revealed that the bed occupancy rate of 110 adult hospice units ranged from 78% to 80% [129]. As Site D does not have a bedded unit, calculating its bed occupancy rate was not possible. At 80% capacity, the cost of the inpatient unit ranged from £326 to £460 *(Table 3.18).* This presented an average of £407, which is not a substantial variance from the average unit cost (£446). For consistency, an 80% occupancy rate was applied to the day therapy unit, which resulted in a range of £84 to £340, whilst the average unit cost was calculated as £169. This reveals a reduction of £123 compared with the average cost presented in *Table 3.16.* The exclusion of volunteer costs was deemed to have had a minimal effect on the average unit costs of hospice care services. Within the day therapy units, there was a decrease of 8% in costs when volunteer costs were excluded and a 2% decrease in costs within the inpatient unit *(Tables 3.17 and 3.18).*

Table 3:17: Inpatient unit sensitivity analysis

Sensitivity Analyses	**Site A**	**Site B**	**Site C**	**Average**	**Site D**
Total inpatient bed days at 80% capacity	2,332	3,502	3,529	3,121	-
Unit cost per inpatient bed day adjusted for 80% capacity (£)	£460	£435	£326	£407	-
Unit cost per inpatient bed day (*excluding volunteer costs*)	£529	£393	£434	£452	-

Table 3:18: Day therapy sensitivity analyses

Sensitivity Analyses	**Site A**	**Site B**	**Site C**	**Average**	**Site D**
Total day therapy visits at 80% capacity	2,496	*1,248*	1,872	1,872	1,600
Unit cost per day therapy visit adjusted for 80% capacity (£)	£84	*£340*	*£84*	*£169*	*£159*
Unit cost per day therapy visit (*excluding volunteer costs*)	£158	£640	*£146*	£315	-

Discussion

This study is the first to estimate the costs of hospice care in Wales and to present an estimated unit cost of palliative care services across four hospice sites. There were substantial variations in how each hospice operationalised their services, in particular, administrative costs and catering. At the time of writing, Site B was arguably the largest hospice site. The least well documented values were for administrative costs. These have the widest margins of error as it was not always possible to verify how these were calculated or what resources were included. Other variances in costs were due to the nurse-led model of care adopted by Site A as their medical model of hospice provision was no longer financially viable [130]. The unit costs were also found to vary greatly, and although this was somewhat expected due to differences in maximum capacity, the variances in utilisation data had one of the greatest influences on the unit cost of each service. Whilst substantial effort was made to ensure that the finances received from each hospice was accurate, it should be noted that there is the possibility that the hospice underreported their finances.

Other variables which impacted the costs of hospice care services were the differences in the replacement value of volunteer time and the staff mix. Only 8% of the total day therapy costs stemmed from volunteer contribution, thus suggesting underutilisation, especially when considering that a recent study exploring the costs of three day therapy units found that replacement value associated with volunteer time was responsible for 30% of the total day therapy costs [128]. Within this study, the inpatient units did not utilise volunteers to the same extent as the day therapy unit as volunteer time only accounted for 2% of the total inpatient bed day costs.

The future sustainability of hospice care has been credited to the use of volunteers [131], however, recent research has established that volunteers required sufficient time and resources to supervise and support [132]. Time banking presents a co-produced model of volunteering whereby volunteers are paid in ‘time credits’ which can be exchanged for a good or service, thus functioning as a mutual aid network [133]. For example, a one hour litter pick is valued the same as one hour of dog-walking. Whilst time banking can be used in hospice care to recognise the value of volunteer contribution and potentially improve the retention and sustainability of hospice care, there is currently little evidence of its effectiveness. In the US, evaluators of a time bank which provided support to elderly social service users, concluded that their existed substantial challenges with recruitment, safeguarding and the organisation of exchanges due to the time and resource intensive nature of the activity [134]. As a result, hospices are currently reliant upon the altruistic nature of volunteers. Notably, research indicates that altruistic attitudes and volunteering makes unique contributions to the maintenance of life satisfaction, and has a positive effect on other well-being outcomes [135].

Notably, it can also be assumed that the consumption of resources such as the complexity and severity of patients admitted, the availability and quality of the data, and the study perspective had an effect on the final unit costs. When examining the individual cost centres, it was found that much of their expenditure could be attributed to human resources, which supports the findings of similar studies [125]. Site A, which transitioned from a medical model of hospice provision in 2009/10 to ensure sustainability [130], had the lowest human resources expenditure (£999,097), which was to be expected due to its nurse-led model of care; however, the difference was marginal. Site B (£1,245,253) and Site C (£1,046,575) both employ full-time doctors, resulting in further outlays. The £246,156 differential between Site A and Site B was much less than expected. The mean cost of providing inpatient care across Sites A, B, and C ranged from £400 to £542 per inpatient bed day, an average of £446 *(Table 3.15).*

At the time of this study, the hospice inpatient sites were operating at a capacity ranging from 59% to 87%. As illustrated in the sensitivity analyses *(Table 3.17)*, the cost of an inpatient bed day was reduced when operating at 80% capacity. However, increased capacity is likely to result in needing additional staff to meet demand, thus increasing the cost. None of the sites, however, calculate their bed occupancy rate, and therefore this information was not readily available to them. There were also substantial variances in costs associated with the day therapy unit at each site. The average annualised cost of delivering day therapy was £292, with a range of £160 to £679. The occupancy rates were extremely low again *(Table 3.13)* for three of the four sites, which raises the question of why these sites struggled to reach maximum capacity. Site D, in contrast, displayed an occupancy rate of 74%, which far exceeds the capacity of the other hospice sites, perhaps due to the absence of an inpatient unit. Often, patients are unwilling to be admitted to a hospice due to the negative stigma surrounding hospice care [136]. As Site D operates within its own facility rather than within a bedded unit, the negative stigma may be dispelled [136].

This could have resulted in the services at Site D becoming a more attractive proposition than those at other units, and location may also have contributed, as Site D is part of the local hospital, which is more visible to the public and is ultimately more accessible.

The results of this study demonstrate that it is important to institute measures to improve the efficiency of the included study sites and to look at ways to further utilise volunteers. Notably, the accuracy of this costing chapter has been substantially affected by the choice of methodology, an approach with limited use within a healthcare setting. The aggregation of hospice cost data therefore had a substantial impact on the choice of methodology, and severely impacted the results of the study. Whilst all assumptions were underpinned by a cost-driver, which is supported in the wider literature, it is acknowledged that the accuracy of the results are likely to be marred.

Strengths and limitations

This study was guided by the step-down costing methodology, which was employed to determine the running costs of three hospice services. The results, however, should be interpreted in the context of the limitations. Firstly, this choice of methodology deviated from the protocol (*Chapter 8)* as the study sites were unable to provide a detailed breakdown of costs. Instead, this study relied on the reliability and accuracy of heavily aggregated financial data. Subsequently, this had a substantial influence on the method used to derive a unit cost. Whilst micro-costing is considered to be the gold standard approach [137], the study sites could not provide the level of detail required for this approach so this option was no longer feasible. The step-down costing methodology, an approach used across a small selection of health-related settings [138, 139], was therefore considered to be the most appropriate option; however, it is heavily reliant on assumptions to allocate costs. Whilst the allocation of costs using cost-drivers grounded in assumptions is an accepted method of resource allocation [140], the final cost allocations are likely to be over or underestimated and thus may not reflect the specific resource use of each unit. Although there is a worked example to illustrate the steps involved in generating a unit cost using the step-down costing approach [140], it is rarely used in published studies, and this has resulted in some confusion [126]. For example, prior to the commencement of this study, the authors of a step-down costing study based in Zambia [126] disclosed that they had overlooked crucial steps in the methodology during the conduct of their study.

It should be noted that capital costs have not been considered in the cost calculations as the lead researcher was unable to determine the value of fixed assets. Site D was unable to meet the minimum data requirement necessary to utilise the step-down costing approach and instead, well-informed estimates provided by the chief executive for both Site D's at home service and day therapy unit were provided. It should also be noted that Site B and Site D merged during this study, which ameliorated the difficulties associated with obtaining correct financial data from Site D. Due to the lack of data, the decision was made to exclude Site D from the mean. To improve on the findings of this chapter, it would be necessary to develop accounting systems that ensure greater transparency.

Notably, a number of assumptions were applied to the data provided for this research study; however, these were supported by the wider literature [126]. To account for disparities in resource intensity, a weighting system was employed. Previous studies have applied an arbitrary weighting system [126], but this study, to aid robustness, applied a weighting system which reflected the longer operating hours of the inpatient unit and represented a novel approach. The reliability of the results is reflected in the alignment of the final cost per bed day (£400-£542) with that of a previous study (£450) which utilised secondary data [141]. A recent study employed a pragmatic before-and-after descriptive cohort which calculated the average day therapy cost as £233 [128].

Conclusion

This study provides basic cost information associated with the cost of running three hospice units and contributes to the limited knowledge of adult palliative care in North Wales. Due to substantial limitations beyond my control, specifically the availability of disaggregated data, further research in this field would be greatly beneficial. *Chapter 8* outlines a future research agenda. The results reveal variances in the utilisation data, the costs of volunteers and overall hospice costs, thus demonstrating the substantial impact these factors have on the unit costs of the hospice services in this study. Whilst it is touted that a nurse-led model of care ensures that the provision of hospice services is fiscally robust and a sustainable option [130], the findings of this study provide some conflicting evidence. Site A employed a nurse-led model of care and had the lowest overall cost; however, its unit costs were heavily impacted by low occupancy rates. To conclude, the mean cost of providing palliative care in both the day therapy (£292) and the inpatient units (£446) will be extracted for contribution to the SROI methodology reported in *Chapter 7.*

Chapter 4 : What do patients and family-caregivers value from hospice care? A systematic mixed-studies review

An edited version of this c*hapter* was published as: Hughes, NM, Noyes, J, Eckley, L & Pritchard, *T* (2019). What do patients and family-caregivers value from hospice care? A systematic mixed-studies review. *BMC Palliative Care*, 18, (1), 18-31.

ABSTRACT

BACKGROUND

It is not known which attributes of care are valued the most by those who experience hospice services. Such knowledge is integral to service development as it facilitates opportunities for continuous improvement of hospice care provision. The objectives of this mixed-studies systematic review were to explore patients' and their family-caregiver views and experiences, to determine what they valued about adult hospice care in the UK.

METHODS

ASSIA, PubMed, CINAHL, and PsycINFO were searched from their inception until March 2017 to identify qualitative, quantitative, and mixed-method studies. Four additional searching techniques supplemented the main search and grey literature was included. A three-stage mixed-studies systematic review was conducted with a sequential exploratory design. Thematic synthesis was done with qualitative data and then a narrative summary of the quantitative data was performed. The qualitative and quantitative syntheses were then juxtaposed within a matrix to produce an overarching synthesis.

FINDINGS

Thirty-four studies highlighted that what patients and family-caregivers valued was generally context specific and stemmed from an amalgamation of hospice service components which both individually and collectively contributed to improvements in quality of life. When the syntheses of qualitative and quantitative studies were viewed in isolation, the value placed on services remained relatively consistent, with some discrepancies evident in service availability. These were commonly associated with geographical variations as well as differences in service models and time frames. Through an overarching synthesis of the qualitative and quantitative evidence, however, notable variations and a more nuanced account of what people valued and why were more prominent, specifically in relation to a lack of social support for family-caregivers, disparate access to essential services, the underrepresentation of patients with a non-cancer diagnosis, and the dissatisfaction with the range of services provided.

CONCLUSIONS

The review findings strengthen the existing evidence base and illuminate the underpinning elements of hospice care most valued by patients and their families. However, because of large disparities in the availability of services, the underrepresentation of non-cancer patients, and the limited research focus on the social needs of family-caregivers, there continue to be considerable gaps that warrant further research.

Chapter contribution to the SROI analysis

The purpose of this chapter is to present a systematic mixed-studies synthesis of qualitative and quantitative studies to establish the current evidence base and understand the value placed on adult hospice services by patients and family-caregivers. The review was designed to build an understanding of the important outcomes of hospice care and helps inform the focus for measurement in the wider Social Return on Investment methodology. The values identified in this review were subsequently used to feed into the qualitative study, where they were further developed and ‘challenged/tested’ with participants during the semi-structured interviews. This study contributes to the mapping outcomes stage of the SROI methodology *(Figure 4.1).*

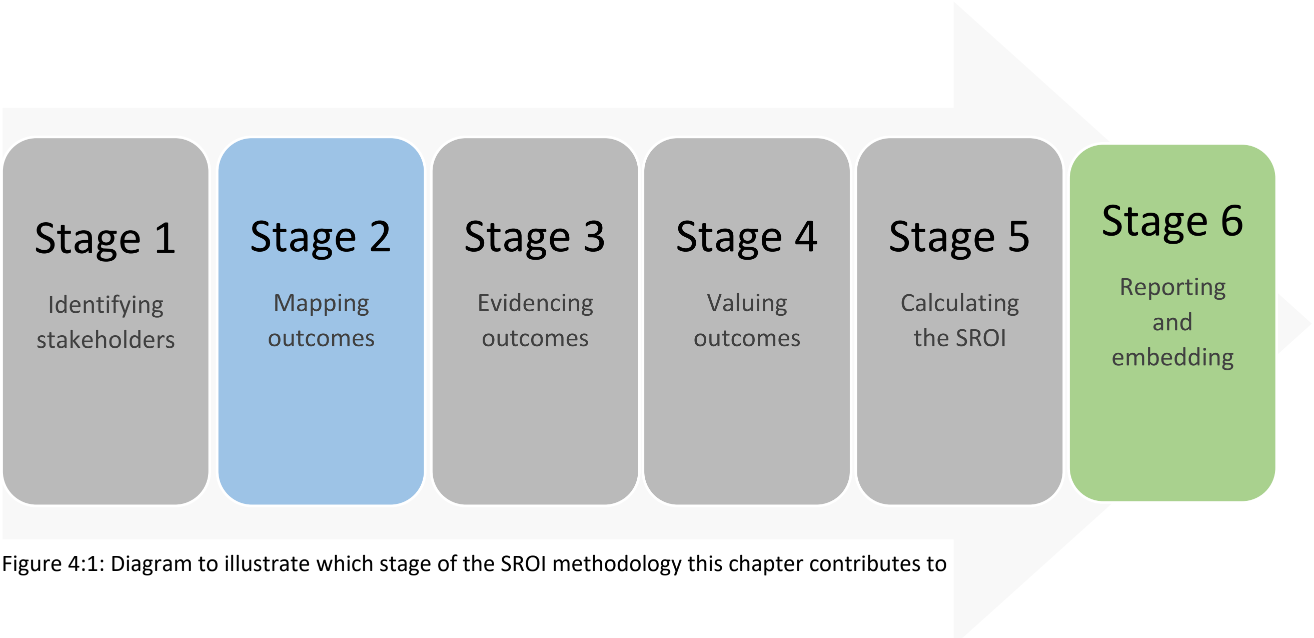


Figure 4:1: Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

With the growing demand for palliative care that is caused by the increasing complexity of chronic illnesses, coupled with limited resources, hospices are under significant financial pressure to continually redesign services. For this reason, along with the temporal nature of the evidence and changes in practice over time, it is important to continually identify patient and family preferences and what they value about the palliative care received. A synthesis of evidence concerning what patients and family family-caregivers value about palliative care has not been conducted before. The review reported in this chapter is designed to address this evidence gap. The purpose of this mixed-studies systematic review was to explore patients' and their family-caregivers' views and experiences and to determine what they valued about adult hospice care in the UK.

Scoping and refining the review purpose, parameters, and questions

Scoping searches were undertaken prior to the systematic review to explore the extent of the literature available to recognise gaps and uncertainties in the evidence; to clarify definitions related to the research question and overall topic; and to help refine the search terms. This provided a structured approach to gathering the necessary contextual and background information, which in turn informed the design of the systematic review, because the study designs that reported the relevant data that addressed the topic area were qualitative and quantitative studies, questionnaire surveys, and mixed-methods studies. This led to the development of a mixed-studies design.

Aim and review question

As the synthesis sought to include multiple stakeholder perspectives, the SPICE question formulation framework was utilised to develop the review question and subsequent search strategy *(Table 4.1).* SPICE is an acronym that stands for setting, perspective, phenomenon of interest, comparison and (method of) evaluation; these are described in quantitative and qualitative reviews. The aim of this evidence synthesis was to search for and synthesise qualitative and quantitative studies to answer the review question, which was 'What do patients and family caregivers value from hospice clinical and non-clinical services?'.

Table 4:1: SPICE framework for structuring synthesis questions

Setting	Perspective	Phenomenon of Interest	Comparison	Evaluation
Adult hospice facilities across the UK	Patients who received care from a hospice, family/ informal care-giver/ loved ones	Values attributed to: • Palliative care services (in hospice/at home). End of life care (in hospice/at home).	Hospital/other type of non-hospice palliative care or no comparison	• Qualitative evidence of views and experiences that attribute values to care and services. • Descriptive quantitative studies such as surveys from which 'values' can be derived • Patient-specified outcomes, e.g. process of care outcomes and satisfaction Family-caregiver-specified outcomes

Methods

Review design

A three-stage mixed-studies systematic review was carried out following a sequential exploratory design [142] whereby the synthesis of the qualitative data was followed by a synthesis of the quantitative data, and finally the two syntheses were integrated in an overarching synthesis *(Figure 4.2)*. The quantitative synthesis was given less weight and was used to refute or support the findings and identify gaps. The quantitative data was derived from forced choice questionnaires which elicited descriptive statistics with no underlying rationale or explanation as to why the patient or family-caregiver answered in a specific way. In contrast, the qualitative data provided a richer account from the perspective of patients and family-caregivers. A mixed-studies systematic review is not without controversy and epistemological issues. The challenges of a mixed-methods approach stem largely from the time required to conduct the review. As multiple forms of data are being collected and analysed, mixed-studies reviews require considerable time, experience, and resources to carry out the many steps involved. Nonetheless, a mixed-studies design was considered the most appropriate to address the review question.

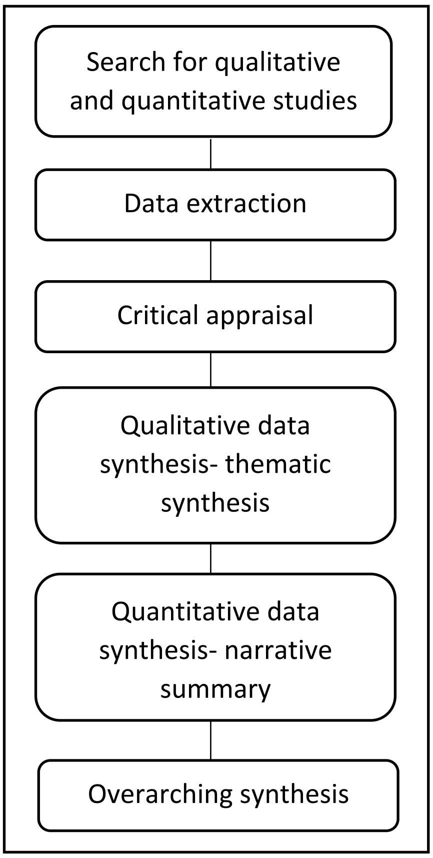


Figure 4:2: Review design

Epistemology

This thematic synthesis of qualitative evidence was approached from a critical realist perspective, which accepts the existence of an independent social world that can only be understood through the interpretations of both the researcher and the research participants [143]. Thomas and Harden's [144] approach to thematic synthesis is located on the critical realist side of the idealist to realist continuum [145]. Critical realism supports the notion that quantitative and qualitative research can work together to address the other's limitations.

Search strategy

Whilst this review follows a sequential exploratory design [142], both data sets were obtained using one search strategy. Whilst this required more time and effort during the study selection phase of the review, it required fewer individual searches to be developed, tested, and conducted. The search strategy for this review, was not restricted by the study design. This facilitated the identification of a diverse range of evidence and hence the findings were maximised.

Electronic searches

The search strategy was designed with an information scientist. The following four online electronic databases were searched from inception to March 2017: ASSIA (Applied Social Sciences Abstracts), PubMed, CINAHL (The Cumulative Index to Nursing and Allied Health Literature), and PsycINFO (Psychology and Psychiatry). As the review question comprised issues related to both health and social sciences, CINAHL, PubMed, and ASSIA were chosen. Due to the psychosocial element that hospice care entails, PsychInfo was also searched. It was anticipated that using these four databases would yield the most relevant results. This was then tested during the initial scoping searches. The search strategy was based on key words and terms from the intervention, perspective, and evaluation of the SPICE framework to help identify relevant studies. There are a variety of nuanced terms which relate to end of life care including, but not limited to, hospice care, terminal care, supportive care, end of life care, and palliative care [146]. To minimise the exclusion of relevant data, these terms were included within the search strategy. In addition, different techniques such as using the medical subject headings (MeSh) 'hospice' and 'palliative' in conjunction with Boolean operators and truncated words were adapted to suit the needs of each individual database searched (See *Appendix 3.1* for an example search strategy).

Additional searching

To enhance the rigour of the search strategy, studies were also found via four additional searching techniques. These complementary strategies were used to minimise the risk of omitting relevant data sources.

(1) Grey literature

Grey literature refers to research that is either unpublished or has been published in non-peer-reviewed form. Grey literature was searched to help offset the impact of publication bias and introduce alternative perspectives that may not be represented in the academic literature. Sources of grey literature include reports, conference abstracts, and theses. The following sources were searched:

- Hospice UK website
- NICE evidence reports
- British Library e-theses Online Service (EtHOS)
- The International Observatory on End of life care (Lancaster University)

(2) Relevant subject-related websites

Relevant subject-related websites were searched to obtain relevant literature relating to hospice care in the UK. Hospice UK is a renowned website which houses an abundance of vital evidence relating to the subject of this review. NICE Evidence (formerly NHS Evidence) is a data-base which holds authoritative evidence relating to health, social care, and public health. The International Observatory on End of life care (Lancaster University) research publication website was searched as it contains and produces many relevant studies, some of which may not have been published in peer-reviewed journals. EtHOS was utilised as it stores an abundance of British PhD theses, which were an important component of the search because relevant peer-reviewed journal articles could have derived from these theses.

(3) Citation searching

Citation searching refers to the process of searching reference lists of studies that met the selection criteria to identify additional relevant studies. It is considered an important aspect of the systematic review process [147]. Whilst a thorough search strategy was employed, some relevant studies are likely to have been missed. Searching through reference lists of relevant studies until saturation helped to generate new citations.

(4) Contact with authors

Authors of relevant studies were contacted, primarily to access unobtainable articles found during the search process, but also to obtain information on unpublished or soon-to-be published studies.

Eligibility criteria

To help decide which studies were eligible for inclusion within the synthesis, a list of inclusion criteria was applied to each screening stage as follows *(Table 4.2)*:

Table 4:2: Summary of eligibility criteria applied to studies

Inclusion Criteria	Exclusion Criteria
Studies written in the English language only	Studies written in languages other than English
Studies conducted in the UK and the Republic of Ireland (Ireland and Northern Ireland have an all-Ireland palliative care alliance).	Studies conducted outside the UK or Republic of Ireland.
Studies which include the perspective of family, patients, and/or families	Studies which only have a focus on staff perspectives Studies only focusing on the clinical outcomes of treatments
The studies were conducted within a dedicated hospice facility with other health care settings only used as comparisons	Studies focusing on diagnostic elements of the illnesses of those in hospice care Studies looking at only hospital palliative/end-of-life care
Studies researching adult hospices or hospice services only	Studies researching children's hospices
	Systematic reviews

Screening of studies

After removing duplicates, the remaining papers were independently screened by title and abstract to determine their eligibility for inclusion; as abstracts are often absent in grey literature, it was also necessary for titles, executive summaries, and tables of contents to be screened. A random sample was taken by a second reviewer and the inclusion and exclusion criteria applied to check that the papers had been reliably kept or dismissed. After the initial screening stage, the full-text copies of included studies were retrieved and read again to apply the inclusion and exclusion criteria; again, a sample was checked by a second reviewer to ensure that the inclusion/exclusion criteria had been applied accurately. Using a second reviewer in the screening process utilises a significant amount of resources. The use of a second reviewer for a random sample reduced the resources necessary, while maintaining a lower level of bias. Any disagreements were resolved through discussion. In the case of discrepant judgements, a third author would be approached.

Quality appraisal

Four method-specific *(Table 4.3)* tools were used to assess any methodological limitations in primary studies and to guide the interpretation of the findings. Quality assessments were not used to exclude articles. A random sample of studies was chosen and checked by a second reviewer (*Appendix 3.4* for full quality appraisal). Disagreements were resolved by consensus.

Table 4:3: Quality appraisal tools

Study Design	Appraisal Tool
Qualitative studies	Critical appraisal skills programme (CASP) [148]
Quantitative studies	Effective public health practice project quality assessment tool (EPHPP) [149]
Questionnaires and surveys	Centre for evidence-based management “critical appraisal of a survey” (CEBMa) [150]
Mixed-method studies	Mixed method appraisal tool (MMAT) [151]

Data extraction and management

Data extraction was performed using a bespoke form. The following domains were included: title, author(*s*), publication date, study design, setting, objectives, data collection, sample characteristics, and analysis methods. Qualitative evidence of interest was coded from the primary study. For the quantitative studies, findings were grouped by topic or outcome. Descriptive statistics, percentages, *p* values, and estimates of precision such as confidence intervals were extracted. Author interpretations were also extracted. This table was then reviewed by a second reviewer. Only data relevant to the research question was extracted.

Data synthesis

A mixed-studies synthesis was conducted in three phases, whereby the studies were separated by design and synthesised sequentially: the qualitative data first, followed by the quantitative data and then an overarching synthesis was carried out.

Phase 1: Qualitative evidence

All studies exploring perspectives and views where value could be interpreted to generally indicate the implied value to patients and family-caregivers were synthesised using the Thomas and Harden [144] approach to thematic synthesis. There are three stages to the approach which are operationalised below:

Stage 1: Free line-by-line coding of textual findings from primary studies

The process of coding and synthesising individual qualitative studies was completed manually rather than using computer software packages such as NVivo. Although this process can be arduous, it ensured that greater knowledge about the material was gained. This coding process involved the allocation of narrative codes to specific sentences, which enabled data to be categorised. For this review, an inductive approach was utilised as codes were derived from the data itself. For each paper, sections which were deemed relevant to the research question were isolated and line-by-line coding of those sections was conducted. From here, ‘free codes’ were formed. During this first stage of the synthesis, the codes mirrored the original context of the data. Due to the fine-grained nature of the coding process, 117 codes were created. Through continual re-examination of the data and redefining of codes via a process known as axial coding, this number was reduced. To ascertain whether a code was appropriately assigned, text segments were compared to segments that had previously been assigned the same code. Decisions could then be made as to whether or not they reflected the same concept. Using this 'constant comparison' method, existing codes were refined and new codes were identified.

Stage 2: Organisation of free codes into 'descriptive' themes

The second stage of the Thomas and Harden [144] approach involved the organisation of free codes into descriptive themes. To increase the validity of the themes, regular collaboration with a second reviewer was undertaken until consensus was achieved.

Stage 3: Generating analytical themes

A defining feature of the final stage of the synthesis involves 'going beyond' the findings of the original data to yield 'analytical themes' which contribute to the creation of a synthesis that is more than just a description of the original studies [144]. With the review question constantly in mind, four analytical themes were inferred from the data.

Table 4:4: Table demonstrating the transition from codes to analytical themes

Analytical Theme What People Valued	**Descriptive Themes**	**Codes**
The importance of highly skilled staff in the provision of high-quality care	1. The value of highly skilled and attentive staff members to patients and family-caregivers 2. The comfort gained from the development of good relationships with healthcare professionals 3. The importance of staff awareness with regard to patients' and family-caregivers' needs 4. Continuity of care	1. Regular monitoring 2. Consistency of staff 3. Inter-and intra-agency co-operation 4. High standard of nursing and medical care 5. Awareness of patient condition 6. Attentive staff 7. Going above and beyond 8. Specialised expertise and knowledge 9. Awareness of patients' and family-caregivers' needs 10. Designated key professionals
The important role of social engagement and participation in social activities in the	1. Social opportunities helped to develop important relationships with other patients and family-caregivers	1. Something to look forward to 2. Welcomed distraction 3. Acceptance and understanding 4. Peer support 5. Learning new skills 6. Developing friendships

maintenance of relationships and a sense of normality	2. Help was provided to develop old and new skills 3. Social opportunities helped to maintain a sense of normality 4. Peer support provided a support network	7. Meeting new people 8. Communication 9. Sharing experiences
The importance of comfort gained from the availability and accessibility of the hospice	1. Access to a wide range of services and staff for patients and family-caregivers 2. Availability of the hospice 3. Hospice atmosphere ensured patient and family-caregiver comfort	1. Hospice transport 2. Therapeutic environment 3. Feels like home 4. Respite care 5. Availability of staff 6. 24-hour support 7. Open visiting hours 8. Phone support 9. Availability in a crisis 10. Time with staff 11. Night aides 12. Access to a range of services 13. Provision of medical equipment
The important role of the hospice in helping promote patient and family-caregiver autonomy through the provision of various support mechanisms	1. Maintenance of psychological, spiritual, and physical well-being 2. Promoting patients' and family-caregivers' independence through choice 3. Practical support for patients and family-caregivers	1. Support to stay at home 2. Being listened to 3. Practical support 4. Signposting to other agencies 5. Clinical information and advice 6. Improved psychological well-being 7. Improved physical well being 8. Preventing unwanted hospital admissions

Phase 2*: *Quantitative evidence synthesis

It was not possible to undertake a meta-analysis because study designs, outcomes, and measures varied. All studies in which value was measured quantitatively were synthesised using a narrative summary approach. The findings were grouped by topic or outcome and summarised.

Phase 3: Cross-study synthesis

The final stage involved the integration of the findings from both the qualitative and the quantitative syntheses by juxtaposing the data in a matrix *(Table 4.7).* This visual representation enabled the identification of new findings which went beyond the information gained from the separate syntheses of the quantitative and qualitative data. First a table was created to map the values expressed by patients and family-caregivers across studies (*Table 4.6*). Then a matrix was created to integrate the comparable findings of the quantitative and qualitative syntheses. There was not a complete fit between the qualitative and quantitative evidence and the matrix represents where evidence on the same issue could be juxtaposed (*Table 4.7*). Other qualitative findings that could not be mapped against comparable quantitative findings remain as standalone qualitative findings.

Confidence in the synthesis findings

Qualitative findings

GRADE CERQual (Confidence in the Evidence from Reviews of Qualitative Research) was used to assess and summarise the confidence in the review findings *(Table 4.8).* The approach focuses on four components: (1) methodological limitations; (2) coherence of the review findings; (3) adequacy of the data; (4) relevance of the findings from the included studies to the review question. There are four levels of confidence that can be assigned to each finding: very low, low, moderate, and high. All findings were initially classified as ‘high confidence’ and then demoted if considerable limitations were discovered across the four components. Primarily, findings were downgraded due to concerns regarding the adequacy of the data as sometimes the richness of the evidence supporting them was limited. Furthermore, relevance issues were prominent as the included studies often failed to directly address the research question, resulting in values being inferred based on participant experiences; however, this was not found to severely affect the confidence levels.

Quantitative findings

GRADE CERQual is primarily designed to assess the level of confidence in the qualitative synthesised findings. There is no GRADE equivalent for questionnaire surveys so it was not possible to assess the confidence in synthesised questionnaire survey findings.

Reporting

The Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) [152] statement was used for the qualitative evidence, and relevant elements of the Preferred Reporting Items for Systematic Reviews (PRISMA) [153] were followed for the quantitative evidence.

Findings

Description of studies

Outcome of the search

After searching four electronic databases and making supplementary searches, a total of 10,176 studies were identified. Each of these studies was then screened by title and abstract to assess their relevance, which resulted in 793 studies in total after duplicates were removed. After the initial screening, the full texts of the included studies were retrieved and read to determine whether they met the inclusion criteria. A total of 34 studies were deemed eligible for inclusion. Seven articles were not included in the final synthesis as they could not be accessed. Rigorous attempts were made to access these articles via inter-library loans, Google searching and contacting the authors directly, but despite all attempts, the seven articles could not be accessed *(Figure 4.3)*.

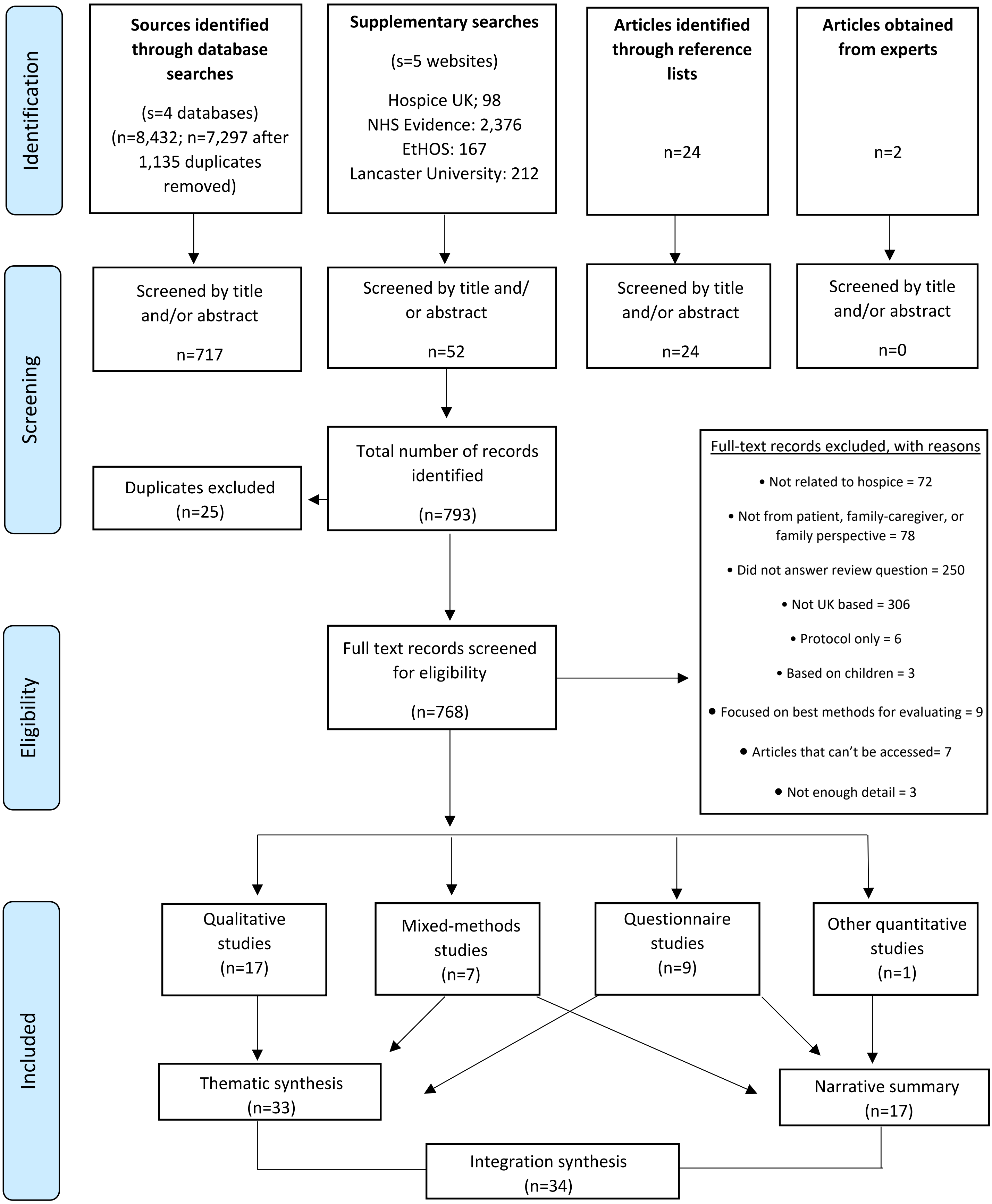


Figure 4:3: PRISMA flowchart

Included studies

Study respondents

A total of 34 studies, from a range of sources were included in the synthesis. These studies primarily included the views and experiences of family members and/or patients. Whilst, the inclusion of staff was beyond the scope of this review, some studies elicited the views and experiences of staff members. As the data could be disaggregated, these papers were included; however, the data exploring staff views were not extracted and included within the synthesis.

Study design

Studies used a range of designs including qualitative, quantitative, and mixed-methods designs. The data collection methods commonly utilised semi-structured interviews, surveys with open-ended questions, and focus groups.

Geographical settings

As disclosed previously, the literature within this review was limited to research conducted in the UK and the Republic of Ireland: England (n=20); Northern Ireland (n=3); Republic of Ireland (n=2); UK (no delineation) (n=9).

Palliative care settings

The studies predominantly included palliative care settings, which were situated at a hospice facility or within the home of a patient who was utilising an at home service. In some instances, hospitals were used as comparators. At the time of writing, 2020, no single model of an at home service exists, and therefore some studies struggled to delineate between the at home service as a service offered by a hospice and that of other palliative care providers such as Macmillan. For this reason, it was not possible to disaggregate the study results.

Quality of included studies

The assessment of each domain of quality for each study is reported and displayed in tables (*Appendix 3.4).*

Synthesised findings

The review design was originally conceptualised, documented in a protocol and carried out using a sequential exploratory design [142] whereby the synthesis of the qualitative data was followed by a synthesis of the quantitative data, and finally the two syntheses were integrated in an overarching synthesis. Nonetheless, a revision was requested whereby the findings should be reported as if a different integrated synthesis review design was retrospectively applied. In an integrated review design the methodological differences between qualitative and quantitative studies are minimised as both are viewed as producing findings that can be readily synthesised into one another because they address the same research purpose and questions. Transformation involves either turning qualitative data into quantitative (quantitising) or quantitative findings are turned into qualitative (qualitising) to facilitate their integration. Although the data in this mixed-studies review were not processed using an integrated design, the findings in this chapter have however been reported as if an integrated design has been retrospectively applied. Readers should refer to the published review in BMJ Palliative Care to see the review findings reported using a sequential exploratory design as originally intended. Four analytical themes demonstrating the value of palliative care and hospices' services to patients and their family-caregivers were developed from a synthesis of 34 studies. The themes were largely homogeneous across studies and stakeholder groups (families/caregiver and patient) and the key findings are reported below. By way of illustration, specific values of the services from a random selection of 15 studies are displayed in *Table 4.7.* Of note, as there is no CERQual equivalent for quantitative data or qualitative findings in a mixed-methods synthesis [154], *table 4.5* refers to the synthesis of data from the qualitative studies only.

Synthesis of findings

Analytical theme 1: The importance of staff in the provision of high-quality care

The personal and professional traits of hospice personnel contributed greatly to the overall value attributed to hospice care. Due to the amalgamation of the personal qualities of staff, their experience, and their specialised knowledge and skills, a close rapport amongst staff, patients, and their families developed. The importance attributed to these qualities was further evidenced as a range of positive adjectives regarding the quality of staff that were mentioned frequently, with typical comments regularly referring to how staff had "*turned* *out to be friends*" [155]. The specialised knowledge and expertise of hospice personnel resulted in the enhanced ability of staff to empathise, use their initiative, anticipate the changing needs of the patient and their family, and provide proactive responses. Through the provision of care which is also tailored to the individual support needs of families, patients were able to regain some semblances of normality, resulting in improvements in their overall quality of life. These were attributes of care that not only provided the necessary reassurance to both patients and their families/caregivers but also contributed to a heightened sense of security. The high levels of trust that ensued between staff, patients, and their families/caregivers, however, would not have blossomed without continuity, in particular, regular contact with designated key personnel. Through regular and consistent contact, staff members were able to learn small, nuanced details about individual patients and their families/caregivers and could provide the necessary support that was tailored specifically to them. For example, staff awareness of families'/caregivers' support needs ensured that respite care was offered before families became fatigued [155], preventing unwanted hospital admissions. In some instances, however, a lack of staff continuity resulted in unease for families, as they believed this resulted in a lack of understanding of the specific support needs of the patient and thus unexpected complications would not be adequately managed [156]. The quality of care was also dependent on the ability of staff to spend longer periods of time with patients and their families. This, along with their willingness to go the extra mile, ensured that a high standard of care was consistently achieved.

The number of bereaved family-caregivers categorising the quality of care as excellent was highest when the care was provided in a hospice setting compared with in the setting of other healthcare service providers [157]. This was further supported across this synthesis as family-caregivers consistently reported high levels of satisfaction (91%–97%) regarding the quality of care that hospices provided [158, 159]. Caregivers' perceptions of quality were further enhanced by the knowledgeable [158, 160], courteous, and approachable staff [160]. These positive traits associated with members of the hospice teams endowed both patients and family-caregivers with high levels of confidence in their capabilities [53, 161–165]. Although the findings suggest that there are differences in the provision of care between healthcare providers, Parkes [166] found minimal discrepancies from spouses' perspectives between hospice and hospital staff in relation to friendliness, approachability, and helpfulness.

Addington-Hall and O'Callaghan [53] found that most family-caregivers (92%) believed that hospice patients were 'always' treated with dignity within the hospice environment. This received further support from both the Office for National Statistics [157] and McKay et al [159], the latter reporting that most family-caregivers (97%) believed that patients' dignity had been maintained. In contrast, only half of the respondents felt that the patients' dignity was maintained in the hospital setting [53]. The percentage that felt they were always treated with respect in day therapy and inpatient units ranged from 90.4% to 94.3% [161–165].

Analytical theme 2: The importance of the role of social engagement and participation in social activities in the maintenance of relationships and participants' sense of normality

The success of hospice care not only stems from the expertise and personal traits of staff, but also from the environment they facilitate [167]. Within the day therapy setting, many patients expressed the value associated with a sense of community that was created by bringing people together who were in the 'same boat' [20, 168]. Frequent use of collective terms such as 'we' and 'us' only served to strengthen this notion [169]. Day therapy provided an environment for patients which enabled them to hold open discussions with each other about how their illness had affected their lives [168]. This was of significant value because patients could regularly share stories regarding their treatment, symptoms, and personal experiences. Often patients would maintain a façade when in the presence of family and loved ones in order to protect them from greater emotional distress, as evident in this comment: *"If I was trying to explain to my wife how I was feeling she'd need therapy. Here people understand"* [20]. Peer support was the aspect of day therapy that was the most valued.

The provision of social opportunities such as meal times often provided an opportunity for patients to socialise and contribute to the community-based ideology which is central to hospice care [169]. For many, feelings of isolation accompanied their illness; one patient described how "*he had had no emotional support during his treatment and said that all of a sudden, he could not do a thing but that coming to the hospice had brought about a change"*

[170]. The social interactions cultivated in the day therapy setting helped to deconstruct these notions of isolation and in turn helped patients to form relationships with other service-users and staff; for some, the opportunity to eat together was *"like being taken out for a meal with old friends"* [169]. This community ideology was facilitated through the comforting and informal hospice environment.

Social opportunities were of considerable value to both patients [17, 170] and family-caregivers [172], with the latter confirming that their social life had been considerably affected by their caring role [172]. The hospices helped to facilitate a 'quiet time to chat', which was valued by more than half of the patients [17], with a further 42% citing the opportunity to meet with others in a similar situation as a reason for asking for a referral to the hospice [17]. The opportunity to meet people was a recurrent finding; Goodwin et al [170] found that just under half of respondents believed it to be the most valued outcome of day therapy. Furthermore, patients' acceptance was promoted, with many voicing feelings of belonging, regardless of mood or state of mind [168, 169, 171] as they were not judged according to their actions and were given the freedom to just be present and accepted [169]. The flexible nature of the service was essential in helping patients to feel at ease "*instead of having it all regimental like"* [168]. Many patients also discussed the concept of 'paying it forward', that is, being able to *"help other people despite your symptoms. Reassure them you know how they feel*" [168], which gave them a sense of purpose and self-worth. These support networks helped patients to regain a sense of normality and fostered feelings of acceptance. Attendance at day therapy enabled patients to 'get out' and participate in the activities available to them, which served to divert attention away from thoughts of themselves and their illnesses [171]. Patients not only placed value on being able to 'get out' but were also very grateful for the ease with which this was achieved due to the transport the hospice provided [161–165]. The provision of opportunities to learn new skills and participate in a variety of activities despite their terminal illness were considered valuable because of the sense of purpose they facilitated [172]. Patients identified escaping from their role as a sick person and regaining a sense of normality as a valuable components of day therapy. This sense of value was reiterated throughout the hospice services by family-caregivers and patients alike [26, 167, 168].

Within the day therapy setting at one hospice, the “welcome on arrival with tea and scones” was considered by many patients (61%) to be the most valued activity [17]. Lunch-time itself was valued by half of the patients (50%) [17]. When asked about the quality of the catering, the percentage of inpatients who considered the quality as excellent ranged from 65.1% to 72.7%. In the day therapy setting, the percentage ranged from 69.4% to 72.7% [161–165]. There was also evidence which demonstrated that a large proportion of patients were happy with the access they had to food outside set meal times (55.4%–69.6%) [161–163]. Between 75% and 81% of family-caregivers who responded to the survey conducted by the Office for National Statistics [157] believed that their loved one had received the necessary support needed to alleviate their hunger and thirst. However, a small proportion (13%) of family-caregivers felt strongly that the patient had not received adequate support to address these needs [157].

Analytical theme 3: The importance of the comfort gained from the availability and accessibility of the hospice

Both family-caregivers and patients placed a positive value on the availability and flexibility of the hospice services and its staff [20, 26, 156, 173]. Availability and flexibility comprise multiple facets, each of which has an individual value to service-users. Patients and caregivers were quick to note that the availability of staff members [156] and the 24-hour support they provided [26], coupled with other influential factors such as open visiting hours [174] and access to a wide range of staff and services, were central to a sense of security [155, 167].

The value associated with the availability and accessibility of the hospice and its staff is inferred by the emphasis placed on this facet of care, with patients agreeing that they had access to an adequate number of staff [157, 160–162, 164]. Most family-caregivers felt that they could reach the hospice medical team when necessary, and this was reflected in the work of Lucas et al [157], who found that 82% of family-caregivers had no difficulties obtaining medical support. In addition, 95% of family-caregivers felt that the at home service was able to provide the help requested for their loved one [159]. This adds to the perception that staff availability is greater within a hospice [53, 165] than in a hospital; however, it is worth noting that less than 60% had gained access to 24-hour support when they needed it [158]. In contrast, the findings demonstrated substantial disparities associated with the availability of staff within hospital settings. The disparities that exist between hospices and hospitals are accentuated by Parkes [165]; spouses reported that they were more likely to talk to a wider range of staff whilst at a hospice. When asked “How many other members of the institution staff did you get to talk to?”, 68% of participants at other hospitals said ‘none’ compared to only 15% at St Christopher’s Hospice ($p< 0.002$) [165].

Family-caregivers felt that hospice services had positively impacted their experience as care-providers. In particular, the provision of phone support, the addressing of worries, general support, reassurance, validation, and help with practical tasks had been a significant help to them in continuing with their caregiving role [26]. Many caregivers suggested that they had willingly taken on the role in order to facilitate the patient’s wish to die at home [173]. This, however, had detrimental effects on their physical and psychological well-being, largely due to the stress created by trying to care for their loved one [173, 175]. For this reason, significant value was placed on the provision of night aides by the hospice [26]. Night aides could be requested as part of the at home service and provided invaluable respite and support. Although value was placed on the availability of daytime aides from the hospice, the presence of night aides, particularly in times of crisis, was reiterated throughout. One participant said, *“I valued that somebody was here the night he died, because the nurse called us when she thought it was time, so my daughter and I were with him”* [176]. The time immediately after death was often reflected on by family-caregivers as a period of difficulty due to the number of tasks that arose following a home death, such as arranging a funeral, returning medical equipment, and seeking bereavement support [156]. For family-caregivers of patients who died in a hospice inpatient setting or were supported by the at home service, the burden associated with these tasks was alleviated by the hospice. Family-caregivers noted the value of this.

Interestingly however, Parkes [165] identified that no systematic attempt was made by the hospice in their study to support bereaved spouses. However, some respondents highlighted that they had been informally asked to remain in contact, an invitation accepted by just under a quarter of them [165]. This is in stark contrast to findings in more recent studies, which show that the majority of respondents (81%) received a follow-up call as a minimum level of support [158, 177]. Other services varied and offered services such as monthly memorial ceremonies, which had high attendance rates (87%), a volunteer bereavement support service [177], and a bereavement information evening [158, 177]. Bereavement information evenings were evident in two studies, but attendance at these was relatively low: 33% at one hospice [177] and 11% at the other [158]. The reason for this could have been a lack of awareness, as some of the respondents (28%) explained that they were unaware of the support networks available [158]. Bereavement support was also extended to patients in some cases [160–162]. It can be inferred from the data that patients would benefit from improved bereavement support. In many instances, the percentage of patients who felt extremely supported rarely surpassed 50% [160–162]. This was a prominent issue within the day therapy setting [160].

Patients and their families/caregivers explained that without the hospice they would have felt more vulnerable [26, 155]. One patient stated, *"If I didn't have that service… I would probably feel very, well, more vulnerable than what I felt"* [26]. The extensive support network available to patients when they were receiving care from the hospice was deemed invaluable as it was crucial to their general sense of well-being. The extensive support network stemmed from having ever-present members of staff. This was consistently identified as a valuable aspect of hospice care as it enabled family-caregivers to obtain 24-hour support, advice, and reassurance [20, 26, 176]. In particular, phone support was mentioned regularly; *"I do think it was good that they were there and I could ring them. I always had their number and I did ring them. I found it reassuring that I had a source that I could ring at any given moment"* [155]. Knowing they could access 24-hour support over the phone took the "*weight off…. Someone is there to help you… I don't feel frightened if [name of patient] isn't very well now. I know I can phone someone and they will give me some advice"* [20]. The certainty of support, even if not actually accessed, was crucial to the overall sense of well-being.

Many of the studies demonstrated the value of equitable access to complementary and diversional therapies [168, 172, 177]. These services were mentioned primarily in relation to palliative day therapy services and varied from those with a direct therapeutic value, such as physical therapy, to those that were more consistent with a social model, where shared activities such as art were encouraged [20, 168, 171, 177]. Diversional and therapeutic activities were regularly discussed as they offered patients the opportunity to improve on existing skills or learn new ones, helped foster positive attitudes, and increased feelings of well-being and a greater sense of self-worth [20, 168, 177]. Many patients placed significant value on the activities available to them, especially social outings [17]; however, a small proportion indicated that they would have liked a wider range of activities to be available. The opportunity to learn new skills was not limited to patients but also extended to family-caregivers in a more practical way. Family-caregivers valued the opportunity to observe staff techniques so that they could improve upon their own caring skills [176]. As family-caregivers often voiced their need for reassurance that they were doing the 'right thing', these skills learnt through observation were essential and highly valued [176].

Flexible visiting hours are a feature which makes hospices unique; however, this feature had mixed responses that reflected different values and perspectives. Patients acknowledged the value of interacting with their family and friends to maintain relationships and allow continuity with their lives outside the hospice [174]. The following comment is an exemplar that supports this view: *"We might chat or just sit and hold hands… We've both been asleep in the ward. I was asleep in the bed and she was sat next to me in the chair asleep and we were holding hands"* [174]. Some family-caregivers (53%) spent in excess of six hours a day visiting, which was considerably higher than the family-caregivers spent visiting within the hospital setting (9%) [166]. However, patients also reported that visitors could be intrusive and could outstay their welcome [174]. Patients therefore indicated that they valued autonomy and therefore needed to feel that they were in control of their visiting arrangements.

Questions relating to the punctuality, comfort, and safety of hospice transport were asked [161–165]. Across all the domains, the percentage of patients who rated these areas as excellent always exceeded 55% [161–165]. Kernohan et al [17] discovered that 38% of patients valued their journey to the hospice the most out of all hospice-related activities and 31% felt that their journey home was the most valued activity.

Analytical theme 4: The importance of the role of the hospice in helping promote patient and family-caregiver autonomy through the provision of various support mechanisms

Through the provision of support for both family-caregivers and patients, hospices enabled patients to fulfil their wish to die at home, which was highly valued by patients [156].

However, fulfilling a patient's wish to die at home was also influenced by the family-caregiver's ability to cope. It was evident that family-caregivers were often concerned that they would be unable to support the ever-changing needs of the patient [156]. Family-caregivers often associated a patient's end of life experience with their own ability to address the needs of the patient [156]. The support provided by the at home service was an invaluable source of support and reassurance during times when family-caregivers were struggling. This in turn helped foster patient autonomy, as evidenced by the following exemplar: *"I want to die at home. I desperately want to die at home but without this [at home Service] I'd have probably ended up in some nursing home somewhere"* [176]. This support was provided through a range of mechanisms including but not limited to physical, psychological, social, and financial help.

Caring was generally perceived as hard work, and for numerous family-caregivers this meant physically demanding work, as revealed by the following excerpt: "*It's hard work. I mean just these past few weeks she hasn't been too bad. When she starts with diarrhoea and that, you know, and I just cannot do that and it's hard work*" [175]. Others described the hard work in terms of mental strain, as many commented on the stress, the emotional worries, and anxieties the caring caused [175]. Respite enabled family-caregivers to have time to themselves during which they could relax and complete other day-to-day chores [26] and regain a sense of normality. This was demonstrated by McKay et al [159] who found that respite care was beneficial to a large proportion of family-caregivers (85%).

In addition, the provision of domestic-related support was highly valued and on occasion it was noted that night aides from the hospice completed domestic chores on behalf of family-caregivers [176]. The benefit of this was twofold: not only did this ensure that practical household activities were accomplished, it also helped alleviate the burden that caring often entails [26]. During periods when family-caregivers felt unable to cope, knowing that scheduled visits were arranged gave them the confidence and determination to continue with their caring role [26]. Not only did staff provide physical, emotional, and social support, but they were also deemed to be an approachable and accessible source of professional knowledge and advice [26]. Many commented on how this support enabled them to continue to care for their loved one at home, which prevented unwanted hospital admissions [176]. By knowing that such support was available, much of the fears family-caregivers had were allayed [20]. It is important to note that respite care was not limited to at home service; day therapy also provided respite to family-caregivers as it was an opportunity for patients to ‘get out’. Although respite care was largely viewed as a positive aspect of the hospice service within the literature, Skilbeck et al [172] determined that five family-caregivers showed improvements in their relative stress score, three demonstrated no change, and four had a negative change in their scores post-respite.

Throughout the hospice services, both patients and family-caregivers consistently voiced positive opinions regarding the ability of the staff to meet any practical needs they had [155]. Borland et al [155] conducted a study in which all participants had left employment to adopt the role of full-time family-caregiver. Whilst individuals were quick to note that they were happy to have done so, they frequently discussed the detrimental impact it had on their income and the resultant stresses this caused [155]. To negate such consequences, hospices provided significant support to alleviate the burden of caring. The delivery of advice regarding financial entitlement, in addition to the provision of the correct forms and assistance with their completion, was extremely valued by family-caregivers and regarded as a vital component in reducing stress and anxiety [155]. Staff not only provided advice and support about financial situations but were also able to arrange for patients to have equipment provided for their homes [176]. The importation of necessary equipment such as a pressure-relieving mattresses or a mobility scooter can sometimes be a necessity for the at home patients [176]. Without access to the required equipment, patient discharge from hospice to home can be delayed. This delay can often cause distress to both patient and family-caregiver; one family-caregiver felt that “*he had lost quality time*” with his loved one [173]. Signposting patients towards specific equipment or medications had a substantial benefit on their quality of life, as revealed in the following excerpt: *“Nurses knowing I needed artificial saliva for night time use. It was very practical, and I’d never heard of it before and it’s invaluable”* [176]. This signposting extended to the navigation of complex caregiving services and enabled patients to choose appropriate agencies for themselves, which resulted in the facilitation of independence in addition to the promotion of choice.

Staff were not only quick to provide advice and ensure practical needs were met, but were also prompt in the provision of information and thus both patients and family-caregivers reported high levels of satisfaction regarding this [53, 158]. Ninety per cent of respondents felt that they had been kept updated by the at home service [158]. In addition, 75% felt that hospice doctors and nurses were able to explain the deceased persons condition, treatment, and tests in a clear and comprehensible way [158]. In contrast, only 46% of respondents felt hospitals were able to do so [53]. Furthermore, Addington-Hall and O'Callaghan [53] noted that family-caregivers were twice as likely to 'always' be kept informed in a hospice setting as opposed to in a hospital setting (90% versus 44%).Within the day therapy setting, the percentage of those who described themselves as 'very satisfied' with their involvement in the planning of their care ranged from 57.3% to 70% whilst in the inpatient setting, this ranged from 66.8% to 71.2% [161–165]. However, satisfaction has fluctuated across the years as a reduction in the percentage of day therapy patients reporting the highest levels of satisfaction was shown [161–165]. Whilst hospices were shown to have involved family-caregivers in the shared decision-making process, thus ensuring they were fully informed, hospitals wavered in comparison [53]. This was evidenced in the findings: only 11% of family-caregivers within a hospice setting felt that decisions had been made which their loved one would not have agreed with, compared with 21% in a hospital setting [53].

Addington-Hall and O'Callaghan [53] found no significant difference ($p < 0.01$) between the pain control measures employed in hospices and hospitals from the perspective of bereaved relatives, though differences in the effectiveness of pain relief were noted. Family-caregivers were more than twice as likely to report that the patient's pain had been relieved 'completely all the time/completely some of the time' within the hospice setting as opposed to in a hospital [53]. The effectiveness of pain relief was a finding which concur with other studies included within this review, as family-caregivers felt that the relief of symptoms far exceeded their expectations [159]. Similarly, Parkes [166] demonstrated that spouses at a hospice in their study were less likely than those elsewhere to worry about a patient's pain or its relief (9% vs 36% <0.05).

Table 4:5: CERQual summary of qualitative findings and their assessment of confidence

Summary of Review Finding: What patients and staff valued	Studies Contributing to the Review Finding	Methodological Limitations	Coherence	Adequacy	Relevance	CERQual Assessment of Confidence in the Evidence
Highly skilled staff members Knowing that hospice staff had specialised knowledge and experience put patients and family-caregivers at ease. Patients in particular believed that access to specialist support was more appropriate to anticipate and meet their health needs.	[20, 26, 155, 156, 169, 176] [160–164]	No concerns or very minor concerns about the methodological limitations of this review finding. Eleven studies contributed to this review finding. Three qualitative studies failed to adequately consider the relationship between the researcher and the participants (the researcher was often a staff member at the research site). Most of the qualitative studies did not use triangulation or member-checking to check the validity of their findings. Whilst there were some limitations to the methodology, specifically limitations regarding the credibility of the primary studies, it was concluded that this did not have a significant effect on this qualitative finding and therefore was categorised as having no	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Minor concerns. Eleven studies contributed to this review finding. Five studies contributed very little information to this review finding as the skills of staff were only mentioned briefly. Six of the studies provided more detailed information and provided a more exploratory view.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High level of confidence

		concerns or very minor concerns.				
Developing good relationships with health-care professionals The development of a close rapport with staff was valuable to both the patient and their family-caregiver. These relationships were ameliorated by the healthcare personnel's personal traits, experience, and flexible boundaries.	[155, 156, 159, 160, 167, 176, 178]	Minor concerns about the methodological limitations of this review finding. Seven studies contributed to this review finding. None of the qualitative studies (n=5) used triangulation or member-checking, and a lack of research reflexivity was evident in three of the studies. One study reduced the bias associated with the researcher's role by excluding all participants known to them. This body of evidence was only seen to be of minor concern because the lack of reflexivity and triangulation of methods was not considered to affect this qualitative review finding. Ethical issues were not adequately discussed in two of the studies. Both failed to discuss whether approval had been sought from the ethics committee; however, some mention was made of the use of anonymisation and measures to minimise	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Minor concerns. Seven studies contributed to this review finding. The information from the primary studies were largely descriptive; however, one study provided more of an exploratory view. The connection between relationships and staff traits was fairly thin within one study.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values.	High level of confidence

		distress. Two studies were found to not have an acceptable response rate.				
Awareness of patients' and family-caregivers' needs Participants referred to the added value of staff members being aware of the needs of both the patients and their family-caregivers.	[155, 173, 176]	No concerns or very minor concerns regarding the methodological limitations of this review finding. Three studies contributed to this review finding. Researcher reflexivity was not considered in two of the studies. One study was found to adequately discuss the ethical issues associated with the study but failed to name the review board from which approval was obtained. Whilst there were some concerns about the rigour of the analysis in one study due to a lack of information, minor concerns regarding the rigour of data analysis in the other two studies because multiple researchers were involved in the analysis and this was considered efficient. It was concluded that there were no concerns or very minor concerns.	No concerns or very minor concerns as it was considered to be well grounded in data from the contributing studies.	Minor concerns. All three studies offered little information. Only a small number of studies contributed to this finding. Additionally, it was concluded that there was also a lack of data richness as the importance of awareness was inferred from the data. However, due to the simplicity of the finding, it was concluded that there were minor concerns about data adequacy.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence

Continuity of care Continuity of care refers to both management and relationship continuity. For management continuity, patients and family-caregivers valued the fact that the hospice took on a co-ordinating role within and between other healthcare agencies. In reference to relationship continuity, this was facilitated by regular contact with the same professionals. Family-caregivers also valued having a smooth transition from pre-to post-bereavement to avoid abrupt discontinuance of services.	[155, 156, 158–160, 175, 178–180]	No concerns or very minor concerns regarding with the methodological limitations of this review finding. Nine studies contributed to this review finding. Two of the studies failed to name the ethics board that approved their study but did sufficiently consider other ethical issues such as informed consent. There were minor concerns regarding researcher bias. Whilst two studies were found to have not adequately considered researcher reflexivity (although one study involved two researchers during the analysis), the other two studies acknowledged the potential bias associated with a dual role as health care professional and researcher. One study attempted to negate this bias by excluding participants known to the researcher. The body of evidence supporting the review finding was assessed as having no concerns or very minor concerns.	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Moderate concerns. The contributing studies all had relatively small sample sizes and had relatively thin data, which gives cause for concern. However, due to the descriptive and simplistic nature of the finding, it was concluded that there were only moderate concerns regarding adequacy.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence

Social opportunities helped to develop relationships with other patients and family-caregivers The hospice provided formal opportunities for patients and family-caregivers to develop relationships with others and to create a support network independent of the family.	[17, 20, 162, 163, 168–172, 177, 178, 181]	Minor concerns about the methodological limitations of this review finding. Twelve included articles contributed to this review finding. Limitations to researcher reflexology were evident in five of the studies, with one failing to mention bias associated with a dual role (researcher and staff member at the research site). Four studies were judged to have not adequately discussed the ethical implications of their study. One study made no mention of the anonymisation of transcripts or how consent was taken. None of the studies used triangulation or member-checking to check the validity of their findings and three studies were found to have not given enough detail regarding their analysis process. Whilst limitations were evident, it was concluded that there were only minor concerns regarding methodological limitations.	Minor concerns. Although the data from the contributing studies was largely consistent across all the studies, discrepancies occurred in relation to social support for family-caregivers. Family-caregivers often noted that they would take advantage of informal social support opportunities but no mention was made to official social opportunities.	Minor concerns. This finding was based on 12 studies. Whilst some studies offered little information regarding this phenomenon, the richness of the data from the other contributing studies along with the descriptive nature of the finding meant that it was concluded that there were no concerns or very minor concerns.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High level of confidence

Maintaining a sense of normality The provision of support to enable a sense of normality to remain for both patients and family-caregivers was a recurrent theme. This sense was often encouraged by the hospice helping to maintain and create relationships within and outside the hospice and the provision of respite. Patients often valued the opportunity to escape their 'sick role', and this was supported by being made to feel like an autonomous individual and being supported to remain connected to their self-identity.	[26, 168, 169, 171, 174, 176]	Minor concerns about the methodological limitations of this review finding. Six studies contributed to this review finding. Two studies did not adequately consider the relationship between the researcher and the participants. The recruitment strategy in one study was found to be inappropriate, not only due to a lack of detail surrounding the recruitment process but also due to the recruitment of a small sample of participants. A lack of triangulation and member-checking in addition to a lack of detail surrounding the analysis of data resulted in the conclusion that there were minor concerns regarding the methodological limitations associated with this qualitative review finding.	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Moderate concerns. Whilst the quantity of the data was deemed sufficient, the richness of the data was absent. The data that this finding was based on offered little information about this phenomenon, and therefore it was not possible to explore the importance of normality to hospice service-users. However, due to the descriptive nature of this finding, it was concluded that there were moderate concerns.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence

Help to develop old and new skills Patients sometimes felt that they had lost the ability to continue with previous hobbies. This resulted in a reduction in feelings of self-worth and independence. Patients valued having the opportunity to continue with their hobbies, even if they had to be changed to better suit their abilities. In some instances, patients were able to learn new skills/hobbies, which helped them to regain a sense of normality.	[171, 172, 177]	Moderate concerns about the methodological limitations of this review finding. Three studies contributed to this review finding. Triangulation and member-checking were not evident in two of the studies. One study lacked detail when discussing the ethical implications of the study. Whilst it was stated in the publication that the research team had approvals from their local ethics committee (not named), other ethical considerations such as informed consent, anonymisation, and support were not referenced. Due to the limited number of studies contributing to this finding, in addition to issues concerning the recruitment strategies, the small sample of participants, and the lack of detail surrounding the ethical considerations in one study, it was concluded that there were moderate concerns regarding this review finding.	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Serious concerns. Whilst this finding is largely descriptive, there were serious concerns about both the quantity and the richness of the data. Due to these issues, we could not conclude that we had a good understanding of this phenomenon.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence

Accessibility and availability of the hospice and hospice services						
Access to a wide range of services and staff The accessibility and availability of the hospice and everything it encompassed was especially important to both patients and their family-caregivers. Particular focus was placed on access to out-of-hours support, the ability to participate in a wide range of activities suited to their needs and abilities, and open visiting hours.	[20, 26, 156, 159, 161–164, 167, 168, 171–174, 177, 179, 182]	Minor concerns about the methodological limitations of this review finding. Seventeen studies contributed to this review finding. Eight studies did not adequately reflect on researcher reflexivity and five studies did not adequately reflect on the ethical implications of their study. The body of evidence supporting this review finding was assessed as involving no concerns or very minor concerns.	Moderate concerns regarding the consistency of this review finding. Inconsistencies in the data were evident in relation to open visiting hours and access to out-of-hours support. Whilst some participants valued open visiting hours, for some it resulted in a loss of autonomy. The value of out-of-hours support for patients and families utilising the at home service was describable. Some participants in the contributing studies felt that they did not have adequate access to out-of-hours support.	Minor concerns. Whilst seventeen studies contributed to this qualitative finding, only six of the studies were considered to provide rich and detailed information specific to the phenomenon of interest. These studies helped us to understand and explore the importance of availability and accessibility. The remaining four contributing articles often discussed the benefits of a particular service but did not directly refer to the importance of the availability of the particular service, resulting in the need to infer this value from the data. Based on the overall assessment of the richness and quantity of the data, it was concluded that there were minor concerns	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High level of confidence

				about the adequacy of this review finding.		
Time In comparison to staff at hospitals, staff at the hospices were able to spend more time with patients. This enabled opportunities for patients to ask questions about their care and to be given sufficient answers. The time spent with other patients was also considered invaluable.	[168]	Moderate concerns about the methodological limitations of this review finding. One study contributed to this review finding. Issues with researcher reflexivity, ethical considerations, and the rigour of the data analysis were evident within this study. As a result, this qualitative finding was found to have moderate methodological limitations.	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Serious concerns. Whilst this finding is largely descriptive, there were serious concerns about both the quantity and the richness of the data. Due to these issues, we could not conclude that we had a good understanding of this phenomenon.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence
Hospice atmosphere The friendly and welcoming atmosphere of the hospice facility ensured that all patients and their families/caregivers felt safe, relaxed,	[20, 161–164, 167, 168, 173, 178]	Minor concerns about the methodological limitations of this review finding. Nine studies contributed to this finding. Researcher reflexivity was not adequately considered in four studies. None of the studies rigorously reported on their data analysis. Three studies did not report enough detail	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Serious concerns. Of the nine contributing studies, eight did not provide enough detail to get a rich understanding of the phenomenon. Whilst the final study did provide more detail, due to issues concerning the richness of the information and issues	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence

and welcome. For those receiving care at home, the welcoming environment was engendered by the hospice staff.		regarding their recruitment process. The body of evidence supporting this review finding was assessed as being of minor concern.		concerning quantity, it was concluded that we had serious concerns regarding the adequacy of this finding. Whilst the finding is largely simple and descriptive, it was unclear how a welcoming environment was facilitated, who contributed positively to this environment, why it was of value, or how important it was.		
Maintenance of psychological, spiritual, and physical well- being The right balance of physical, psychological, and spiritual support enhanced the quality of life of both patients and family-caregivers.	[156, 160, 167, 168, 172, 174, 176–178]	Minor concerns about the methodological limitations of this review finding. Nine studies contributed to this finding. Of these nine, four studies did not adequately consider the relationship between the researcher and the participants. Two studies did not rigorously analyse their data and three studies failed to adequately discuss the ethical implications of their study. One study was found to not have an acceptable response rate.	This review finding was assessed as involving no concerns or very minor concerns as it is well grounded in data from the contributing studies.	Moderate concerns. Most of the studies contributing to this review finding referred to the importance of symptom control as an outcome of a service but this was not directly mentioned as a value. For example, one study explained how a lack of control when it came to visitors resulted in a negative effect on physical symptoms. From this, it was inferred that physical well-being was important. One study provided a rich	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High level of confidence

				explanation of the phenomenon. Considering the quantity and the richness of the data, we concluded that there were moderate concerns.		
Promoting patient and family-caregiver independence through choice The hospice helped to facilitate independence by helping to promote choice. The promotion of choice was facilitated in numerous ways. These included providing support to ensure patients die in their preferred place, enabling patients to decide whether they want to take part in activities, and involving them	[20, 156, 159–164, 168, 169, 174, 176, 177]	No concerns or very minor concerns about the methodological limitations of this review finding. Thirteen studies contributed to this finding. Limitations were evident regarding researcher reflexivity in two studies. Five of the studies did not include enough detail on the rigour of the data analysis process. The ethical implications of the studies were not adequately described in two studies. Limitations to the recruitment process were evident in five studies. The body of evidence supporting the review finding was found to be of no concern or very minor concern.	Minor concerns as it is considered to be well grounded in data from the contributing studies. Some studies referred to a lack of patient autonomy due to open visiting hours.	These studies described how having choice was important. Whilst the data from the contributing studies was relatively thin, due to repetition and the descriptive and simplistic nature of the finding, it was concluded that there were only minor concerns about the adequacy of this review finding.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High level of confidence

in the decision-making process.						
Practical support for patients and family-caregivers Practical support meant ensuring patients and family-caregivers were signposted to the correct agencies and that they had access to equipment, domestic support, and help when patients needed moving.	[155, 158–160, 173, 176]	No concerns or minimal concerns about the methodological limitations of this review finding. Six studies contributed to this review finding. One study did not adequately reflect on the relationship between the researcher and the participants. One study was also found to have limitations regarding the description of the analysis process. This finding was found to have no or minimal methodological limitations.	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Moderate concerns. Whilst the data within five of the contributing studies was thin, due to the richness of the final paper along with the descriptive nature of the finding, it was concluded that there were moderate concerns about the adequacy of this review finding.	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	Moderate level of confidence
Preparation Open discussions with staff ensured that both patients and family-caregivers were prepared for death, which reduced the fear of the unknown.	[20, 26, 155, 156, 173, 178]	Minor concerns about the methodological limitations of this review finding. Six studies contributed to this review finding. Reflexivity was an issue in three of the included studies. The analysis of the data was found to not be sufficiently rigorous. Researchers failed to provide enough detail regarding their	No concerns or very minor concerns as it is considered to be well grounded in data from the contributing studies.	Minor concerns. Only two of the included studies provided a rich exploration of the phenomenon of interest. However, due to the descriptive nature of the review finding along with the richness of the data within two of the studies, it was concluded that	No concerns or very minor concerns. Whilst the aims of the included primary studies do not directly answer the research question posed by this review, it was possible to determine important values. In some cases, values could be inferred.	High Confidence

Information about the patients' illness and predicted illness trajectory further facilitated a sense of preparedness.		analysis process in all but one study. Sufficient ethical consideration was absent from one study as it failed to provide any information regarding any ethical considerations. This finding was found to have minor methodological limitations.		there were minor concerns about the adequacy of this review finding.		

Cross study overarching synthesis

The overarching synthesis of the qualitative and quantitative findings enabled the identification of new findings which extend beyond the synthesis of the qualitative and quantitative data when analysed in isolation. There was not a complete fit between the qualitative and quantitative findings, and the matrix in *Table 4.7* represents where evidence on the same issue could be juxtaposed. Other qualitative findings that could not be mapped against comparable quantitative findings remain as standalone qualitative findings.

Table 4:6: A breakdown of values across a random sample of studies.

What do patient and family-caregivers value from hospice services?	Borland et al [155]	Carlebach and Shucksmith [179]	Exley and Tyrer [173]	Gambles et al [167]	Hayle et al [178]	Holdsworth [156]	Hopkinson and Hallett [168]	Hyde et al [169]	Jack et al [26]	Jack et al [176]	Kennett [177]	Low et al [20]	Lucas et al [158]	McKay et al [159]	McLaughlin et al [160]
Availability and accessibility of the hospice services and staff were a source of reassurance, especially out-of-hours support	✖	●✖	✖			●✖	●		✖			●	✖	✖	✖
Both patients and family-caregivers benefited from the personalities, expertise, and specialised skills of staff	✖		✖	●	●	●✖	●	●✖	✖	●✖		●✖	✖	✖	✖
Patients and family-caregivers valued the opportunity to develop meaningful relationships with staff	✖					●✖				●✖					
Patient needs were always met by staff; however, staff members were also aware of family-caregivers' support needs and health needs, and this was valued	✖		✖							●✖					✖
Continuity of care ensured that patients were regularly monitored, staff were consistent and therefore were aware of the patients' individual health needs; there was good intra-and inter-agency cooperation and pre-and post-bereavement support		●✖	✖		●	●✖		●✖				●	✖	✖	

The provision of social opportunities enabled patients to talk to other patients that they considered understood what they were going through; this helped reduce isolation as meaningful friendships developed	✗				●	●✗	●	●		●✗	●	●✗			
The ability to maintain a sense of normality was important				●			●		✗						
Timely access to a wide range of staff, services, and activities	✗	●✗		●			●				●	●	✗	✗	✗
Time spent with staff was especially important as it ensured that patients felt that they were being listened to				●	●		●	●✗	✗					✗	
Hospice atmosphere encouraged a sense of comfort and provided a homely feel				●	●		●								
Support to maintain psychological, spiritual, and emotional well-being	✗			●	●		●	●		●✗	●			✗	
Symptom management	✗		✗	●	●	●✗				●✗			✗	✗	
Promoting patient and family-caregiver choice by ensuring their priorities and choices were at the forefront of end of life care planning						✗	●	●	✗	●✗	●			✗	
Practical support for patients and family-caregivers, including financial and domestic support and signposting to other agencies	✗		✗						✗	●✗				✗	✗
Being prepared for death, knowing what to expect as the illness progressed, and	✗					✗		✗●	✗	●✗			✗	✗	✗

having access to bereavement support when needed. This was often facilitated through honest conversations															
The provision of clinical information and advice and the opportunity to ask questions and obtain reassurance	✗			●		✗		●	✗			✗		✗	✗
Respite care to allow valued breaks for family-caregivers	✗		✗						✗	✗		✗		✗	✗
Being treated respectfully													✗		✗
Being able to share ideas and experiences with others in similar situations who understood what they were going through							●					●			
Care which is tailored around the individual patient					●			●		●✗				✗	
Patients valued the fact that the hospices facilitated activities which were suited to their capabilities which ultimately enabled them to build upon old skills and develop new ones. Family-caregivers often watched staff members work so that they could learn new techniques and improve their caring capabilities.			✗				●		✗	●✗	●			✗	
Family-caregivers needed validation so that they know that they were providing their loved one with the best possible care	✗					✗				✗				✗	
Family-caregivers valued household support (laundry, etc.) as it helped alleviate their burden									✗	✗					

Key: Family-caregivers ✗ ● Patients

Table 4:7*:* Synthesis matrix

Qualitative findings regarding what patients and family-caregivers valued	**Quantitative findings regarding what patients and family-caregivers valued**	**What this means**	**Overarching finding**
Availability of staff and access to out-of-hours support for individuals receiving support from Hospice at Home to ensure that patients and family-caregivers had their physical and psychological needs met. Not everyone was able to access certain services associated with Hospice at Home.	Family-caregivers valued the support provided to them to ensure a patient's wishes to stay at home were met. Hospice staff were mentioned more positively than hospital staff.	Access to specialist staff and out-of-hours support was valued by patients and family-caregivers but it was not always available to them.	*Equity in the provision of support is an essential value to ensure that patients and their family-caregivers are receiving timely interventions day or night*.
Those nearing the end of life valued a wide variety of diversional and therapeutic activities that suited their changing needs and preferences.	Patients valued a wide range of activities but patient satisfaction relating to the range of activities offered by the hospices has consistently declined over the years.	Diversional and therapeutic activities were valued by people at the end of life, but hospices appear to be limiting their range and availability.	*Choice was consistently valued by patients, thus creating a need for a wide range of activities.*
Those closely affected by death valued the fact that they were communicated with in a sensitive way and were offered immediate and ongoing bereavement, emotional, and spiritual support.	Some family-caregivers felt abandoned by the hospice after the death of a loved one and others mentioned the benefits associated with a follow-up call.	Family-caregivers valued empathetic and appropriate bereavement care and follow-up, but not everyone received the same level of access to	*Family-caregivers placed a high value on bereavement support, but the reactive nature of this or a lack of services*

		bereavement services and support.	*resulted in family-caregivers foregoing support.*
Patients valued the provision of social opportunities, with many believing this had helped them retain some semblances of normality. Family-caregivers sometimes referred to the isolating nature of caring and some mentioned that they had taken advantage of ad hoc social opportunities (talking to other family-caregivers in shared rooms).	Family-caregivers attended a bereavement support group to talk to someone outside their family.	Patients and family-caregivers valued the social aspects of care and support, but family-caregivers also need to be offered planned social opportunities.	*Family-caregivers valued the provision of social opportunities and could therefore benefit from access to official social support networks.*
Continuity, accessibility, and consistency of contact between patients, family-caregivers, and key medical and social care professionals were clearly expressed as vital by both family-caregivers and patients.	Family-caregivers identified that the lack of consistency in staff resulted in care-providers who were unaware of the patient's medical needs. This was especially prevalent within the at home hospice setting.	Patients and family-caregivers highly valued continuity of care, but the standard of continuity varied and did not always meet expectations.	*Equity in the provision of support is an essential value to ensure that patients and their family-caregivers are receiving timely interventions day or night.*
Respite care offered valued breaks for family-	Respite care was valued by family-caregivers	Respite care was highly valued, but in	*Family-caregivers*

caregivers, which helped them retain a sense of normality and ensured that they were able to continue their caring role, but in some instances, respite could have been offered sooner.	across all services and was a prominent reason for patient referral to day therapy.	some instances needed to be offered sooner.	*appeared to place a high value on proactive support, but they did not always consistently receive it.*
The provision of hospice staff night aides during times of crisis were of great importance to family-caregivers. Despite this, some family-caregivers described feelings of abandonment during times of need.	A large proportion of family-caregivers were especially grateful for the ease with which they could access a wide variety of staff. No reference was made to a lack of necessary staff.	The provision of staff who were able to support patients in their own homes at night were valued highly but their availability varied.	*Equity in the provision of support is an essential value to ensure that patients and their family-caregivers are receiving timely interventions day or night.*

Overarching finding 1: Equity in the provision of support is an essential value to ensure that patients and their family-caregivers are receiving timely interventions day or night

The value of out-of-hours support for those receiving care from the at home service is irrefutable. For instance, McLaughlin et al [160] identified that most family-caregivers within their study believed that the at home service had played a vital part in ensuring that their loved one remained at home. However, varying levels of satisfaction associated with some components of the at home service were apparent. Whilst some participants gave nothing but positive accounts of the support provided [176], others reported feelings of abandonment in times of need [173]. These conflicting accounts demonstrate the inequities in the provision of certain services that exist across regions, especially access to out-of-hours support.

Overarching finding 2: Family-caregivers appeared to place a high value on bereavement support, but the reactive nature of the service resulted in family-caregivers foregoing support

Family-caregivers placed a high value on bereavement support but did not always receive it. The most common criticism associated with the bereavement needs of caregivers was the lack of contact from the hospice following the death of a family member [159]. Whilst some respondents felt that the support from the hospice ended abruptly after the passing of their loved one [166], others were able to access adequate levels of post-bereavement support [183]. The domains of support ranged from an initial follow-up call to monthly memorial ceremonies [183]. The proactive nature associated with the bereavement follow-up contact provided by some hospices resulted in many benefitting from the service [159, 166, 183]. This is in line with caregiver preferences, as family-caregivers said that they valued the proactive contact from the hospice [179, 183]. This could also be considered as the minimum level of support necessary to ensure a gradual readjustment to a life without hospice involvement. This gradual adjustment could also be facilitated through the provision of pre-bereavement support whereby interventions delivered prior to death could help enhance the caregivers’ preparedness and acceptance [160].

Overarching finding 3: Family-caregivers appeared to place a high value on proactive support but they did not always consistently receive it

Family-caregivers valued staff acknowledgement of family-caregivers' needs [155, 173, 176]. In some instances, the evidence demonstrated the value that family-caregivers placed on respite care, especially during the terminal phase. However, some of the evidence suggests that the provision of some support mechanisms is likely to be reactive as opposed to proactive, although this was not openly acknowledged by family-caregivers. This is reflected in the following excerpt: "*the family was beginning to suffer from 'sitting up'*" [160]. This statement demonstrates that the family had already begun to feel the strain associated with caring for a loved one, particularly at night, before support was offered, thus demonstrating the reactive nature of the service.

Overarching finding 4: Choice was consistently valued by patients, thus creating a need for a wide range of activities

Patients placed significant value on having access to a wide range of activities; however, patient satisfaction seems to have dwindled [161–165]. Within the day therapy setting specifically, patients highlighted that the least satisfactory area of service was the limited number of activities that were available [161]. This is a crucial finding, as having access to a wide range of activities at the hospice was not just considered to be the sole reason for referral for some [17] but also one of the pinnacle components of day therapy, as evidenced by the substantial research focus on this aspect of hospices [17, 170, 177]. Throughout the included studies, reference is made to the need to consider the entire person and to meet their physical, emotional, spiritual, and social needs. Whilst it is abundantly clear that a patient's emotional and social needs are being adequately met, in reference to their physical needs, the evidence does not go beyond the remit of the alleviation of physical symptoms. This shortcoming left some respondents indicating that they would like access to activities to help keep them fit [17].

Overarching finding 5: Family-caregivers valued the provision of social opportunities and could therefore benefit from access to official social support networks

Whilst many caregivers highlighted that the help they received had a positive influence on their ability to cope [20, 26, 155, 173, 176], there are notable areas for refinement and improvement, especially in relation to the availability of social support. The evidence suggests that caregivers were not accessing official social support networks prior to the death of their loved one [183]. The evidence assimilated within this review demonstrates that caregivers are under tremendous amounts of psychosocial pressures; caregivers regularly discussed exasperated feelings of social isolation as a result of their role [155]. Whilst it is acknowledged that the need for social support was often met through the social interaction and relationships with immediate or extended family, for some family-caregivers, conversing with other members of the family could be challenging [155]. These challenges could range from finding it difficult to talk about the patient's physical condition to the altruistic nature of the caregiver themselves, which meant that they did not wish to burden their loved one [26]. The provision of a support network which extends beyond the family was seen as providing increased benefits [183]. This is further evidenced by Williams and Gardner [181], who demonstrated that caregivers would often take advantage of informal social opportunities resulting from shared rooms.

Discussion

This mixed-studies systematic review utilised patient and family experiences to infer values from the data, which in turn helped to identify outcomes of care that are important to all those who benefit most from its services. Whilst the qualitative studies map onto some but not all of the quantitative findings, it was the synthesis of studies in a matrix which helped not only to further emphasise the importance of hospice care but also to highlight the discrepancies in accounts across studies. This in turn provided a more robust narrative and elucidates to further work which needs to be done to negate the disparities evident in care across regions and between different hospice services.

Certain attributes of care were valued more depending on the hospice setting: social support for patients utilising the day therapy units, 24-hour support for families supported by the at home service, and pain and symptom management within the inpatient units. Despite this, the identification of shared priorities, that is, what patients and families deemed valuable, remained relatively consistent across the literature despite some discrepancies which could be attributed to geographic variation. This suggests that there are pivotal attributes associated with a 'good death' irrespective of the setting. The concept of a ‘good death’, however, can be complex and highly individual, which highlights the importance of neglecting a ‘one-size-fits all’ approach to care in favour of a system which offers continuous holistic assessments in response to the changing needs of both the patient and their family.

The quality of pain and symptom management received frequent commendation from patients and caregivers; however, perhaps surprisingly, it was the ability of hospices to deliver on the psychosocial domains of care which received consistently high praise. The social model of care associated with specialist palliative day therapy, where the importance of supporting the patients psychosocially is widely acknowledged, was considered one of the pinnacle domains of hospice care. This model was facilitated through the delivery of suitable activities specifically tailored to patients’ abilities, the encouragement of communication through the provision of peer support, and the development of friendships, which resulted in reduced feelings of isolation. In the context of this review, however, family-caregivers often expressed feelings of social isolation largely caused by insufficient social support [175]. The findings demonstrated that family-caregivers frequently sought informal methods to address these needs; however, such opportunities were scarce. When observing the wider literature, one can say with some degree of certainty that a social support network which understands the complexities associated with caring for an individual at the end of life would be beneficial [184].

Whilst it is beyond the purview of this review to demonstrate whether family-caregivers were receiving adequate social support from independent sources, the provision of social support within the hospice setting was lacking, and this issue remains. This lack of support may be due to an inequity in services that is caused by geographic variation, which has been highlighted across various domains within this review. It is safe to conclude that the provision of such services would complement and strengthen those which family-caregivers are already receiving.

Variations in hospice services were further accentuated when discussing out-of-hours telephone support, a service primarily utilised by family-caregivers. Whilst some family-caregivers recounted that they felt abandoned due to the lack of 24-hour telephone support, others recalled the great sense of comfort gained from knowing that this service existed, even if they never used it. Additionally, variations in the accessibility of the at home service were evident. Because a home death is often a patient's preferred choice [157], the at home service is a vital community resource. Whilst the End of life Care Implementation Board acknowledges the importance of supporting patients to die at home, this notion is heavily reliant on the availability of families who often have no or very little experience of caring for someone nearing the end of life. Some family-caregivers referenced the inequality of access to this specialist support, which demonstrates critical gaps in its availability; this is certainly not a new criticism in the literature. With the growth in the chronicity of certain malignant and non-malignant diseases, a greater demand on both palliative care services and family-caregivers will ensue and perhaps further accentuate these disparities in care. It is important to highlight that the views and experiences of patients suffering from a non-malignant disease are underrepresented in both this review and in the wider literature and therefore their needs cannot be fully understood.

The physical and mental burden associated with the caregiver role has been shown to influence bereavement outcomes, outcomes which are modifiable through the provision of suitable support [184]. Despite advisory bodies such as the National Institute for Health and Clinical Excellence (NICE) in the UK advocating for immediate and ongoing bereavement support being offered to close family and/or friends who are most affected by a death. These contrasting accounts within this review suggest that in some instances there is a lack of effective translation of policy in to practice. The universalistic approach to bereavement care whereby support is proactively offered to everyone was extremely valued; however, evidently this approach was not adopted by all hospices. Accounts about inequities surrounding this provision of care could in part be a result of the hospices using different approaches. Alternatively, the accounts about inequities surrounding access to suitable bereavement support could also demonstrate the temporal nature of the evidence and how practice has changed over time. Therefore, what people want from and value about hospice services seems to have evolved.

Finally, and perhaps unexpectedly, despite both patients and family-caregivers placing substantial value on the support they received, there was a lack of evidence to demonstrate the importance of hospice volunteers in helping to deliver this support. As recent years have seen the boundaries of the volunteer role expanding, one can only speculate that the minimal evidence base for this aspect within this review is the result of patients and family-caregivers having difficulty distinguishing between people who are staff and those who are volunteers. This role development may in part be due to the recommendations put forth by a number of reports published in recent years such as that commissioned by Help the Hospices entitled 'Volunteers Vital to the Future of Hospice Care' [131], which formulated a number of recommendations concerning the future development of volunteers. This report was based on the premise that they are vital in ensuring that those who are accessing support from hospices are receiving a high quality of care.

Strengths and Limitations

The strengths of the systematic literature review (*Chapter 4)* lay in the a priori protocol, triangulation of synthesised qualitative, quantitative, and mixed-methods data coupled with an explicit, rigorous, and systematic approach which helped to identify an empirically derived answer to a focused research question [185]. Exhaustive data-searching helped minimise bias, thus placing this method ahead of alternative methods such as rapid evidence reviews [186] and ensuring future replication is possible [185]. Qualitative findings were then appraised using GRADE CERQual to identify issues related to methodological limitations, coherence, adequacy, and relevance which, ultimately determined the confidence in the findings. Each of the qualitative review findings were judged using a confidence level of 'moderate' or 'high', thus suggesting that a reasonable representation of the phenomenon of interest had been provided and that transparency had been increased.

Although a comprehensive search strategy was created and informed by an information scientist, the search was restricted to English language studies only and thus, there is a possibility that potentially relevant papers were missed, which affects the generalisability of the findings beyond UK and Irish contexts (Ireland and Northern Ireland have an all-Ireland palliative care alliance). Whilst the single-screening approach has been lauded as an appropriate methodological shortcut, this is dependent on the experience of the reviewer [187]. This is therefore a limitation of this systematic review, as the screening process was conducted independently by a novice researcher with only a random sample selected to be cross examined by a second reviewer.

Further complexities were added when attempts were made to extract patient and carer-specific data from studies which investigated both groups. As the data were synthesised, it created a possible risk that group-specific values may have been overlooked. As most of the included studies were not designed to address the review question, the findings represent hypotheses and propositions regarding what people value based on an interpretation of their experiences, attitudes, or level of satisfaction. This could, however, be deemed a strength, as it provides a theoretical basis to explore in future studies.

The review as reported in the thesis is methodologically incoherent as a different review design was retrospectively applied after the analysis, synthesis and reporting was completed. In doing so, the findings reported in the thesis align more with an integrated review design whereas the methods were originally conceptualised, reported in the protocol, and methods section of this thesis as a sequential exploratory review design.

Conclusion

This is the first review to explore what patients and family-caregivers value about hospice care. The findings strengthen the existing evidence base and provide new insights beyond symptom management and health outcomes. Of particular importance was the value placed on services that are only usually provided by hospices, such as highly individualised care (e.g. personalised catering), befriending, social support, meaningful occupation, and bereavement support. The large disparities in the availability of services, the underrepresentation of patients with non-malignant diseases and the limited evidence base demonstrating whether the social needs of family-caregivers are adequately addressed mean that there continue to be considerable gaps in evidence that warrant further research. These findings are important for the further advancement of interventions and supportive services. The findings from this study informed the subsequent qualitative study (*Chapter 5).*

Chapter 5 : Qualitative study of the key benefits and outcomes experienced and valued by patients and family-caregivers accessing- a hospice day therapy unit, inpatient unit, or at home service

ABSTRACT

INTRODUCTION

The existing literature provides limited insight into the combined views and experiences of hospice care and fails to determine the values imbued from services by multiple stakeholder groups. To address this, stakeholders must be directly involved stakeholders in palliative care research despite the ethical challenges associated with this (C*hapter 1*). By doing so, a greater understanding of the services they value is achieved which in turn informs practice and ensures that care is aligned with their preferences. The purpose of this qualitative study was 1) to explore patients', family-caregivers', and paid and volunteer personnel's experience of hospice care and ascertain what aspects of service provision matters to them, and 2) to identify the outcomes experienced by the stakeholder groups post hospice intervention to develop indicators for the quality of palliative care.

METHOD

This multi-site qualitative study employed semi-structured interviews and focus groups, conducted across four stakeholder groups between March 2017 and November 2018. Participants were purposefully recruited from subsets of hospice stakeholders with direct or indirect experience of one or more of the following hospice services: 1) inpatient unit, 2) day therapy service, or 3) at home service in either a personal or professional capacity. The interviews and focus groups were recorded, transcribed verbatim, and analysed using Framework analysis.

FINDINGS

Seven principal phenomena were derived that best described patients' and family-caregivers' experiences of hospice care and what they valued. For the purposes of SROI methodology, the following phenomena were considered outcomes: improvements in relationships, physical and psychological symptomology, mobility, informedness, social isolation, and autonomy. The alleviation of patient symptomology had a profound impact on the psychological well-being of both patients and their family-caregivers. Differences exist between various stakeholders regarding the perceptions of some dimensions of quality of

care. With suicidal ideations rife amongst patients prior to their admission, the availability of hospice care to underrepresented populations warrants further research. Despite the rigorous ethical processes commonly associated with palliative care research, the value of understanding patient and family-caregivers experiences has been revealed within this study.

CONCLUSION

The findings that identify what patients and family-caregivers value about hospice care have strengthened the existing evidence base and begin to address gaps within the current literature. As with previous studies, the inherent difficulties associated with recruiting participants for palliative care research have been identified; however, despite such challenges, the target sample size was still achieved.

Contribution to the SROI analysis

The qualitative research presented in this chapter was undertaken to explore what patients and family-caregivers valued and the outcomes they desired or experienced from hospice care. Interviews were undertaken with key stakeholders including patients, family-caregivers hospice volunteers, and staff. To ensure that each outcome experienced by stakeholders was not shown as duplicated in the results, a chain of events (represented by flow charts) was established to guarantee that each outcome represented the end point in the chain (and was thus included in the impact map). Semi-structured data collection methods comprising open-ended questions that were informed by the findings and the framework developed during the mixed-studies evidence synthesis (*Chapter 4*) were used to organise and collect data. This qualitative study contributes to the mapping outcomes stage of the SROI methodology *(Figure 5.1).*

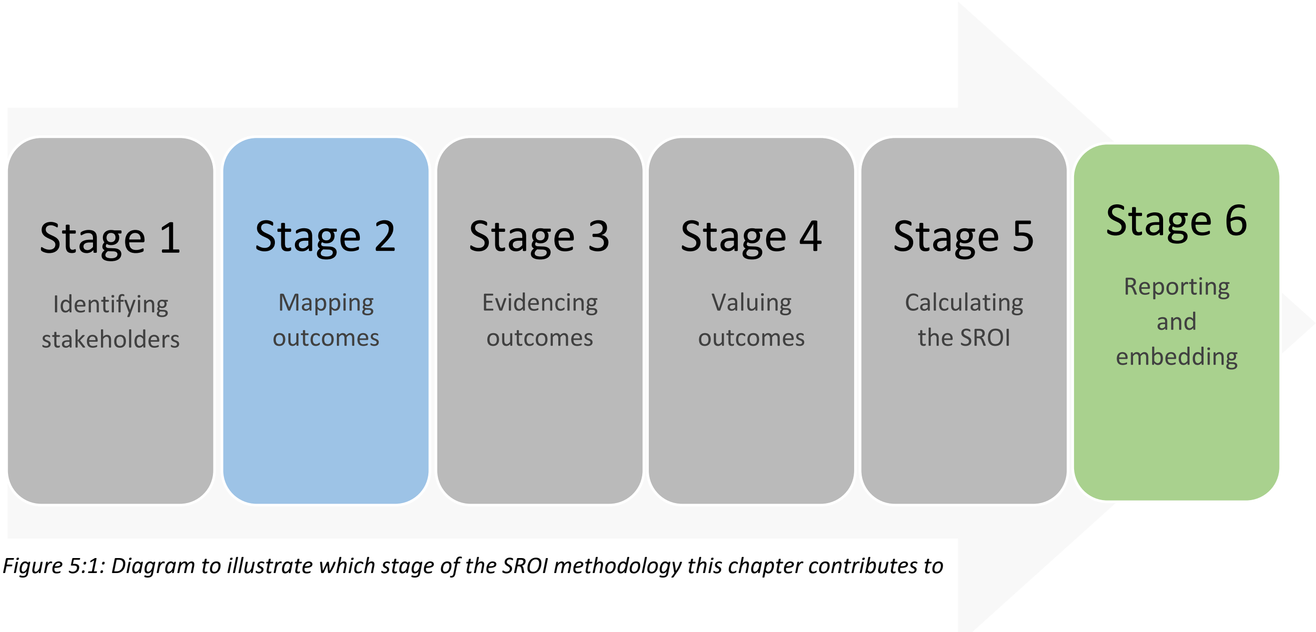


Figure 5:1: Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

The scope of palliative care research has often proved limited because, in recent years hospice care has become synonymous with cancer – the primary determinant of access to palliative care [188] (*Chapter 1*). Furthermore, the scarcity of research carried out within hospice inpatient units and at home services (*Chapter 4*) hinders the generalisability of the findings and results in substantial gaps in the evidence base. Although ‘National Guidance for End of Life Care’ [189] has been published to ensure that evidence gaps are addressed, the extent to which these recommendations have been met to date remains unclear.

Prominent within the literature, however, is the existence of participant- and system-level barriers, which are numerous and complex and influence the design of the research [58]. These challenges relating to recruitment into palliative care research are commonplace due to the nature of the patient population, the heterogeneity of the symptomology, and the unpredictability of illness trajectories. Augmenting these challenges is the assertion by some that patients suffering from a terminal illness are unable to benefit from participating in research [190]. Consequently, much of the debate surrounding stakeholder experiences, particularly the patient experience, has often been defined by and filtered through the views of others or through the inclusion of patients who are not considered to be nearing death – typically those utilising day therapy or respite services. Failing to engage directly with and understand the views, experiences, and values of all patients, irrespective of age, diagnosis, socio-economic background, and ethnicity, will inevitably result in consequences for future health care delivery because services will fail to adapt to individual patient need [191]. Whilst indicators of quality are often determined using satisfaction questionnaires, the responses to these often lack the richness of data that can be acquired through active involvement of stakeholders in qualitative research, and thus may not be sufficiently grounded in the values of stakeholders when used in isolation [191]. Despite well-documented ethical concerns [51], more in-depth methods with palliative populations are required to explore experiences which are often complex and multifaceted.

Aims and review question

The qualitative study reported in this chapter was undertaken with patients, family-caregivers, paid personnel, and volunteers recruited from across three hospice service types. The research aims were: (1) to explore patients', family-caregivers', paid personnel's, and volunteers' experiences of hospice care and ascertain which aspects of service provision matter to them and (2) to identify the outcomes experienced by patient and family-caregiver stakeholders post-hospice intervention.

Methods

Study design

This primary research study employed a qualitative design informed by the framework method of data collection and analysis as described by Ritchie et al [192]. Framework analysis is an applied method deemed appropriate for this research study due to its suitability for clinical and applied policy questions such as those explored within this thesis. The deductive process involved deriving pre-determined themes and codes from the mixed-studies evidence synthesis (*Chapter 4*), which was subsequently used to develop the a priori framework depicting what patients and family-caregivers valued about hospice care and the outcomes of care, and gaps in current knowledge. In turn, this framework contributed towards the design of both the sampling strategy and the interview schedules. The a priori coding framework was later expanded to include additional inductive codes to incorporate emerging new concepts and explanations in the primary qualitative data.

Epistemology

Framework analysis is epistemologically congruent with the methodological approach (thematic synthesis) used earlier in the mixed-studies evidence synthesis (*Chapter 4*). Thomas and Harden's [144] thematic synthesis and Framework analysis are both located on the critical realist side of the idealist to realist continuum. The initial a priori coding framework (*Chapter* 4) ensured that the primary qualitative data collected in this study was immersed in real-world experiences obtained directly from patients' and family-caregivers' experience of practice, which fits well with a critical realist epistemological position. The mixed-studies review also revealed gaps in what we know about real-world experiences, which were identified in the initial a priori framework and explored in this primary study.

Participant recruitment

Participant sample

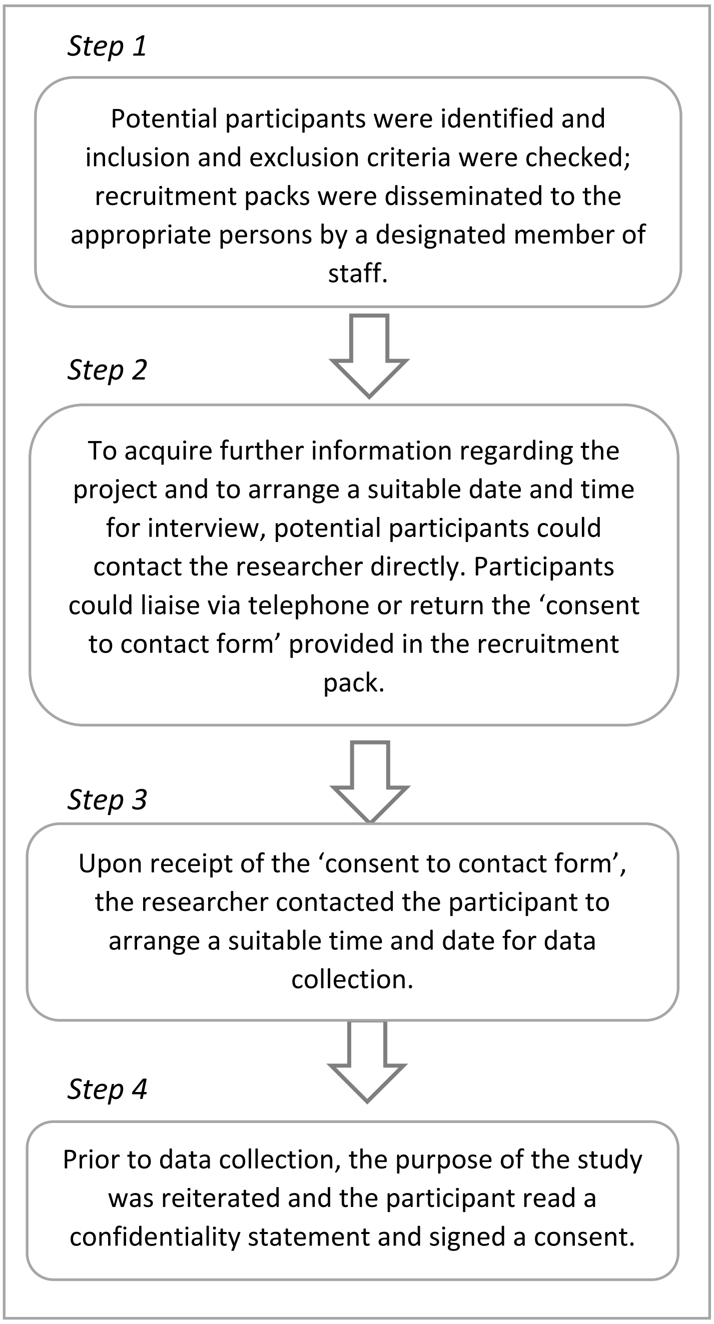
The aim of this multi-site study was to purposefully recruit subsets of hospice stakeholders who had direct or indirect experiences of one or more of the following hospice services: 1) inpatient unit, 2) day therapy service, or 3) at home service in either a personal or a professional capacity. Purposive sampling was considered to be the most appropriate method of obtaining relevant and rich data relevant to the research question. The sampling framework *(Table 5.1)* was designed to recruit a total of 40 paid and/or volunteer personnel from both clinical and non-clinical backgrounds and 64 patients and/or family-caregivers (see findings for participant breakdown). The home-based service at Site D did not have the capacity or capability to aid in the recruitment of patients and family-caregivers.

Table 5:1: Sampling framework

Recruitment Phase	Hospice Stakeholder	Method	Rationale
Phase 1	Clinical and non-clinical personnel	1-2-1 interview	A range of clinical and non-clinical roles were purposively sampled by profession (e.g. doctor, nurse, chef) to explore their perspectives on working within a palliative care setting and the perceived effect of their role on patients and family-caregivers. All hospice sites contributed to this data set.
	Volunteers	Focus group	
Phase 2	Patients	1-2-1 interview or interviews as patient-family-caregiver dyad	Patients and family-caregivers were purposefully sampled to explore their experiences of hospice care.
	Family-caregiver	1-2-1 interview or interviews as a patient–family-caregiver dyad	

Recruitment

As a consequence of upgrading the author from a Research Masters qualification to a PhD, the recruitment of participants was conducted in a stepwise process. After the appropriate ethical approvals were received from Bangor University College of Business, Law, Education and Social Sciences (CBLESS), the first phase of the recruitment could begin; it aimed to purposefully recruit both paid and volunteer personnel to report as proxies on patient and family-caregiver outcomes. Upon confirmation that the author had upgraded to a PhD, ethical approval was sought and received from NHS REC 4 (ethical procedures are detailed below) to directly recruit both patients and family-caregivers from each hospice site. To ensure compliance with the ethics application submitted to NHS REC 4, the recruitment of patients and family-caregivers was capped at 64 or alternatively, had to cease on reaching data saturation. Two strategies were employed to improve recruitment: 1) the facilitation of regular meetings with the hospice personnel to promote the study, 2) the appointment of a designated member of staff who was responsible for the dissemination of recruitment material to the appropriate person(s) (*Appendices 4.2–4.16*). The recruitment process is shown in *Figure 5.2.*



Step 1

Potential participants were identified and inclusion and exclusion criteria were checked; recruitment packs were disseminated to the appropriate persons by a designated member of staff.

Step 2

To acquire further information regarding the project and to arrange a suitable date and time for interview, potential participants could contact the researcher directly. Participants could liaise via telephone or return the ‘consent to contact form’ provided in the recruitment pack.

Step 3

Upon receipt of the ‘consent to contact form’, the researcher contacted the participant to arrange a suitable time and date for data collection.

Step 4

Prior to data collection, the purpose of the study was reiterated and the participant read a confidentiality statement and signed a consent.

Figure 5:2: Recruitment process

Inclusion criteria

The inclusion criteria for each participant group differed. Staff and volunteers had to be current employees with experience of the day therapy, inpatient or at home service. Patients and family-caregivers also needed to have experience of one of the three services and be over the age of 18. As the hospices are adult only, all patients met the age requirements. Patient participation was not dependent on the enrolment of their family-caregiver. For those deemed unable to provide informed consent, exclusion from the research was not definitive as personal consultees were sought, as advocated by the Department of Health [193]. The consultee process is detailed later in this chapter.

Exclusion criteria

If patients were unable to provide consent and a personal consultee was unavailable, they were excluded from this study. Where personal consultees provided consent, participants were excluded if it was clear they were not well enough to participate. Participants were also excluded if they had not received support from the day therapy, inpatient, or at home service. Due to resource restrictions, participants unable to communicate through the medium of English or Welsh were excluded.

Recruitment material

As part of 'patient and public involvement' (PPI) [194], participant-facing materials were developed in collaboration with the North West Wales Cancer Patient Forum.[2] In an attempt to maximise recruitment, posters (*Appendix* 4.8) advertising the research were displayed intermittently across each study site and multidisciplinary staff meetings were attended weekly by the lead researcher to promote and encourage the recruitment of participants. All documents were bilingual.

Topic guides

To elicit the views and experiences of key stakeholders in sufficient depth, a conversational approach was adopted alongside the use of four semi-structured topic guides (paid

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[2] The North Wales Cancer Patient Forum is a collection of individuals who have been directly or indirectly affected by cancer. This forum provides an opportunity for stakeholders to share their knowledge and experiences to facilitate the improvement of cancer services across North Wales.

personnel, volunteers, patients, and family-caregivers) *(Appendices 4.17-4.20).* Informed by the literature review in *Chapter 4,* the topic guides were developed and piloted to ensure that the data collected addressed the aims of the study and explored any gaps in the knowledge base without causing additional distress to participants. The topic guide was exposed to the rigours of the field as the first couple of interviews from each of the separate stakeholder groups were used to pilot the topic guide and the necessary changes were made. The data received during the piloting phases was retained.

Setting

A mutually convenient time and location for the interviews/focus groups was arranged via telephone. Whilst the focus groups and interviews with hospice personnel and volunteers took place within the hospice, interviews with patients and family-caregivers were conducted either in the hospice or in their homes. Although all attempts were made to ensure the interviews were uninterrupted, there were instances when minor disruptions occurred. Sometimes volunteers entered and asked patients what they wanted to eat, participants had to take phone calls, and family-members came to visit. The majority of interviews involved the lead researcher and the interviewee; however, in some cases, the patient and family-caregiver chose to participate as a dyad. In one instance, an interviewee requested to be interviewed in Welsh so the interview was conducted by a colleague of the lead researcher who speaks fluent Welsh, although the lead researcher remained in the room and was able to ask additional questions via this colleague.

Data collection

To obtain a comprehensive understanding of the phenomena of interest, two data collection methods were employed. There is strong evidence to suggest that conducting semi-structured interviews is the best method of investigating sensitive topics [195], and therefore these were conducted with 1) patients, 2) family-caregivers, and 3) paid personnel in this primary research study. Volunteers, however, participated in focus groups as they were integrated into routine meetings and consequently were deemed the most appropriate data collection method for this stakeholder group (*Table 5.1*). All data was collected between March 2017 and November 2018. Participants were given the option of participating through the medium of Welsh or English and a suitably qualified Welsh-speaking researcher was chosen to facilitate in these instances. Field notes were made at the end of each interview to reflect on the experience, the setting, responses to questions, and the non-verbal expressions of the participants.

Validity, reliability, rigour, and researcher reflexivity

To establish a high degree of rigour, validity, and reliability, qualitative research must be conducted in a manner which is precise, consistent, and exhaustive. By recording and systematising findings in sufficient detail, it is hoped that the reader is able to determine whether the findings are reliable. Widely recognised criteria developed by Lincoln and Guda [196] provide a number of recommendations which aim to enhance a study's validity; one suggestion is that there should be 'prolonged engagement'. Prior to the commencement of this thesis, the author had had no involvement with any form of palliative care setting in either a personal or a professional capacity. Subsequently, everything learnt during the data collection phases was new to the author. Through regular stakeholder meetings and on-site visits, thorough immersion in the research field was achieved, thus contributing to the lead researcher's knowledge base. Although palliative care is considered to be a sensitive field of healthcare with a range of challenges for research, Woodthrope [197] argued that death is more than just a sensitive subject as it is a universal phenomenon with far-reaching effects. Consequently, it is likely that the research conducted within this field will resonate with any personal losses experienced by the researcher. This will inevitably blur the boundaries between the research and researcher. Poignantly, during this primary research study, a hospice volunteer who was a participant and who later facilitated the recruitment of a range of stakeholders sadly passed away. To minimise the emotional impact of this, various reflexive practices were encouraged. The number of interviews and/or focus groups conducted in a day was limited, an appropriate amount of time was scheduled between each interview and/or focus group, regular debriefing meetings were held with the supervisory team, and a reflective journal was maintained.

To enhance the auditability of the data-handling and analysis, the framework approach (operationalised below) coupled with the use of the data management software NVivo contributed heavily towards the creation of a clear audit trail. This was further supported through attendance at weekly supervisory meetings where the progress of the study was discussed and any issues resolved. Pilot interviews were initially undertaken with colleagues from Bangor University to screen questions in the topic guide to ensure appropriateness. The audio recordings then offered further guidance for reducing bias as cues of encouragement such as ‘uh huh’ and ‘yeah’ were discouraged by the supervisory team to ensure neutrality. Through the use of a reflective journal, the paralinguistic features which could affect the context of the interviews and/or focus groups were adequately recorded. Member checking, which involves returning transcripts to participants to check for accuracy, was not employed during this qualitative research study. Due to the unpredictable trajectory often associated with a palliative diagnosis, participants may have been in a different phase of their illness and thus there was the potential for distress. Notably, some participants with neurological conditions disclosed that they were self-conscious of their ability to talk and therefore, returning verbatim transcribed data could have exacerbated feelings of discomfort or embarrassment.

Ethical considerations

Ethical approval was gained from two separate bodies prior to the commencement of this dual-phase primary research study. For the first phase, ethical approval to recruit hospice personnel was obtained from Bangor University College of Business, Law, Education and Social Sciences (CBLESS) (date: 21.10.2016). A separate application was made for patient and family-caregiver recruitment, which was approved by the NHS Wales Research Ethics Committee (REC) (date: 17.08.2017, reference number: 17/WA/0399) and the Bangor University College of Business, Law, Education and Social Sciences (date: 17.08.2017). Prior to the commencement of data collection, Disclosure and Barring Service (DBS) clearance was obtained by the researcher so that they could interview vulnerable people in this research study. Annual reports were submitted to the NHS REC in accordance with their research governance requirements. For any interviews conducted at a participant’s home, Bangor University’s lone working policy had to be followed. As the research involved meeting vulnerable people for the first time, there was an ‘unknown’ element and this therefore had to be managed. Through voluntary commitments with Victim Support, the lead researcher had extensive experience of such scenarios. Both before and after the interview, the lead researcher called their colleague to inform them that they were safe. If no call was received after 90 minutes, authorisation was given to open a sealed envelope at the office which contained the address of the interview participant. Additional help could then be sought if required. If for any reason an interview was expected to last more than 90 minutes, the lead researcher would contact their colleague to provide a new check-in time.

Consent processes

Initially, participants were provided with a recruitment pack containing a consent to contact form. Following the completion and return of this document, potential participants were contacted to confirm their involvement in the project and a suitable time, date, and location for the interview/focus group was arranged. Despite the recruitment pack providing a detailed overview of the study, the information was reiterated at the beginning of each interview and focus group. Prior to the commencement of each interview/focus group, participants were reminded that their involvement in the study was voluntary and thus could be withdrawn without any repercussions. It was stated clearly within the information pack, however, any data obtained prior to their withdrawal would be retained. The consent process for all participants followed a similar process; however, for patients, it was necessary to continually reassess their ability to provide informed consent.

Assessing mental capacity and competence to consent

Before conducting each interview, written or verbal consent was obtained from each participant. Due to the nature of the research, it was expected that some patients and family-caregivers would be living with various physical and/or cognitive impairments, communicative difficulties, or other complex needs. Thorough discussions were undertaken with the supervisory team and a final decision was made by the lead researcher regarding including participants who lacked capacity (either temporarily or permanently). Excluding person(s) who lack the capacity to consent was deemed discriminatory and was considered to limit improvements in the standards of evidence-based healthcare for this population. The guidance of the 'Royal College of General Practitioners' [198] on assessing capacity was utilised to ascertain participants' suitability and the steps are set out below:

1. Can the person(s) communicate their decision?
2. Does the person(s) demonstrate an understanding of the information provided to them?
3. Can the person(s) retain the information long enough to make an informed decision?
4. Does the person(s) have the ability to weigh up the information provided to them in order to make an informed decision?

As asserted in the Mental Capacity Act 2005, participants were assumed to have the capacity to give informed consent unless proven otherwise through discussion [199]. As specified in the Mental Capacity Act 2005, where participants were found to be lacking capacity, a personal consultee could be appointed.

Data storage, confidentiality, and data protection

In compliance with the terms of the General Data Protection Regulation (GDPR) [200], all personal data received during the study was collected and stored following the necessary safeguards. Bangor University served as the study sponsor and data-controller. Assurance of confidentiality was discussed with each participant at the outset and was further addressed during the data-collection, data-cleaning, and dissemination phases as identifiers were removed. Often, the experiences of participants were unique, and careful consideration regarding the use of certain illustrative quotes was required in order to prevent them from being linked to a participant. Participants were informed that the information they shared throughout the duration of the data-collection phases was considered confidential unless a disclosure was made which raised concerns that they or someone else was at risk of serious harm. Disclosures of medical misconduct would be discussed with the supervisory team and the appropriate safeguarding procedures followed, if deemed necessary.

Paper documentation, such as consent forms, was stored securely in a locked filing cabinet which was located in an office with a keypad-controlled entry. Electronic data such as digital recordings and subsequent transcripts of them were stored on a password-protected computer. The transcripts were cleaned and anonymised, thus removing any identifiable data, and a unique reference number was provided to each participant. All digital recordings were erased from the digital recording device and uploaded onto an encrypted computer. Following the completion of this study, all data will be stored securely for a minimum of five years and entrusted to the custodial care of Bangor University.

Data analysis

The use of Framework analysis [192] offered a structured approach to analysing the qualitative data set across the focus groups and interviews. The initial a priori coding framework, derived from the evidence synthesis (*Chapter 4*), provided the initial grounding in the data and the inductive component ensured that the experiences of the participants and the perspectives attained as part of this primary research study are clearly represented within the analysis. The next section sets out the five distinct phases of this practice as promoted by Ritchie et al [192]: familiarisation, identifying a thematic framework, indexing, charting and mapping, and interpretation. To complement this approach, NVivo was used as a qualitative data analysis tool to assist with the organisation of the data.

Stage 1: Familiarisation

Familiarisation with the phenomenon of interest and research questions started during the mixed-studies review and the development of the a priori framework. Familiarisation with the data set was a substantial stage in this process as the interviews were conducted over an extended period of time. Due to time constraints, 26 interviews and two focus groups were transcribed verbatim by the lead researcher and the remainder were sent to an independent transcription company. Listening to recordings, reading transcripts, and transcribing ensured thorough immersion within the raw data and subsequently enabled the lead author to gain a feel for the richness, depth, and diversity of the data set. In turn, this facilitated the identification of emergent themes. Line-by-lining coding was the main aspect of the first phase. Transcripts were not returned to participants for comment or correction.

Stage 2: Identifying a thematic framework

This stage of the process involved balancing different procedures: deriving deductive coding using an a priori framework (developed through the evidence synthesis), identifying gaps in evidence, and inductively deriving new codes from the primary qualitative data. This continued development resulted in several iterations of the thematic framework being produced until it was finalised and ensured a comprehensive data-driven approach. This reduced the potential for elements to be missed, which may have happened if an a priori approach had been solely relied on. *Table 5.2* presents an example of the coding framework.

Table 5:2*:* Example of a coding framework (family-caregiver example)

Theme, Code	**ID/Page/Line No.**	**Demonstrative code**
Improved relationships: • *Time to themselves*	FC-27/04/174-177	I do the donkey work in the house. I've had to take it on which is fine, not a problem. I come back and occasionally, it's the one time in a week where I can get an hour with the newspaper and have an hour to myself, which helps.
Psychological improvements: • *Psychological improvements*	FC-27/02/46-52	*She's a better person. She's happier. So psychologically, there is no treatment for her but these Monday's she can't be helped physically, but my goodness it helps her psychologically, and it helps me psychologically.*

Stage 3: Indexing

During this stage of the process, the framework of codes was systematically applied to each transcript. Facilitated by line-by-line coding, relevant passages of text were highlighted and assigned a particular code by the lead researcher. Throughout this process, there was an opportunity to refine the framework if deemed necessary. The thematic framework was routinely scrutinised during supervision and revised.

Stage 4: Charting

Once the data had been coded with reference to the thematic framework, a matrix was designed to both manage and summarise the data by theme. To ensure clarity, separate matrixes were constructed for each stakeholder group *(Figure 5.3).* The format of each matrix facilitated the identification of potential patterns which emerged in and between stakeholder groups.

ID/Page/Line no.	Improved sense of informedness for patients and family-caregivers	<Files\\Day Therapy Patient and Family-caregiver 32> 1 reference coded [11.46% coverage]
P03/05/245-267	Financial worries Signposted to appropriate service by hospice Advice attained from hospice regarding ability to work	**I: Earlier, you made reference to the financial implications associated with your diagnosis; are you able to discuss this?** **P:** After statutory sick pay ran out, we weren't getting any money and as the wife said, she was phoning all the time and she was getting passed from one department to another. **FC:** They say [day therapy staff], he can't go to work because of the risk of infection. He has a feeding tube. He had letter off the counsellor as well explain [that he was unfit to work] and the first time they refused it [Personal Independence Payment (PIP)]. **P:** Because I worked for all those years, I should have had enough money to keep myself. The this is, the money I've earnt and saved, that's for when I'm old. **FC:** National insurance is for when you're out of work. **P:** I failed the assessment. I didn't have enough points and I was in a hell of a state. **FC:** He could hardly speak [consequence of throat cancer] so I was doing the talking. **P**: I was signposted by the hospice to a service, and they were able to help. I was reassessed eventually and they found me eligible for PIP.

FC = Family-caregiver, P = Patient, I = Interviewer

Figure 5:3: An extract from NVIVO demonstrating the charting process used for one theme

Stage 5: Mapping and interpretation

In line with the central tenet of Framework analysis, this stage of the process highlights the transparency of the method as it provided scope for the data to be checked against its original form (i.e. transcripts, audio recordings, and field notes). The field notes helped to guide the interpretation and understanding of the interview transcripts.

It is at this stage when further amendments such as the merging of themes could be made; however, no further changes were required and the final thematic framework for this primary research study became fixed.

Reporting

The Consolidated Criteria for Qualitative Research (COREQ) reporting guideline and checklist [201] was used to guide the reporting of this qualitative study *(Appendix 4.21).*

Findings

The following section begins with a description of participant characteristics before providing a summary table to demonstrate the value of hospice services to patients and family-caregivers. This is followed by a report concerning the thematic findings. Ninety-six participants were recruited from three hospice services (inpatient, day therapy, and at home services). Despite multiple attempts, the researcher received no response from two patients and two family-caregivers after receipt of their consent to contact forms.

Participant characteristics are displayed in *Table 5.3 and Table 5.4.* This primary research study included one patient who was unable to give informed consent. Resultantly, a personal consultee was appointed. Although both the semi-structured interviews and the focus groups were scheduled to last between 30 and 60 minutes, there was flexibility to allow for longer or shorter timescales to fit with the participants' requirements. Consequently, interviews lasted between 11 and 105 minutes and data was produced for a total of 2,724 minutes (45 hours); focus groups lasted between 65 and 99 minutes. Whilst the final purposive sample was predominantly female, this imbalance is reflective of the gender divide present at each of the study sites at the time this study was conducted (*Chapter 3*). All data is reported as a single entity but individual stakeholder values and perspectives were teased out. To demonstrate the causality between outcomes and prevent double counting, a diagram referred to as a chain of events was created for each identified outcome *(Figures 5.4–5.10).*

Table 5:3: Participant characteristics of patients and family-caregivers

Participant characteristics		**Inpatient Unit**		**Day Therapy Unit**	
		Patients (n=10 (%))	Family-caregivers (n=4 (%))	Patients (n=35 (%))	Family-caregivers (n=14(%))
Gender	Female	7 (70)	3 (75)	20 (57)	8 (57)
	Male	3 (30)	1 (25)	15 (43)	6 (43)
Age (Years)	25–34	-	1 (25)	-	-
	35–44	-	-	-	1 (7)
	45–54	-	2 (50)	2 (6)	2 (14)
	55–64	-	-	7 (20)	6 (43)
	65–74	6 (60)	-	10 (29)	3 (21)
	75–84	3 (30)	-	10 (29)	2 (14)
	85+	1 (10)	1 (25)	6 (17)	-
Diagnosis	Cancer	7 (70)	N/A	22 (63)	N/A
	Non-cancer	3 (30)	N/A	13 (37)	N/A
Ethnicity	White/White British	10 (100)	4 (100)	35 (100)	14 (100)
Total participants *N*=63					

Table 5:4: Participant characteristics of hospice personnel

Professional Category	**Role**	**Inpatient Unit**	**Day therapy Unit**	**Home Service**	**Total n=33 (%)**
Healthcare professionals	Nurse	X	X	YZ	03 (09)
	Senior specialty doctor	X[1]	X	-	01 (03)
	Health support worker	X	XY	Z	03 (09)
	Advanced nurse practitioner	XY	XY	-	02 (06)
	Consultant	X	-	-	01 (03)
	Matron	X	X	-	01 (03)
Social care professionals	Social worker	X	X	-	01 (03)
	Day therapy lead	-	X	-	01 (03)
Therapists	Physiotherapist	XY	XY	-	02 (06)
	Occupational therapist	X	X	-	01 (03)
	Music therapist	X	X	-	01 (03)
	Complementary therapist	XY	XY	-	02 (06)
	Diversional therapist	X	X	-	01 (03)
Volunteers	Volunteers	Q R S T U V W X Y Z		-	10 (30)[2]
Other personnel	Chef	X	X	-	01 (03)
	Community fundraiser	X	X	-	01 (03)
	Reverend	X	X	-	01 (03)
Total participants n=33 Total interviews n=31, Total focus groups n=2					

[1]Different letters indicate different staff members whereas the same letter indicates that the staff member worked across one or more of the units (e.g. the second row reveals that just one senior specialty doctor was recruited but worked across both the inpatient and the day therapy unit).[2]Ten participants participated in two focus groups. The first focus group consisted of four participants whilst the second had six participants.

Table 5:5: A summary of values across stakeholder groups

What do patient and family-caregivers value about hospice services?	**Inpatient**					**Day Therapy**			
	Patient	*Family-caregiver*	**Paid personnel*	**Volunteer*		*Patient*	*Family-caregiver*	**Paid personnel*	**Volunteer*
Availability and accessibility of the hospice services and staff were a source of reassurance	✖	●	✖●	✖●		✖	●	✖●	✖●
The personalities, expertise, and specialised skills of hospice personnel	✖	●				✖	●		
Opportunities to develop meaningful relationships						✖			
The provision of social opportunities enabled patients to talk to others who they considered understood what they were going through						✖		✖	
Timely access to a wide range of staff, services, and activities	✖	●				✖	●		
Time spent with staff was especially important as it ensured that participants felt that they were being listened to	✖		✖●	✖●		✖		✖●	✖●
Support to maintain psychological, spiritual, and emotional well- being	✖			✖●		✖		✖	✖●
Symptom management	✖		✖			✖		✖●	
The sense of control and autonomy attained through the promotion of opportunities to make well-informed decisions	✖		✖			✖		✖	
Access to practical support including financial and domestic support and signposting to other agencies			●			✖	●	✖●	
Being prepared for death, knowing what to expect as the illness progresses, and having access to bereavement support when needed. This is often facilitated through honest conversations	✖		✖●					✖●	
The provision of clinical information and advice and the opportunity to ask questions and obtain reassurance	✖	●	✖●			✖	●	✖●	
Respite care to allow valued breaks for family-caregivers	✖	●	●				●	●	

Access to personalised catering	✖		✖	✖		✖		✖	✖
Non-clinical hospice atmosphere provided a great sense of comfort to patients and family-caregivers.	✖	●	✖			✖	●		
The availability of hospice volunteers provided additional company			✖●	✖				✖●	✖
Access to an onsite café to ensure that family-caregivers did not have to leave the hospice to get food		●		●					●
Physical, practical, and psychological support for family-caregivers	✖●	✖●	✖●	✖●		✖●	✖●	✖●	✖●
Provision of alcohol as a treat (sparingly)				✖					✖
Access to a range of complementary therapies to help ease physical symptoms and psychological distress	✖		✖	✖		✖	✖	✖	✖

*Proxy views (*hospice personnel)* of what patients and family-caregivers value

Key: • Family-caregiver ✖ Patient

Table 5.5 summarises the wide range of elements that patients and family-caregivers valued across each service. Patients seemed to experience the greatest value due to their position as primary beneficiaries; however, the findings demonstrate the importance of hospice services to family-caregivers, albeit to a lesser extent. Volunteer and staff perspectives on what patients and family-caregivers value aligned with the information they provided; however, the volunteers and staff felt they were not personally valued.

Descriptive themes

Theme 1: *Increased feelings of autonomy and control over their life/personal environment due to the relationships formed with hospice staff*

Patient and family perspectives

The presence of highly qualified staff was pivotal to the experiences of patients and their family-caregivers; however, it was their personable qualities which became the central factor contributing to a higher standard of care. Honesty and patience were two traits which were regularly cited, but it was the ability of staff to go above and beyond their standard duties of care which had the greatest impact.

> *"One nurse last night, she came and sat with us, myself and my brother and sister and she just sat with us and explained what was happening. She was so kind and calm and gentle. Certainly my brother, who was just touched by how at the end of a long shift, she was able to just give us that time and explain how things were and they never seem to be rushed. It's always… whatever we need, it's been great" (Family-caregiver, Inpatient unit).*

The development of relationships with hospice personnel was crucial to the patients' and family-caregivers' sense of security. Opportunities for frequent interaction with nurses, healthcare assistants, and volunteers resulted in a degree of informality which helped to establish a rapport. Subsequently, service-users were able to partake in sensitive conversations which helped to address their worries and move from a place of fear to confidence.

> *"Meeting people, we all know why we're there, it's bonding with people as well. The staff, official and nursing, the care again and attention, but what's most important [is] that [it] keeps your mind on the go" (Patient, Day therapy).*

Commonly, participants highlighted the value of staff availability. The increased contact time resulted in the provision of a fundamentally different service to that rendered by alternative clinical settings.

> *"They're very caring, and you know, they always come up, would you like this would you like that. You know, they're just so nice, and even when we play games and things, charades and bowls. They're really nice, they join in with you, you know they don't...you know like some places, you see the staff going up talking, they don't here, they come in and they mix with you and that's what I like" (Patient, Day therapy).*

Notably, participants often reflected upon their past experiences of care and drew comparisons between clinical settings. As a consequence of limited resources, high patient turnover was commonplace, which resulted in insufficient levels of contact time between patients and personnel in other clinical settings. The lack of time afforded denoted a lack of care, as evidenced by the following exemplar.

> *"I would have to say on a positive side, because I have nothing but positive to say about them, it's just changed my opinion of hospice care. They actually do care, and compared to any hospital in this Trust or even outside this Trust, it was far superior care. You felt they care. You often don't feel that in a hospital" (Patient, Inpatient unit).*

The negative connotations associated with the term 'hospice', however, often acted as a barrier to early referral. Post-admittance, though, participants regularly noted the stark contrast between their original preconceptions and the reality of the care they received.

> *"People annoy me, they tend to think of, it's a hospice, well you go there you only go there to die. That's not true, that's not, that's not true by a long chalk; yes there are some people who are on their own going for end of life and there's not a lot they can do about it, but they certainly make everybody feel prepared and ready for it and cared for. But, if there is any way they can get you up and running again they will do; they'll move heaven and earth to do it, they really do" (Patient, Day therapy).*

Staff and volunteer perspectives

The perspectives of hospice personnel aligned with those of patients and family-caregivers in that they recognised the value of spending time with patients and their families. Unlike in other care settings, hospice staff were able to have more contact time, although their accounts did highlight barriers such as increased paperwork which could negatively impact their ability to maintain high levels of contact time.

> *"We've got more time definitely for patients, whereas I think the hospital is more task orientated and driven by medical things, you know, if the doctor required this and that and investigations. So more time definitely and the support comes into it again, we have more time, we can support them and then time again for difficult conversations and going into symptom management and stuff like that really " (Hospice personnel).*

A reduction in contact time is likely to negatively affect a service which is regularly described as the 'gold standard'. Because the contact time allowed was not very restricted, hospice personnel revealed that they were able to go far beyond their standard duties of care to provide a service unlike any other.

> *" I think they like to be able to spend time in the hospice. There is no restrictions on visiting times here, we try to adapt to individuals; everybody is different, there isn't any special rules for any one person, we try to adapt to the different ways that families want to be and different sort of things they want to do and if there is a special thing that patients want? Like we had two weddings last week. You know, we do our best, we have christenings, we had a horse in the other week, a lady wanted to see her horse so you know, you wouldn't get any of that in a hospital" (Hospice personnel).*

**Day therapy: This outcome was experienced by 15 patients; Inpatient unit: This outcome was experienced by 5 patients*

Figure 5:4: Chain of events for increased feelings of autonomy and control

Theme 2: *Improved friendships/greater support network which helped to reduce social isolation and loneliness*

Patient and family perspectives

The diagnosis of a life-limiting illness was often considered to be an isolating experience which contributed heavily to significant psychological decline. Loneliness, depression, and a lack of understanding from others were themes that featured prominently across patient interviews and, when coupled with the absence of an adequate support network, further compounded their deterioration.

> *"Do you know, to be honest, right before I came to the hospice, I had nobody" (Patient, Day therapy).*

Notably however, in instances where a strong support network was present, often the heightened sense of isolation had not been alleviated. This was understood to be a consequence of the inability of the patient's support network to fully comprehend all that living with a life-limiting illness entails. Subsequently, the patient's sense of loneliness was exacerbated.

> *"I've got loads of good friends, but none of them have got cancer. Bless them, you know? They really, really think the world of me, but they can frequently make me feel quite sad and worried, because they're concerned about me having cancer, whereas these friends here, we're all in the same boat… so we don't seem to upset each other at all" (Patient, Day therapy).*

Peer support, obtained through continued attendance at a day therapy unit, provided a forum in which whereby patients could share their experiences. In turn, this helped to create a sense of camaraderie, thus resulting in an overall improvement in their general well-being and an alleviation of previously noted deficiencies.

> *"You always think to yourself, well, there's somebody worse off than me, you know? You feel sorry for yourself sometimes, and then think, well, they have a lot more to be sorry for than I have" (Patient, Day therapy).*

Families also recognised the overwhelming patient benefit that peer support facilitated, as evidenced in the following excerpt.

> *"I think it is definitely valuable. For instance, there is two other ladies who are motor neurone disease. So, again, not that you'd ever wish this awful disease on anyone, but it was almost a comfort when she came home and said, there's this other lady, because they're going through and understand. It helps you put things in perspective. It's not a competition, but at the same time, you do actually see other people there who are maybe better off, but there are people there who are worse off too". (Family-caregiver, Day therapy).*

Peer support was not unequivocally positive, however, as the death of friends was often inevitable given the nature of palliative care settings and had a substantial effect on the well-being of patients.

> *"We've had a few – there have been a few hiccups, haven't there? We lost Richard, didn't we?" (Patient, Day therapy).*

Although patients received appropriate support, families did not and frequently deemed caring for a loved one an isolating experience.

> *"And I am a sole carer. All his family are in Coventry. So, I would have felt very much more isolated. And also, there are couples here as well. With this sort of thing, the change in the relationship is enormous, and you don't realise until it's happening how very big the changes are. It can be simple things, like, you know, Tom still makes the cup of tea. Well, the coffee. I'm useless… But, you know, it's other things. It's everything else you're responsible for, and it can be pretty heavy. And that in itself can be pretty isolating" (Family-carer, Day therapy).*

Further to this, there was no evidence to suggest that families had adequate access to a social support network whereby the views and experiences of like-minded individuals could be shared.

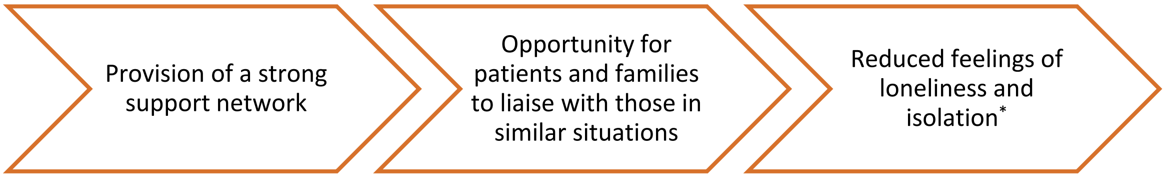
Staff and volunteer perspectives

Hospice personnel echoed the sentiments of patients and family-caregivers by reiterating the importance of peer support for patients. Staff believed that patients struggled to discuss their illness with those who had no experience of living with a life-limiting illness. This therefore exacerbated feelings of loneliness.

> *“[T]hey want to talk about the side effects quite a lot and they all pass on little bits of knowledge – have you tried this, have you tried that and it is lovely…. Quite often, they will say I can’t talk to my family because their families don’t want to talk about it, they just want to talk about them getting better, but it is important for them to talk about it” (Hospice personnel).*

Whilst there was no data to refute the absence of formal social support measures for family-caregivers, hospice personnel recounted many examples of how they were able to provide other supportive measures.

> *“You can sometimes go and see somebody and you’ll spend longer with their carers than you will with the patient themselves because they need that support and the same level of reassurance and care that everything is OK, that they’re doing everything that they should and it’s just reassuring them isn’t it that we will manage this and we will get through it. Even though the outcome isn’t good” (Hospice personnel).*



**Day therapy: This outcome was experienced by 24 patients and 4 family-caregivers; Inpatient unit: This outcome was experienced by 3 patients*

Figure 5:5: Chain of events for reduced feelings of loneliness and isolation

Theme 3: *Provision of information and advice which enhanced the ability to address practical issues*

Patient and family perspectives

Due to the unpredictable trajectory associated with a palliative care diagnosis, unrestricted access to support was pivotal to both the patient’s and their family’s sense of comfort, particularly in instances where specialised advice was warranted.

> *“He’s under a lot of clinicians and you get these worrying niggles that something is happening and you think, “Is that …?” But he comes here every Wednesday and they’ve got a doctor here. So I can pop in and say to the staff here “I’m concerned about this.” So it’s a complete medical back-up for me. You know that’s very important” (Patient, Day therapy).*

Easily accessible advice obtained through methods such as informal ‘drop-ins’ and telephone support resulted in psychological improvements and the mitigation of worries. In many instances, this often contributed to the prevention of unwanted hospital admissions. Across many accounts, patients reiterated that they would rather suffer at home than be admitted to hospital.

> *“It could be described as a drop-in centre as well, you can just drop-in and talk to people if you wanted to” (Family-caregiver, Day therapy).*

For patients, palliative diagnoses carried a substantial financial burden for themselves and their families, resulting in a diminished quality of life. The financial burden could be dictated by factors such as household income, socio-economic status, marital status, or the extent of the disease. In some instances, a diagnosis resulted in the loss of employment and associated income, thus resulting in an inability to cover related expenses such as childcare, domestic help, and medical equipment.

> “*My finances were really in a mess because I had to stop work, and I hadn’t worked long enough to receive statutory sick pay, so I only had one month of statutory sick pay. Then from January to April, I didn't receive any income at all. So when I started coming here, that was quite a priority with me, that I needed help to try and figure out what was going on, and they referred me to lots of different people, and the welfare officer came to see me. He started the ball rolling on getting me – what's it called? ESA. And that's a long process. So that’s a really practical thing. I was trying to support two children at home with no money coming in, and so that was something – I needed to see somebody every week till that got sorted. It was just lovely the way they [hospice] made everything so easy*” (*Patient, Day therapy*).

Whilst participants were aware that there was a benefits system, several were unaware of the finances they were entitled to and whilst others had previously received the wrong information. Sign-posting to appropriate agencies was pivotal to the improvement in their general well-being. The perceived limited capacity, however, particularly within the day therapy unit, resulted in participants longing for additional days. This perception was wrong, though, because the findings described in *Chapter* 3 reveal that the day therapy units at three of the hospice sites (A–C) were operating at just 35% to 42% capacity.

Staff and volunteer perspectives

The importance of accessing financial support was also highlighted across staff accounts. Many recounted scenarios in which they assisted the patient or family-caregiver despite the absence of a formal financial service.

> *"There's a lady who has very very poor sight who has been sent forms that she has to fill in but she can't because she has no family. She's going to bring them in and if we can't help her we will find somebody who can. [We will] make that appointment for her so she doesn't have to" (Hospice personnel).*

Hospice personnel recognised that the allayment of fears was a substantial aim for patients and, through information provision, could be easily achieved. Information regarding complex issues such as diagnosis and prognosis may placate certain patients, but for others, offering simple information regarding service availability may suffice.

> *"I think the majority of patients, their end would be very different, we help them to a degree to accept what's going to happen and talk through the fears where they can't with their family and I think they will miss out on that and I'm not saying they aren't afraid but I think they are less afraid and more aware of their illness then they would be if we weren't here" (Hospice personnel).*

**Day therapy: This outcome was experienced by 14 patients and 6 family-caregivers; Inpatient unit: This outcome was experienced by 3 patients*

Figure 5:6: Chain of events for improved sense of informedness

Theme 4: *Opportunity to have both the condition and the symptoms appropriately managed resulted in psychological improvements* for both patients and family-caregivers

Patient and family-caregiver perspectives

The enrolment of patients at a hospice facility often resulted in improvements in both physical and psychosocial well-being, although this was often limited. Due to the unpredictable trajectories typical of a palliative diagnosis and the natural deterioration associated with it, the management of symptoms is often challenging and requires a flexible approach. Perhaps surprisingly, a substantial finding unearthed suicidal ideations in a proportion of participants prior to their admission.

> *"So, without the hospice, I don't think I would still be here to be honest with you, because they were fantastic, and they still are" (Patient, Day therapy).*

Whilst psychological symptoms in patients with a terminal illness were prevalent, participants were not always explicit regarding their intent and their meaning was assumed. Subsequently, it could be deduced that prior to their admission to a hospice facility, depression amongst patients was commonplace.

> *"I wasn't seeing anybody, I'd just sit there and I thought, do you know what, I feel as if I'm just sitting here waiting to die" (Patient, Day therapy).*

This state of mind was somewhat reflective of the wider hospice population, although to varying degrees as the general consensus was that the absence of hospice care would have dire consequences. One patient said that they would probably:

> "[k]*ill myself or do something to myself" (Patient, Day therapy).*

Through access to a range of services and support mechanisms, however, patients were able to adapt to their circumstances. Ultimately, they were able to establish coping methods and benefited immensely from symptom management schemes, resulting in reduced feelings of worry.

Staff and volunteer perspectives

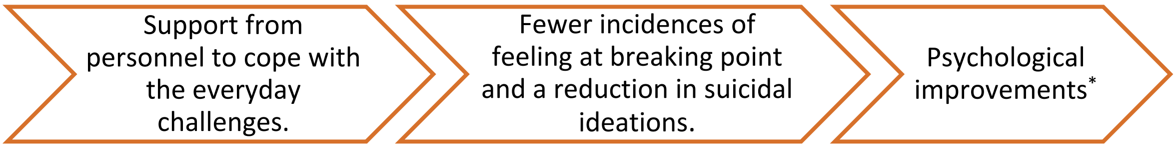
As the terminal nature of the disease unfolded, hospice personnel reiterated the range of psychological challenges faced by patients and family-caregivers. At a time when these two stakeholder groups are aiming to cope with concurrent losses of independence, status, a sense of self, and in some cases communication, extensive psychological challenges exist. These include, but are not limited to, depression, anxiety, and fear of death.

> *"I think for people that have a terminal illness, obviously it is really difficult for them, they have a lot to take in and they get quite anxious and worried about what is going to happen and it's almost like the illness takes over everything, it effects everything and I think that if they can have a time where they get to make music, have music therapy, it just, because you have to be, because it is all live and improvised, and in the moment, I think it gives*

> *them that chance, in music therapy, the illness isn't the main focus, it is more focusing on what they can do and so I think that's another benefit" (Hospice personnel).*

Personnel strived to minimise the impact of patient losses by helping them adapt and accept their new normal. This, in conjunction with the management of physical symptoms, provided much-needed relief to both the patients and their families.

> *"We speak through things, we listen, we go through any anxieties and uncertainties, we can speak through their actual disease if they are not clear on something; some people want to know what's ahead so we go through that and try do it as gentle as possible." (Hospice personnel).*



**Day therapy: This outcome was experienced by 20 patients and 5 family-caregivers; Inpatient unit: This outcome was experienced by 4 patients and 1 family-caregiver*

Figure 5:7: Chain of events for psychological improvements

Theme 5: *Improvements in patient functionality and mobility*

Patient and family-caregiver perspectives

Symptom management, whether related to the disease or a specific treatment, often had a substantial effect on a patient's overall quality of life. The pervasiveness of symptoms for both malignant and non-malignant conditions were reported to have resulted in a high level of functional dependence. Subsequently, the inability to maintain the physical capabilities necessary to live autonomously resulted in a loss of independence, thus leading to a heavy reliance on others. Enhanced mobility provided patients with a modicum of relief from a substantial stressor.

> *"I was restricted to what I could do. 'Don't do that, don't do this'. But I've been finding lately, well, not lately. Say, for a while now. I'll go in the garden and do a little bit of weeding for about half an hour. Come in and have a sit down, and a bit of a break, a cup of coffee. Go out, do a little, another half an hour, and then come in" (Patient, Day therapy).*

Through a range of support services such as physiotherapy, patients were strongly motivated to preserve their physical functioning through regular activity in a safe and controlled environment. As a result, patients experienced substantial improvements which helped them to regain some semblance of normality.

> *"Through having the exercise on the exercise bike, that's got my lungs working again which meant I was able to start taking the dogs for a walk… so that had an added benefit of giving me extra fitness as well. This last week, I was seeing the Rolling Stones in Manchester and that was a hell of a walk from where we parked the car. We took a couple of breaks but it was okay. So my fitness has improved coming here" (Patient, Day therapy).*

Staff and volunteer perspectives

The preservation of function was considered vital to overall patient well-being as a decrease in mobility can have substantial effects on a patient's daily life. Therefore, the implementation of measures to preserve, and in some instances improve, physical function helped patients reach important personal goals.

> *"Assisting someone to stand and take a few steps so they could walk down the aisle is a nice memory" (Hospice personnel).*

**Day therapy: This outcome was experienced by 7 patients; Inpatient unit: This outcome was experienced by 2 patients*

Figure 5:8: Chain of events for improved mobility

Theme 6: Improvements in overall physical health

Patient and family-caregiver perspectives

Debilitating issues such as pain, breathlessness, nausea, and poor appetite were prevalent across the sample. Consequently, their relief was prioritised by patients and provided the primary motivation for hospice admission. Notably, clear communication, active pain assessment, and access to immediate pain relief were crucial to the successful management of pain.

> *"Well I was in a lot of pain with a pain at the top of my spine, which I was told by my GP was a trapped nerve. I see the doctor every day here and its very much on a one-to-one basis, which is a lot more than I get when you go to the hospital, the main hospital" (Patient, Inpatient unit).*

Markedly, sources of physical symptoms were broad, have multiple aetiologies and their relief was complex due to co-occurring symptoms. As a result, individualised approaches to pain management are required.

> *"When I came in I was basically a bag of bones tied up with a bit of loose string, but I weighed probably something under seven stone. I couldn't stand because of pain in my ankles and knees, I couldn't walk obviously and at that time the prognosis wasn't very good and they were talking a matter of weeks. Fortunately, nobody told me the prognosis, so, I decided to get better thanks to the care and the fabulous food that this place provides. They got me a wheelchair and I was terrorising the place with my wheelchair and basically just getting better all the time" (Patient, Inpatient unit).*

Staff and volunteer perspectives

Whilst the pervasiveness of symptoms could be managed through a combination of medication, the use of alternative treatments such as aromatherapy and massage proved beneficial; personnel perceived improvements in physical outcomes for patients following such treatments.

> *"If somebody was a bit sickly we could get them some anti-sickness, get them complementary therapies if they had, you know, for example sore shoulders, we can massage the shoulders; we offer physiotherapy so if somebody is breathless sorting that out for them, acupuncture for different symptom management as well, the physiotherapist does that, so by them coming over here, improving the quality of life, making them a little bit better" (Hospice personnel).*

**Day therapy: This outcome was experienced by 14 patients; Inpatient unit: This outcome was experienced by 5 patients*

Figure 5:9: Chain of events for improvements in symptoms

Theme 7: *Hospice support helped to relieve family-caregiver burden which contributed towards improved patient-family-caregiver relationships*

Patient and family-caregiver perspectives

As a consequence of concurrent responsibilities often associated with the caregiver role, physical and psychological burden was rife amongst family-caregivers. This stemmed from the lack of prioritisation given to their general health and well-being, resulting in their needs often being overlooked. Consequently, family-caregivers were often forced to temporarily relinquish their role, thus sometimes causing unwanted admissions to the hospice. In turn, this had a detrimental impact on patient and family-caregiver relationships; this was reflected in the resentment present in the tone of certain patient accounts.

> *"My husband can't cope, basically; he has a chest infection so he's poorly himself so the only choice we have was for me to give and therefore I have come and I am in here" (Patient, Inpatient unit).*

Because of their increasing needs, a patient was often no longer able to contribute the same level of constancy to their relationships as they were once able to. Over time, due to both the physical restrictions often associated with a palliative diagnosis and the growing need for emotional support from the family-caregiver, a power imbalance was created. Subsequently, the patient–family-caregiver dyad often had to manage unfamiliar depressive symptoms such as irritability and anger.

> *"She's not been very helpful in that respect… so we've never been ill. We don't know what illnesses are about and now I have one and she's difficult, really difficult. I'm a victim here, I'm the one who's got cancer, she hates me because yes, I'm not getting better" (Patient, Inpatient unit).*

Due to the dynamic and non-linear trajectory associated with palliative patient populations, the complexity and scope of caregiving responsibilities are likely to expand over time. The negative impact of caregiving, however, can coexist with the positive; many caregivers revealed the benefits which could be derived from the experience. However, when family-caregivers were no longer able to assume the caregiving role, high levels of guilt were experienced.

> *"I suppose for me, it was quite hard taking him in because it's giving up that caring role. I'd retired to take care of [patient name], so realising I couldn't do it, was quite hard" (Family-caregiver, Day therapy).*

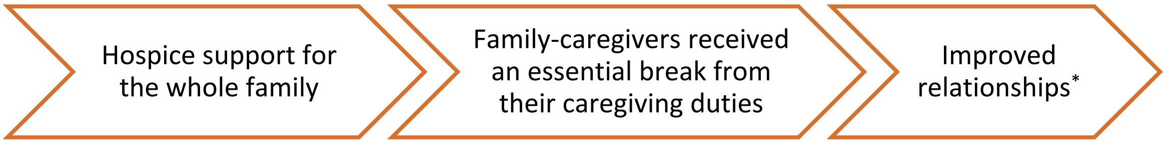
Respite was obtained through various means. For some families, an admission to the inpatient unit was the most appropriate option whereas for others a short stay at the day therapy unit was sufficient. Irrespective of the service utilised, in most instances, family-caregivers received the break that was necessary to enable them to continue in their caregiving role. Resultantly, they confirmed that respite had a positive effect on the patient–family-caregiver relationship.

> *"My relationship with my wife is usually better, certainly for a few days. Then she starts saying, when are you going back again?" (Patient, Inpatient unit).*

Staff and volunteer perspectives

The physical and emotional exhaustion of some family-caregivers was a concern for hospice personnel. Often, family-caregivers' exhaustion precipitated a patient's admission into the inpatient unit for respite care. To help alleviate the pressure, support from the hospice was made available to all families.

> *"She probably would have been very exhausted, the mental side to it as well because they were an elderly couple and sometimes the strain of it can also make them ill, and it's when they come here, it gives the carer that day to go off and do her hair or go shopping, knowing that he is safe and cared for here. Not like when she leaves him at home and she's rushing back because he's on his own or he needs something" (Hospice personnel).*



**Day therapy: This outcome was experienced by 8 patients and 12 family-caregivers; Inpatient unit: This outcome was experienced by 2 patients and 1 family-caregiver*

Figure 5:10: Chain of events for improved relationships

Discussion

The findings of this qualitative study offer important insights into the valuable role that hospices play in end of life care, and the positive effects on the quality of life of patients and their families were clearly evidenced. This study also provides, however, an insight into the detrimental effect of a palliative diagnosis on a patient's psyche and the necessity for adequate support networks, as many of our palliative sample revealed suicidal ideations prior to hospice admission. The systematic review, reported in *Chapter 4*, also showed that the debilitating impacts of a palliative diagnosis were found to be well documented, but suicidal themes were never discussed. Whether this presents a novel finding is yet to be determined; however, it does serve to highlight the importance of early access to palliative care interventions to alleviate symptom burden [1]. As noted by the sample population and supported by the wider literature [2], functional impairment and pain are indicators of suicide risk. Inpatient hospice personnel prioritise the physical management of symptoms and pain control [3], using opioids as the mainstay of pain control [4]. In this study, however, complementary therapies were heralded for their potential to reduce physical symptoms.

In line with the findings of the systematic review, reported in *Chapter 4*, family caregivers highlighted the isolating nature of their caregiving role and voiced concerns regarding the insufficient hospice support network. When assuming the role of family-caregiver, individuals often give priority to the needs of their dependent family member and hence become overlooked by health care providers [202]. In this qualitative study, the caregiver burden, a multidimensional concept, was attributed to the perception of patient symptomology, psychological distress, impaired social relationships, and financial crisis that arose from their caregiving duties. Respite care presents a resolution, but despite being a cornerstone service for family-caregivers and often the rationale for patient admission to the inpatient unit, it remains under-researched (*Chapter 4*). Although the objective of palliative care is to provide relief to both patients and family-caregivers, the evidence suggests that services fail to sufficiently deliver regarding the latter [203]. Notably, Barker et al [204] recognised that the development of trusting relationships with healthcare professionals helped to reduce the burden on the caregiver.

Patients consistently referenced the quality of care they received and how it surpassed that provided by hospitals. Staff were deemed more patient centric and were able to afford patients substantially more time than they would have received in alternative clinical settings. The existing literature indicates that although hospices look after fewer patients than their NHS counterparts, the patients generate greater workloads [205]. Despite this, hospices continue to receive higher-quality service scores, perhaps due to their superior staffing ratios [205]. It is well documented that hospitals are becoming increasingly short staffed [206] [207] and hence insufficient levels of contact time between patients and staff may result from this.

It is evident that the negative connotations related to hospice care are still prevalent; patients acknowledged the stark contrast between their preconceptions and the reality of the care they received. Although efforts have been made to dispel such predeterminations, most notably by the 'End of Life Care Strategy' [14], they remain present and continue to act as a barrier to early referral. It is therefore paramount to build on such work to overcome the cultural inhibitors to accessing palliative care services.

Strengths and weaknesses

This research represents one of the largest qualitative studies conducted in the hospice sector as 96 participants (63 patients and family-caregivers, 33 members of staff) were recruited. This qualitative study employed semi-structured interviews as the method of data collection which unearthed subtleties and complexities that are often missed when positivistic approaches are used in isolation [208]. Furthermore, a detailed field diary was constructed which facilitated the contextualisation of interviews and focus groups, whilst ensuring a reflexive approach to data collection and analysis was adopted (*page 199)*.

The greatest strength of the qualitative research was the unearthing that suicidal ideations are rife amongst palliative care patients; however, such notions were not identified whilst conducting the systematic review. This finding demonstrates social value with a high level of gravitas but was substantially undervalued within this SROI analysis as a result of methodological constraints. Amongst palliative care populations, complex psychological issues are prevalent and multifaceted; therefore, the choice of an overarching financial proxy was difficult. Although 'relief from depression/anxiety' from the HACT database was chosen, it is acknowledged that there is a risk of underestimating the extent of the issue. The findings from the primary qualitative study revealed that a number of patients disclosed prior suicidal ideations, the frequency of which is somewhat higher in cancer patients than in the general population [209]. The IPOS was inaccurate when used to measure the severity of the level of this disclosure, as although depression is considered to be a relevant risk factor for suicide [210], the hopelessness scale has been touted by the wider literature as it provides a better indication of suicidal risk than a depression inventory [211].

The acceptability of conducting interviews with palliative care patients and their family-caregivers remains highly contentious [212] due to the perception that research involving palliative populations causes further distress [213]. This was further purported by the NHS Research Ethics committee (REC) used in this study; however, it is a premise that is contradicted by evidence which documents the contribution of qualitative research to palliative care [212]. When conducting qualitative interviews, the importance of developing and trialling a topic guide cannot be understated [214]. Initially, the preliminary topic guides were developed based on the findings from the systematic review (*Chapter 4*) and were subsequently scrutinised by the North Wales Cancer Patient Forum prior to ethical review. After the topic guides were deemed suitable the topic guides were trialled with a small patient sample and made amendments where necessary before conducting final interviews.

Overall, data collection was successful and, although some of the final interviews with palliative care patients were short, the information gleaned from those exchanges was invaluable. Despite the limited time, there was an opportunity to establish a rapport with patients and family members and the process became an enjoyable experience which added to the quality of the dialogue. There were instances however, in which individuals were difficult to engage or, in the case of the patient with multiple sclerosis, understand. In hindsight, an additional ethnographic approach could have been adopted to mitigate these issues. Over the past decade, there has been a substantial increase in the use of qualitative data collection methods, particularly interviews and focus groups [215]. Although this has provided insightful accounts within a number of fields, the evidence is largely perceptive as opposed to observational [215]. Ethnographical approaches provide a method of overcoming such limitations by triangulating observations, interviews, and documentary data to provide a robust account of social phenomena [215]. By performing 'in-situ' data collection, the researcher becomes immersed within the research setting thus yielding a richer understanding of social action and presenting opportunities to gain empirical insights previously overlooked [216].

Recruitment is often cited as a limitation of palliative care studies [217], and despite the engagement of gatekeepers [218], it proved to be inherently difficult in this research study. In an attempt to reduce such barriers, the lead researcher was embedded within one hospice study site for approximately 15 days. Whilst this approach generated more interest from participants, the final inpatient sample remained limited. The final sample predominantly consisted of patients with a malignant diagnosis, therefore this study cannot purport to be representative of those with non-malignant diagnoses. This aligns with previous work which revealed that patients admitted with metastatic cancer are more likely to access palliative care than other disease groups [219]. The final sample was homogeneous in terms of ethnicity, which is congruent with the general demographic of North Wales [220]; however, it denotes an apparent racial disparity in palliative care - a finding which is common across the wider literature.

Within qualitative research, there is always the risk of researcher bias due to their position as both data collector and data analyst [221]. To mitigate such effects, member checking is often employed through which participants are actively involved in checking and confirming the results of data collection [222]. This can be achieved by presenting the participant with transcripts, or by re-engaging with them via a second interview or focus group. Due to the nature of the sample population within this study, coupled with gatekeeping, this was not deemed feasible. In the event that gatekeeping could be circumvented, patient's health may have deteriorated, or they may have passed away, thus rendering additional data collection impossible. Interviews were conducted with staff and volunteers which, in the absence of member checking, provided a degree of bias mitigation. Although not as rigorous, these interviews provided a secondary perspective regarding what patients and family-caregivers value, thus facilitating a comparison of responses and affirmation of congruency.

Conclusion

Whilst the findings of this qualitative study help to address the gaps recognised in the systematic review *(Chapter 4)* and add to the limited evidence base pertaining to hospice inpatient units, there were substantial recruitment challenges, which is indicative of the difficulties commonly associated with palliative care research [217]. Although it is unclear whether the recruitment strategies adopted within this qualitative research study had a substantial impact on the enrolment process, recruitment seemed to improve within the inpatient unit at Site B when the researcher was embedded into hospice Site B and this approach should therefore be encouraged in future research.

This research represents one of the largest qualitative studies conducted within a palliative setting: interviews were conducted with 96 participants (63 patients and family-caregivers, 33 members of staff). According to the literature identified in the initial systematic review (*Chapter 4*), only Goodwin et al [171] conducted research on a larger scale, having interviewed 102 patients across five hospice sites. The findings therefore help to address the gaps recognised in *Chapter 4*, particularly the lack of research conducted within inpatient units, and add to the limited evidence base pertaining to hospice care as a whole. The seven outcome domains of importance are personal relationships, physical and psychological symptoms, mobility, informedness, social isolation, and autonomy, and they will be mapped against the Integrated Palliative care Outcome Scale (IPOS) in *Chapter 6*.

Chapter 6 : Using routine data to determine changes in pain, symptom management, and quality of life: A multicentre evaluation

ABSTRACT

BACKGROUND

To ensure the alignment of palliative treatment with patient needs, it is necessary to obtain information from patients regarding their perception of their own health and well-being. Through the implementation of health-related outcome measures, patient care preferences can be gleaned, thus informing clinical practice. By utilising data obtained through the Integrated Palliative Outcome Scale (IPOS), this chapter seeks to determine the physical, psychosocial, and practical changes experienced by patients post-hospice attendance.

METHODS

The outcome measures were implemented within two services (day therapy and inpatient unit) across three hospice sites between June 2018 and April 2019. The data was collected by hospice nurses at irregular (non-systematic) time points for each patient. Facilitated by SPSS, Wilcoxon Signed Rank Tests were utilised to determine any change between the baseline assessment and two follow-up assessments.

RESULTS

470 questionnaires were collected from across two hospice services (inpatient units: 276, day therapy units: 194), with the majority completed by proxies (inpatient units: 99%, day therapy units: 64%). The drop-off in completion rates for both units was considerable. At time point 2, the drop-off rate for the inpatient and day therapy units was 71% and 72% respectively. By time point 3, this had increased to 84% for the inpatient units and 83% for the day therapy units. ‘Poor mobility’, ‘appetite loss’, and ‘weakness’ were prevalent issues amongst patients within the inpatient units. Despite patients demonstrating a deterioration in their perceived ability to share feelings with friends and family, the psychosocial aspects of care were generally well managed and did not present themselves as severe difficulties. It is worth noting, however, that there was a high proportion of missing data relating to psychosocial aspects at subsequent assessments. On average, 59% of data pertaining to psychosocial elements of care was absent at time point 2 and 63% was absent at time point 3. Within the day therapy units, ‘breathlessness’, ‘patient anxiety’, ‘family anxiety’, and ‘weakness’ were the items which had the highest proportion of ratings described as severe. In contrast to the inpatient units, it was found that the psychosocial elements of care were often described as severe.

CONCLUSION

This multi-centre study was able to demonstrate that using the IPOS is a valid approach to measuring palliative care outcomes however; inherent difficulties exist regarding its implementation. The ability to obtain patient-completed questionnaires is limited and thus there is a heavy reliance on proxies which, despite being a valid approach, is not without its flaws. Furthermore, the IPOS is dependent on consistent data collection at specified time points, which, given the restricted capacity of hospice staff to do this, was unachievable. Nevertheless, despite the study's limitations, five key themes were identified which align with the qualitative data presented in *Chapter 5*: pain, poor mobility, anxiety, information and patients perception of family anxiety. These findings will be added to the impact map and will contribute towards the final SROI calculation.

Chapter contribution to the SROI analysis

A principal stage in the Social Return on Investment (SROI) process requires that the outcomes experienced by stakeholders are evidenced *(Figure 6.1).* In this study, routinely collected questionnaire data collected at the baseline time point and two follow-up time points (ad hoc) were used to measure changes experienced by patients. Where appropriate, this phase involves the collection of evidence directly from the stakeholders (patients) who are in the best position to communicate these changes. As the study sites in this study had not yet introduced outcome measures for family-caregivers, this chapter was only able to measure the changes experienced by patients.

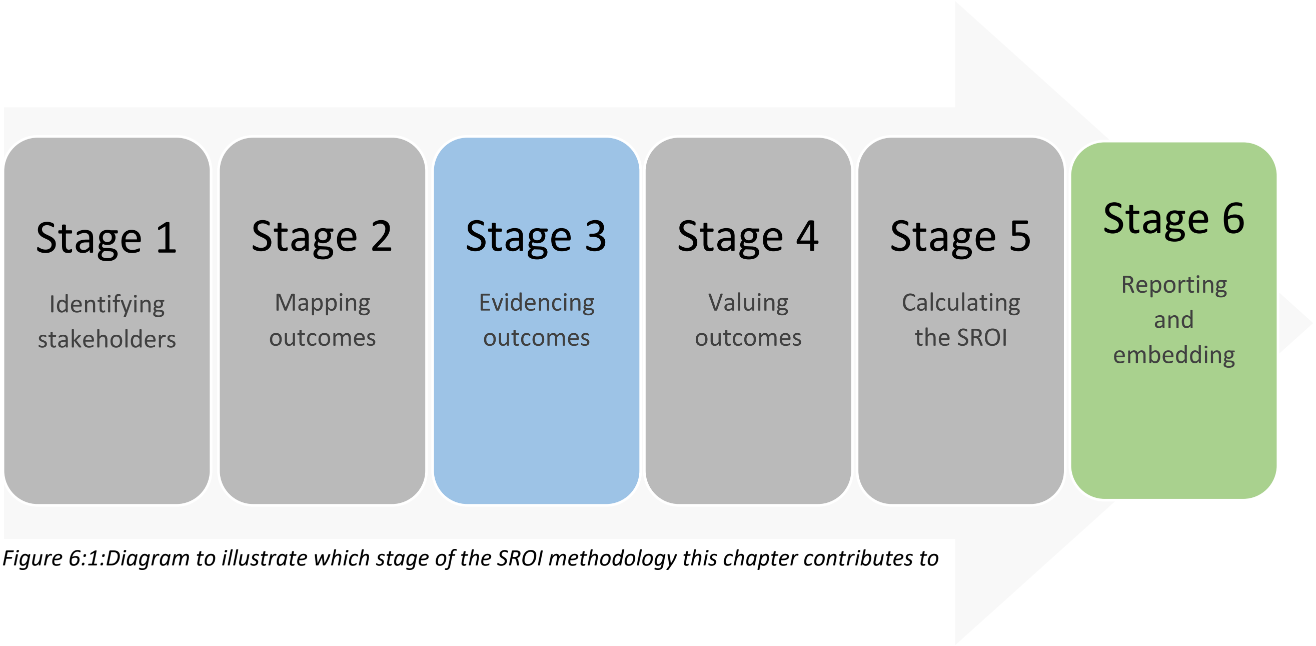


Figure 6:1:Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

Outcome measurement scales are standardised tools used to attain information from stakeholders regarding their perception of their own health and well-being [223]. International and national health policies have provided a clear rationale for the use of self-reported outcome measures to facilitate patient-centred care, improve awareness of unmet needs, and align treatment with patient values and priorities [224]. The routine collection of data from outcome measures in clinical practice has been lauded for its potential to enhance the quality of patient care [225]. Over time, a wide range of generic and condition-specific outcome measures have been developed. Whilst for some conditions and for some contexts there are agreed outcome measures of choice, such as the EQ-5D, which is routinely used to summarise health-related quality of life for economic evaluations [92], within a palliative care setting, there is no universally preferred option. Whilst the EQ-5D is appropriate for measuring interventions which seek to improve physical health, it is less suitable when evaluating interventions pertaining to broader psychosocial quality of life indicators [226]. Given the need to account for such aspects when accurately determining the social value of end of life care, alternative methodologies such as the ICECAP-SCM questionnaire and the IPOS have been developed, and they will be examined in further detail below. Ultimately, the choice of outcome measure is dependent on its intended purpose and whether it fits the research/and or organisation. Outcome measurement scales operate by recording changes across subsequent assessments after the collection of a baseline measurement. These regular ongoing assessments are pivotal to understanding the effectiveness of an intervention, to monitoring and detecting symptoms, and to assessing the ‘value’ associated with the service. In research, outcome measures are at the root of assessing responses to treatments; however, owing to a series of practical, methodological, and attitudinal barriers such as lack of time, resources, and training, there has not been an easy transition for these measures into routine clinical practice [227]. The introduction of outcome measures into end of life care presents further issues as patient trajectories will fluctuate as patients transition through different stages of their disease, including the progressive deterioration of physical and cognitive functions. Previous research has evidenced that in some palliative care settings, almost 60% of all patients were unable to complete an outcome measure unaided [228], and thus the availability of data evidencing the priorities of patients nearing the end of life will remain limited [229]. In some instances, proxy measures completed by healthcare professionals or relatives can be a way to capture what patients values, at least partially. This in itself, however, has its own limitations as proxies tended to overestimate health and functional limitations in patients [230]. Nonetheless, outcome measures are useful for ensuring that healthcare organisations are accountable – specifically in financial terms to their external stakeholders as they are able to provide tangible evidence demonstrating the value of the organisations’ services.

Aims and objectives

Through the analysis of routinely collected data, the aim of this chapter was to determine whether the Integrated Palliative Care Outcome Scale (IPOS) was a valid symptom questionnaire to assess the trajectory of symptom severity over time and the quantity of outcomes achieved.

Methods

Setting and population

The outcome measures were introduced into routine clinical practice in two services (day therapy and inpatient units) spanning three hospice sites (A, B, and C). Site D was unable to introduce outcome measures into routine clinical practice due to limited resources and was therefore excluded from the analysis reported in this chapter. This reinforces claims that more could be done to support clinicians who wish to implement outcome measures [231]. The IPOS was subsequently used with a cohort of palliative care patients admitted to any of the three study sites between June 2018 and April 2019.

Choice of outcome measurement tool

An array of approaches to measuring change in health-related quality of life is available for adoption in research and clinical practices, including cognitive, functional, and quality of life measures. Initially, the intention was to integrate the ICECAP-SCM questionnaire into routine clinical practice due to its ability to provide a comprehensive and accurate overview of the end of a patient's life and because participants find the questionnaire easy to understand [232]. Furthermore, the questionnaire's suitability within a palliative care setting is well documented [232–234] and therefore seemed to be the most effective methodology. Licences were obtained to allow the use of the ICECAP-SCM questionnaire in this research and instruction manuals were subsequently created by the researcher which detailed how to implement the ICECAP-SCM questionnaire. Prior to the commencement of the quantitative data collection, however, the three hospice sites decided to introduce the Outcome Assessment Complexity Collaborative (OACC) suite of measures. The OACC suite of measures includes the Phase of Illness, the modified Karnofsky Performance Status (AKPS), the Integrated Palliative Outcome Measure (IPOS), Views on Care, and Caregiver burden [102]. The suite of measures, which had been recommended as a standardised approach to use across all hospices [235], had not been systematically integrated into routine clinical practice across the study sites and instead the measures were being introduced inconsistently in a step-wise process. As the hospices lacked the capacity to implement both the ICECAP and the IPOS outcome measurement tools, a decision was taken to use the IPOS as the sole measure and to integrate it into routine practice across the three study sites. A comparison of the two questionnaires relative to the qualitative outcomes described in *Chapter 5* is presented in *Table 6.1.*

Table 6:1:Demonstration of how IPOS and ICECAP-SCM map on to the qualitative findings

Qualitative Outcomes	IPOS	ICECAP-SCM	Explanation
Improvements in symptoms	Item 1: Pain	Item 3: Physical suffering	For this outcome, 'physical suffering' maps on to the qualitative outcome more effectively as it is a broader theme. Due to the specificity of 'pain', there is the potential for responses to be missed.
Improved mobility	Item 10: Poor mobility	N/A	ICECAP-SCM lacked a suitable domain.
Psychological improvements for patients	Item 11: Patient anxiety	Item 4: Emotional suffering	'Emotional suffering' encompasses a broad range of symptoms and therefore maps on to the qualitative outcome more effectively. In contrast, 'patient anxiety' relates to one symptom and therefore patients experiencing alternative psychological issues may be overlooked.
Improved sense of informedness	Item 16: Information	Item 7: Being prepared	'Information' the item on the IPOS questionnaire maps on to this qualitative theme: improved sense of informedness more effectively. In contrast, the 'being prepared' item does not just pertain to information, it encompasses multiple facets related to preparation for death.
Psychological improvements for family-caregivers	Item 13: Family anxiety	N/A	ICECAP-SCM lacked a suitable domain.
Increased feelings of autonomy and control	N/A	Item 1: Having a say	IPOS lacked a suitable domain.
Improved friendships/greater support network	N/A	Item 2: Being with people who care about you	IPOS lacked a suitable domain.
Improved relationships	N/A	N/A	Both IPOS and ICECAP-SCM lacked a suitable domain.

The Integrated Palliative Care Outcome Scale (IPOS)

The IPOS is a 17-item multi-dimensional tool completed by patients (self-reported), family-caregivers, or staff (proxy-reported) *(Appendices 5.1-5.2)* [236] that was formed through the integration of the Palliative Outcome Scale (POS), Palliative Outcome Scale - Symptom (POS-S), and the APCS African Palliative Outcome Scale [237]. This tool provides patients with the opportunity to reflect on their concerns and priorities including their physical, psychological, social, emotional, and spiritual needs. If patients lack the capability to complete a self-reported measure, the proxy version should be utilised. Each question is scored on a five-point Likert scale with both numerical and descriptive labels as scores ranging from 0 (no issues) to 4 (overwhelming issues). Responses can also be summed to provide a total score ranging from 0 to 40. A higher score indicates a higher prevalence of symptoms. Although the IPOS is still undergoing further validation, each of the individual questions has been validated for use in palliative populations [102]. Furthermore, POS and POS-S, which form the foundation of the IPOS, have undergone extensive psychometric testing which has demonstrated their consistency and validity as measurement tools [238]. The suitability of the IPOS for use within a clinical setting is therefore implied and, since its inception, it has been welcomed by patients and professionals as a streamlined approach which ensures the capture of important concerns [239].

Data collection

As part of routine care, patients receiving hospice intervention were approached by a member of their nursing team on an ad hoc basis and asked to complete the IPOS. Data was collected from its integration (June 2018) into routine clinical practice until April 2019 (*Table 6.2*). It is recommended that the IPOS is used at least twice [102], and therefore patients for whom there was no data after the baseline time period were not included in the analysis. The IPOS should be implemented in relation to inpatients on admission and after 3–5 days, whilst for community patients the timeline is 7–21 days [102]. In this study, these recommendations were not followed as the hospice personnel were unable to adhere to this timeline. Instead, the data was collected by hospice nurses at irregular intervals (non-systematic time points) for each patient. The completed IPOS forms were stored with patients' paper-based records and a designated member of staff at each hospice anonymised the data to ensure compliance with the GDPR. Unfortunately, this meant that demographic data could not be collected. The records were then either collected in person by the researcher or sent as a password-protected file via email. In some instances, the lack of staff availability coupled with various priorities prevented the anonymisation of some questionnaires. After numerous reminders were sent to staff and an external member of staff was hired from an NHS bank using the research budget to carry out this task, it was still not completed so the decision was made to exclude these questionnaires.

Data analysis

The data was analysed using non-parametric tests because the data collected from the IPOS was ordinal. Wilcoxon signed rank tests were used to compare the Likert scale responses. Two-Related-Samples tests were used to determine whether the median scores for patients were significantly different when follow-up assessments were compared with their baseline counterparts. Using SPSS version 25, the statistical significance was set at p=0.05. Additional analyses were then carried out using descriptive statistics to describe both overall scores (min 0; max 40) and individual item scores (min 0; max 4) using median and interquartile ranges. Higher scores are indicative of poorer patient health. Frequency distributions demonstrate the number of patients who experienced either a positive or a negative change post-baseline assessment. These were expressed as frequencies and percentages (*Table 6.3*). Due to the difficulties associated with data collection at each site, the completed IPOS questionnaires were aggregated.

Ethical considerations

Ethical approval for this research was granted by both the NHS Research Ethics Committee (Wales REC 4) and the College of Business, Law, Education and Social Sciences (CBLESS) at Bangor University. Following extensive discussion with the advisory team, the dissemination of recruitment letters directly to patients and/or their families was deemed inappropriate as the ability to screen potential participants prior to sending was not possible. Failure to sufficiently screen would increase the likelihood of contacting potential participants at inappropriate and insensitive times. Thus, this chapter relies solely on the anonymised data obtained from routinely embedded outcome measurement questionnaires. These were shared with the researcher under a comprehensive data-sharing agreement.

Results

Overview

Key findings from 470 questionnaires, completed across two hospice services *(Figure 6.2),* have been summarised in the subsequent chapter. Within the inpatient units, questionnaires were predominantly completed by a proxy (99%), with only two questionnaires completed by patients. The day therapy units experienced a high self-completion rate (36%); however, the majority were still completed by proxies (64%). *Table* 6.2 provides a site-specific breakdown of the IPOS completion for each unit.

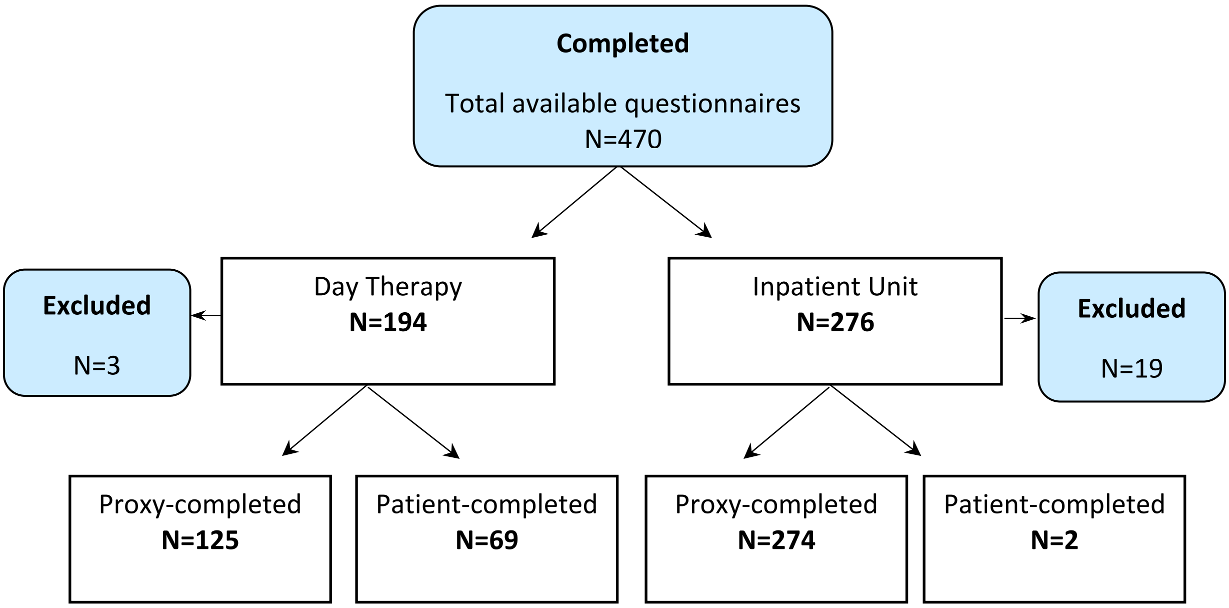


Figure 6:2: Sample selection flow diagram

Table 6:2: Number of completed IPOS forms by times points across study sites

Department	**Site A**		**Site B**		**Site C**	
	Inpatient	Day Therapy	Inpatient	Day Therapy	Inpatient	Day Therapy
Baseline	0	90	129	17	22	0
Time point 2	0	46	80	8	0	0
Time point 3	0	30	45	3	0	0
Total (470)	**0**	**166**	**254**	**28**	**22**	**0**

Questions which identified substantial problems

To aid clarity, median IPOS scores were categorised as low (0-1), moderate (2) or severe (3-4). Symptoms were considered to be problematic for patients if their median score was ≥3. This is in line with recommendations, which identify item scores of ‘3’ or ‘4’ as indicative of a severe problem, ‘2’ as a slight/moderate problem and a score of ‘0 or 1’ as a minimal issue [240]. This grouping of responses into a three-point scale makes comparisons easy. The results received from the inpatient unit highlighted that ‘poor mobility’ and ‘weakness’ were two problematic symptoms, with both items returning median scores of 3 across all three time points. In contrast, the median scores for both the ‘poor mobility’ and ‘weakness’ items were 2 across all three time points within the day therapy unit and thus were not considered problematic.

Distribution of IPOS scores

Inpatient Unit

At baseline assessment, ‘poor mobility’ (62%), ‘weakness’ (55%), ‘patients’ perception of family anxiety’ (47%), and ‘appetite loss’ (46%) had the highest proportion of ‘severe’ scores (*Figure 6.3)*. This trend continued at time point 2, with ‘poor mobility’ (60%), ‘weakness’ (54%), ‘appetite loss’ (39%), and ‘patients’ perception of family anxiety’ (33%) remaining prominent, alongside ‘drowsiness’ (33%), which had a 7% increase from the baseline. At time point 3, the following five items had the highest proportion of ‘severe’ scores: ‘weakness’ (61%), ‘poor mobility’ (54%), ‘appetite loss’ (44%), ‘patients’ perception of family anxiety’ (39%) and ‘drowsiness’ (33%).

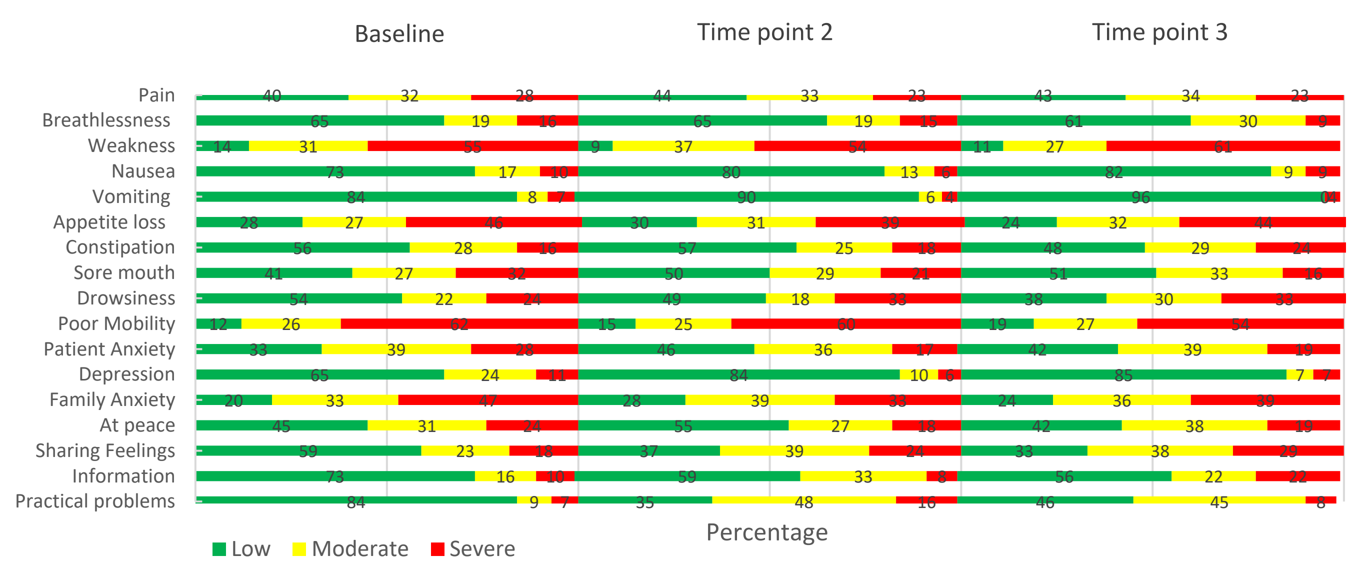


Figure 6:3: Distribution (%) of inpatient IPOS scores across the three time points

Day Therapy

The day therapy unit had a more even spread of severe scores across IPOS items at the initial baseline assessment *(Figure 6.4).* Both ‘the patients’ perception of family anxiety’ (34%) and ‘breathlessness’ (34%) had the highest proportion of ‘severe’ scores, closely followed by ‘patient anxiety’ (32%). By the time of the first follow-up assessment, minor changes that had been observed as ‘breathlessness’ (32%), ‘pain’ (32%), and ‘patient anxiety’ (29%) became the three modal symptoms of highest severity. By time point 3, ‘family anxiety’ was considered most acute (41%), followed by ‘weakness’ (36%) and ‘breathlessness’ (31%).

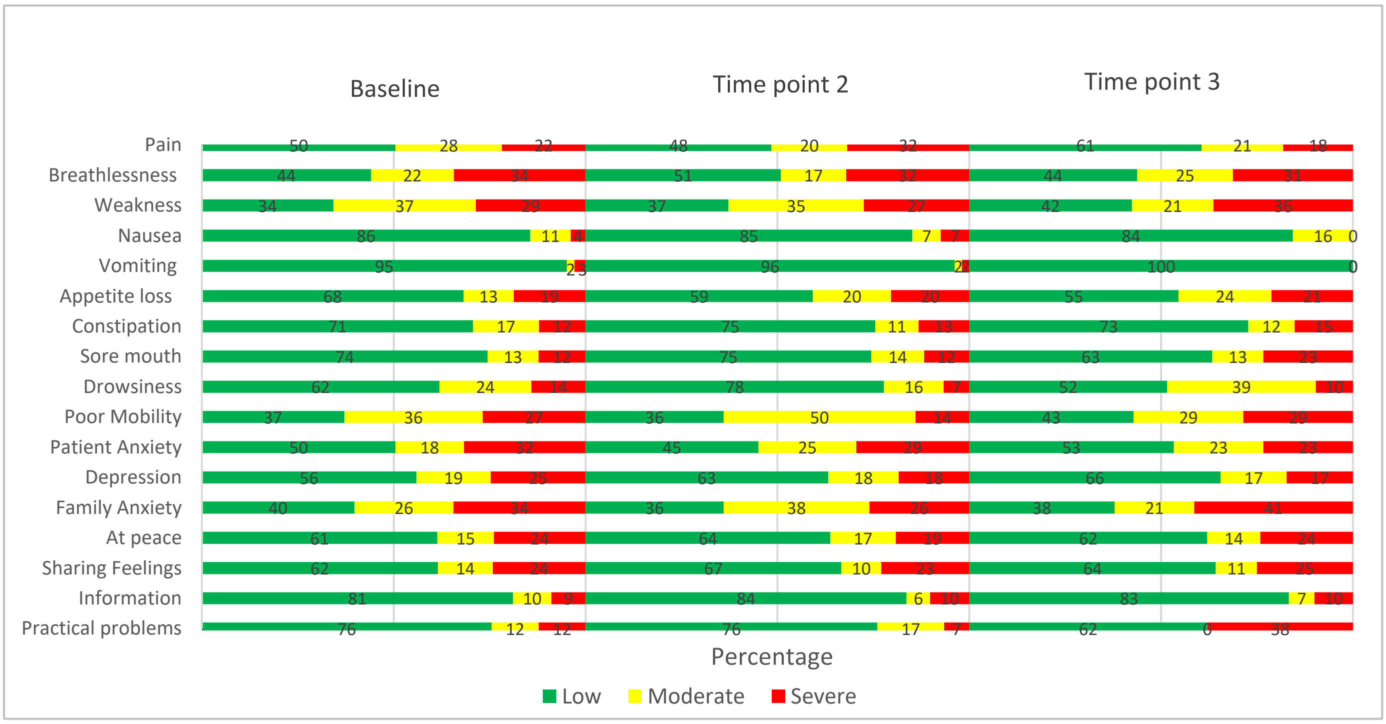


Figure 6:4: Distribution (%) of day therapy IPOS scores across the three time points

Table 6:3: Number of inpatients who experienced change between the baseline time points and any subsequent time points

	Baseline – Time point 2 (n=80)								Baseline – Time point 3 (n=45)							
Items	Negative change (%)	Positive change (%)	No change (%)	Missing values (%)	Median score @ *baseline (IQR)*	Median score @ *time point 2 (IQR)*	Median change	*p* Value	Negative change (%)	Positive change (%)	No change (%)	Missing values (%)	Median score @ *baseline (IQR)*	Median score @ *time point 3 (IQR)*	Median change	*p* Value
Pain	17 (21)	19 (24)	42 (53)	02 (03)	2 (2)	2 (2)	0	0.674	08 (18)	16 (36)	18 (40)	03 (07)	2 (2)	2 (2)	0	0.342
Breathless	17 (28)	14 (18)	46 (58)	03 (04)	1 (1)	1 (1)	0	0.212	08 (18)	11 (24)	23 (51)	03 (07)	1 (1)	1 (1)	0	0.899
Weakness	29 (36)	07 (09)	43 (54)	01 (01)	3 (3)	3 (3)	0	<0.001*	20 (44)	07 (16)	16 (36)	02 (04)	3 (3)	3 (3)	0	0.043*
Nausea	08 (10)	14 (18)	55 (69)	03 (04)	0 (0)	0 (0)	0	0.151	05 (11)	14 (31)	24 (53)	02 (04)	0 (0)	0 (0)	0	0.070
Vomiting	05 (06)	09 (11)	23 (29)	43 (54)	0 (0)	0 (0)	0	0.320	03 (07)	11 (26)	29 (67)	02 (04)	0 (0)	0 (0)	0	0.015*
Appetite loss	21 (26)	21 (26)	37 (46)	11 (14)	2 (2)	2 (2)	0	0.214	17 (38)	07 (16)	14 (31)	07 (16)	2 (2)	2 (2)	0	0.142
Constipation	17 (21)	14 (18)	38 (48)	11 (14)	1 (1)	1 (1)	0	0.386	13 (29)	10 (22)	13 (29)	09 (20)	1 (1)	2 (2)	+1	0.496
Sore mouth	22 (28)	12 (15)	42 (53)	04 (05)	2 (2)	2 (2)	0	0.124	16 (36)	11 (24)	14 (31)	04 (09)	2 (2)	1 (1)	-1	0.255
Drowsiness	32 (40)	05 (06)	40 (50)	03 (04)	1 (1)	2 (2)	+1	<0.001*	20 (44)	03 (07)	16 (36)	06 (13)	1 (1)	2 (2)	+1	<0.001*
Poor mobility	23 (29)	11 (14)	38 (48)	08 (10)	3 (3)	3 (3)	0	0.191	14 (31)	09 (20)	12 (27)	10 (22)	3 (3)	3 (3)	0	0.387
Patient anxiety	09 (11)	14 (18)	35 (44)	22 (28)	2 (2)	2 (2)	0	0.442	05 (11)	08 (18)	14 (31)	18 (40)	2 (2)	2 (2)	0	0.712
Depression	05 (06)	11 (14)	34 (43)	30 (38)	1 (1)	0 (0)	-1	0.180	05 (11)	05 (11)	13 (29)	22 (49)	1 (1)	0 (0)	-1	0.715
Family anxiety	11 (14)	06 (08)	35 (44)	28 (35)	2 (2)	2 (2)	0	0.134	04 (09)	05 (11)	14 (31)	22 (49)	2 (2)	2 (2)	0	0.957
At peace	06 (08)	01 (01)	10 (13)	63 (79)	2 (2)	1 (1)	-1	0.597	06 (13)	01 (02)	10 (22)	28 (62)	2 (2)	2 (2)	0	0.035*
Sharing feelings	09 (11)	02 (03)	19 (24)	50 (63)	1 (1)	2 (2)	+1	0.014*	05 (11)	02 (04)	08 (18)	30 (67)	1 (1)	2 (2)	+1	0.083
Information	02 (03)	02 (03)	17 (21)	59 (74)	1 (1)	1 (1)	0	1.000	00 (00)	01 (02)	06 (13)	38 (84)	1 (1)	1 (1)	0	0.655
Practical problems	01 (01)	00 (00)	05 (06)	74 (93)	1 (1)	1 (1)	0	0.655	01 (02)	00 (00)	05 (11)	39 (87)	1 (1)	1 (1)	0	0.317

□ *Positive change* □ *Negative change *Significance level p= 0.05*

Table 6:4: Number of day therapy patients who experienced change between the baseline time point and any subsequent time points

	Baseline – Time point 2 (n=54)								Baseline – Time point 3 (n=33)							
Items	Negative change (%)	Positive change (%)	No change (%)	Missing values (%)	Median score @ *baseline (IQR)*	Median score @ *time point 2 (IQR)*	Median change	*p* Value	Negative change (%)	Positive change (%)	No change (%)	Missing values (%)	Median score @ *baseline (IQR)*	Median score @ *time point 3 (IQR)*	Median change	*p* Value
Pain	14 (26)	14 (26)	21 (39)	05 (09)	1 (1)	1 (1)	0	0.971	11 (33)	08 (24)	12 (36)	02 (06)	1 (1)	1 (1)	0	0.350
Breathless	08 (15)	08 (15)	35 (65)	03 (06)	2 (2)	1 (1)	-1	1.000	09 (27)	05 (15)	17 (52)	02 (06)	2 (2)	2 (2)	0	0.512
Weakness	11 (20)	10 (19)	29 (54)	04 (07)	2 (2)	2 (2)	0	0.769	11 (33)	10 (30)	12 (36)	00 (00)	2 (2)	2 (2)	0	0.583
Nausea	09 (17)	08 (15)	35 (65)	02 (04)	0 (0)	0 (0)	0	0.540	06 (18)	08 (24)	17 (52)	02 (06)	0 (0)	0 (0)	0	0.580
Vomiting	03 (06)	05 (09)	44 (81)	02 (04)	0 (0)	0 (0)	0	0.608	01 (03)	04 (12)	27 (82)	01 (03)	0 (0)	0 (0)	0	0.157
Appetite loss	18 (33)	12 (22)	24 (44)	00 (00)	1 (1)	1 (1)	0	0.082	08 (24)	07 (21)	18 (55)	00 (00)	1 (1)	1 (1)	0	0.204
Constipation	13 (24)	11 (20)	25 (46)	05 (09)	0 (0)	0 (0)	0	0.479	08 (24)	07 (21)	16 (48)	02 (06)	0 (0)	0 (0)	0	0.840
Sore mouth	12 (22)	05 (09)	31 (57)	06 (11)	0 (0)	0 (0)	0	0.138	15 (45)	04 (12)	10 (30)	04 (12)	0 (0)	1 (1)	+1	0.058
Drowsiness	06 (11)	15 (28)	18 (33)	15 (28)	1 (1)	0 (0)	-1	0.022*	08 (24)	09 (27)	11 (33)	05 (15)	1 (1)	1 (1)	0	0.609
Poor mobility	12 (22)	14 (26)	21 (39)	07 (13)	2 (2)	2 (2)	0	0.817	10 (30)	06 (18)	09 (27)	08 (24)	2 (2)	2 (2)	0	0.424
Patient anxiety	19 (35)	14 (26)	15 (28)	06 (11)	1 (1)	2 (2)	+1	0.301	08 (24)	08 (24)	13 (39)	04 (12)	1 (1)	1 (1)	0	1.000
Depression	12 (22)	09 (17)	22 (41)	11 (20)	1 (1)	1 (1)	0	0.697	04 (12)	07 (21)	15 (45)	07 (21)	1 (1)	1 (1)	0	0.413
Family anxiety	16 (30)	13 (24)	18 (33)	07 (13)	2 (2)	2 (2)	0	0.817	12 (36)	09 (27)	07 (21)	05 (15)	2 (2)	2 (2)	0	0.163
At peace	09 (17)	11 (20)	21 (39)	13 (24)	1 (1)	1 (1)	0	0.488	08 (24)	07 (21)	12 (36)	06 (18)	1 (1)	1 (1)	0	0.793
Sharing feelings	09 (17)	06 (11)	27 (50)	12 (22)	1 (1)	1 (1)	0	0.522	10 (30)	07 (21)	09 (27)	07 (21)	1 (1)	1 (1)	0	0.660
Information	11 (20)	09 (17)	23 (43)	11 (20)	0 (0)	1 (1)	+1	0.706	09 (27)	07 (21)	11 (33)	06 (18)	0 (0)	0 (0)	0	0.851
Practical problems	09 (17)	10 (19)	21 (39)	14 (26)	0 (0)	0 (0)	0	0.712	09 (27)	06 (18)	12 (36)	06 (18)	0 (0)	0 (0)	0	0.862

□ *Positive change* □ *Negative change* Significance level p=0.05*

Only the aspects of care which are either strongly or moderately congruent with the qualitative findings will be examined, brought forward, and included as part of the SROI analysis (*Table 6.5*). Those which displayed poor congruence will not be included within the final SROI and therefore will not be discussed in more detail. This ensures compliance with the SROI principle "value the things that matter"[241].

Table 6:5: Level of congruency between quantitative and qualitative findings

IPOS Domains	Interviews and Focus Groups	Level of Congruency	Reasoning
Pain	Improvements in overall physical health	Strong	IPOS included domains relating to level of pain. Interviews revealed that active pain assessment and access to immediate pain relief were crucial.
Poor mobility	Improvements in patient functionality and mobility	Strong	IPOS included domains relating to patient mobility. Interviews revealed that patients were strongly motivated to preserve their physical functioning.
Patient anxiety	Opportunity to have their condition and their symptoms appropriately managed resulted in psychological improvements	Strong	IPOS included domains relating to anxiety regarding illness or treatment. Interviews revealed that patients benefited psychologically by attending the hospice.
Information	Patients are provided with information and advice which enhanced their ability to address practical issues	Strong	IPOS included domains relating to level of information received. Interviews revealed that ease of access to advice and information resulted in mitigation of worries.
Family anxiety	Opportunity to have their condition and their symptoms appropriately managed resulted in psychological improvements	Moderate	Family anxiety was identified in both survey and interview data. However, as the IPOS questionnaires were completed by patients, and not family-caregivers, the accuracy of their assessment is questionable, hence deeming these items moderately congruent.
Breathlessness Weakness Vomiting	No corresponding qualitative data	Poor	Qualitative themes emerged during interviews that were congruent with multiple IPOS domains. To prevent over-

Nausea			claiming, as stipulated by the SROI principles, these themes were attributed to only one IPOS domain, as differentiation between patient responses is unachievable.
Appetite loss			
Constipation			
Sore mouth			
Drowsiness			
Depression			
At peace			
Sharing feelings			
Practical problems			
No corresponding quantitative data	Increased feelings of autonomy and control over their life/personal environment due to the relationships formed with hospice staff	Poor	Surveys did not include domains specific to these themes.
No corresponding quantitative data	Improved friendships/greater support network which helped to reduce social isolation and loneliness	Poor	
No corresponding quantitative data	Hospice support helped to relieve family-caregiver burden which contributed towards improved patient-family-caregiver relationships	Poor	

Pain

Inpatient Unit

The proxies reported that 53% of patients reported no change in symptomology between the baseline time point and time point 2, 24% reported an improvement, and 21% revealed an increase in pain. This pattern continued when comparing the baseline assessment against time point 3. Forty per cent of participants did not experience a change in pain, 36% improved, and 18% experienced an escalation.

Day Therapy Unit

At time point 2, 39% of patients did not experience a change in pain; however, this figure had decreased to 36% by the third time point. Whilst an equal proportion of patients experienced an improvement or deterioration (29%) in pain at time point 2, 33% had deteriorated by the third assessment and 24% had improved.

Poor mobility

Inpatient Unit

Between the baseline assessment and the first assessment, 48% of patients had not experienced a change in their mobility. A further 29% of the sample reported a decline in mobility, and 14% felt they were less restricted. The scores attained from the second follow-up questionnaire revealed that a large proportion of patients (31%) reported less mobility post-intervention, 27% experienced no effect, and 20% reported improved mobility.

Day Therapy Unit

At the second follow-up assessment, 39% of the sample population had experienced no change in mobility, 26% felt they had improved, and 22% were less mobile. By the third time point, a large proportion of participants reported reduced mobility (27%) and just 18% reported improved mobility.

Anxiety

Inpatient Unit

A large proportion of the sample (44%) had not experienced a change in anxiety levels at the time of the baseline assessment; 18% reported a decrease and 11% reported an increase. This trend was similar when comparing baseline to time point 3, as 31% of participants had not experienced a change, 11% reported a deterioration, and 18% reported an improvement.

Day Therapy Unit

Between the time of the baseline assessment and the first follow-up questionnaire, a high proportion of the sample population (35%) had experienced an increase in anxiety, but 28% had experienced no change, and 26% revealed that their anxiety had reduced. By the time of the second follow-up assessment, 39% of participants had experienced no effect. An equal number of participants had reported either an improvement (24%) or a deterioration (24%).

Information

Inpatient Unit

Between the time of the baseline assessment and time point 2, 21% of participants had not experienced a change in informedness, 3% had reported an improvement, and 3% had deteriorated. Notably, 74% of responses were missing. By the second follow-up, 13% had not experienced a change and 2% had reported an improvement but no patients had indicated that they had deteriorated. The response rate had dropped further, with 84% of the sample population not answering this item.

Day Therapy Unit

Forty-three per cent of participants did not report any change in informedness, whilst 20% felt less informed, and 17% felt more informed. By the second follow-up assessment, this trend had continued, with 33% reporting no change, 27% feeling less informed, and 21% feeling more informed.

Patients' perception of family anxiety

Inpatient Unit

Comparing baseline scores to the first follow-up assessment revealed that a high proportion of the sample (44%) had not reported a change, 14% had deteriorated, and 8% had improved. By the third follow-up assessment, 31% remained unchanged, 11% improved, and 9% deteriorated.

Day Therapy Unit

At time point 2, 33% of patients reported that their family's anxiety had remained the same, 30% reported a deterioration, and 24% indicated an improvement. By the third follow-up, however, 36% of the sample population reported that their family's anxiety had worsened, 27% reported an improvement, and 21% indicated no change.

Discussion

Often beset with a range of difficulties, research studies conducted within the field of palliative care have faced heavy criticism for their poor study designs [242]. Because of the unpredictability of a terminal diagnosis, the accessibility and availability of patients are often hindered, which consequently affects the design of the research. Despite these inherent difficulties, this multicentre study was able to provide comprehensive data on pain and symptom control, patients' and families' psychological needs, and their communication and information requirements.

This study relied on effective data collection; however, this was limited by multiple factors. To ensure effective integration of the IPOS into routine clinical practice, it is recommended that patients self-complete the assessment at time point 1 and staff subsequently complete the second assessment. Furthermore, clinicians need to be able to collect the same measures within the same time frames in order to ensure consistency [102]. Prior to the commencement of this study, the hospices were not research active and therefore the introduction of outcome measures was a new approach. Staff did receive training in the use of the IPOS, given its unfamiliarity, data collection was not always efficient. This resulted in questionnaires being completed at irregular time points and thus, the recommended practice was not followed. Due to the data being collected at different time points, the ability to solely use statistically significant results within the SROI impact map was not possible. However, the survey data was still useful to show the general trend for outcomes over time, and to explore the issues with data collection in this population. If the ICECAP-SCM questionnaires had been implemented as set out within the original protocol, there is no guarantee that this issue would have been addressed. The ICECAP-SCM questionnaire is shorter than the IPOS and the questions are broader; however, even if the hospice sites had implemented it as a novel approach, the issues would have remained. It is widely acknowledged that the adoption of outcome measures in routine clinical practice is a continuous process [243].

There was considerable attrition in this study as the number of the IPOS questionnaires completed varied considerably across study sites; this has meant that definitive conclusions are difficult to determine. This difficulty may stem from the issues surrounding the integration of outcome measures into routine clinical practice. The absence of patient-completed questionnaires received from Site B suggested that staff were potentially attempting to minimise patient burden by acting as gatekeepers; hence, it is inevitable that some patients were overlooked. Within palliative care research, gatekeeping is regularly touted as the primary reason for research failure, but it is difficult to avoid [58], especially given this study's heavy reliance on proxies. Whilst the IPOS has a valid component that staff complete, previous studies focusing on the reliability of proxy ratings have misreported the patient's symptoms and preferences [244]. The inter-rater reliability of this study must also be brought into question as patients were not always assessed by the same member of staff, thus introducing inconsistent subjectivity which has not been accounted for.

Nevertheless, the data presented in this chapter elucidated the items of care which remain prominent and thus met the aim of this research study. Within the inpatient unit, ‘poor mobility’, ‘appetite loss’, and ‘weakness’ were rated as ‘severe’ for a large proportion of the sample, which, given the nature of the study population, was expected. Palliative diagnoses have a downward trajectory and therefore symptoms such as ‘appetite loss’, ‘poor mobility’, and ‘weakness’ often worsen in the time period leading up to death [245]. Markedly, the psychosocial elements of care were, for the most part, maintained or alleviated within the inpatient units, which represents a divergence from the previous literature [245]. The results did, however, reveal a significant deterioration in the perceived ability of inpatients to share their feelings with friends and family. Within the day therapy units, ‘breathlessness’, ‘patient anxiety’, ‘family anxiety’ and ‘weakness’ were items were often rated as ‘severe’. These results should, however, be viewed in the context of this study’s limitations.

The results of the completed questionnaires revealed a substantial drop-off in response rates for the final questions, particularly within the inpatient units. When reviewing the questions in the questionnaires, it’s apparent that the focus shifts away from physical symptomology. This therefore resulted in a marked absence of data for specific facets, particularly access to information, the ability to share feelings, and practical problems.

The systematic review conducted in C*hapter 4* provided evidence that supported the trope of patients frequently commending hospices on their ability to address psychosocial needs; the value of this aspect of hospice care was therefore inferred. It was also noted, however, that the attributes of care most valued varied between hospice services. Whilst day therapy patients often placed emphasis on social support, inpatients prioritised pain and symptom management, which perhaps suggest that the latter IPOS questions were not relevant to their preferences and hence went unanswered.

Furthermore, as discussed previously, this study was heavily reliant on proxies, and previous studies have revealed poor agreement between patient and proxies regarding the more subjective aspects of care [246]. ‘Family anxiety’ in particular is likely to have been inaccurately assessed as proxies were answering on behalf of patients’ families. To avoid this, the use of a family-caregiver assessment tool is required, which, although available as part of the OACC suite of measures, was yet to be implemented in routine clinical practice.

Strengths and limitations

Prior to the commencement of the data collection process, the IPOS was introduced into routine clinical practice at each of the study sites, with the exception of Site D. The IPOS is an individual measure which has been included in the OACC suite of measures, developed to improve services and outcomes for patients receiving palliative care and their families across the UK [247]. Underpinned by the symptoms and concerns deemed valuable to patients (as determined in *Chapter* 5), both the patient self-report and staff proxy-report versions provided a valid and reliable outcome measure, which were able to assess and monitor change across two time points. Of note, however, the exact time between each successive assessment was unknown and thereby prevented the use of significant change as a determinant of material change due to the aforementioned inconsistencies. The absence of a control group also meant that it could not reliably be determined how much change should be attributed solely to the hospice intervention. Notably, patient reported outcomes would have provided a more rigorous approach.

Due to the study sites unfamiliarity with IPOS, notable data entry failures occurred as patient ID numbers were not used. This prohibited multiple questionnaires from being linked to the same patient and thus they were treated independently within the analysis. Despite the integration of outcome measures into routine clinical practice, limited staff training promoted the employment of a convenience sampling technique at certain sites whereby patients were often chosen ad hoc to complete the questionnaire. Staff's lack of familiarity with the IPOS was further reflected by inconsistencies in form completion. Two IPOS forms exist depending on whether a three day or one week recall period has been established however, as no recall period had been set, there was no consistency regarding which form was completed. Although the questions are uniform across both surveys, thus not impacting the data, it does serve to highlight the lack of communication and education regarding the data collection process across sites.

Across the day therapy unit and the inpatient unit, 470 questionnaires were completed, predominantly by proxies. Within the inpatient unit, proxies accounted for 99% of the survey responses, whilst within the day therapy unit, proxies accounted for 64% of the survey responses. Although this trend was somewhat expected given the nature of the research setting, it does raise questions regarding potential gatekeeping by staff and, although difficult to avoid, this has a demonstrable ability to misrepresent results [244]. A lack of congruency between proxy-reported and patient-reported findings is well documented, with proxies often providing lower quality of life

(QOL) scores [248]. Such discrepancies may be explained by the proxies' tendency to focus on physical functioning as opposed to the psychosocial elements of care [249]. In contrast, patients are more likely to view their health within the context of their illness, thus shifting the focus away from physical attributes and instead placing emphasis on relationships with family and friends [249]. Acquiring data directly from patients therefore provides a more accurate insight into their perspectives of care; however, this is not always feasible with palliative populations and therefore the reliance on proxies remains [248]. In this study, concerns regarding inter-rater reliability also endure, as patients were not always assessed by the same member of staff. Due to the study's reliance on proxy responses, conducting inter-rater reliability tests would have strengthened the robustness of the findings; however, as all surveys were anonymised, this was not possible as both the patient and the staff member were unknown.

Conclusion

The introduction of the IPOS into routine clinical practice will ensure that the impact of the services is appropriately measured and monitored, resulting in overall improvements in the delivery of palliative care. Within this study, however, despite each site wishing to play an active role in the research, it became clear that barriers existed which prevented the successful integration of the IPOS. The principal limitation for hospice personnel was the rigidity of the time frames, which resulted in an ad hoc data collection process and thus limited the possibility of comparison. Furthermore, due to a heavy reliance on proxies, the reliability of the data was diminished. Notably, there has been international recognition that there is a need for a standardised core set of tools in palliative care [250], and the IPOS, as part of the Outcome Assessment and Complexity Collaborative (OACC), contributes to this aim. To prevent the recurrence of these aforementioned barriers in future work, hospices need to adopt a research-focused culture in which staff have access to regular IPOS training and have the capacity to implement the questionnaire effectively. Despite the study's limitations, five key themes were identified which are congruent with the qualitative data presented in *Chapter 5 (Table 6.5)*: pain, poor mobility, anxiety, information and patients perception of family anxiety. These findings will be included in the impact map and will contribute to the final SROI calculation.

ABSTRACT

INTRODUCTION

Hospice services have the potential to benefit those living with a life-limiting illness; however, it is difficult to place a monetary value on the positive impacts they provide. With the demand for palliative care continuing to grow as a result of a rise in the cases of complex illnesses, an ageing population and limited resources, hospices need to demonstrate their worth. Given their reliance on charitable donations and statutory funding, both of which are limited and competitive, their utility must be evidenced to justify funding. SROI analysis, a form of cost-benefit analysis, has the potential to capture the value of hospice care, but few rigorous SROI analyses exist. This chapter presents a novel SROI analysis.

METHODS

A mixed-methods approach was adopted for this study. The unit costs of hospice services calculated in *Chapter 3* via the step-down costing methodology were used to ascertain the total cost of inputs. The systematic review conducted in *Chapter 4* and the qualitative research undertaken in *Chapter 5* informed the development of a theory of change, thus facilitating the identification of relationships between inputs, outputs, and outcomes. The values of patients and family-caregiver were also extracted from the qualitative interviews. Quantitative data obtained in *Chapter 6* was used to form input parameters to measure the change in outcomes experienced by stakeholders post-hospice intervention.

RESULTS

The average input and output values for the day therapy units were £155,928 and £1,847,347 respectively, thus returning a base case ratio of £11.85: £1. The inpatient units had average input and output costs of £602,100 and £1,667,861 respectively and hence a return of £2.77: £1. Sensitivity analyses yielded estimates of between £0.98: £1 and £6.83: £1 for the inpatient units and between £2.44: £1 and £19.51: £1 for the day therapy units. Outcomes for patients were seen to generate the most social value within the day therapy units, whilst outcomes for family-caregivers generated the most social value within the inpatient unit.

CONCLUSION

Unlike alternative methods such as cost-benefit analysis (CBA), SROI provides a methodology that is underpinned by stakeholder engagement, thus providing a deeper understanding of how interventions result in changes to the outcomes that stakeholders value. This study has demonstrated that the social value generated by both the inpatient unit and the day therapy unit outweigh the cost of the inputs required to deliver them. The SROI ratio produced will hopefully assist with the attraction of future funding and ensure financial security for each site.

Chapter contribution to the SROI analysis

In this chapter, the Social Return on Investment framework is populated with qualitative and quantitative evidence reported in previous chapters to track and monitor the value of hospice services and assess their economic value. A novel SROI analysis is presented that will be of benefit to the hospice consortium; it can use the information to 1) understand what drives the services' value, 2) demonstrate effectiveness to funding bodies, and 3) make positive changes to the way that it delivers services.

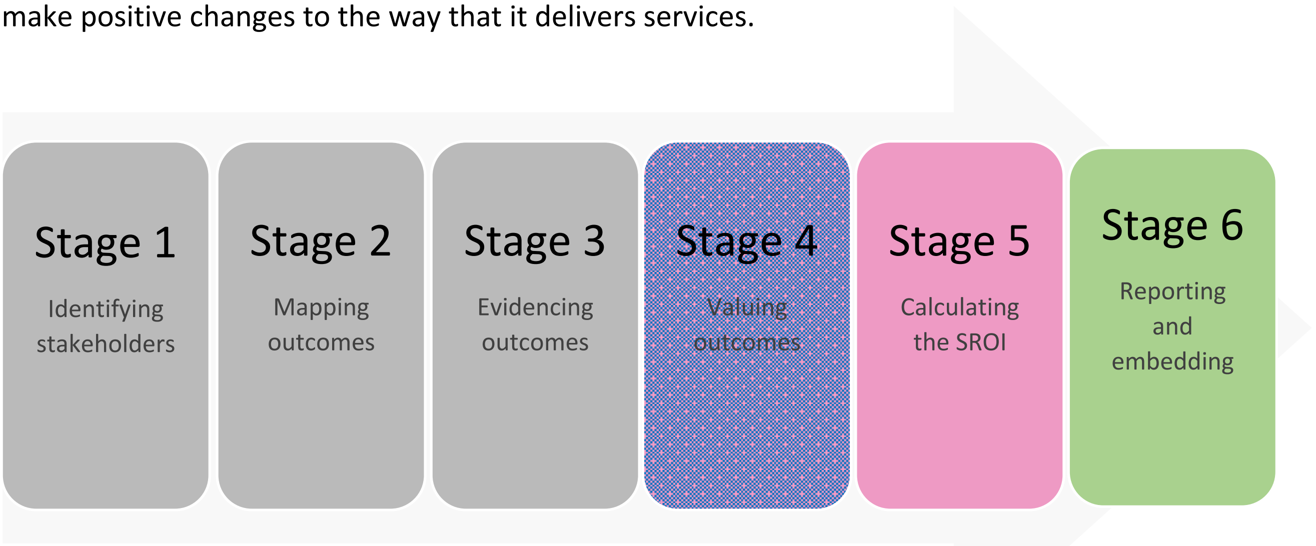


Figure 7:1:Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

The ability to measure and place value on outcomes is of great benefit to third sector organisations given their need to demonstrate their positive social impact and thus maximise funding [251]. This is not always simple, however, as often outcomes are intangible and multifaceted, which leads to difficulties in identification and measurement [67]. As a result, elements which constitute value are often overlooked despite making significant contributions [101]. The health sector in particular suffers from an inability to accurately quantify value despite it being fundamental to decision-making and service reform [252]. Demonstrably, health and well-being comprise social, environmental, and economic factors [253], and therefore tools are required which can measure all attributes as opposed to those that are immediately quantifiable [254]. Frequently, approaches such as cost-effectiveness analysis (CEA), cost-utility analysis (CUA) and cost-benefit analysis (CBA) have been utilised; however, the social return on investment (SROI) methodology has attracted attention recently [1].

The SROI methodology, unlike other social impact measurement tools, involves all relevant stakeholders as it provides them with an opportunity to inform the researcher about what matters [255]. By providing a platform for meaningful stakeholder engagement, the benefits of the interventions are presented in a way which is unique to the stakeholders themselves [94]. The ability for SROI analysis to determine this so-called subjective well-being is what has placed the methodology at the forefront of social impact assessment [65]. As such, SROI analysis provides a detailed understanding of why value is generated and produces a single ratio which accounts for the broader impacts of interventions [94]. As noted in *Chapter 1*, a complete SROI analysis has never been conducted within a hospice setting and minimal literature exists regarding its implementation within a palliative care setting. This SROI therefore represents a novel approach. The findings of this research are presented in line with the SROI stages 1-6.

Aim

The overarching aim of the SROI analysis was to assess the social value generated by the outcomes experienced by key stakeholders of hospice services over a one-year period and to estimate the SROI ratio of costs to benefits.

Methods

Study design

Underpinned by the principles of the SROI methodology outlined in *Chapter 2*, a six-stage process was followed. Each of the stages, how they were operationalised, and how the data was used is detailed next. To identify key stakeholders and map their outcomes, a mixed-methods approach was implemented whereby qualitative methods (*Chapter 5*) were used in tandem with a mixed-studies systematic review (*Chapter 4)*. These methods were then triangulated with quantitative evidence to determine the impact of the intervention (*Chapter 6)*. Quantitative methods were also used to establish the financial cost of the hospice service (*Chapter 3).* A series of one-way sensitivity analyses tested the robustness of the analysis.

Scope of the study

Stage 1a: Establishing scope

To establish the scope of the SROI analysis, an all-day research event was arranged (September 2016) and was attended by a predetermined combination of hospice personnel and included the project funders (*Table 7.1).* As discussed in *Chapter 4*, at this stage of the process, due to time constraints it was not ethically feasible to include patients and family-caregivers. Through a variety of activities, the scope of the study was refined substantially and a theory of change began to emerge. Subsequently, an evaluative-type SROI analysis (*Chapter 2)* focusing on three core services: 1) inpatient, 2) day therapy, and 3) at home service was agreed upon. It should be noted that the at home service and the day therapy services associated with Site D were excluded from the final SROI calculations due to an absence of data. Any information obtained prior to their exclusion was retained and displayed in the relevant chapters. Each phase of this project was guided by the chief executive at Site B, who acted as the lead spokesperson for the hospice consortium and provided direction and feedback when required. There was, however, a lack of design input from patients and family-caregivers at the initial meeting, which is a limitation of stage 1a.

Table 7:1: Stakeholder meeting attendees

Job role	**Hospice sites**			
	Site A	Site B	Site C	Site D
Chief executives	✓	✓	✓	✗
General manager	✗	✗	✗	✓
Matron	✗	✓	✗	✗
Volunteer project co-ordinator	✗	✗	✓	✗
Consultant in palliative care	✗	✗	✗	✓

Participants

Stage 1b: *Stakeholder identification*

A provisional list of stakeholders, that is, those who might affect or be affected by the hospice services, was created during the initial stakeholder meeting and later refined to ensure that the focus of the analysis was assigned to direct beneficiaries: hospice patients and their family-caregivers. The choice of data collection methods used to collect data relating to patients and family-caregivers was informed by the hospice consortium. To supplement patient accounts, the perspectives of hospice personnel (both paid and volunteer) concerning what they perceived patients and family-caregivers valued about the services that they provided were included; however, their personal professional outcomes (i.e. what staff and volunteers gained from delivering care) were not included in the analysis. The rationale behind the exclusion of other stakeholders is detailed in *Table* 7.2. Stakeholders were often excluded because of the expectation that there would be no material impact for them or because their involvement was beyond the scope of the evaluation.

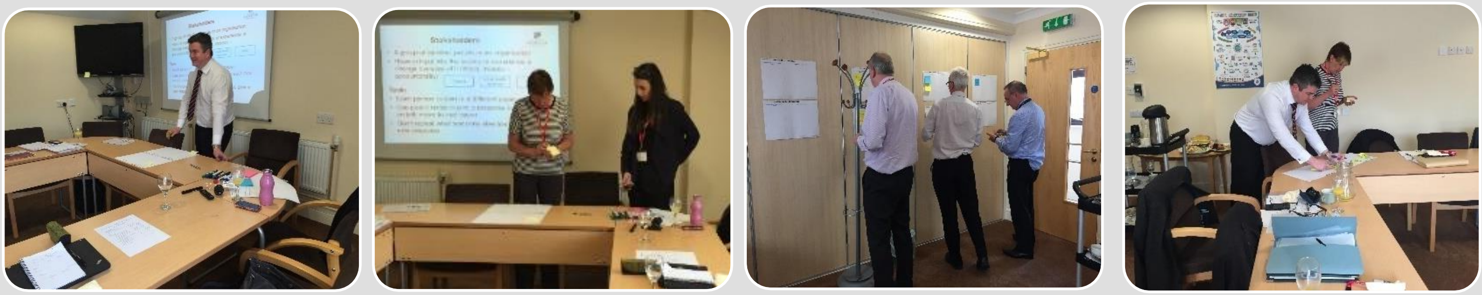


Figure 7:2: Pictures captured during stakeholder meeting

Table 7:2*:* Rationale for inclusion in/exclusion of stakeholders from the analysis

Stakeholders	Included/Excluded	Rationale
Paid personnel	Excluded as beneficiaries but involved as proxy respondents for patients and family-caregivers	Personnel costs (i.e. wages) were included; however, personnel outcomes were excluded as any value gained from working at the hospice could be replicated within another setting. The perspectives of paid personnel relating to their effect on patients and family-caregivers were included.
Volunteers	Inputs included and outcomes excluded	Volunteer time was quantified and a monetary value assigned. Volunteers' perspectives on how their role affected patients and family-caregivers were also included; however, it was anticipated that there would be a negligible material impact.
Patients	Included	Patients attending the hospice services were the primary targets of the intervention.
Family-caregivers	Included	It was anticipated that family-caregivers would experience material outcomes through direct and indirect support from the hospice sites.
NHS Wales	Inputs included and outcomes excluded	NHS Wales contributes financially to the hospices; however, its financial input could not be teased apart from the financial data provided by the hospices. A hospice admission could correlate with a reduction in admission to the hospital. This was beyond the purview of this study.
Local authority	Inputs included and outcomes excluded	The financial investment could not be teased apart from the financial data provided by the hospice sites.
The local community	Inputs included and outcomes excluded	The local community contributes financially to the hospice by investing in and organising fundraising events and visiting the onsite café; however, its potential outcomes were considered to be negligible and beyond the scope of this analysis.

Data collection

Study site contribution to data collection

Table 7.3 presents each study site's data contribution to each data collection phase. It should be reiterated that due to a lack of data, Site D was excluded from the final SROI ratios.

Table 7:3*:* Chapter specific contribution from each study site

Data collection chapters	**Hospice Sites**							
	Site A		**Site B**		**Site C**		**Site D**	
	IU	***DT***	***IU***	***DT***	***IU***	***DT***	***AH***	***DT***
Chapter 3: Cost data	✓	✓	✓	✓	✓	✓	✓	✓
Chapter 4: Qualitative data	✓	✓	✓	✓	✓	✓	✗	✓
Chapter 5: Questionnaire data	✗	✓	✓	✓	✓	✗	✗	✗
*IU = Inpatient unit, DT = Day therapy, AH= at home service								

Quality assessment

For this SROI analysis, Krlev et al's [108] 12-point quality assessment framework was used (*Chapter 8)*. This framework was selected because it is the first and only publicly available framework for judging the quality of SROI reports.

Reporting

The SROI assurance standard checklist was used to guide the reporting of this study *(Appendix 6.4).*

Findings

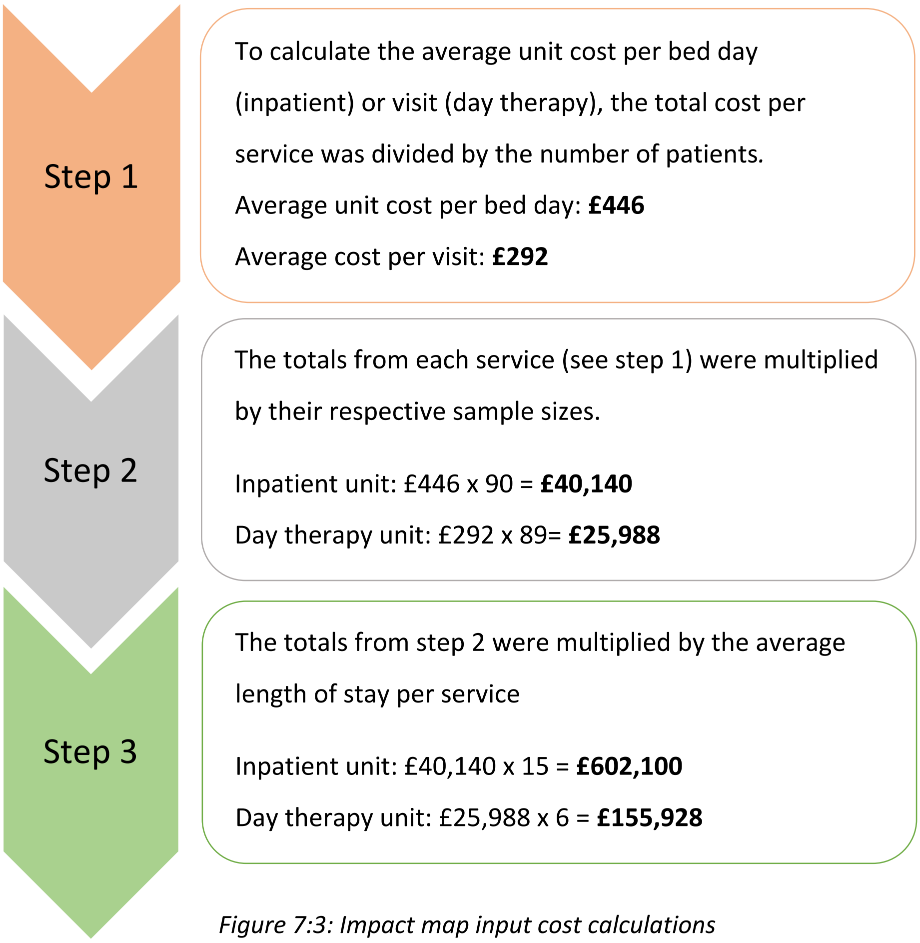
Stage 2: *Mapping outcomes*

Theory of change

In this stage of the process, an impact map (also referred to as a theory of change) informed by stakeholder engagement was constructed to demonstrate the relationships between inputs, outputs, and outcomes. Specifically, the impact map (*Appendix 6.1*) provides a visual representation to demonstrate how the hospice services use certain resources (inputs) to deliver their activities (outputs) to produce the outcomes experienced by stakeholders.

Costing hospice services

A partial economic analysis (*Chapter 3)* was conducted from the service provider's perspective to determine the input cost for the two models of hospice services (inpatient and day therapy). The financial data (January-December 2016) from each hospice could be grouped into the following categories: human resources, administration, housekeeping, transport, pharmacy, and catering. By using a step-down costing methodology, the financial aggregated data from each of the hospice sites was assigned to one of the two services under analysis using appropriate cost-drivers. Whilst NHS Wales, the local authority, and the community invest financially in the hospice, their individual inputs could not be teased apart from the initial financial data provided. In this analysis, volunteer time was assigned a financial value based on the cost of replacing volunteers with non-voluntary equivalents [40][256]. All patient-related and other societal costs were excluded as there is no charge to patients for using hospice services. The financial data was used in tandem with service utilisation data to determine the average cost for the sample size. For clarity, the calculations are detailed further in *Figure 7.3.*



Step 1

To calculate the average unit cost per bed day (inpatient) or visit (day therapy), the total cost per service was divided by the number of patients.

Average unit cost per bed day: **£446**

Average cost per visit: **£292**

Step 2

The totals from each service (see step 1) were multiplied by their respective sample sizes.

Inpatient unit: £446 x 90 = **£40,140**

Day therapy unit: £292 x 89= **£25,988**

Step 3

The totals from step 2 were multiplied by the average length of stay per service

Inpatient unit: £40,140 x 15 = **£602,100**

Day therapy unit: £25,988 x 6 = **£155,928**

Figure 7:3: Impact map input cost calculations

Outcome identification

Through a sequential two-stage process, and informed by the engagement of stakeholders, a comprehensive list of outcomes for patients and family-caregivers was created. For the first stage of this process, a mixed-studies evidence synthesis was performed to search and synthesise qualitative and quantitative studies (*Chapter 4).* These findings, used in conjunction with staff perspectives, informed the development of topic guides which helped to elicit the experiences of patients and family-caregivers through qualitative data collection methods in the subsequent stage. The final sample comprised 45 patients (inpatient: 10, day therapy: 35) and 18 family-caregivers (inpatient: 4, day therapy: 14).

Table 7:4*:* Stakeholder outcomes derived through qualitative methods

Outcomes	**Outputs**			
	Day therapy		Inpatient	
	Patients (n=35)	Family-caregivers (n=14)	Patients (n=10)	Family-caregivers (n=4)
Increased feeling of autonomy	15	-	5	-
Reduced feelings of loneliness and isolation	24	4	3	-
Improved sense of informedness	14	6	2	3
Physical symptom improvements	14	-	7	-
Psychological improvements	20	5	4	1
Improved relationships	8	12	2	1
Improved mobility	7	-	2	-

Stage 3: *Evidencing outcomes and assigning a value*

Evidencing outcomes

Data obtained through the embedding of the Integrated Palliative Outcome Scale IPOS) *(Chapter 6*) was included in this stage. Data from the first follow-up questionnaire, collected between June 2018 and April 2019 at irregular time points, was used to determine whether patient outcomes improved or were maintained post-hospice admission. This data set was formed by using data reported by individuals, staff proxies, and family proxies (day therapy: 54, inpatient unit: 80). It should be noted that these outcome measures were aimed at patients; however, one question utilised proxy responses to determine the psychological experiences of family-caregivers.

Due to the reliance on data collected as part of routine clinical practice, the questionnaires did not always map onto the outcomes experienced by patients and family-caregivers (*Chapter 6*). Thus, in the absence of data, responses from qualitative interviews were used as indicators of change. Whilst this approach is not ideal, the use of qualitative methods to determine change has been used elsewhere [257]. Any improvements in or maintenance of the outcome scores experienced by patients and family-caregivers were considered meaningful [258] and thus met the threshold criteria in this study for demonstrating that material change had occurred. This approach provided valuable insights regarding meaningful change and acted as an alternative when it was not possible to quantitatively measure change.

Table 7:5*:* Stakeholder outcomes and how material change was measured

Stakeholder	Outcome	Inpatient	Day therapy	Material change defined by
Patients	Increased feeling of autonomy	5	15	The number of patients who reported a change during qualitative interviews post-hospice admission
	Reduced feelings of loneliness and isolation	3	24	
	Improved relationships	2	8	
	Improved sense of informedness	19	32	Change in IPOS score
	Psychological improvements	49	29	
	Physical symptom improvements	61	35	
	Improvements in mobility	49	35	
Family-caregivers	Reduced feelings of loneliness and isolation	-	4	The number of patients who reported a change during qualitative interviews post-hospice admission
	Improved sense of informedness	2	6	
	Improved relationships	1	12	
	Psychological improvements	41	31	Change in IPOS score (proxy-reported)

Outcomes valuation

This SROI analysis benefited from the use of the well-being valuation methodology to monetise the non-marketable goods (e.g. improved relationships) [259]. This approach employs existing data sets pertaining to well-being and was used in lieu of the ‘value game’, which directly involves stakeholders in the valuation process through a card game based on accepted economic techniques [260]. The ‘value game’ was not used as an approach to monetise stakeholder outcomes because of its potential to cause psychological distress within the palliative sample population. Instead, the Housing Associations’ Charitable Trust

(HACT) database (version 4) was utilised, which assigns a monetary value (per annum) to personal, social, and community outcomes [261]. This approach, which is common amongst published SROI analyses, minimises subjectivity in the monetisation process and creates a degree of standardisation [2]. The per annum proxy value associated with each stakeholder outcome is listed in *Table 7.6.*

Customarily, the duration of outcomes within an SROI analysis will exceed 1 year; however, owing to the nature of a palliative diagnosis, it was assumed that this would not be plausible. As a result, financial proxies for patient outcomes were adjusted depending on the service to reflect their average life expectancy (*Table 7.7)*. The average life expectancy of patients utilising the inpatient services was 102.86 days and the average life expectancy for day therapy patients was 290.66 days. It should be noted that this method of pro-rated financial proxies is a novel approach. The duration of family-caregiver outcomes were assumed to be 1 year.

Table 7:6: Sources of monetary valuations for outcomes based on adjusted time scale

Outcome	**Monetary Valuation Source**	**Full One-Year Value**[1]	**Pro-rated for Day Therapy**[2]	**Pro-rated for Inpatient**[2]
Increased feeling of autonomy	HACT social value bank: Feel in control of life	£15,894	£12,620	£4,466
Reduced feelings of loneliness and isolation	HACT social value bank: Feel belonging to a neighbourhood	£3,753	£2,980	£1,055
Improved sense of informedness	HACT social value bank: Able to obtain advice locally, any age	£2,457	£1,951	£690
Improvements in physical symptoms such as pain	HACT social value bank: Good overall health, any age	£20,141	£15,992	£5,660
Psychological improvements	HACT social value bank: Relief from depression/anxiety (adult), any age	£36,766	£29,192	£10,331
Improved relationships	HACT social value bank: Can rely on family	£6,784	£5,386	£1,906
Improvements in patient functionality and mobility	HACT social value bank: Walking	£5,281	£4,193	£1,484

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[1] Sources of monetary valuations for outcomes based on a 12 month period

[2] As the average life expectancy of patients at Site A was less than one year, the financial proxy values required adjustment to ensure proportionality. The calculations below demonstrate how this was achieved in relation to the 'Increased feeling of autonomy' outcome above.
Day therapy: Average life expectancy= 290.66 days
(290.66/366) x 100 = 79.4%
(£15,894/100) x 79.4% = £12,620
Inpatient unit: Average life expectancy = 102.86 days
(102.86/366) x 100 =28.1%
(£15,894/100) x 28.1% = £4,466

Table 7:7: Final proxy values for each stakeholder group

Outcomes	**Gross Value of the Outcomes**			
	Day therapy		Inpatient	
	Patients	Family-caregivers	Patients	Family-caregivers
Increased feeling of autonomy	£189,300	£0	£22,330	£0
Reduced feelings of loneliness	£71,520*	£15,012	£3,165	£0
Improved sense of informedness	£62,432	£14,742	£13,110	£4,914
Psychological improvements	£846,568	£1,139,746	£506,219	£1,507,406
Physical improvements	£559,720	£0	£345,260	£0
Improved relationships	£43,088	£81,408	£3,812	£6,784
Improved mobility	£146,755	£0	£72,716	£0
Total	£1,919,383	£1,250,908	£966,612	£1,519,104
Unit total	**£3,170,291**		**£2,485,716**	

*A demonstration of how the financial proxies above were determined is displayed below using the 'reduced feelings of loneliness' outcome as a real-world example.
Day therapy patient: £2,980 (*Table7. 6*) x 24 (*Table 7.3*) = £71,520

Establishing impact

To ensure the credibility of the results and minimise the risk of over-claiming, the influence of deadweight, displacement, attribution, and attrition needs to be accounted for. Deadweight refers to the proportion of change that an individual would have experienced over time independent of the hospice's involvement. Given the nature of a palliative diagnosis, it is expected that a patient's quality of life will deteriorate over time. Displacement assesses the proportion of an outcome that resulted in the displacement of other outcomes. For instance, hospices may choose to cancel or rearrange activities in favour of an alternative service. Attribution accounts for the proportion of change that can be ascribed to the hospice service without any influence from external services such as Macmillan. Hospice patients may receive supplementary care from Macmillan in the form of information, for example; however, the benefits of receiving such services must be negated for the purpose of the SROI analysis. Attrition does not refer to participation rates; it refers to the proportion of the outcomes that depreciate after the first year. Questions were included in the qualitative interviews with stakeholders to establish deadweight, displacement, attribution, and attrition percentages that could be used in the SROI analysis using the percentage descriptors set out in *Table 7.8.*

Table 7:8: SROI filters

Category	**Assigned (%)**
The outcome would not have occurred without hospice involvement	0%
The outcome would have occurred, but to a lesser extent without hospice involvement	25%
The outcome would have occurred in part without hospice involvement	50%
The outcome would have occurred to a large extent without the hospice involvement	75%
The outcome would have fully occurred without hospice involvement	100%

Attribution

The hospices acted as the primary care provider for patients, particularly within the inpatient unit. An attribution rate of 25% of outcomes accruing from elsewhere has therefore been applied (*Table 7.9)*. Within the day therapy unit, however, patients accessed support from external medical professionals such as GPs, and therefore a higher attribution rate of 50% of outcomes accruing from elsewhere has been applied *(Table 7.9).*

Deadweight

The respondents felt that the changes they experienced would not have been achieved without access to hospice care. A deadweight rate of 25% of outcomes accruing from elsewhere has been applied, however, to account for respondent bias and to minimise the risk of over-claiming benefits *(Table 7.9).*

Attrition

Given the nature of a palliative care diagnosis, it is highly unlikely that a patient's length of life will exceed one year. An attrition rate of 100% has therefore been assigned to patients in both the day-therapy and inpatient units *(Table 7.9)*. As family-caregivers still have access to services such as bereavement support, an estimation of the attrition rate (75%) has been made based on their responses during interviews (*Table 7.9*). These figures are only applied to outcomes occurring in year two and beyond. As the study is set as a one year period, the percentages reported won't impact the final ratio, but it is still useful to report them.

Displacement

The displacement associated with hospice care is minimal. Respondents consistently explained that in the absence of hospice care, they wouldn't have sought additional support. Other palliative care services do exist, however, and therefore by choosing to access hospice care, these are effectively displaced. A rate of 25% of potential outcomes being displaced was used for this analysis *(Table 7.9).*

Table 7:9: The rate of attribution, deadweight, attrition and displacement across stakeholder group across and hospice units

Stakeholder		Attribution	Deadweight	Attrition	Displacement
Day therapy	Patient	50%	25%	100%	25%
	Family-caregiver	50%	25%	75%	25%
Inpatient	Patient	25%	25%	100%	25%
	Family-caregiver	25%	25%	75%	25%

Results

SROI ratio calculation

Through the application of the SROI principles, this analysis returned a base case ratio for the two hospice models of interest *(Table 7.10).* The average input and output values for the day therapy unit were £155,928 and £1,847,347, thus returning a base case ratio of £11.85:£1. The inpatient unit had average input and output values of £602,100 and

£1,667,861 respectively, which returned a base case ratio of £2.77:£1. The formula for calculating the SROI ratio is as follows:

$$\text{SROI ratio} = \frac{\text{Total impact value (minus deadweight, displacement, attribution, drop off)}}{\text{Total investment}}$$

The outcome that created the most social value within the inpatient unit was improved psychological well-being, which generated £635,936 for family-caregivers and £214,561 for patients. Within the hospice day therapy unit, improved psychological well-being also returned the highest social value for patients and family-caregivers, with £357,146 and £480,830 generated respectively. Family-caregivers received £640,872 of social value within the inpatient unit, which represented 61% of the total. This trend was reversed within the day therapy unit as patients received social value worth £809,740, which represented 61% of the total value for the unit. The inputs and outcomes for each stakeholder group were transferred to an impact map which revealed the scale of material changes for each stakeholder group and the subsequent value produced.

Sensitivity analysis

To determine the robustness of the assumptions underpinning the base case scenario, a series of one-way sensitivity analyses were undertaken (*Table 7.10*). Within the initial SROI analysis, suppositions were made (*Chapter 3*) regarding the apportioning of costs across the inpatient and day therapy units potentially resulting in inaccuracies. By assuming equitable distribution of input costs across both units, the day therapy unit returned its lowest ratio of £2.44:£1 - a 79.4% reduction from the base case. When it was assumed that the outcomes experienced by patients and family-caregivers would all last up to 1 year, the inpatient unit returned its highest ratio of £6.83:£1- an increase of 146.6% from the base case. When the same sensitivity analysis was applied to the day therapy unit, the highest ratio (£19.51:£1) was also returned, with a 64.6% increase from the base case.

Table 7:10*:* Sensitivity analysis

Scenario	**SROI Ratio (£)**			
	Inpatient	Proportion of change	Day therapy	Proportion of change
Base case	**2.77:1**	-	**11.85:1**	-
Using HACT deadweight values	2.70:1	-2.5%	11.69:1	-1.4%
Assuming all outcomes last up to 1 year	6.83:1	+146.6%	19.51:1	+64.6%
Assuming all outcomes did not last up to 1 year	0.98:1	-64.6%	7.88:1	-33.5%
The total hospice expenditure was shared equitably across the two services	2.20:1	-20.6%	2.44:1	-79.4%

Discussion

In this study, a social return on investment (SROI) framework was used to establish the social value of two models of hospice services. The day therapy unit was ascertained to have a base case ratio of £11.85 whilst the inpatient unit yielded a base case ratio of £2.77. Because the services are patient centred, it was expected that patients would experience the highest proportion of social value for them, but although this was reflected within the day therapy unit, it was family-caregivers who generated the highest proportion of social value from inpatient services (77% of the entire social impact created for this unit). Whilst this finding could have been marred by the difficulties associated with patient recruitment, it is also possible that the proxy and proxy-assisted responses used to indicate the psychological improvements for family-caregivers were over estimated. As psychological improvements were the highest generator of social value for patients and family-caregivers in both units, an overestimation would have had a substantial impact on the social return.

This study was dependent on the use of pre-prepared financial proxies obtained from the Housing Associations' Charitable Trust (HACT) [261]. The use of this database helped to improve standardisation and remove the subjectivity in the valuation process; however, the financial proxies are provided as an annual figure. In *Chapter 3*, it was determined that the average life expectancy of patients accessing support from the hospice in 2016 equated to less than a year, and thus to avoid over-claiming, financial proxies for all patient outcomes were pro-rated to reflect the average life expectancy of the unit. To the best of our knowledge, this is a novel approach. Although the majority of financial proxies effectively mapped on to outcomes, improved mobility lacked a specific proxy and was therefore assigned the HACT financial proxy 'walking'. The value of £5,281 per year did not truly reflect the importance that patients placed on improved mobility. The sensitivity analysis which did not pro-rate the financial proxies and thus assumed that all stakeholder outcomes would last 1 year returned the highest SROI ratio for both the day therapy (£6.83:£1) and inpatient unit (£19.51:£1). The lowest SROI ratios were returned for both services when the total hospice expenditure was shared equitably across the two models of services. Due to the substantial number of assumptions applied to proportion costs in *Chapter 3*, which was a consequence of this study's reliance on heavily aggregated financial data, a sensitivity analysis was conducted to demonstrate its impact on the base case scenario.

The economic theory that underpins the SROI methodology and the heterogeneity of the processes involved prevent the comparability of SROI ratios across organisations. Although direct comparisons cannot be made, examining ratios generated by similar services does provide a context for the results produced. Unfortunately, due to the limited number of published SROI reports in both peer-reviewed and grey literature in this field, it is not clear where these findings stand in relation to those relating to other organisations. A Nottinghamshire hospice publicised the commencement of an SROI project [68]; however, numerous attempts to contact the research team have been unsuccessful. An SROI analysis of an integrated care team in Essex, which provided a palliative service was conducted and produced an SROI ratio of £9.97:£1 [262]. However, the palliative care service could not be unpicked from the other services provided by the team, thus marring the generalisability of the analysis. In this study, however, through consultation with stakeholders, a robust theory of change was developed which demonstrates how the hospice activities bring about material change for the different stakeholder groups.

Strengths and limitations

The SROI methodology provided a transparent and accountable method that was informed by and designed in collaboration with stakeholders. Due to the nomenclature of the SROI stages, however, there were some issues regarding this thesis's structure and organisation. Although stage 2 is entitled 'mapping outcomes', the requirements extend beyond this and encapsulate the inputs, outputs, and outcomes necessary to construct the theory of change [40]. From experience, this sequence feels illogical, and stage 2 should have focused solely on outcomes and the costing of inputs and outputs should have been integrated into stage 5 – ‘calculating the SROI’. In this thesis, the costing methodology is detailed in *Chapter* 2, in line with the SROI stages.

Whilst traditional economic evaluations (*Chapter 2*) often provide a unidimensional insight, with a substantial focus on factors which have direct applicability to the marketplace, the SROI framework provides a holistic approach to capture the broader concepts of value. Reduced to a single ratio, the SROI analysis is able to reach a wider audience because the complexities often associated with communicating value are simplified. To the best of my knowledge, this study presents the first SROI analysis of hospice care and thus, the transparency of the processes involved serves to demonstrate the suitability of the framework for sensitive research fields such as palliative care. Novel to the this SROI methodology, the duration of outcomes for patients were prorated to reflect that the outcomes experienced would not surpass a one-year period to prevent over-claiming.

In a substantial deviation from the original protocol, both the number of proposed SROI analyses and their scope, were reduced. Due to difficulties in obtaining the level of data required, coupled with time constraints, an agreement was reached to produce one SROI analysis per study site which focused solely on the inpatient and day therapy units. To ensure an adequate level of detail, a consensus was reached regarding sharing resources across study sites was reached, although Site D was still unable to provide thorough data and thus was subsequently excluded from the SROI analysis. Consequently, only an SROI analysis of the day therapy and inpatient units was conducted, which represents a considerable gap between the ideal output and the actual output.

Whilst substantial stakeholder involvement is a strength of this methodology, patient and family-caregiver engagement in the derivation of financial proxies was deemed unsuitable. Social Value UK [260] promotes the use of a ‘value game’ when an organisation is attempting to determine a financial proxy for the outcomes experienced by service-users. This involves the use of a card game through which stakeholders rank outcomes in order of importance and assign value through comparison with alternative products [260]. Ethically, this raised concern as palliative populations would be comparing end of life health outcomes against ‘luxury goods’ such as cars or holidays. Whilst value games offer bespoke financial values determined by the stakeholders, there was the potential to cause unnecessary distress. The Housing Associations' Charitable Trust's (HACT) database was therefore used as an alternative approach. This approach minimises subjectivity in the monetisation process and creates a degree of standardisation [2]. For the purpose of an SROI analysis, each outcome must be viewed as a separate entity in order to determine its value and avoid double-counting, but, given the interrelatedness of patient outcomes within a palliative setting, extrication presents a substantial challenge. It remains contentious to compare the SROI figures of organisations with differing objectives, because the generalisability of SROI ratios is so context specific and variation exists in the instruments used to measure and value outcomes. It is, however, valid to compare SROI ratios for the same setting at various points in time. It should be noted, nevertheless, that an SROI analysis is largely dependent upon a substantial number of informed assumptions and other discretionary decisions such as which method to deploy when determining impact. Thus, the degree of standardisation is limited, making it unlikely that two analysts conducting an SROI analysis within the same organisation at the same time would arrive at an identical SROI ratio.

Following the completion of an SROI analysis, it is necessary to report back to stakeholders and the organisations involved as this enables them to apply the findings and subsequently improve service delivery. Initially, the intention was to facilitate meetings with the hospice consortium to present my findings; however, due to the time constraints associated with a PhD, coupled with the detrimental impact of Covid-19, the hospice sites were not accessible and thus these plans have been curtailed. Currently, the hospices are facing additional pressures as working practices have had to be adapted however, once a degree of normality returns, an online meeting will be arranged.

Conclusion

With third sector organisations facing increasing pressure to demonstrate their worth, there is a need to capture the value associated with their wider and often intangible outcomes [263]. This chapter has demonstrated that the SROI framework provides a suitable methodology for determining these broader social impacts. Through the employment of the triple bottom line approach, SROI analysis represents a useful alternative to traditional economic investment evaluations due to its ability to account for social value from the stakeholders' perspective and to build upon the theory of change [264]. As a result, the SROI framework provides an opportunity to expand the scope of impact analysis to encompass all dimensions of impact created [264]. By applying financial weightings to the social, environmental, and economic outcomes and producing a single fiscal metric, SROI's importance as a social impact measurement is demonstrated [40]. Presenting the results as a simple ratio comparing the value generated against the value of inputs ensures that the findings are easily interpreted, which is beneficial when communicating with stakeholders and potential funders [107]. The SROI analysis in this chapter has demonstrated that the social value generated by both the inpatient unit and the day therapy service outweighs the cost of the inputs required to deliver them, even after the application of multiple one-way sensitivity analyses. Perhaps more important to the organisations themselves is the construction of a theory of change which examines how value is generated for individual stakeholders. This facilitates the measurement of changes that are relevant to specific stakeholder groups and informs future practice.

Chapter summary

As per stage 6 of the Social Return on Investment (SROI) methodology (*Figure 8.1*), this chapter provides a summary of the principal findings reported in this thesis and reiterates their relevance to the overarching research question. Through critical discussion and conclusions, the SROI methodology will be reviewed in the context of the strengths and limitations, thus providing the basis on which discussions surrounding the suitability of this approach within a palliative context will be based. This thesis will conclude with a description of the unique contribution to the wider literature and the recommendations for future research, policy, practice, and service development will be outlined.

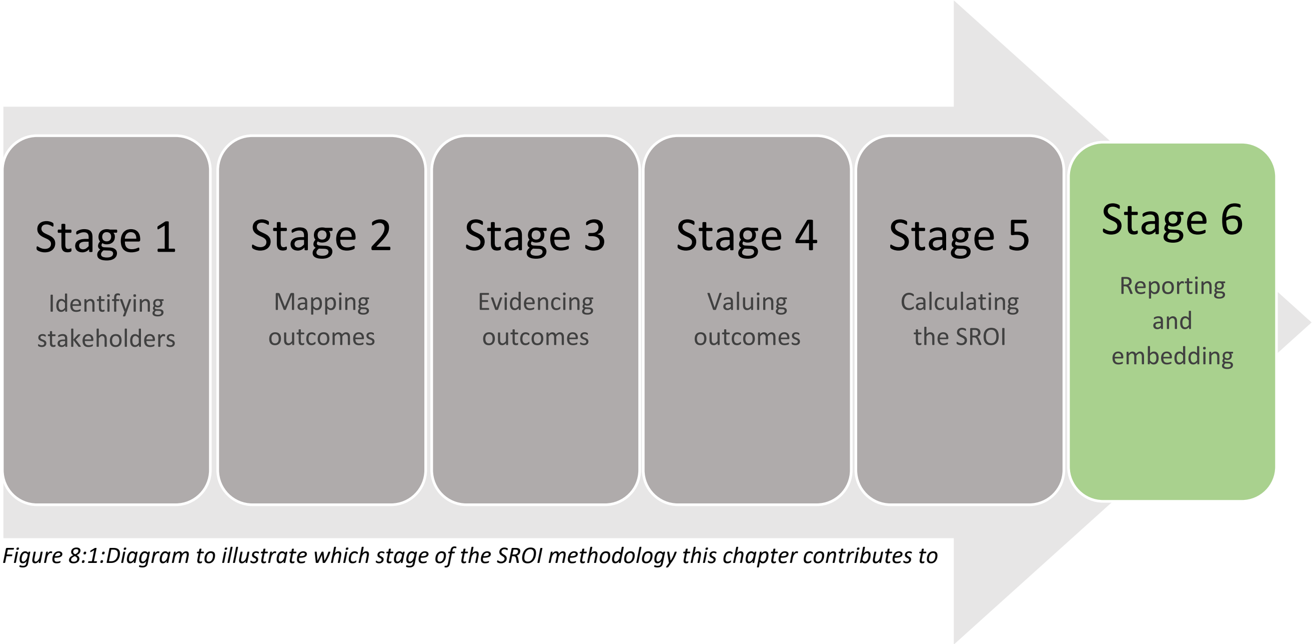

Figure 8:1:Diagram to illustrate which stage of the SROI methodology this chapter contributes to

Introduction

This thesis presented a mixed methods study which included a systematic review, qualitative and quantitative data collection approaches along with a SROI in palliative care setting. The research presented in this thesis presents the first completed SROI analysis within the hospice sector and thus provides a unique opportunity to critically discuss the suitability of this methodology within a palliative care setting. Although a Nottinghamshire hospice began an SROI analysis prior to 2016, there is no evidence that it was completed, and multiple attempts to contact the hospice were unsuccessful (*Chapter 1*). This thesis is a co-produced research study and presents the results of an evaluative SROI analysis of three hospice sites and evidences the extent to which the services under evaluation have contributed towards the change experienced by two stakeholder groups: patients and family-caregivers using day therapy and inpatient services. Nevertheless, the work reported in this thesis provides the academic intervention frequently sought to aid the development of the SROI methodology [251] whilst also embedding the necessary tools and processes to enable the hospice study sites to continue measuring their social value. To date, many SROI analyses have been conducted by third sector organisations without academic input [251]. The current SROI analysis is an advance in that it was co-produced between the third sector hospice organisations and a higher education institution specialising in SROI methodology. Input from higher education institutions helped the hospices to complete a rigorous SROI analysis which will support them to fulfil their strategic aim of aligning with the prudent health care principle of reducing variation through evidence-based practice [47] (*Chapter 1).* The application of the SROI methodology through the use of convergent, parallel mixed-methods [142] approach (qualitatively using semi structured interviews, focus groups and quantitative stakeholder surveys) contributed towards demonstrating a greater understanding of the impact that hospices have on health and well-being. The findings of each empirical chapter, and how they relate to the research questions initially posed in *Chapter 1*, will be critically discussed in this chapter. Subsequently, each of the methods utilised are critically appraised using method-specific and validated tools and their strengths and limitations discussed. Finally, the practical implications that lead to actionable recommendations in relation to policy and practice, education, and future research are outlined.

Novel contribution of the thesis

The overall aim of this thesis was to conduct an evaluative SROI analysis of two hospice services; day therapy and inpatient units. To achieve this aim, the research questions listed in *Chapter 1* were addressed across each empirical study (*Chapters 3-7)* which have resulted in important and novel contributions to hospice and palliative care research (*Table 8.1)*.

Table 8:1: Thesis aims and novel contributions

Study	Thesis aims	Novel Contributions
Partial economic analysis	To determine the per patient unit costs of the day therapy, inpatient unit, and at home service.	Currently, limited literature exists regarding the cost of palliative care for UK hospices and is missing entirely for Wales specifically. This research therefore represents a unique contribution as not only does it provide an estimate of hospice care costs in Wales but it also utilises data from actual financial accounts. Furthermore, the use of the step-down costing methodology is limited across the wider literature and therefore, this study provides an addition to the current knowledge base.
Systematic review	The determine the value of hospice care to patients and family-caregivers.	This systematic review posed and answered a novel review question. The systematic review which was subsequently published within the BMC Palliative Care Journal also identified further research gaps to inform a future research agenda.
Qualitative research study	To explore patients, family-caregivers, paid personnel, and volunteers' experiences of hospice care and ascertain values.	To date, this qualitative research study presents one of the largest qualitative studies undertaken. Conducted across four hospice sites, this study provides generalisable findings to other similar contexts. In total, 96 participants (63 patients and family-caregivers, 33

		hospice staff or volunteers) were recruited.
Quantitative research study	To assess the trajectory of symptom severity over time, and the quantity of outcomes achieved.	The results of this study will support the current evidence-based decision-making within the hospice study sites.
SROI analysis	To determine the social value of two hospice services; day therapy and the inpatient unit.	The publication of this thesis and the subsequent academic journal papers will present a novel contribution to the current literature. Furthermore, the duration of outcomes for patients were pro-rated to reflect their average length of life and prevent over claiming (*Chapter 7*). This is in contrast to standard practice which places a one-year time horizon on outcomes.

Deviations from the protocol

The extensive and often intricate data required to conduct an SROI analysis has been regularly cited [104] and presented a series of challenges throughout this research. Ultimately, this resulted in deviations from the original protocol which are listed below:

- Reduced scale and scope of the SROI analysis: Initially, the hospices had requested individual SROI analyses. Due to the time constraints of the PhD, and inability to acquire sufficient data from each hospice, a decision was taken to amalgamate hospice resources and complete a combined SROI analysis. This resulted in the production of two SROI analyses, as opposed to eight, which focused on the inpatient and day care units of Sites A, B, and C collectively.
- Exclusion of Site D: Site D was unable to provide the data required to conduct an SROI analysis and were subsequently excluded from the study.

- Change of costing methodology: The hospices were unable to provide adequate costing data and therefore, in lieu of the required information, the micro-costing methodology was replaced with the step-down costing approach.
- Change of quantitative outcome measure: It was initially intended that the ICE-CAP-SCM well-being instrument would be used for quantitative data collection; however, the hospice consortium proposed the use of the IPOS as an alternative measure due to its increasing deployment across UK hospices.

These deviations will be discussed further within the critical analysis section of this chapter.

Challenges of conducting palliative care research

The challenges associated with palliative care research are well documented in *Chapter 1*, and, when coupled with the resource intensity of an SROI analysis, proved increasingly difficult, which subsequently resulted in the withdrawal of Site D from the final SROI analyses due to their inability to provide sufficient data. Notably, some challenges were somewhat alleviated by the co-produced nature of this research and the collaboration with a consortium of three hospice sites. The exception, however, was the at home service (Site D), which was undergoing significant reorganisation at the time of this research and none of the other sites offered a similar service.

Whilst the hospice consortium endeavoured to become more research active, it was apparent that staff struggled to balance their clinical priorities with the research requirements. This was reflected in the initial difficulties with recruitment which could, in part, be attributed to time-constraints, but also due to their position as gatekeepers, as discussed within *Chapter 6.* As hospice staff were responsible for recruiting patients, this added an element of subjectivity regarding who they deemed suitable for interview and may explain the small inpatient sample size. Initially, recruitment across all inpatient units was particularly slow. To accelerate the process, the lead researcher (the author) was embedded within Site B for 15 days to mitigate gatekeeping and ensure a conscious effort was made to recruit participants. Whilst this alleviated the problem, it was not feasible to be present at all times. Throughout this research, there were also a number of staff changes which resulted in the disruption of communication which required relationships to be re-established. To summarise, a new chief executive was appointed at Site C and a number of managerial changes occurred at Site D due to long term sickness and death. Whilst the chief executive of Site B adopted a lead role for the consortium which helped to mitigate the impact of these changes, their time was also limited as Site B and Site D were in the process of merging.

Despite attempts to minimise the potential for ethical and moral challenges posed by this research, there were two notable ethical challenges faced. Firstly, an incident occurred whereby a participant drifted in and out of sleep which resulted in the termination of the interview despite insistence by the participant and their family to continue. It was apparent that the patient was no longer able to participate so they were informed that the interview would cease and reassured that this would not negatively affect the study. Contact details were provided which allowed them to contact the researcher if they wished to participate again at a later date. Secondly, during this research study, a volunteer who participated within a focus group died unexpectedly, raising ethical questions regarding the retention and use of their data. The consent forms stipulated that, in the event of a participant's withdrawal, all data obtained up to this date would be retained therefore, the volunteer's information was kept in accordance with this policy.

These aforementioned challenges were logged within a reflexive diary and presented to my supervisory team for discussion. Meetings were arranged with the lead chief executive and, where possible, with the hospice consortium to discuss progress, issues and potential resolutions. Lead nurses were also consulted to ensure that planned actions were feasible within their working capacity. Although the problems faced were rectified through continued collaboration, the research process was not always seamless, and compromises were made. The limitations of each study will be discussed individually within the limitations section of this chapter.

Reflexivity

A core feature of qualitative work is the explicit acknowledgement of the researchers own biases and assumptions. Researchers can exert an enormous influence on the research and reflexivity provides the readers with an opportunity to draw their own conclusions about the interpretations that are presented throughout the research [275]. As objectivity is not guaranteed, an insight into 'who the researcher is' will provide some context and thus, a summary of pertinent information about me, my background and my prior experiences has been presented.

Firstly, it should be noted that prior to the commencement of this KESS studentship, my research experience was attained through a Criminology and Criminal Justice undergraduate degree. This, coupled with my limited knowledge of hospice care, resulted in false preconceptions of hospice care. Most notably, I considered hospice care to be a healthcare setting which focused solely on end of life care which I now acknowledge is a restricted outlook. Whilst my understanding of hospice care was limited at the outset, one year into this KESS studentship, I experienced a range of personal challenges as, sadly, three family members passed away, one of whom received support from the at home service (Site D). These insights, whilst brief, permitted a brief understanding of familial experiences.

Palliative care is a sensitive and protected field of research, which presented additional challenges when conducting qualitative research. For four years prior to my appointment as a postgraduate researcher, I volunteered with Victim Support, an independent charity dedicated to supporting people affected by crime and traumatic incidents. Through regular discussions with victims of crime, distressing conversations became commonplace and thus I was somewhat prepared. When questioned about my suitability as an interviewer by the Research Ethics Committee (REC), I drew upon these experiences to demonstrate my competence.

The importance of building rapport within qualitative research cannot be understated [278]. By establishing relationships with interviewees, the researcher is able to gain their trust, thus fostering meaningful dialogue through which their lived experiences can be accurately shared [279]. A balance must be maintained however between rapport building and adherence to the protocol of the interview to avoid inadvertent bias [280]. Following the first couple of interviews, the recordings were reviewed by my supervisor who noted that I was subconsciously using reassuring sounds. In doing so, I was providing verbal affirmation that interviewee responses were ‘correct’ and therefore leading conversation as opposed to facilitating natural dialogue. Although such actions may seem trivial, upon reflection, it is clear that their impact upon data collection can be substantial.

Rapport was not solely built with interviewees, but also hospice staff. As they were responsible for disseminating consent forms and identifying appropriate participants, there was a necessity to develop my relationship with them. A stipulation of KESS is that the researcher must spend a minimum of 30 days embedded within their partner organisation. I used this time to introduce myself to staff, discuss my research with them and answer any questions they had, thus creating an environment conducive to effective research.

Critical analysis

In the following sections, individual critical analyses and appraisals of the five empirical studies and their methods will be presented.

Chapter 3: *Step-down costing of hospice care services*

A partial economic analysis was conducted, and the step-down costing methodology applied to determine the unit cost of 1) the inpatient unit, 2) the day therapy unit, and 3) the at home service. The unit costs calculated in this study informed the mapping stages component of the SROI methodology.

Quality appraisal of step-down costing methodology

The Consolidated Health Economic Evaluation Reporting Standards (CHEERS) [125] were used to assist with the reporting of the partial economic analysis (*Chapter 3)* but the corresponding quality assessment checklist [265] was not implemented in this study. Although the BMJ, Philips, QHES, CHEC, and CHEERS checklists were found to be the most commonly used quality appraisal tools by economic analysists [266], they were not suitable for the partial economic analysis presented in this thesis as they are designed for use with full economic analyses. Therefore, a more appropriate modified costing quality checklist [267] comprised of 15 questions was used to ascertain methodological quality. Of note, it is not explicitly stated how the checklist is applied and therefore, dichotomous Yes or No categories were employed as is synonymous with alternative costing checklists such as CHEERS. The Cochrane Handbook advises against scoring or using total quality scores as indicators of quality or assessment of bias due to their inability to accurately assign weights to each individual domain [268]. Although they offer simplicity, there is a lack of empirical evidence to support their use [269] and concerns exist regarding their reliability and transparency [270]. To assess the quality of this study, it must therefore be viewed in the context of its methodological strengths and limitations to determine their impact upon the confidence in the findings. These are presented in *Table 8.2.*

Table 8:2*:* Costing quality checklist [267]

Question	**Assessment**
Are the costing objectives clearly identified?	Yes - The step-down costing methodology was used to calculate the unit cost per inpatient bed day and day therapy visit. Whilst the unit costs of the day therapy and inpatient unit were estimated using the stepdown costing methodology, this could not be applied to Site D due to insufficient data. Therefore, the at home service costs were roughly calculated by dividing the estimated total running cost by the estimated number of patients. Such inaccuracies resulted in Site D's exclusion from the final SROI analysis.
Does the methodology selected match the objectives of the costing study?	Yes - In a deviation from the original protocol, the step-down costing methodology was employed in lieu of micro-costing. The latter approach, although it is more time intensive, would have allowed for a more precise estimate of units costs for the two units [271]. The aggregation of the data provided by the hospice study sites prevented this approach from being used and thus the step-down methodology was employed. Although this provided less detail and probably resulted in large variances in the final unit costs, it presented a viable alternative for use within the confines of the data set provided.
Is the methodology suitable for calculating marginal or average costs?	No - Although this methodology is suitable for calculating average costs, there was heavy reliance on multiple cost-drivers to apportion costs between the day therapy and inpatient unit due to the aggregation of data. Difficulties were also present when

	determining which rooms were relevant to which service, with many being utilised by both. The inpatient weighting was applied to account for this; however, inaccuracies are likely to remain. The costs of both catering and pharmacy were apportioned based on the number of day therapy or inpatient days respectively as it was assumed that higher patient volumes within a particular unit would equate to higher costs. Previous studies have collected expenditure records for each department or have been able to access catering contracts from which relevant expenditure could be calculated [140]. Without access to such data, patient volume was deemed a viable alternative metric, although less accurate. If different cost-drivers had been used when calculating unit costs, it is likely that a different result would have been produced, suggesting that the accuracy of this methodology is impaired. This is perhaps reflected in its lack of use within a healthcare setting.
Does the meth**o**dology address opportunity costs or just accounting costs?	Yes - For the costing methodology, the hospices' financial accounts were utilised; however, when conducting sensitivity analyses, the replacement cost of volunteer time was examined. It was found to have a minimal effect on the final unit costs.
Does the study clearly (explicitly) state the perspective of the costing?	Yes - Costing is provided from a healthcare provider's perspective. Some consideration was given to the inclusion of societal perspectives; however, hospice care is free, so for the purpose of this work, there was no need to account for it.

Does the study define the time horizon (time span) of the costing study?	Yes - The time horizon for this study was set as one year to account for any seasonal variations.
Are appropriate data collection methods used?	Yes - Standardised extraction forms were used to collect data from designated hospice personnel for the period from January to December 2016. Information was obtained from central accounting and patient administrative databases (CANASC), staff and volunteer rotas, and patient attendance records. Anonymised salary information and working hours were acquired from the hospice's payroll and full-time equivalents (FTE) were calculated from these figures. Anonymised patient-level data was accessed retrospectively from the administrative databases and paper registers and linked using unique patient identifiers.
Does the methodology account for overhead costs?	Yes - Overhead costs were acquired from central accounting databases and split between relevant cost centres.
Does the methodology correctly apportion joint costs?	Yes - Where joint costs were present, suitable cost-drivers were implemented to facilitate apportioning them. Building costs and housekeeping costs were disaggregated based on surface area and a weighting was applied to the inpatient unit due to it having longer opening hours. Catering and pharmacy were apportioned based on the number of day therapy or inpatient days respectively as it was assumed that higher patient volumes equated to higher costs. Ultimately, the accuracy of this process was inhibited by the restrictions of the data presented.
Does the methodology distinguish between fixed and variable costs?	No - Although fixed and variable costs were identified, they were not viewed in isolation. Instead, they were

	amalgamated with the other costs of the relevant cost centres.
Does the methodology distinguish between recurrent and capital costs?	No - Although recurrent and capital costs were identified, they weren't viewed in isolation. Instead, they were amalgamated with the other costs of the relevant cost centres.
Does the costing study take advantage of all data sources?	Yes - Due to an inability to undertake primary data collection, this step-down costing was heavily reliant on secondary data. A list of required information was supplied to each hospice, which subsequently returned data which was available. An assumption must therefore be made that all data sources were utilised.
Are all the assumptions clearly and explicitly stated and realistic (plausible)?	Yes - All assumptions have been explicitly stated; however, if the ability to perform primary data collection had existed, better options could have been chosen. The results created by and the potential variances caused by the assumptions made will have a substantial effect on the accuracy of the input costs.
Were sensitivity analyses undertaken to test the robustness of the assumptions?	Yes - Two sets of sensitivity analyses were completed. Hospice UK had previously demonstrated that the bed occupancy rate of 110 adult hospices remained at between 78% and 80%. The hospice capacity was therefore adjusted to 80% to reflect this. The second sensitivity analysis compared the unit cost for each site inclusive and exclusive of volunteer costs.
Were the resource utilisation, unit costs and results separately presented, in a well tabulated form?	Yes - The total cost of each cost centre per hospice site was presented in *Table* 3.3 alongside a description of what each cost centre comprised and how it had been calculated. *Table*s *3.10-3.12* then presented the step-down allocation of cost centres to

	the supportive and final cost centres for each site. Following this, the unit cost of both the inpatient and the day therapy units at each site was calculated and presented in *Table*s *3.16* and *3.17* respectively. Subsequently, a sensitivity analysis was conducted, and the results were discussed further.

Due to an inability to employ the micro-costing methodology, the step-down costing methodology was deemed the most suitable alternative, given the limited access to data. Although it aligns with the objectives of this study, much of the costing is based on assumptions and aggregated secondary data which mars its accuracy and thus, its reliability.

Chapter 4: *Mixed-methods systematic literature review*

To summarise, the systematic literature review (*Chapter 4),* which contributed towards the mapping stage of the SROI analysis, sought to include multiple stakeholder perspectives to determine what patients and family-caregivers value about clinical and non-clinical hospice services. The findings from this review informed the subsequent chapters.

Quality appraisal of the mixed-methods systematic review

The systematic review reported in *Chapter 4* has been subjected to critical appraisal via the 10-item Critical Skills Appraisal Programme (CASP), a validated and widely used appraisal tool, to evaluate its methodological quality. For eight of the ten items, a response of Yes, No or Can't Tell was applied, whilst for two items, only statements were required. As recommended by Singh [272], a standardised checklist was used to assess quality as it ensures identification of bias and other methodological weaknesses, thereby enhancing the quality of the review. The following critical analysis is guided by these ten quality standards.

Table 8:3: Critical Appraisal Skills Programme (CASP) checklist for systematic reviews

Question	Assessment
Did the review address a clearly focused question?	Yes - The SPICE (setting, phenomenon of interest, comparison, and evaluation) acronym was used to help formulate a review question. The adoption of this method assisted in the organisation of the main

	concepts underpinning the study and contributed to the development of a novel review question. The cultivation of a well-formulated research question ensured that this thesis was able to determine the facets of care considered valuable by patients and family-caregivers, thus providing a foundation on which the development and design of subsequent chapters was built.
Did the authors look for the right type of papers?	Yes - The systematic review employed a three-stage mixed-methods approach which incorporated mixed evidence streams. This sequential, exploratory design was informed by a series of scoping searches which unearthed relevant data from qualitative studies, questionnaire surveys, and mixed-methods studies. Due to the novelty of the question, the value that patients and family-caregivers placed on hospice care were inferred from the data. Although it is argued that qualitative and quantitative strands warrant different search strategies due to their differing aims [273], a combined search strategy was used in this review. Although this required more time during the study selection phase, it ensured fewer individual searches needed to be developed, tested, and conducted.
Do you think all the important, relevant studies were included?	Yes - A robust search strategy was created in collaboration with an information scientist to examine relevant databases. This was supplemented by searching grey literature and relevant subject-related websites, citation-searching, and direct contact with authors. Nevertheless, relevant studies could have been missed. Central to a systematic review is the screening of abstracts to ensure that potentially relevant studies are selected. For the purpose of this study, abstracts were screened by a sole researcher and a random sample were then reviewed by a second reviewer. A lack of consensus remains regarding the accuracy of sole screening [274] and, although very few methodological evaluations exist which posit that studies will be overlooked when sole reviewing, dual reviewer screening is promoted by institutions such as the National Institute for Health and

	Care Excellence (NICE) [275] and Cochrane [276]. Regardless of which methodology is employed, it is possible that incorrectly indexed articles will have inadvertently been missed from the search.
Did the review's authors do enough to assess quality of the includes studies?	Yes - Four method-specific tools were used to assess the methodological limitations in primary studies: 1) qualitative Studies: Critical Appraisal Skills Programme (CASP), 2) quantitative Studies: Effective Public Health Practice Project Quality Assessment Tool (EPHPP), 3) questionnaires and surveys: Centre for evidence-based management "critical appraisal of a survey" (CEBMa), and 4) mixed-method studies: Mixed method appraisal tool (MMAT): Mixed Method Studies (*Appendix* 3.4). Articles were not excluded from the systematic review due to their methodological limitations, however, as the risk of bias was deemed minimal. This approach, whilst considered a core strategy by the Cochrane Qualitative and Implementation Methods Group's online supplemental guidance [277], is contentious within the wider literature, although there is evidence to suggest that the exclusion of inadequately reported studies has no meaningful effect on the synthesis [278].
If the results of the review have been combined, was it reasonable to do so?	Yes - Prior to the commencement of the systematic review, a range of scoping searches were conducted which identified relevant qualitative and quantitative studies. As a result, a sequential mixed-methods synthesis ensued whereby qualitative data was thematically synthesised, followed by a narrative summary of the quantitative data. The qualitative and quantitative syntheses were then juxtaposed within a matrix to produce an overarching synthesis. This was necessary to facilitate the identification of congruency between findings.
What are the overall results of the review?	Thirty-four studies were deemed eligible, none of which were conducted in Wales. There was also a distinct under-representation of patients suffering from non-malignant diseases. The results indicated that the facets of care that patients and family-caregivers value are

	generally context specific. In general, patients felt that their pain and psychosocial domains of care were well managed; however, family-caregivers did not receive sufficient support. Overall, the systematic review answered a novel question and provided new insights beyond those concerning symptom management and health outcomes.
How precise are the results?	GRADE CERQual was used to assess and summarise the confidence in synthesised qualitative findings. The primary issues identified related to adequacy and relevance. Due to the novelty of the question, the findings of the qualitative synthesis were unlikely to directly map on to the question and thus it was inevitable that there were some problems with relevance. Nevertheless, it was concluded that the review findings were a reasonable representation of the phenomenon of interest. It should be noted that an equivalent assessment tool was not used for the questionnaire surveys.
Can the results be applied to the local population?	Yes -The results of the systematic review are applicable to local palliative populations, although research from specific services is noticeably lacking. Studies that were not written in English were excluded, and thus this review is only applicable to patients and family-caregivers within the UK. It is difficult to judge solely from the systematic review whether these findings are applicable to Wales, as there were a limited number of studies pertaining to Wales and therefore cultural differences or language preferences may be overlooked. When these studies are viewed in tandem with the qualitative findings of this thesis, however, there is a high degree of congruency and thus it can be surmised that the findings are applicable to the local population.
Were all important outcomes considered?	Can’t Tell - This question is more suited to an intervention effect review and therefore is not entirely applicable to this mixed-methods review design. The quantitative and qualitative findings were both synthesised individually before subsequently being juxtaposed within a matrix as part of the overarching synthesis. This allowed for new

	findings to be identified which extended beyond the synthesis of the quantitative and qualitative data in isolation. Regardless of whether outcomes were positive or negative, they were included within this synthesis.
Are the benefits worth the harms and costs?	Yes

Overall, the use of a mixed-method systematic review methodology worked well and the subsequent manuscript received positive feedback when submitted to BMJ Palliative Care for publication [279]. Rapid reviewing offered an alternative method to systematic reviewing however, it posed a risk of missing potentially relevant literature. This systematic review was initially conducted as part of an MRes and was therefore reliant on a robust literature review to adequately capture the views and experiences of patients and family-caregivers. The conduct of a systematic review, although more time consuming, offered a more robust and rigorous methodology which helped to inform future chapters, particularly the primary qualitative study, as the results assisted in the creation of topic guides. Undertaking a systematic review also provided an opportunity to develop higher level systematic review skills that can be used in the future.

Chapter 5: *Qualitative study exploring stakeholder perspectives*

Qualitative research methods were employed to explore the experiences of key stakeholders and ascertain what they valued. The analysis involved a hybrid process of an inductive and deductive approach whereby descriptive and explanatory themes were generated to determine the outcomes which were deemed important to patients and family-caregivers.

Quality appraisal of the qualitative study

The CASP tool, which is endorsed by Cochrane studies [280], is a generic tool for appraising the strengths and limitations of qualitative research. The tool is comprised of ten questions which focus on a different methodological aspect of a qualitative study to determine whether the research methods used were appropriate and if the findings are relevant. The first nine questions can be answered as ‘yes’, ‘no’ or ‘can’t tell’ and are followed by a final open-ended question. CASP is the most commonly used checklist for quality appraisal within health and social care related qualitative evidence synthesis [281]. It has therefore been applied to assess the quality of the qualitative study reported in this thesis. As ‘yes’ was applied to all nine questions and provided substantial evidence of this studies value in response to question ten, it becomes apparent that this is a high-quality study.

Table 8:4*:* Critical Appraisal Skills Programme (CASP) checklist for Qualitative research

Question	**Assessment**
Was there a clear statement of the aims of the research?	Yes - Building on the findings of the systematic review, this primary qualitative study sought to: (1) explore patients’, family-caregivers’, paid personnel’s, and volunteers’ experiences of hospice care and ascertain what they value and (2) to identify the outcomes experienced by primary stakeholders post-hospice intervention.
Is a qualitative methodology appropriate?	Yes - Qualitative research seeks to understand a research question as a humanistic or idealistic approach [282]. Although quantitative methods are deemed more reliable due to their emphasis on numerical data and objectivity, they are not suitable for trying to understand individuals’ beliefs, experiences, attitudes, behaviours, and interactions [282]. Previously, qualitative research was considered philosophically incongruent with experimental research; however, this belief has since been dispelled and is now recognised for its ability to add a new dimension to research which cannot be achieved through the measurement of quantitative variables alone [283]. For the purpose of the SROI analysis, it was necessary to elicit the views and experiences of various stakeholders, which could not be achieved through the application of quantitative methods. A qualitative approach was therefore adopted and was justified.

Was the research design appropriate to address the aims of the research?	Yes – Although this study adopted the framework method of data collection and analysis, which was appropriate for this study, an ethnographic approach could have provided a richer exploration of the phenomenon of interest and is likely to have improved recruitment. Furthermore, an ethnographic approach is likely to have enhanced rapport with both gatekeepers and potential participants. Due to the number of study sites included, however, an ethnographic approach was not plausible. If I had been employed by the hospice to conduct this qualitative study, then an ethnographic methodology could have more easily been pursued. Nonetheless, the research design that I used was considered appropriate and produced the required data.
Was the recruitment strategy appropriate to the aims of the research?	Yes - Purposive sampling was an appropriate recruitment strategy and it was favoured by hospice staff. The purposive sampling strategy was carefully planned to capture maximum variation sample that included desired participant characteristics. Although there were some challenges with recruiting inpatients, this is not unusual in palliative care research and overall, my sample was large. The final sample included 45 patients, 18 family-caregivers, 10 volunteers, and 23 paid personnel.
Was the data collected in a way that addressed the research issue?	Yes - Semi-structured interviews and focus groups were selected as the most appropriate method to acquire, with sufficient depth, the data needed to address the aims of the qualitative study and answer the primary overarching research question. Flexible topic guides, informed by the systematic review, were developed for each stakeholder group, enabling the researcher to collect open-ended data, explore participants' thoughts, feelings, and beliefs about a particular topic and to delve deeply into personal and

	sometimes sensitive issues. To ensure that participants were comfortable, they were able to choose whether interviews were conducted at their home or at the hospice.
Has the relationship between researcher and participants been adequately considered?	Yes - To ensure rigour, quality, and trustworthiness, it is necessary for qualitative researchers to be reflexive. Insights from a reflexive journal was mentioned on *page 200* which provide a summary of pertinent information about me and my background, as well as an exploration of my experiences and preconceptions of hospice care. Prior to beginning this study, I had no prior contact or relationship with any research participants and our interactions were solely part of the research process. Following data collection, I had no further contact with any participants.
Have ethical issues been taken into consideration?	Yes - As part of the MRes, ethical approvals were obtained from the School of Business, Law, Education, and Social Sciences (CBLESS) for the first phase of the recruitment which involved the recruitment of volunteers and hospice personnel. Upon upgrade to a PhD, ethical approvals from NHS REC 4 were received to include patients and family-caregivers. All recruitment-related documents were reviewed by the North Wales Cancer forum prior to their admission for ethical approval. The lead researcher also underwent a successful enhanced Disclosure and Barring Service check. The recruitment process has been outlined in *Chapter 5*. The guidance of the Royal College of General Practitioners regarding assessing capacity was used when assessing mental capacity and competence to consent. Just one participant was considered to lack the capacity to consent. During one interview, despite consultee consent and

	insistence from both the patient and their family that they were happy to continue, the session was cancelled as it became apparent that the patient was not in a suitable condition to continue. This was reflected upon in supervision. The second ethical challenge that was faced arose due to the unexpected death of a volunteer who had participated in a focus group, and therefore questions regarding data retention were posed. The consent forms stipulated that in the event of a participant's withdrawal, all data obtained up to this date would be retained, therefore, the information about the volunteer was kept in accordance with this policy. To ensure compliance with GDPR, all transcripts were stored on an encrypted device and paper documents were stored in a locked cabinet.
Was the data analysis sufficiently rigorous?	Yes - As detailed in *Chapter* 5, Framework analysis was adopted as it provided a structured approach to analysing qualitative data. This was used in tandem with the a priori coding framework that was developed following the systematic review in *Chapter* 4 and assessed by my supervisors, who had prior experience of using it. Throughout the process, a reflective journal was maintained which allowed appraisal, documentation, and mapping of the methodology. Supplementary to this, detailed supervisory notes were recorded to ensure that decision-making trails were clearly logged and any discussion regarding interviews, transcription, or analysis were noted and referred to when necessary. Twenty-six interviews were transcribed and two focus groups verbatim, whilst the remainder were sent to an independent transcription company. By listening to

	recordings, reading transcripts, and transcribing, the lead researcher became fully immersed within the raw data and subsequently gained an appreciation of the richness, depth, and diversity of the data set. Repetition ensured rigour as the lead researcher became familiar with the nuances and vocal cues used by participants, which subsequently facilitated the identification of emergent themes. The resultant transcripts were then reviewed, and codes were inductively added to the a priori framework as they were identified within the primary qualitative data.
Is there a clear statement of findings?	Yes - *Table*s *5.4* and *5.5* display participant demographic data and are followed by *Table 5.6,* which presents a summary of the values gleaned from the qualitative data collection. These values were subsequently grouped in to overarching themes and examined successively alongside explicit extracts from participant interviews to support the findings.
How valuable is the research?	The literature pertaining to palliative care in the UK is limited and, from a Welsh perspective, is non-existent, thus making this qualitative research unique. For the most part, the findings of this qualitative study are congruent with the wider literature; however, an example of a particularly novel finding is described below. Although the debilitating effects and the subsequent detrimental impact on the mental health of people with a palliative diagnoses are well-documented. In this study, many patients noted that prior to attending the hospice, they had thought about committing suicide and that if they had not engaged in the hospice service, may have done so. This serves to highlight the importance of early access to palliative care interventions to alleviate symptom burden and presents an area for further research.

Chapter 6: *Use of routine data to evidence change*

The ICECAP-SCM questionnaire was initially intended to be embedded in routine clinical practice to measure change in patient and family-caregiver outcome. As discussed in *Chapter 6*, licences were obtained allowing for its use and instruction manuals were created; however, the three study sites (A, B, and C) decided to embed the Integrated Palliative Outcome Scale (IPOS) into routine clinical practice as an alternative. The IPOS is a 17-item tool which was mapped onto four of the outcomes experienced by patients: improved physical symptoms, access to information, improved functionality, and psychological improvements.

Quality appraisal of the quantitative study

The CASP Checklist for Cohort Studies [284] was initially considered as a possible critical appraisal tool; however, many of the questions posed were not relevant to this study. CASP considers a cohort study to be one which observes a group of individuals with a particular exposure over a period of time and compares them to an unexposed group. Due to the absence of a control group, this study was deemed to be an uncontrolled cohort study and thus the checklist was not applicable.

Chapter 7: *Calculation of the Social Return on Investment*

The SROI ratio was estimated as £2.77:£1 for the inpatient unit and £11.85:£1 for the day therapy unit. As a result, it has been demonstrated that the services provided by the hospice deliver value for money. As there were no similar analyses reported in the literature, these findings could not be compared. To increase the transparency and reliability of the analysis and to test the assumptions made, a series of one-way sensitivity analyses were conducted.

Quality appraisal of the Social Return on Investment methodology

Krlev et al's [285] 12-point quality assessment framework was employed to assess the standard of this SROI analysis. For each criterion deemed 'present', one point was awarded, whilst for each criterion deemed absent or unascertained, zero points were awarded. Papers that achieved a score of 70% or greater were deemed high quality, whilst papers that achieved a score of less than 70% were deemed low quality [108]. This study achieved a score of 83%. It must be noted however that given the Cochrane Handbook’s [268] disregard for the use of scoring systems as indicators of quality, the outcome is generally considered meaningless due to its inability to apply suitable weightings for each domain.

Table 8:5: Krlev et al's [285] 12-point quality assessment framework

Question	Criterion	Assessment
Transparency about why the SROI was chosen	Linked to context discussion?	In order for hospices to maximise their funding, it is necessary for them to demonstrate their social value. Although methods such as CBA have often been adopted, concerns exist regarding their ability to overlook social, environmental, and economic factors [253]. In recent years, the SROI methodology has grown in popularity within the third sector and has since been endorsed by the Cabinet Office as an appropriate social value measurement tool [40]. The three hospice sites within this study formed a consortium and made a commitment to become increasingly research active. The opportunity to employ a methodology currently at the forefront of social value measurement therefore complemented this aim.
Documentation of the analysis	Analysis well documented?	The qualitative and quantitative data analyses have been outlined in *Chapter*s *5* and *6* respectively. The results of these analyses were then triangulated within *Chapter 7* to perform the SROI calculation (*Appendices 6.1 and 6.2).* As part of this process, the impact map was populated to demonstrate the relationships between inputs, outputs, and outcomes *(Figure 7.3).*
	Impact map used?	

Study design (approximation of ‘dead-weight’)	Control group setup applied?	Within research, the control group can be defined by the researcher as the group that does not receive treatment; it is then used as the benchmark against which other tested subjects are measured. Within this study, the use of a control group was not feasible as this would have involved withholding treatment from an individual with an end of life diagnosis. To determine change before and after hospice intervention, IPOS surveys were administered; however, implementation was difficult due to a heavy reliance on proxies, limited staff time, and issues regarding gatekeeping, all of which are discussed further in *Chapter 6.* There was also a lack of congruency between the IPOS domains and the qualitative findings (*Table 6.5*) and therefore where there was no relevant quantitative domain, qualitative interviews were used to measure change instead. Attribution, deadweight, attrition, and displacement were approximated based on responses from qualitative interviews (*Table 7.9*), but doubts exist regarding their accuracy. It was apparent from the qualitative interviews that participants struggled to fully comprehend the SROI methodology and the purpose of the questions. Often, when asked questions to determine attribution, the participants would worry about no longer receiving hospice care. To allay any fears, reassurance was provided, and the hypothetical nature of the question was explained. Due to concerns regarding accuracy, best estimates were used.
	Ex ante-ex post observations performed?	

Precision of the analyses	Indicators valid and comprehensive?	As discussed previously, the IPOS was used to measure change post-hospice intervention but, owing to a lack of congruency with the qualitative findings (*Table 6.5*), not all domains were valid. Despite these flaws, the findings remained comprehensive. A similar issue existed with financial proxies as not all of them mapped on to the findings. This was largely due to the complex nature of palliative care which means it is difficult to account for all eventualities. To ensure standardisation against other published SROI analyses however, this method had to be adopted. Again, despite its limitations, a comprehensive analysis was achieved. The social effects of hospice care were captured both qualitatively and quantitatively. Initially, a mixed-methods systematic review was conducted which allowed patient and family-caregiver values to be unearthed. These findings were then triangulated with the qualitative research (*Table 7.4*) and subsequently mapped on to the quantitative research (*Table 7.5*).
	Proxies valid and comprehensive?	
	Social effects captured? (Qualitatively)	
	Social effects captured (Quantitatively)	
Reflection of the results	Limitations discussed?	SROI analyses are inherently resource intensive, and this was reflected in the difficulties experienced when trying to obtain adequate data from each site. This resulted in the initial scope of the study being refined from site-specific SROI analyses to two overarching SROI analyses (inpatient; day therapy), but despite this change, Site D was still unable to provide the level of data needed and was subsequently excluded. It is also apparent that an SROI analysis is largely based on assumptions, which results in minimal

		standardisation across SROI analyses. The ability to compare analyses is therefore limited as two analysts are unlikely to follow the same procedure. Whilst there were weaknesses within the SROI methodology, the widely accepted procedures for conducting an SROI analysis were followed. A logic model was developed that was underpinned by both a mixed-methods systematic literature review and qualitative interviews. Although frailties existed within the quantitative data due to difficulties embedding IPOS into routine clinical practice, these were largely supplemented by the qualitative data. The final SROI calculations returned base case ratios of £2.77:£1 and £11.85:£1 for the inpatient and day therapy units respectively. Following this, a series of sensitivity analyses were conducted to determine the robustness of the assumptions underpinning the base case scenarios (*Table 7.10*).

Conclusion

The research reported in this thesis has proven to be additionally timely due to the unprecedented 2020 Covid-19 pandemic which has stifled the income of charitable organisations [286]. Many of the hospice's fundraising activities have been cancelled and, with this comprising a significant proportion of their revenue, has resulted in financial uncertainty. The necessity for hospices to demonstrate their worth, and justify their selection for additional funding, is therefore paramount.

It becomes apparent from this research that challenges exist regarding the implementation of the SROI methodology, and these are exacerbated by the nature of the hospice setting; however, there are substantial benefits associated with its outputs. The SROI methodology provides an ability to measure social value [257], foster organisational learning [95] and create legitimacy for external stakeholders [287]. Developing a synergy between researchers and practitioners is therefore pivotal in ensuring the SROI methodology is embedded in clinical practice and effective decision making is facilitated. In particular, there is a need to consider how financial proxies are estimated in addition to determining how mixed-methods are utilised and developing a standardised approach to establishing impact. Increasing the methodologies robustness will in turn ensure that hospice interventions can remain competitive for limited resources which, due to the financial impact of Covid-19, is crucial.

To conclude, this KESS studentship and associated research studies helped to develop a successful partnership with the hospice organisations and contributes towards their ambition of becoming increasingly research active. This aligns with recommendations made by a report for the commission into the future of hospice care which suggested that research active hospices should be regarded as a key quality marker [60]. In addition, the demonstration of a positive SROI ratio for both the inpatient and the day therapy units, will provide additional evidence to help consolidate the financial security of hospice care.

The KESS studentship and the conduct of a SROI analysis has also produced an unforeseen personal benefit as I have recently obtained employment with Welsh Women's Aid, where I will continue to be the lead researcher on a number of SROI analyses. This is an opportunity that was only made possible by my involvement in this studentship and research study.

Recommendations

The research presented in this thesis has shown the social value of the three hospice sites but has also highlighted areas in which not just the SROI process could improve, but hospice practice as a whole. Specific recommendations based on the findings of this research are as follows:

Policy and Practice

- The costing study in *Chapter 3* revealed that hospice care continues to be underutilised by patients diagnosed with a non-malignant disease. This study has highlighted that expansion of hospice services, increased involvement of the wider community, and more collaborative working are required to encourage equity in the provision of care.

- The sustainability of hospice care has been extrinsically linked to volunteering [288]; however, findings from the sensitivity analysis reported in *Chapter 3* as part of the costing study suggests that, contrary to the Prudent Healthcare Act (*Chapter 1),* the hospice study sites were not making effective use of skills and resources. When the replacement costs of volunteers were considered, just 8% of day therapy costs, and 2% of inpatient unit costs were attributable to volunteer time. This indicates that the hospice study sites are underutilising volunteers thus greater volunteer involvement is required.
- Although family-caregivers generated the most social value from the inpatient unit, there was limited formal long-term services for family-caregivers *(Chapter 5)*. Those services that were available, such as the bereavement service, were often developed ad hoc. An opportunity therefore exists to establish formal, well-structured services that allow family-caregivers to attend as individuals or groups at specific times, thus amplifying the value that is currently generated.
- There is a need for the hospice consortium to instil better communication as evidenced by their inconsistent implementation of IPOS. Neither the three day or seven day recall periods were adhered to and accurate records were not maintained regarding the date of data collection. If the hospices want to continue working as a consortium, and sharing resources, they need to improve inter-hospice communication to ensure consistency and best practice.

Education

- It is evident that the hospice services are under-utilised by individuals from Black, Asian and minority ethnic (BAME) groups (*Chapter 5*). BAME groups account for 5.8% of Wales's population; however, the lack of diversity within this study was striking, as all participants were white. When reviewing the wider literature, however, it is clear that this is an issue that extends beyond Wales and encompasses the entirety of the UK [289]. Representatives with such demographics have cited an inability of hospice care to meet their dietary needs, an inability to communicate with them in a language other than English if English is not their first language, a lack of GP referrals, and a lack of understanding of palliative services, amongst other reasons as explanations for their lack of service utilisation [289]. There is a clear need for increased community engagement and education to ensure that BAME communities are aware of the services that are available and how to access them. To maximise outreach, adverts need to be placed in places of worship, community centres, and GP practices and leaflets need to be distributed and made readily available, in either physical or digital form. To address dietary and communication concerns, hospices must ensure that they have the necessary facilities or services in place. Kitchens must have designated areas where food can be prepared in line with religious customs and patients should have access to an interpreter if required.

Research

- The development of the SROI methodology is an ongoing process; however, it should still be noted that further work in relation to the standardisation of financial proxies is required. For this study, the HACT's value database was used, which does not account for the trajectory of palliative diagnoses as all proxies are based on a one-year time period. To avoid over-claiming, a novel approach to the SROI analysis conducted in *Chapter 7* was taken which pro-rated proxies accordingly by dividing costs by patients' average length of life. It can be argued, therefore that there is a need to develop more refined methods to account for attrition within palliative populations.
- The extension of the SROI methodology to the at home service and other palliative care patients will address a gap in the evidence base.
- Recruitment within a palliative care setting is challenging, largely as a result of staff gatekeeping. As evidenced by this study, embedding the lead researcher within the research site had a positive impact. For future palliative care studies, it would be beneficial for this practice to be followed.

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Appendix 1.1: Data Sharing Agreement

DATA SHARING
AGREEMENT

between

School of Social Sciences, Bangor University

And

______________________North Wales Hospice Group ________________

This Data Sharing Agreement is intended for individuals interested in gaining access to <u>existing, new or original data</u> belonging to St David's Hospice, Nightingale House Hospice, St Kentigern Hospice and Hospice at Home Gwynedd and Anglesey.

Postgraduate Research is retained for 5 years after the award of the degree unless subject to conditions set by funders/external partners, or if part of a longitudinal study.

Parties and Individuals

Hospices:	**Bangor University research team:**
St David’s Hospice	Nicole Hughes
Nightingale House Hospice	Professor Jane Noyes
St Kentigern Hospice	Dr Lindsay Eckley
Hospice at Home Gwynedd and Anglesey	

Intended Use of Data

The KESS funded Masters by Research will collate anonymised raw data pertaining to the North Wales Hospice group databases (such as CANISC and hospice owned data collection systems) to help determine the ‘Social Value Exploration of Hospices in North Wales.’ Information covered by this agreement will include:

- Printed or written on paper,
- Stored electronically,
- Transmitted by post or using electronic means,
- Broadcast
- Spoken

Data Handling and Security

This section sets out the commitments that each organisation will make in regards to the handling of other partners’ information.

In accordance with Bangor University’s policy:

[a] “The information that is managed (both manual and electronic) shall be appropriately managed and secured to:

(i) Ensure compliance with relevant legislation and guidance; and

(ii) Ensure information is made available solely to those who have a legitimate need for access, and to protect against unauthorized access and,

(iii) Ensure confidentiality is maintained, especially where third party or personal data is held; and

(iv) Ensure business continuity and the protection of assets;

(V) Prevent failures of integrity or interruptions to the availability of that information” (Bangor University, 2015).

Custodianship

Dr. Lindsay Eckley from the school of social sciences at Bangor University has agreed to be the data custodian for this project. The custodian is responsible for adequate and appropriate storage of the data. Custodians of data and information must ensure appropriate records storage, maintenance, security and archiving of the data. Overarching responsibilities of a data custodianship includes accountability and responsibility for the data in addition to management and maintenance.

Application of this policy

This policy shall apply to all locations from which University systems, data or information are stored or accessed. This policy will extend to home use and all other off campus sites where applicable.

Keeping personal information secure

All personal data must be stored in a secure environment with controlled access. The level of security applied to the information should be applied following a risk assessment which should establish the potential risk of unauthorized access and/or theft. When the data has been collected, the data will be handled with the utmost of care in order to ensure confidentiality and commitment to the data protection act. In addition to the specified safeguards which will be put into place to protect the data, hospices should anonymize their data prior to it being sent to prevent individuals from being identified.

[a] **Paper Records**

Appropriate storage for paper/ manual records would include:

- Locked cabinets
- Locked draw in a desk
- Locked room only accessed by key or coded lock where access to the key/code is limited.

[b] **Electronic records and database systems**

Good practice guidelines for electronic records would include:

- Not disclosing any passwords
- Logging off shared computers
- When confidential work is being carried out, ensuring no one else can read the screen
- Protecting equipment from physical theft
- Only using encrypted devices

Secure Sharing of Information

Throughout the project, the data obtained from the hospices may be transported through the use of encrypted pen drives, portable devices and e-mail. In order to ensure the security of the data in these instances, numerous safeguards such as encryptions, limited access to named individuals and passwords will also be adopted. In addition to the aforementioned safeguards, all data stored on portable devices will be encrypted and stored in a safe and secure place when not in use.

Data Retention and Disposal

All data obtained will be kept on a Bangor University shared drive which will also be subject to a number of stringent safeguards such as encryption, limited access to individuals outside of the research team and password protection. In addition, all devices which hold any of the collected data will be fully encrypted and password protected to prevent unauthorized use of the device and unauthorized access to the information held on the device.

The Data Protection Act applies equally to personal data held on paper files. Paper records and files containing personal data will be handled in such a way as to restrict access only to those persons who have ties to the research. This will entail the operation of a policy whereby paper files containing such data will be locked away when not required. Paper records will not be held longer than necessary and will be destroyed using the cross cut shredding method to ensure that any information cannot be reconstructed.

Archiving

Long term storage will require effective institutional data management protocols to be developed and policed, and ongoing review of the adequacy of technical and organisational measures pertaining to the data, e.g. the research data is archived securely, in a known location, and is only accessible to authorised parties. In order to adequately protect the data, it must be stored securely. The data must be secured and the access to the data, whether electronically or physically must be guarded. The purpose of the data archival system is to keep data secure. As a best practice, the data must be kept secure at every stage of its collection and storage. The data should be transmitted securely within the network. The data will have strict controls on who can access archival data which will be extended to both physical and electronic access to the data.

Caldicott Guardian

The Caldicott Guardian (Llandudno hospice Chief executive, Trystan Pritchard) is a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information-sharing. The Guardian plays a key role in ensuring the highest practicable standards for handling patient identifiable information. Any research involving the use of routinely collected patient data must be approved by the Caldicott Guardian of that particular dataset. This will ensure that national and local guidelines and protocols on the handling and management of confidential personal information are in place. The principles are:

- Justify the purpose for using confidential information
- Only use it when absolutely necessary
- Use the minimum that is required
- Access should be on a strict need to know basis
- Everyone must understand their responsibilities
- Understand and comply with the law

The Caldicott Guardian will be able to actively support work to enable information sharing in addition to representing and championing confidentially and adhering to information sharing requirements.

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Acknowledged and agreed to by:

Bangor University

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North Wales Hospice Group

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Knowledge Economy Skills Scholarships

Appendix 1.2: Risk assessment for MRes project

Example of detailed risk assessment (CI / PI / relevant members of research team)

(to be provided to IRP for their risk assessment)

Study Risk Assessment (study title): An exploration of the Social Value of hospice care across North Wales

Date: 29.11.16 **Assessment Team:** Nicole Hughes, Professor Jane Noyes, Dr Lindsay Eckley, Chief Executive Trystan Pritchard

Sponsor: Professor Phillip Molyneux

Financial Studies Room A3.01,
Alun Building College Road,
LL57 2DG
E-mail p.molyneux@bangor.ac.uk

Background – The Risk assessment is being conducted in order to ensure that all potential risks associated with the study have been reviewed and where necessary addressed.

Approach

- Consider the likelihood and potential severity of a systems failure, scoring each as e.g. : 1 (rare, negligible severity), 3 (possible, moderate severity) or 5 (almost certain, catastrophic severity)
- Give each item a scored risk, calculated as the likelihood X severity, operational history is taken into account when scoring likelihood,
- Consider what further action is necessary
- Assign responsibility for carrying out the action
- Assign an expected date for the action to be completed

Guide:

🟩	1 – 3	Low Risk – Action only if low cost remedy, easy to implement, re-assess if process/procedure, guidance or legislation changes, keep under review

🟧	5 - 9	Moderate Risk – Action that is cost effective in reducing the risk and planned and implemented within a reasonable time scale.
🟥	15 – 25	High Risk – Immediate action to remove or reduce risk. Consideration given to stopping process. Inform Senior Management & Risk Management/Health & Safety Department at once.

What are the hazards?	**Existing control measures already in place**	**Additional control measures identified specific to study**	**Severity**	**Likelihood**	**Risk rating**	**Action by when & by whom?**	**Status review e.g. N/S WIP Complete**	**Any monitoring requirements identified**
Patient/Study Population **Potential risk to participants:** **Vulnerability?** **Fully informed consent?**	Participant information sheet. Consent forms Recruiting through hospice. Ensure that participants know their taking part will be voluntary and confidential. Participants will be told that they don’t have to answer any question they don’t feel comfortable answering	Identifying someone who can help in adverse conditions. Using private rooms to conduct interviews and focus groups. Interviews and focus groups recorded using encrypted Dictaphone.	1	1	1	Researcher will provide information regarding study to participants, and contact details will be left for potential participants in the event that they want more information.	Regular supervisory meetings will take place. Will discuss at these meetings whether the questions are being well received.	Interview schedule will be monitored to see how questions are received. Questions might need to be changed (will go through ethics committee if big changes need to be made). May need cut off point for participants to express interest to take part in study may need to be altered if there isn’t enough interest. Minimum 72 hours.

Potential risk to participants privacy (data protection)	Data sharing agreement sent out to all hospice sites to sign before exchange of data. One copy will stay at Bangor University and the other with the Caldecott Guardian. Access to data will be restricted to the direct project team, encrypted devices, and locked cabinets for paper documents.	Caldecott guardian is in place. Any possible breaches to confidentiality will be disclosed immediately.	1	1	1	Principal researcher will deliver data sharing agreement to each hospice via email for them to read, and agreement will be signed prior to the exchange of any data.		
Potential risks to patient safety (each component of the study to be assessed as an individual line item): e.g. **Non-invasive** **Questionnaires** **Blood samples** **Phase 3 or 4 clinical trial (moderate)** **Phase 2/3**	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Potential for protocol deviation	If study deviates, research will be stopped and Bangor research ethics committee will be notified by the principal investigator, Nicole Hughes.		1	1	1	Researcher will stop the researcher immediately if the study deviates.	Thesis committee meetings every 6 months. Advisory groups Regular supervisory meetings.	
Potential for fraud or misconduct	Disclosure of misconduct will be disclosed.		1	1	1	As per protocol issues of misconduct and safeguarding issues will be disclosed.		

Other study risks **e.g.** **Recruitment** **Retention/ follow up** **Unblinding** **Timelines**	Protocol stated a time line and Gantt Chart has been developed to help direct the project. Researcher will take breaks if affected by topic discussed or move onto the next question		1	1	1		Thesis committee meetings every 6 months. Advisory groups	
Staffing **Experience/ qualifications** **Training** **Turnover**	Regular meetings with project team.							
Resources **Equipment** **Space**	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Finance implications	Finance already in place. Fully funded project	N/A	N/A	N/A	N/A	N/A	N/A	N/A
Expand as required								

Risk Rating

Likelihood (L) Score	1 Rare/ unlikely,	3 Possible	5 Likely/almost certain,
Severity Score (S)			
5 Major/Catastrophic	5	15	25
3 Moderate	3	9	15
1 Negligible	1	3	5

Summary of overall risk:

(Risk assessment team to propose what they deem the overall risk of the study is e.g. low, medium or high)

Local Risk Assessment carried out by:

Name: Nicole Hughes

Position: Principal Investigator (MRes Student, Bangor University)

Signature:

Date: 29.11.2016

Appendix 2.1: Consolidated Health Economic Evaluation Reporting Standards (CHEER) checklist [265]

Section/item	Item No	Recommendation	Reported on page No/line number
Title	1	Identify the study as an economic evaluation or use more specific terms such as "cost-effectiveness analysis", and describe the interventions compared.	27
Abstract	2	Provide a structured summary of objectives, perspective, setting, methods (including study design and inputs), results (including base case and uncertainty analyses), and conclusions.	28-29
Background and objective	3	Provide an explicit statement of the broader context for the study. Present the study question and its relevance for health policy or practice decisions.	30-32
Target population and subgroups	4	Describe characteristics of the base case population and subgroups analysed, including why they were chosen.	32
Setting and location	5	State relevant aspects of the system(s) in which the decision(s) need(s) to be made	32
Study perspective	6	Describe the perspective of the study and relate this to the costs being evaluated.	30-32
Comparators	7	Describe the interventions or strategies being compared and state why they were chosen.	33
Time horizon	8	State the time horizon(s) over which costs and consequences are being evaluated and say why appropriate.	34
Discount rate	9	Report the choice of discount rate(s) used for costs and outcomes and say why appropriate.	N/A
Choice of health outcomes	10	Describe what outcomes were used as the measure(s) of benefit in the evaluation and their relevance for the type of analysis performed.	N/A
Measurement of effectiveness	11a	Single study-based estimates: Describe fully the design features of the single effectiveness study and why the single study was a sufficient source of clinical effectiveness data.	N/A
	11b	Synthesis-based estimates: Describe fully the methods used for identification of included studies and synthesis of clinical effectiveness data.	N/A
Measurement and valuation of preference based outcomes	12	If applicable, describe the population and methods used to elicit preferences for outcomes.	N/A

Estimating resources and costs	13a	Single study-based economic evaluation: Describe approaches used to estimate resource use associated with the alternative interventions. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	33-44
	13b	Model-based economic evaluation: Describe approaches and data sources used to estimate resource use associated with model health states. Describe primary or secondary research methods for valuing each resource item in terms of its unit cost. Describe any adjustments made to approximate to opportunity costs.	N/A
Currency, price date, and conversion	14	Report the dates of the estimated resource quantities and unit costs. Describe methods for adjusting estimated unit costs to the year of reported costs if necessary. Describe methods for converting costs into a common currency base and the exchange rate	33-44
Choice of model	15	Describe and give reasons for the specific type of decision analytical model used. Providing a figure to show model structure is strongly recommended.	34
Assumptions	16	Describe all structural or other assumptions underpinning the decision-analytical model.	33-34
Analytical methods	17	Describe all analytical methods supporting the evaluation. This could include methods for dealing with skewed, missing, or censored data; extrapolation methods; methods for pooling data; approaches to validate or make adjustments (such as half cycle corrections) to a model; and methods for handling population heterogeneity and uncertainty.	33-44
Study parameters	18	Report the values, ranges, references, and, if used, probability distributions for all parameters. Report reasons or sources for distributions used to represent uncertainty where appropriate. Providing a table to show the input values is strongly recommended.	N/A
Incremental costs and outcomes	19	For each intervention, report mean values for the main categories of estimated costs and outcomes of interest, as well as mean differences between the comparator groups. If applicable, report incremental cost-effectiveness ratios.	52-57
Characterising uncertainty	20a	Single study-based economic evaluation: Describe the effects of sampling uncertainty for the estimated incremental cost and incremental effectiveness parameters, together with the	N/A

		impact of methodological assumptions (such as discount rate, study perspective).	
	20b	Model-based economic evaluation: Describe the effects on the results of uncertainty for all input parameters, and uncertainty related to the structure of the model and assumptions.	N/A
Characterising heterogeneity	21	If applicable, report differences in costs, outcomes, or cost effectiveness that can be explained by variations between subgroups of patients with different baseline characteristics or other observed variability in effects that are not reducible by more information.	N/A
Study findings, limitations, generalisability, and current knowledge	22	Summarise key study findings and describe how they support the conclusions reached. Discuss limitations and the generalisability of the findings and how the findings fit with current knowledge.	52-59
Source of funding	23	Describe how the study was funded and the role of the funder in the identification, design, conduct, and reporting of the analysis. Describe other non-monetary sources of support.	N/A
Conflicts of interest	24	Describe any potential for conflict of interest of study contributors in accordance with journal policy. In the absence of a journal policy, we recommend authors comply with International Committee of Medical Journal Editors recommendations.	N/A

Appendix 3.1: Example Search Strategy

	Hospice [Abstract] AND		
OR	**Intervention / interest** **(hospice care, palliative care, end of life care)**	**Perspective** **(patients, families, family-caregivers)**	**Evaluation (quality of life, outcomes, quality of death, value)**
	Palliative care [Mesh Terms]		
	“Care” AND “palliative” OR “end-of-life” OR "end of life" OR “terminal*” OR “respite”	"caregiver*" OR "care giver*" OR "informal caregiver*" OR "informal family-caregiver*" OR "family caregiver*" OR "family carer*" OR "spousal carer*" OR "spousal caregiver*" OR “carer*”	“quality of life" OR "quality of death” OR “QOL” OR “QOD” OR “quality” OR “satisfaction” OR “comfort” OR "well-being" OR “well-being” OR “experience*” OR “preference*” OR “value*” OR “outcome*” OR “perspective*” OR “effectiveness”
	“Home” AND “palliative” OR “end-of-life” OR "end of life" OR “terminal*” OR "day care"	“Family” or “family member*” or “families” OR “spouse*” or “parent*” or “loved one*”	
	“Service*” AND “palliative” OR “end-of-life” OR "end of life” OR “terminal*” OR "day care" OR "inpatient unit" or “respite”	“Patient*” or “service user*” or “client*” or “consumer*” or “care recipient*”	
	“Support” AND “palliative” OR “end-of-life” OR "end of life" OR “terminal*”		
Total	English only		
			3,101

Appendix 3.2: PRISMA Checklist

Section/topic	#	Checklist item	Reported on page #
TITLE			
Title	1	Identify the report as a systematic review, meta-analysis, or both.	60
ABSTRACT			
Structured summary	2	Provide a structured summary including, as applicable: background; objectives; data sources; study eligibility criteria, participants, and interventions; study appraisal and synthesis methods; results; limitations; conclusions and implications of key findings; systematic review registration number.	61-62
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known.	63-64
Objectives	4	Provide an explicit statement of questions being addressed with reference to participants, interventions, comparisons, outcomes, and study design (PICOS).	64
METHODS			
Protocol and registration	5	Indicate if a review protocol exists, if and where it can be accessed (e.g., Web address), and, if available, provide registration information including registration number.	Yes, but not reported
Eligibility criteria	6	Specify study characteristics (e.g., PICOS, length of follow-up) and report characteristics (e.g., years considered, language, publication status) used as criteria for eligibility, giving rationale.	68
Information sources	7	Describe all information sources (e.g., databases with dates of coverage, contact with study authors to identify additional studies) in the search and date last searched.	66-68
Search	8	Present full electronic search strategy for at least one database, including any limits used, such that it could be repeated.	66-68 275
Study selection	9	State the process for selecting studies (i.e., screening, eligibility, included in systematic review, and, if applicable, included in the meta-analysis).	68
Data collection process	10	Describe method of data extraction from reports (e.g., piloted forms, independently, in duplicate) and any processes for obtaining and confirming data from investigators.	69-70
Data items	11	List and define all variables for which data were sought (e.g., PICOS, funding sources) and any assumptions and simplifications made.	N/A
Risk of bias in individual studies	12	Describe methods used for assessing risk of bias of individual studies (including specification of whether this was done at the study or outcome level), and how this information is to be used in any data synthesis.	69
Summary measures	13	State the principal summary measures (e.g., risk ratio, difference in means).	N/A
Synthesis of results	14	Describe the methods of handling data and combining results of studies, if done, including measures of consistency (e.g., I^2) for each meta-analysis.	70-73

Section/topic	#	Checklist item	Reported on page #
Risk of bias across studies	15	Specify any assessment of risk of bias that may affect the cumulative evidence (e.g., publication bias, selective reporting within studies).	73
Additional analyses	16	Describe methods of additional analyses (e.g., sensitivity or subgroup analyses, meta-regression), if done, indicating which were pre-specified.	N/A
RESULTS			
Study selection	17	Give numbers of studies screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally with a flow diagram.	74-75
Study characteristics	18	For each study, present characteristics for which data were extracted (e.g., study size, PICOS, follow-up period) and provide the citations.	284-299
Risk of bias within studies	19	Present data on risk of bias of each study and, if available, any outcome level assessment (see item 12).	84-95
Results of individual studies	20	For all outcomes considered (benefits or harms), present, for each study: (a) simple summary data for each intervention group (b) effect estimates and confidence intervals, ideally with a forest plot.	Qual:84-95 Quant: N/A
Synthesis of results	21	Present results of each meta-analysis done, including confidence intervals and measures of consistency.	Qual: 84-95 Quant: N/A
Risk of bias across studies	22	Present results of any assessment of risk of bias across studies (see Item 15).	N/A
Additional analysis	23	Give results of additional analyses, if done (e.g., sensitivity or subgroup analyses, meta-regression [see Item 16]).	N/A
DISCUSSION			
Summary of evidence	24	Summarize the main findings including the strength of evidence for each main outcome; consider their relevance to key groups (e.g., healthcare providers, users, and policy makers).	109-112
Limitations	25	Discuss limitations at study and outcome level (e.g., risk of bias), and at review-level (e.g., incomplete retrieval of identified research, reporting bias).	203-204
Conclusions	26	Provide a general interpretation of the results in the context of other evidence, and implications for future research	112
FUNDING			
Summary of evidence	27	Describe sources of funding for the systematic review and other support (e.g., supply of data); role of funders for the systematic review.	N/A

From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. PLoS Med 6(7): e1000097. doi:10.1371/journal.pmed1000097

Appendix 3.3: ENTREQ statement

No.	Item	Guide and Description	Reported on page #
1	Aim	State the research question the synthesis addresses.	64
2	Synthesis	Identify the synthesis methodology or theoretical framework which underpins the synthesis and describe the rationale for choice of methodology (e.g. meta-ethnography, thematic synthesis, critical interpretive synthesis, grounded theory synthesis, realist synthesis, meta-aggregation, meta-study, framework synthesis).	63-64
3	Approach to searching	Indicate whether the search was pre-planned (comprehensive search strategies to seek all available studies) or iterative (to seek all available concepts until they theoretical saturation is achieved).	66
4	Inclusion criteria	Specify the inclusion/exclusion criteria (e.g. in terms of population, language, year limits, type of publication, study type).	68
5	Data sources	Describe the information sources used (e.g. electronic databases (MEDLINE, EMBASE, CINAHL, psycINFO, Econlit), grey literature databases (digital thesis, policy reports), relevant organisational websites, experts, information specialists, generic web searches (Google Scholar) hand searching, reference lists) and when the searches conducted; provide the rationale for using the data sources.	66-68
6	Electronic search strategy	Describe the literature search (e.g. provide electronic search strategies with population terms, clinical or health topic terms, experiential or social phenomena related terms, filters for qualitative research, and search limits	66-67 275
7	Study screening methods	Describe the process of study screening and sifting (e.g. title, abstract and full text review, number of independent reviewers who screened studies).	69
8	Study characteristics	Present the characteristics of the included studies (e.g. year of publication, country, population, number of participants, data collection, methodology, analysis, research questions).	284-299
9	Study selection results	Identify the number of studies screened and provide reasons for study exclusion (e,g, for comprehensive searching, provide numbers of studies screened and reasons for exclusion indicated in a figure/flowchart; for iterative searching describe reasons for study exclusion and inclusion based on modifications t the research question and/or contribution to theory development)	75
10	Rationale for appraisal	Describe the rationale and approach used to appraise the included studies or selected findings (e.g. assessment of conduct (validity and robustness), assessment of reporting (transparency), assessment of content and utility of the findings)	69
11	Appraisal items	State the tools, frameworks and criteria used to appraise the studies or selected findings (e.g. Existing tools: CASP, QARI, COREQ, Mays and Pope [25]; reviewer developed tools; describe the domains assessed: research team, study design, data analysis and interpretations, reporting).	69
12	Appraisal process	Indicate whether the appraisal was conducted independently by more than one reviewer and if consensus was required	69

13	Appraisal results	Present results of the quality assessment and indicate which articles, if any, were weighted/excluded based on the assessment and give the rationale.	281-284
14	Data extraction	Indicate which sections of the primary studies were analysed and how were the data extracted from the primary studies? (e.g. all text under the headings “results /conclusions” were extracted electronically and entered into a computer software).	69-70
15	Software	State the computer software used, if any.	70
16	Number of reviewers	Identify who was involved in coding and analysis	71
17	Coding	Describe the process for coding of data (e.g. line by line coding to search for concepts)	70-72
18	Study Comparison	Describe how were comparisons made within and across studies (e.g. subsequent studies were coded into pre-existing concepts, and new concepts were created when deemed necessary)	72-73
19	Derivation of themes	Explain whether the process of deriving the themes or constructs was inductive or deductive.	70
20	Quotations	Provide quotations from the primary studies to illustrate themes/constructs and identify whether the quotations were participant quotations of the author’s interpretation.	77-83
21	Synthesis output	Present rich, compelling and useful results that go beyond a summary of the primary studies (e.g. new interpretation, models of evidence, conceptual models, analytical framework, development of a new theory or construct).	77-109

From: *Tong, A., Flemming, K., McInnes, E., Oliver, S. and Craig, J. (2012). Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. BMC Medical Research Methodology, 12(1).*

Appendix 3.4: Quality appraisal tools and outcomes

Qualitative Study Appraisal Outcomes: Critical Appraisal Skills Programme

	Question									
Author	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
Borland et al [155]	Yes	Yes	Yes	Yes	Yes	Yes	Can't Tell	Yes	Yes	High
Jack et al [176]	Yes	Yes	Yes	Yes	Yes	No	Yes	Can't tell	Yes	Medium
Jack et al [26]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Medium
Hopkinson and Hallett [168]	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Low
Hyde et al [169]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Medium
Kennett [177]	Yes	Yes	Yes	Can't tell	Yes	No	No	No	Yes	Low
Kennett and Payne [170]	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Medium
Low et al [20]	Yes	Yes	Yes	No	No	No	Yes	No	Yes	Medium
Williams and Gardener [181]	Yes	Yes	Yes	Yes	Yes	No	No	No	Yes	Low
Hayle et al [178]	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	No	Yes	High
Gambles et al [167]	Yes	Yes	No	Can't tell	Can't tell	No	No	No	Yes	Medium
Kirk [290]	No	Can't tell	Can't tell	Can't tell	Yes	No	Can't Tell	No	Yes	Low
Woolf and Fisher [172]	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Yes	Yes	Medium
Holdsworth [156]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Low
Exley and Tyrer [173]	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Yes	Medium
Carlebach and Shucksmith [179]	Yes	Yes	Yes	Yes	Yes	No	Can't Tell	No	Yes	Low
Thomas [174]	Yes	Yes	Yes	No	Yes	Yes	Yes	No	Yes	Low

Mixed Methods Appraisal Tool (MMAT)

			Questions																		
Author	**Screening questions**		**1.1**	**1.2**	**1.3**	**1.4**	**2.1**	**2.2**	**2.3**	**2.4**	**3.1**	**3.2**	**3.3**	**3.4**	**4.1**	**4.2**	**4.3**	**4.4**	**5.1**	**5.2**	**5.3**
Field et al [180]	Yes	Yes	Yes	Yes	Yes	Yes	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Can’t tell	Can’t tell	Yes	Yes	No	No	No
Kernohan et al [182]	Yes	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	No
Goodwin et al [171]	Yes	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	N/A	No	Can’t tell	Can’t tell	No
McKay et al [159]	Yes	Yes	Yes	Yes	No	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Can’t tell	Can’t tell	Yes	No	Yes	Yes	No
McLaughlin et al [160]	Yes	Yes	Yes	Yes	Can’t Tell	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	Yes	Yes	No
Roberts and McGilloway [183]	No	Yes	Yes	Can’t tell	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	No	No	No
Skilbeck et al [175]	No	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	Yes	Yes	No

Questionnaire Survey Appraisal Outcomes: Centre for Evidence-Based Management Critical Appraisal of a Survey

			Questions																		
Author	**Screening questions**		**1.1**	**1.2**	**1.3**	**1.4**	**2.1**	**2.2**	**2.3**	**2.4**	**3.1**	**3.2**	**3.3**	**3.4**	**4.1**	**4.2**	**4.3**	**4.4**	**5.1**	**5.2**	**5.3**
Field et al [180]	Yes	Yes	Yes	Yes	Yes	Yes	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Can’t tell	Can’t tell	Yes	Yes	No	No	No
Kernohan et al [182]	Yes	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	Yes	Yes	Yes	No
Goodwin et al [171]	Yes	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	N/A	No	Can’t tell	Can’t tell	No
McKay et al [159]	Yes	Yes	Yes	Yes	No	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Can’t tell	Can’t tell	Yes	No	Yes	Yes	No
McLaughlin et al [160]	Yes	Yes	Yes	Yes	Can’t Tell	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	Yes	Yes	No
Roberts and McGilloway [183]	No	Yes	Yes	Can’t tell	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	No	No	No
Skilbeck et al [175]	No	Yes	Yes	Yes	Yes	No	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Yes	Yes	Yes	No	Yes	Yes	No

Quantitative appraisal tool: Effective Public Health Practice Project

	Questions												
	A		**B**		**C**		**D**		**E**		**F**		
Author	**1**	**2**	**1**	**2**	**1**	**2**	**1**	**2**	**1**	**2**	**1**	**2**	
Parkes [166]	Can’t Tell	Can’t Tell	Case Control	No	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	Can’t Tell	N/A	Can’t Tell	
	Weak		**Moderate**		**Weak**		**Moderate**		**Weak**		**Weak**		**Global rating**
													Weak

Appendix 3.5: Included studies table

Author and year	Purpose of the study	Study participants	Study location/Setting	Study design (& method)	Main findings (significant results for quant findings)
Addington-Hall and O'Callaghan [53]	To compare hospice in-patientcare and hospital care from the perspectives of bereaved relatives.	40 bereaved relatives (24 female, 15 male).	Inpatient, London	Survey. A comparative study using postal surveys	The provision of hospice care had a significant positive effect on patient involvement in decision making (p 0.09, 66% vs 46%) compared to the hospital comparator. Patients were also more likely within the hospice to agree that they had been adequately involved in the decisions about their treatment. There were statistically significant differences in reported pain control between hospice and hospital (p <0.01, 81% vs 39%).
Borland et al [155]	To retrospectively explore the experiences of bereaved partners who had cared for a loved one living with a terminal illness in order to identify gaps in the literature.	A total of 7 caregivers (1 female, 6 male) participated in the study. The age of family-caregivers ranged from 50-68 years.	Hospice at Home service, Northern Ireland.	Qualitative Interpretative research design. Semi-structured interviews were conducted with bereaved family-caregivers and analysed using thematic content analysis.	Key values identified included the need for support to help informal family-caregivers continue with their caring role. The development of a close relationship with staff who were deemed by family-caregivers to be experts ensured that they were able to understand family-caregiver needs and provide the necessary support and advice.
Carlebach and Shucksmith [179]	To evaluate an out-of-hours service which was run out of a local hospice.	6 patients, 8 family-caregivers, 4 district nurses, 6 Macmillan staff members, 2 General Practitioners, 1 out-of-hours emergency care service participated in the study.	None specified, North East England.	Qualitative Qualitative in-depth interviews. Thematic content analysis was utilised analyse the interview transcripts.	An out of hour's telephone service providing both reactive and proactive support was heavily utilised by patients and family-caregivers. This service provided an informal support network which resulted in patients and family-caregivers feeling reassured and also helped patients to retain some semblance of independence.
Exley and Tyrer [173]	To evaluate a pilot Hospice at Home scheme from the perspectives of bereaved family-caregivers	12 family-caregivers (9 female, 3 male) were included in this study. Other demographic	Hospice at Home service, East Midlands.	Qualitative Semi structured interviews analysed using a method informed by the	Family-caregivers were grateful that there was a service which helped alleviate the burdens of caring and ensure that their loved ones wishes to die at home were fulfilled. The quality of staff, the availability of services specifically respite care and

		information not specified.		framework approach (Ritchie and Spencer, 1994).	access to pain medications and the necessary equipment was also deemed important.
Field et al [180]	To explore the quality of adult bereavement support from the perspectives of bereaved people.	105 bereaved family members and professional and volunteer bereavement workers	Five hospice research sites, England.	Mixed method A multi-method study. A national postal survey utilising both open and closed questions. Using SPSS, descriptive statistics were used to analyse the numerical data. Interviews and five in-depth organisational case studies were coded using thematic categories.	Bereaved family-caregivers valued the continuity between pre-bereavement and bereavement support. Four out of the five included hospices in phase 2 utilised volunteers in the delivery of bereavement support. 96% of the included organisation in phase 1 offered 1-2-1 support to bereaved people. It was noted that some hospices needed to better integrate their bereavement support. The delivery of bereavement support differed across the different hospices.
Gambles et al [167]	To explore patient perception of reflexology treatments	34 patients (33 female, 1 male) were included in this study, all participants had a cancer diagnosis (n=34).	Outpatient department, North of England.	Qualitative Semi structured questionnaires incorporating both open and closed questionnaires. Thematic analysis was used to analyse patient responses.	Reflexology was said to have provided both emotional and physical benefits. Falling under the purview of both categories, the opportunity to relax was the principle benefit for 91% of participants. By providing a service in a friendly atmosphere, a range of other positive outcomes ensued. Such outcomes included but were not limited to improved sleep, a reduction in anxiety and help with side effects.
Goodwin et al [171]	To describe the services at five palliative day therapy from the patients' perspective.	102 patients (Response Rate (RR) 41%). (50 Female, 52 male) participated in the study. Patient diagnosis was specified as either cancer (n=89) or non-cancer diagnosis (n=4). All	Five palliative day therapy centres, London.	Mixed method Semi-structured interviews were conducted with patients at a maximum of 3-time points. The third interview was only completed by 33% of patients.	Five hospices were the focus of the research and were subdivided into either social, medical/therapeutic or medical/social. Whilst there were changes between baseline interview and third interview and between different models of care, patient responses largely fell under three categories 1) meeting people, 2) getting out, 3) the place. By the third interview, there was a noticeable difference in responses from participants receiving support from the medical model. At baseline 'support' was the most important to 48% of

		patients age ranged from 35-87 years).			participants in the medical model by third interview the theme ‘meeting people’ had become more prominent (30%).
Hastie et al [161]	To seek the views of patients on the quality of the treatment and care provided.	53 hospices distributed self-completion surveys to their patients. 2324 patients returned their survey (1398 day therapy users, 926 inpatients.	53 hospices from across the UK. List of specific locations not included.	Survey/questionnaire The quantitative data from the surveys were entered and analysed using SPSS v12 whilst the qualitative (textual comments) were entered and analysed using Excel.	The availability of staff and volunteers at the hospice obtained many positive survey responses. Hospice staff helped to provide a service which encourage patient confidence in their work. The results indicate that staff worked hard to help ensure patients felt their privacy was respected as high levels of satisfaction were shown in the survey responses for both in-patients (88.1%) and day-care (89.8%). Patients also felt that their needs had been sufficiently met. Other areas which received high praise included cleanliness (83-88%), the general environment (84-85%) and involvement in the decision-making process with the opportunity to ask questions. Some of the weaker areas of the service was the availability of activities for service users.
Hastie et al [162]	To seek the views of patients on the quality of the treatment and care provided.	49 hospices distributed self-completion surveys to their patients. 1052 patients from the inpatient unit and 1352 day-care across the included hospices returned a valid survey.	49 hospices from across the UK. List of hospice locations not included.	Survey/questionnaire The quantitative data from the surveys were entered and analysed using SPSS v14 whilst the qualitative (textual comments) were entered and analysed using Excel.	Patient responses demonstrated high levels of satisfaction in many areas. Responses pertaining to staff in particular indicated that they were successful in helping to foster patient confidence and in ensuring patients were treated with respect. The availability of staff also achieved notable recognition as they worked to meet patients individual needs and wishes. However, positive responses were higher within the day therapy setting. Not unlike previous surveys, cleanliness and the general environment were rated highly. Survey responses also demonstrated that the level of support provided to patients when another group member died or was discharged was lacking as this received the lowest levels of satisfaction. The

					range of activities available to patients also identified as one of the weaker services provided, along with the availability of food outside meal times and patient involvement with care.
Hastie et al [163]	To seek the views of patients on the quality of the treatment and care provided.	52 hospices distributed self-completion surveys to their patients. 2222 patients returned their survey (1259 day therapy users (Response Rate (RR) 62%), 963 inpatients (Response Rate (RR) 41%).	52 hospices from across the UK (only England, Scotland and Ireland had participating hospices).	Survey/questionnaire The quantitative data was entered in SPSS and analysed, producing descriptive statistics. Textual comments were analysed separately using Microsoft Excel.	The hospice provided a service which helped reduce anxiety levels for patients after their first visit. The hospices excelled in many areas of care such as cleanliness, patient satisfaction with their involvement in their care and the opportunity to ask questions. However, it was the staff and the care provided which received overwhelmingly positive comments from patients. Patient confidence with staff was especially prominent in the day therapy setting. Irrespective of the many improvements, comments demonstrated that work was needed within the inpatient unit as some patients wanted time to make decisions about their care and individual needs where somewhat overlooked. Other areas where advancement needed was access to food for inpatients, the availability of activities and support in the event of a death or discharge of another patient.
Hayle et al [178]	To evaluate the experiences of patients suffering from chronic obstructive pulmonary disease who also received support from specialist palliative care services.	A total of 8 patients (5 male, 3 female) participated in this study. The age ranged from 63-77 years). Patients included in this study all had a primary diagnosis of chronic obstructive pulmonary disease.	Inpatient and outpatient services, North West England.	Qualitative Semi-structured interviews using a topic guide ensued. Hermeneutic phenomenological approach was utilised.	Palliative care for patients suffering with Chronic obstructive pulmonary disease was said to alter the patients physically, psychologically and spiritually. Changes also occurred in the patients preconceptions of hospice care. Physically patients improved as their symptoms were better managed resulting in a reduction in the number of hospital admissions. Psychologically, patients described that they felt a reduction in anxiety and stress. The changes to patients spiritually resulted in positive changes regarding death as patients were not as worried about

					the dying process as they had been previously. Additionally, by utilising a service which provided support to others, COPD patients explained how this gave them perspective.
Holdsworth [156]	To describe the experiences of bereaved family family-caregivers and the role that care providers play in these experiences.	45 informal caregivers (Response Rate (RR) 16.3%) (28 female, 17 male) participated in this study. The diagnosis of patients were categorised as either cancer (n=38) or non-cancer (n=6).	Location not specified.	Qualitative Forty-four 1-2-1 interviews were conducted (2 family-caregivers interviewed jointly). Interpretive thematic analysis using the Framework approach was utilised to analyse the interview transcripts.	The findings fell under six core themes 1) Social engagement, 2) care provider characteristics and actions, 3) family-caregivers ability, 4) preparation and awareness, 5) presentation of the patient at death, 6) after death support for protected grieving. The family-caregivers ability to maintain a sense of self was dependent on their ability to spend time with their family and the connections they were able to make with staff. Further to this, the provision of family-caregiver support ensured that patients wishing to be cared for at home were able to have their requests fulfilled. Family-caregivers also found it important to play an integral role in the decision-making process of the patient. However, family-caregiver involvement in decisions relating to symptom management was difficult. The balance between pain relief and sedation was difficult as family-caregivers wanted the patient to be comfortable but also able to communicate. It was therefore necessary to ensure that family-caregivers were fully aware of what to expect and were suitably prepared for the patient's death. It was then essential to ensure that family-caregivers received the necessary support after the event.
Hopkinson and Hallett [168]	To explore the experiences of patients whilst attending hospice day therapy in order to find out what is important to them.	12 patients were interviewed (5 female, 7 male). Patients ranged from 50-86 years of age. All patients had some	Hospice day-care unit.	Mixed method Using a phenomenological approach, 1-2-1 interviews were used to explore patient	The findings of the study fell under four headings; 1) Feeling comfortable, 2) Feeling good, 3) Feeling less isolated, 4) Personal preferences. The hospice atmosphere ensured that patients were made to feel comfortable. The comforting nature of the hospice was further accentuated by the staff. Day therapy also

		form of terminal cancer.		experiences of hospice day-care.	helped patients' self-worth by having the opportunity to make choices and their involvement in activities tailored to their abilities. Social isolation was an issue for many patients, this issue was said to have been alleviated through attendance at day care. Within this study, patients could be separated into those who "tolerating" their issue and those who were "adapting". Those who were seen to be adapting valued having the opportunity to share stories, learn new skills and talk about their illness. Comparatively, those who were seen to be tolerating valued the distraction of day care.
Hyde et al [169]	To explore service users experiences of palliative day therapy to understand what they value from the service.	29 patients and 8 family-caregivers participated in the study. Patient diagnosis included cancer n=10, multiple sclerosis n=10, motor neurone disease n=3, other n=6).	One hospice palliative care unit, England.	Qualitative Descriptive, cross-sectional study. A semi-structured topic guide was used when conducting focus groups and 1-2-1 interviews utilising open-ended questions and analysed using the framework methodology (Richie and Spenser, 1994).	The findings from this study fell under four main themes; 1) The quality of staff, 2) Sense of community, 3) Relationships. The skills and expertise of staff were important to family-caregivers especially when it came time to handing over their caring responsibilities to the hospice. Family-caregivers also had the opportunity to obtain any advice which contributed to the overall positive experiences of day care. For patients, day therapy provided an opportunity for relationships and a sense of community developed.
Jack et al [26]	To explore the perceptions and experiences of bereaved family family-caregivers' receiving support from hospice at home services.	The participants in this study included 20 family-caregivers (15 Female, 5 male). Their family member was most likely to suffer from a cancer diagnosis (n=16). Age of family-caregivers	Hospice at Home services across the UK, North West England.	Qualitative A qualitative study drawing upon a naturalistic interpretative approach. Semi structured interviews were conducted with family-caregivers and analysed using a thematic	End of life care provided to patients at home was shown to positively impact upon informal family-caregivers. The three themes that derived from the study were: (1) A valued presence (2) In good hands (3) Supporting normal life. The provision of support at home ensured that family-caregivers felt supported and great comfort was drawn from the presence of hospice staff. Family-caregivers were also able to obtain the necessary reassurance and validation from staff during scheduled visits. These scheduled visits

		ranged from 20-69 years).		approach (Braun and Clarke, 2006).	ensured that family-caregivers were adequately supported and also provided family-caregivers with a small break which ensured that they could continue with their caring responsibilities. This service was said to help family-caregivers maintain a sense of normality.
Jack et al [176]	To explore the perceptions of both patients and family caregivers in relation to the Hospice at Home service.	A total of 16 patients (Female n=10, Male n=6) and 25 family caregivers took part in the study. Patient diagnosis were split into cancer (n=12) or non-cancer (n=4). Patient age primarily ranged between 81-90 (n=11).	Hospice at Home Service, North West England.	Qualitative A prospective qualitative approach drawing upon a naturalistic interpretative design was utilised within this study. Using a topic guide, semi structured interviews ensued, and transcripts analysed using a thematic analysis approach (Braun and Clarke, 2006).	The findings within this study fell under two main themes: (1) Embracing Holism, (2) Service organisation. The four subthemes (1) Talking about, (2) Knowing and doing, (3) Caring for caregivers, (4) Promoting choice all contributed to the theme 'Embracing Holism' which was the main focus of the research. The provision of a hospice at home service meant that patients and caregivers were given choices. A service which enabled patients to die in the place of their choice and provides support to caregivers to help fulfil this wish was highly valued. The knowledge and expertise in addition to the personal qualities of staff ensured that relationships were formed. These relationships comforted both patients and family-caregivers and also meant that staff were able to engage patients and family-caregivers in difficult conversations about illness trajectories, death and dying. These relationships also provided a form of social stimulation resulting in improvements in psychological well-being.
Jenkins and Codling [164]	To seek the views of patients on the quality of the treatment and care provided.	39 hospices distributed self-completion surveys to their patients. 1984 patients returned their survey (1150 day therapy users (Response Rate (RR) 62%), 834 inpatients (Response Rate (RR) 45%).	39 hospices from across the UK (only England, Scotland and Ireland had participating hospices).	Survey/questionnaire The quantitative data was entered in SPSS Version 19 and analysed, producing descriptive statistics. Textual comments were analysed separately using Microsoft Excel.	Few disparities existed between inpatients and day therapy responses regarding their stay at the hospice as many commented on their high levels of satisfaction with the services provided. The general environment and cleanliness of the hospice were but two factors contributing towards the positive feedback expressed although the number of favourable responses were slightly higher within the inpatient units. Contributing to the high-quality service, was the availability of staff and the ethos they created as they

					provided patients with respect, dignity and privacy. However, qualitative statements demonstrated the need for improvements within the inpatient setting to ensure privacy is maintained as issues of noise were a regularity. The ethos promoted by the hospice also ensured that day patients ended their first day with less anxiety then they arrived with. Nonetheless the day therapy unit was not without criticism, as the number of day patients who felt that they were adequately involved in their care did not surpass that of inpatients. Other suggested improvements included the need for a wider range of activities. The use of transport provided by the hospice was utilised by 70% of day patients, a service which was rated highly.
Jenkins and Codling [165]	To seek the views of patients on the quality of the treatment and care provided.	20 hospices distributed self-completion surveys to their patients. 1039 patients returned their survey (574 day therapy users (Response Rate (RR) 64%), 465 inpatients (Response Rate (RR) 50%).	39 hospices from across the UK (only England, Scotland and Ireland had participating hospices).	Mixed method The quantitative data was entered in SPSS Version 21 and analysed, producing descriptive statistics. Textual comments were analysed separately using Microsoft Excel.	As with previous surveys, hospices excelled in areas relating to respect and dignity. In contrast to the previous year, patient satisfaction with privacy also received high praise also results demonstrated an increase in both the day therapy and inpatient units. These improvements were seen across other areas such as advanced care planning, the variety of activities available, confidence in staff and hospice cleanliness. These were but few improvements. For day therapy patients, higher percentages of those demonstrating a reduction in levels of anxiety after their first visit were evident. However, improvements were not noted in all areas as satisfaction with hospice transport had decreased. Qualitative statements were able to clarify issues with pick up times, certain drivers and comfort. Specific to inpatients, improvements were seen in the following areas: disturbance from noise, food quality and visiting arrangements.

Kennett [177]	To understand the experiences of terminally ill patients who were participating in art exhibition.	This study included 10 patients (6 male, 4 female). The majority of patients had a cancer diagnosis (n-8) compared with having a non-cancer diagnosis (n=2). Age ranged from 23-80 years. 11 members of staff were also interviewed.	A palliative care day centre at one London hospice (St Christopher's).	Qualitative A phenomenological study. In depth semi-structured interviews were conducted with patients on a one to one basis whilst staff interviews were conducted in pairs. The interviews were transcribed and analysed to identify themes.	The themes that developed within this primary study demonstrate the positive outcomes of hospice day therapy on patients. (1) Enjoyment, (2) enthusiasm, (3) excitement, (4) pride, (5) achievement, (6) satisfaction, (7) sense of purpose, (8) mutual support, (9) permanence. Hope and a sense of purpose and encouragement through mutual support were the overwhelming outcomes within this study. These feelings were encouraged through the creation of a mural and the development of new skills. Some patients commented on how these positively affected patient symptoms.
Kennett and Payne [170]	To analyse patients' accounts of how living with a terminal illness affects their quality of life and experiences of attending St. Christopher's Hospice.	This study included 34 patients (female n=11, Male n=23). Age range between 40-95 years.	A palliative care day centre at one London hospice (St Christopher's).	Qualitative 34 patients took part in six audiotaped recorded "goldfish bowl" teaching sessions. The data was analysed to identify themes	Patient responses were relatively consistent. The principle issues derived within this study focused how the patients illness affected their quality of life and their relationships with their families, their interactions with healthcare professionals and the experiences of attending the Creative living centre. Patients often discussed the difficulties transitioning to a life with a terminal or life limiting illness and the ultimate loss of their independence. Whilst some patients recounted feelings of anxiousness before their first visit but noted a change in mood over time. Other positive outcomes for patients included a sense of achievement, a feeling of belonging due to the mutual support and a chance to talk about their illness with others.
Kernohan et al [17]	To explore and describe patient perspective on the provision of medical, social and therapeutic out-patient services	26 patients participated in the study (10 male, 16 female). All patients ranged from 31-70 years and were diagnosed with a form of cancer.	A day therapy centre at one hospice in Northern Ireland	Survey/questionnaire Semi-structured questionnaires were completed by 26 of the 50 day therapy patients attending one day therapy centre. The responses to closed questions were entered	This paper explored patient satisfaction with hospice day care. The most common reason for patient attendance at hospice day therapy was to obtain emotional/spiritual support (61%), followed by the opportunity for families to have some respite (42%) and to meet other patients (42%). These opportunities provided significant benefits and resulted in positive outcomes such as reduced isolation and the development of relationships. Day therapy also

				into SPSS for basic descriptive analysis whilst qualitative statements were subject to content analysis.	provided the opportunity to get out. From a predetermined list, the most valued aspect of hospice day therapy that were valued the most included welcome on arrival with tea (n=16) followed by the provision of quiet time to chat with others. The facilitation of group discussions was valued by 58% of patients. Whilst most respondents felt that the hospice provided enough activities, 27% suggested the need for more craft orientated activities. Most patients (69%) found comfort in knowing that the hospice could meet their changing needs, facilitated by the availability of medical staff.
Kernohan et al [182]	To access the spiritual needs of patients and their interactions with the hospice chaplains against the national standards for Hospice and Palliative care Chaplaincy	62 patients (Response Rate (RR) 64%) participated in the study (31 female, 31 male). All patients were 41 years of age or older. Patient diagnosis was not specified, however, it was explained that "most" had been diagnosed with cancer.	Hospice day-care services, community care and Hospice inpatient unit in Northern Ireland.	Surveys/Questionnaire Two methods of data collection were utilised. The first method involved reviewing participant pastoral notes followed by semi-structured interviews utilising both open and closed questions. The two data sources were linked and analysed using SPSS Version 11.5 to obtain descriptive statistics. Content analysis was used on the data generated from the open-ended questions.	With a high proportion of participants having religious beliefs (92%) access to spiritual support was found to be helpful to 90% of patients with the frequency of visits found to be appropriate for 52% however, 43% found that the visits needed to be more frequent. This service encouraged feelings of hope, helped patients prepare for death and reassured patients that their families were supported. Additionally, the chaplaincy service helped facilitate patient communication needs.
Kirk [290]	This study explored patient preferences of single or shared rooms within the hospice.	24 patients (12 female, 12 male) participated in this study.	Hospice inpatient. Specific location not specified.	Qualitative 1-2-1 structured interviews were conducted with patients.	The opportunity to stay in a single room was favoured over staying in a shared room by 75% with many patients previously having experiences of staying in a single room (96%). Privacy was the principle reason for wanting to stay in a single room, closely followed by

				Mode of analysis not specified.	the quiet nature associated with a single room, and to reduce embarrassment of symptoms.
Low et al [20]	To explore the experiences of patients utilising palliative day therapy services.	The sample in this study included 18 patients, 12 family-caregivers, 11 palliative care day service managers and 22 volunteers.	Palliative care day services across the UK.	Qualitative A qualitative methodology was utilised. A total of four focus groups were facilitated by the research nurse and the Senior Research Fellow. The focus groups were transcribed verbatim for thematic content analysis.	Access to palliative day therapy professionals situated in one location was important to patients, where they could monitor patients regularly and pre-empt further health issues. The reasons behind admission to day therapy was often for either social or medical benefits. The overwhelming social benefit associated with admission was peer support where a reduction in isolation was felt and provided a service which patients looked forward to attending. Some patients acknowledged that they attended day therapy for improvements in physical functioning and mobility. Day therapy also provided family-caregivers with respite resulting in improved quality of life. The medical knowledge of staff members ensured that family-caregivers could confidently leave patients at day care. Patients were disappointed when they had to be discharged.
Lucas et al [158]	The aim of the study was to evaluate the Bradford hospice at home service through the exploration of family-caregivers, nurses and General Practitioners perspectives.	This study included family-caregivers (n=289) (Response rate (RR) 50.7%), district nurses (n=508) and GP's (n=44). Participant characteristics not specified.	Hospice at Home service, Bradford.	Survey/Questionnaire Postal questionnaires were sent to family-caregivers. The Quantitative data was analysed using SPSS frequency analysis. Qualitative data was analysed using grounded theory techniques.	The hospice at home service provided accessible support to family-caregivers which ensured that they were able to fulfil patients wish to die at home. This service was valued by 97% of family-caregivers who felt that the hospice staff were knowledgeable about patient conditions (92%). Whilst 80% of participants felt that there was sufficient nursing help, negative comments about the use of agency staff were said in abundance.
McKay et al [159]	To examine whether a model established in one hospice helped to mitigate family-caregiver burden.	122 family-caregivers (17 bereaved, 81 current family-caregivers) returned questionnaires.	A Hospice at Home service. Midwest Ireland.	Mixed method design that included a postal survey and interviews. Different versions were given to current family-	The hospice at home service provided support to both patients and family-caregivers and 96% of respondents felt that referral to the hospice at home service had happened at the right time, however knowledge regarding some services was lacking. Access to 24-

		29 family-caregivers agreed to participate in qualitative interviews. The age of participants ranged from 25-85+.		caregivers and bereaved family-caregivers. Questionnaire data was analysed using SPSS 18.0. The qualitative responses were coded and thematically analysed.	hour support and night time visits often provided a form of respite for family-caregivers. Respite was valued by 83% of family-caregivers and support at night was valued by 74%. Accessibility of the team was noted by 77% of family-caregivers. 75% of patients and 69% of family-caregivers felt communication, specifically staff sensitivity and continuity of care were good. Despite the positives expressed about 24-hour support and open communication, these failed to match or exceed respondent expectations. With regards to place of death, there was a statistically significant correlation between those who had discussed place of death with staff and the location in which the patient had died. After the patients' death, 72% of family-caregivers had contact with the hospice at home team and 11% chose to attend a bereavement support service. 53% of family-caregivers also indicated that they would have liked to take a course to optimise their caring skills.
McLaughlin et al [160]	To explore bereaved caregivers' experiences of Hospice at Home	128 family family-caregivers (Response Rate (RR) 41%) responded to the questionnaire. (Demographic details not provided).	Hospice at Home setting. Location not specified.	Mixed method Postal Questionnaire made up of primarily closed questions and one open ended question. Quantitative data was analysed using SPSS, windows 11. Descriptive analysis was performed on all closed variables. Content analysis was performed on the qualitative data.	The findings within this study fell under five headings: (1) Awareness of service, (2) Home care, (3) Help requested, (4) Relieving family-caregiver burden, (5) Hospice at home staff. Whilst 94% of family-caregivers were aware of the involvement of hospice at home staff in their care, the qualitative comments revealed a lack of awareness regarding the hospice at home service. Whilst reasons behind why family-caregivers chose to care for patients differed, 95% felt that the hospice at home service ensured that family-caregivers could continue to support a patients' wish to die at home, which was the most valued aspect of the service. Such support mechanisms included a night sitting service, family-caregiver relief reassurance and skilled services. Some family-caregivers did note that they would have liked more support. On the contrary, 95% of patients agreed that the service was available

					to provide the requested help such as accessing equipment and relieve the burden placed on family-caregivers. The courteous and approachable nature of the hospice personnel were said to have positively affected family-caregiver experiences (98%). Ninety-four percent of family-caregivers were said to hold enough knowledge regarding patient conditions however, qualitative statements suggest more training was needed for patients who were cognitively impaired. Suggested improvements included more support after bereavement.
Office for National Statistics [157]	To collect information on the views on the quality of care provided to a friend or relative in the last 3 months of life from the perspective of bereaved people.	A sample of approximately 49,000 adults in England. Other information not specified.	Postal survey	Survey/questionnaire Analysis was conducted using various statistical packages (None specified).	By looking at the views on the quality of care provided to a friend or relative in the last 3 months of life, it was discovered that 75% rated the overall quality of end of life care as excellent, outstanding or good across all care settings. However, it was the hospices who excelled in many areas, specifically, in relation to pain, dignity and respect. Healthcare personnel at hospices were said to excel in 'always' treating patients with dignity compared with any other care setting. Of note, is the disparities between cancer patients and patients with Cardiovascular diseases as cancer patients were more likely to agree that they had been treated with dignity. Additionally, pain was said to have been relieved "completely, all of the time" more frequently than other healthcare providers. Co-ordination of care within the hospice could improve as it was discovered that the co-ordination of care within the home setting exceed all other health care provider settings included in the study.
Parkes [166]	To evaluate in-patient services at St Christopher's Hospice	34 bereaved spouses (22 female, 12 male). Demographic and diagnosis not specified.	St Christopher's Hospice. 'Other' hospitals unknown.	Quantitative Self-assessments of 34 spouses of patients at one hospice were compared with the self-assessments of a	An evaluation of St Christopher's hospice discovered that the number of spouses spending 6 or more hours at the hospice exceeded that of spouses visiting patients at other hospitals. Other differences between care settings included the increased likelihood that spouses from the hospice would see a doctor

				matched group of spouses of patients who had died in a hospital. Data analysis not specified.	compared to spouses at another hospital. Significant differences were evident in the perceived busyness of staff as staff at the hospice were less likely to be considered busy (Ward nurses p=<0.01; ward sister p=<0.05; ward doctor, <0.01). The support provided by both the hospice and the hospital were reported to have reduced anxiety for spouses compared to when patients were cared for at home however, spouses at a hospital were more likely to have anxiety symptoms (p<0.05). Specifically, loss of appetite was greater within a hospital setting (p<0.05) and the level of worry regarding patient pain. There were no support systems in place to support spouses during bereavement.
Roberts and McGilloway [183]	To evaluate a hospice-based bereavement support service in Ireland	243 family-caregivers participated in this study (Demographic details not stated).	A hospice located in Ireland.	Mixed method A cross-sectional postal survey. Family-caregivers completed: 1) a Bereavement Services Questionnaire; 2) a measure of grief reaction (TRIG) and 3) a measure of religiosity (SCSORF).	The focus of the study evaluated the utilisation of three bereavement support services. The services, a bereavement follow up service which had contacted 84% of respondents, a monthly memorial ceremony attended by 87% of respondents, a bereavement information service attended by 33% of respondents and a volunteer bereavement support service. A number of reasons were given as to why some respondents did not attend services. Additionally, respondents who had attended a bereavement service demonstrated higher levels of grief symptoms.
Skilbeck et al [175]	To explore family-caregiver experiences and expectations of respite.	25 patient/family-caregiver dyads recruited (17 male patients, 8 female). Family-caregiver gender not reported in detail. Age ranged between 36-88 years. Diagnosis was separated into cancer (n=15) and	Independent hospice providing inpatient respite beds. North of England.	Mixed method. Prospective study using mixed methods data collection. The first method utilised Semi-structured interviews at 2 time-points. The additional method used was the Relative Stress Scale Inventory which was	The physical, and psychologically demanding nature associated with caring for a loved one was noted. The Relative Stress Scale inventory (RSSI) indicated that providing care for someone else had a considerable impact on their lives. Whilst many family-caregivers (76%) believed that respite had met their expectations, the RRSI indicated that only four family-caregivers had received a positive change in their score post respite whilst 3 family-caregivers demonstrated no change and for 5 family-caregivers, there was a negative change in scores. Irrespective of

		neurological conditions (n=12).		administered at both interviews conducted with family-caregivers. The qualitative data was analysed using constant comparison. Categorical data from the structured questionnaire were entered in to SPSS and descriptive and comparative statistical analysis ensued.	this, qualitative statements demonstrated that a majority of family-caregivers felt that respite had held been beneficial with only a small proportion expressing dissatisfaction with the service, specifically a lack of awareness and the frequency at which respite occurred.
Thomas [174]	Patient preferences were explored regarding visiting	6 patients (Demographic information not specified).	Inpatient setting. Location not specified.	Qualitative Phenomenological approach. Semi-structured interviews. Thematic analysis was utilised.	Opening visiting hours was shown to bring many benefits to patient. In particular, some patients felt visits helped them to cope by enabling them to maintain connections and gain support. However, some patients felt that open visiting hours inhibited them as they explained how they felt that they were not in control. This lack of control often negatively affected a patient's ability to cope.
Williams and Gardner [181]	To understand the preferences of patients, family and staff for single or shared rooms within the hospice.	29 patients (8 female, 6 male), 23 family-caregivers (16 female, 7 male) and 10 hospice staff participated in this study. Age of participants ranged from 44-89. Information on diagnosis not stated.	Inpatient and day therapy patients, and staff from one hospice in Sheffield.	Qualitative Semi-structured interviews following an interview schedule. Audio recordings were not taken therefore hand-written notes were made and analysed using thematic content analysis.	The findings of this study determined that patients and family-caregivers should be offered the choice of single or shared rooms. The social aspects that derive from a shared room were the principle benefit of shared room. However, the lack of privacy was a consequence of a shared room, due to this many patients and family-caregivers preferred the single room alternative.

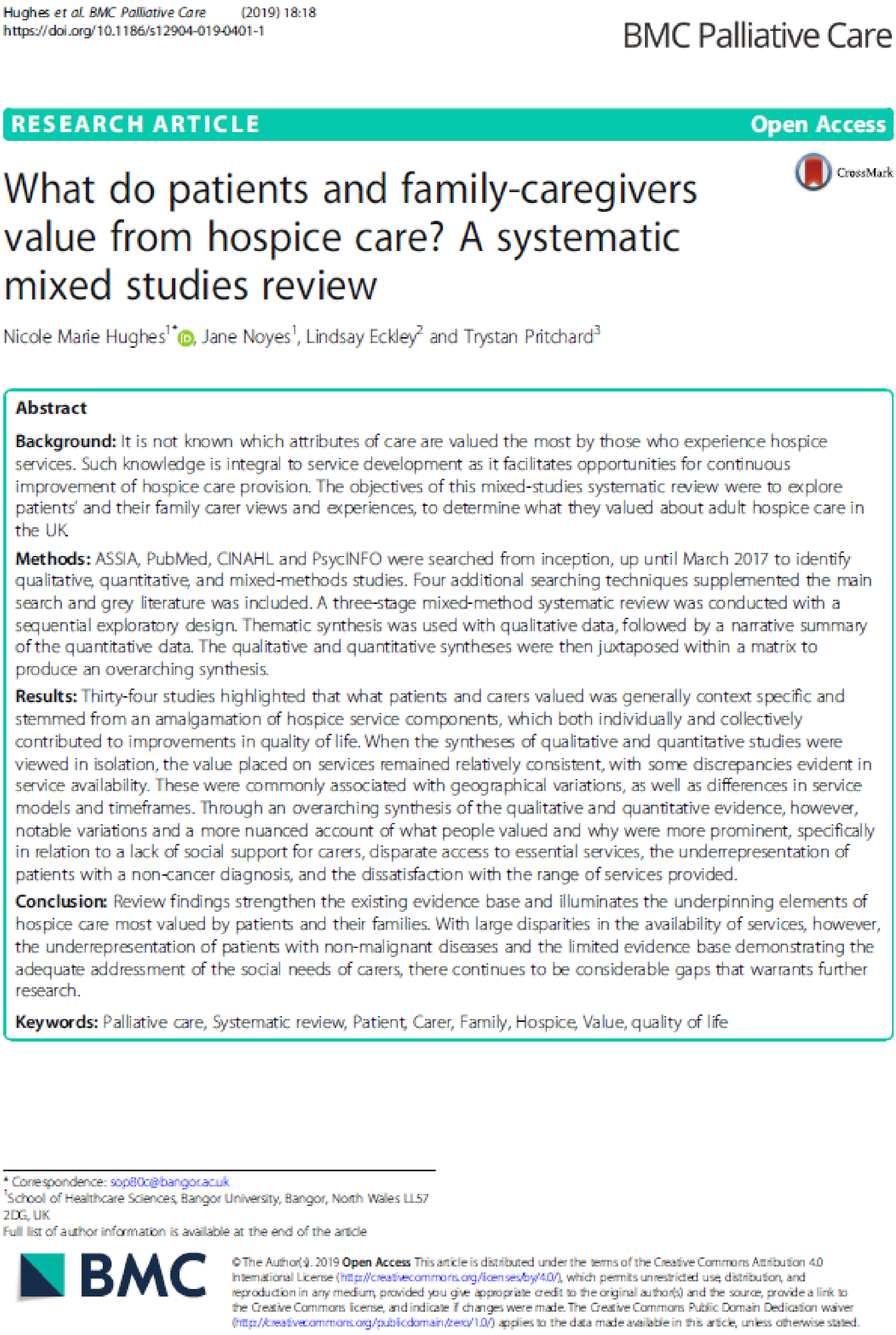
Woolf and Fisher [172]	To explore patient experiences of dance movement psychotherapy in day care.	4 patients (Female (n=2), Male n=2). Age of participants ranged from 82-95 years. Diagnosis varied (cancer, cardiac disease, chronic obstructive pulmonary disease, diabetes, and rheumatoid and osteoarthritis.	Day hospice. Location not specified	Qualitative A case study approach triangulating both verbal and non-verbal data analysed using thematic analysis following modified phenomenological techniques.	Dance movement psychotherapy (DMP) was a service able to positively affect patients psychically, emotionally and socially. The conditions of the service ensured that patients felt safe, and relaxed.

Appendix 3.6: Data extraction tools

DATA EXTRACTION TOOL 1- Qualitative	
STUDY DETAILS	
Publication type	
Study Title	
Year of publication	
Author(s)	
Aims/Objectives	
Setting of study	
Location	
METHODS	
Study type/methodology	
Inclusion/Exclusion criteria for participants	
Recruitment strategy *(How were potential participants approached and invited to participate in the study?)*	
Sample size *(Are participants in the study likely to be representative of the target population)*	
PARTICIPANTS	
Type of participant (bereaved, family-caregivers, patients or professionals?).	
Participant demographics (age, sex, ethnicity)	
Participant prognosis (if applicable)	
Inclusion criteria	
Exclusion criteria	
Reasons for withdrawal	
SUMMARY OF RESULTS	

Brief summary of results	
Identified themes/concepts	
Participant quotations	

Appendix 3.7: Published Systematic Review



Hughes *et al. BMC Palliative Care* (2019) 18:18
https://doi.org/10.1186/s12904-019-0401-1

BMC Palliative Care

RESEARCH ARTICLE Open Access

What do patients and family-caregivers value from hospice care? A systematic mixed studies review

Nicole Marie Hughes[1*], Jane Noyes[1], Lindsay Eckley[2] and Trystan Pritchard[3]

Abstract

Background: It is not known which attributes of care are valued the most by those who experience hospice services. Such knowledge is integral to service development as it facilitates opportunities for continuous improvement of hospice care provision. The objectives of this mixed-studies systematic review were to explore patients' and their family carer views and experiences, to determine what they valued about adult hospice care in the UK.

Methods: ASSIA, PubMed, CINAHL and PsycINFO were searched from inception, up until March 2017 to identify qualitative, quantitative, and mixed-methods studies. Four additional searching techniques supplemented the main search and grey literature was included. A three-stage mixed-method systematic review was conducted with a sequential exploratory design. Thematic synthesis was used with qualitative data, followed by a narrative summary of the quantitative data. The qualitative and quantitative syntheses were then juxtaposed within a matrix to produce an overarching synthesis.

Results: Thirty-four studies highlighted that what patients and carers valued was generally context specific and stemmed from an amalgamation of hospice service components, which both individually and collectively contributed to improvements in quality of life. When the syntheses of qualitative and quantitative studies were viewed in isolation, the value placed on services remained relatively consistent, with some discrepancies evident in service availability. These were commonly associated with geographical variations, as well as differences in service models and timeframes. Through an overarching synthesis of the qualitative and quantitative evidence, however, notable variations and a more nuanced account of what people valued and why were more prominent, specifically in relation to a lack of social support for carers, disparate access to essential services, the underrepresentation of patients with a non-cancer diagnosis, and the dissatisfaction with the range of services provided.

Conclusion: Review findings strengthen the existing evidence base and illuminates the underpinning elements of hospice care most valued by patients and their families. With large disparities in the availability of services, however, the underrepresentation of patients with non-malignant diseases and the limited evidence base demonstrating the adequate addressment of the social needs of carers, there continues to be considerable gaps that warrants further research.

Keywords: Palliative care, Systematic review, Patient, Carer, Family, Hospice, Value, quality of life

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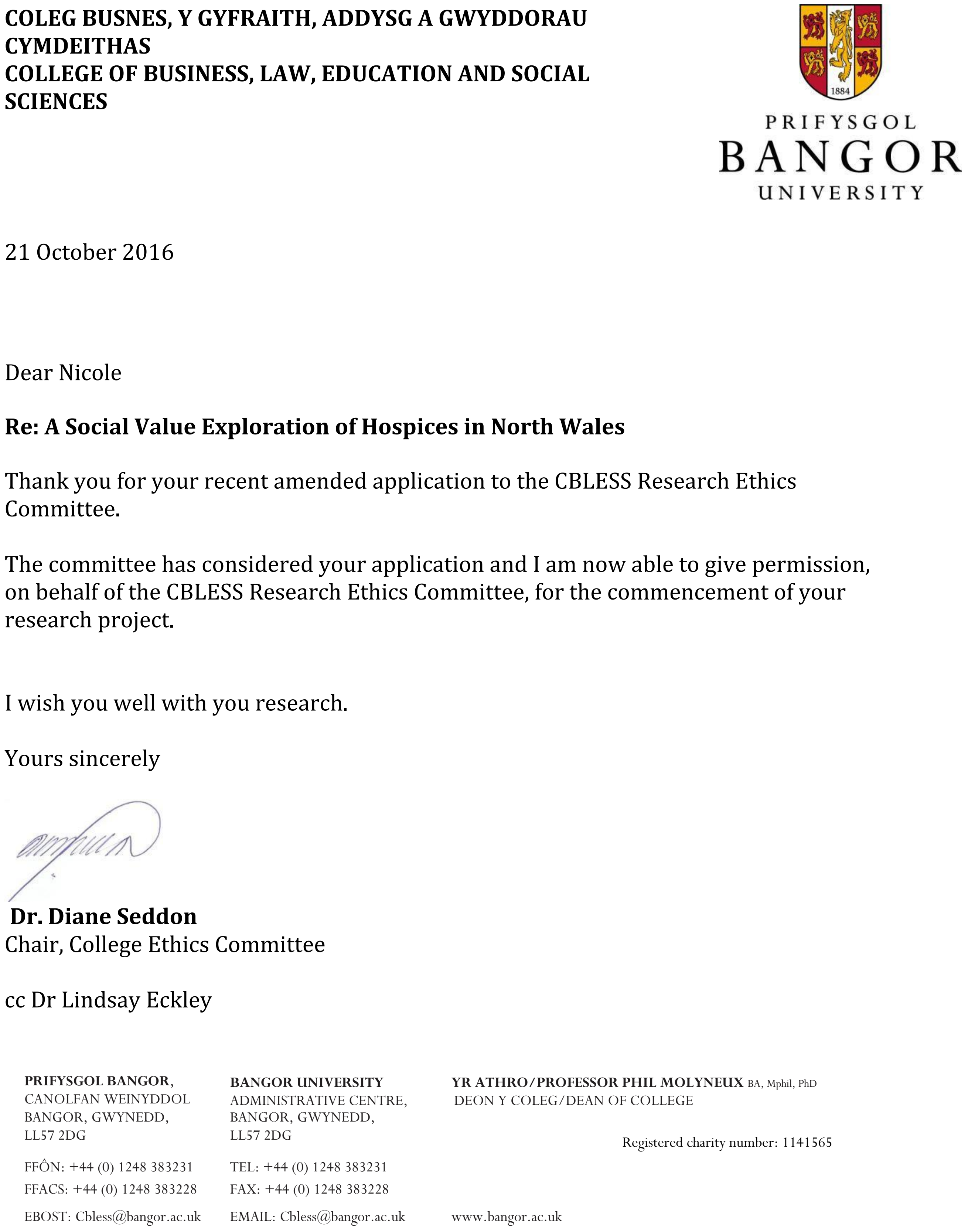
Full list of author information is available at the end of the article

Appendix 4.1: CBLESS approval letter for MRES



COLEG BUSNES, Y GYFRAITH, ADDYSG A GWYDDORAU CYMDEITHAS
COLLEGE OF BUSINESS, LAW, EDUCATION AND SOCIAL SCIENCES

PRIFYSGOL BANGOR UNIVERSITY

21 October 2016

Dear Nicole

Re: A Social Value Exploration of Hospices in North Wales

Thank you for your recent amended application to the CBLESS Research Ethics Committee.

The committee has considered your application and I am now able to give permission, on behalf of the CBLESS Research Ethics Committee, for the commencement of your research project.

I wish you well with you research.

Yours sincerely

Dr. Diane Seddon
Chair, College Ethics Committee

cc Dr Lindsay Eckley

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Appendix 4.2: Risk assessment of PhD research

Location:	- St David's Hospice - St Kentigern Hospice - Hospice at Home, Gwynedd and Anglesey - Nightingale house hospice	**Activity (Summary):**	Interviewing patients and family-caregivers Receiving patient level data and anonymized responses to routinely embedded questionnaires.
Date of Event:	January 1st, 2018 - onwards.	**Assessor:**	

WHAT ARE THE HAZARDS?	WHO / WHAT MAY BE HARMED?	EXISTING CONTROLS	FURTHER CONTROLS	SEVERITY	LIKELIHOOD	RISK RATING	ACTION BY WHOM	ACTION BY WHEN
Interviews with participants								
Participant may not fully understand the project and what it entails (Not due to a lack of capacity to consent).	All participants (i.e. patients and informal carers)	Recruitment pack which includes, 'a letter of information', a participant information booklet' and a 'consent to contact form.' The recruitment packs will be produced bilingually. Participants can contact the student via e-mail to ask any questions they may have. The student researcher will ensure that all the participants' questions have been answered prior to the commencement of the interview.	Recruitments packs will be administered to the patients and the patients have time to decide whether they would like to participate in the research.	3	2	Low	The researcher will create the recruitments packs and the hospices will distribute them. The student researchers contact details will be in the recruitment pack so participants can contact the student researcher to ask questions. Participants will also have the opportunity to ask any questions once the student researcher has received a consent to contact form.	Ongoing

		A Welsh speaking member of staff from Bangor University (who has been DBS checked and has interviewing experience) will attend the interviews with the student researcher. If participants find it difficult to read the information sheets, it will be read out to them. The student researcher has undergone qualitative interviewing training						
Participants may get upset during the interviews. - Although it is unlikely that these interviews will result in a distressing result for the participant, it is the interviewer's duty of care to the participant that these strategies are put in place prior to commencing the interviews.	All participants (patients and informal carers)	Participants will be made aware before the interview that participating is completely voluntary. The participants will be informed that they can pause or stop the interview at any point. Participants will also be made aware that they can skip any question, if they do not feel comfortable answering. Participants will be made aware that the interviews are voluntary. Offer to cease the interview Interview distress protocol in place. The student researcher will look out for signs of distress and a distress protocol followed. A topic guide which was deemed suitable by the North Wales Cancer Patient Forum will be followed Regular supervisory meetings will take place. In these meetings we will	The interview schedules were reviewed by North Wales Cancer patient forum and deemed suitable. The chief investigator has experience of working with individuals from sensitive environments which will be beneficial when interviewing patients and carers receiving palliative care from the hospices.	4	1	Low	The student researcher will continuously assess the situation to ensure that nonverbal ques which signal distress are not being missed. In the event that a participant is distressed the student researcher will follow the distress protocol.	Ongoing

		whether the questions are being well received. Time will be spent with the participant and assistance provided, within the scope of interviewers abilities, to discuss their concerns and support them, if appropriate. The participant will be recommended to speak to a member of their clinical team to discuss their concerns.						
Participants may lack the capacity to consent	Patients	A patients’ capacity to consent will be determined using a framework. Capacity will be tested in four ways: - Can the participant communicate their decision? - Does the participant demonstrate that they can understand the information that has been given to them? - Can the participant retain the information that has been given to them? - Can the participant weigh up the pros and cons? In the event that it is determined that a patient cannot give informed consent, a personal consultee will be sought. If a personal consultee believes that the participant should not participate		4	3	Medium	A patient’s capacity to consent will be determined by the student researcher.	Ongoing

		in the research, their wishes will be followed.						
A personal consultee agrees that a patient should be involved with the research, but the student researcher observes body language/signs from the patient which suggests otherwise. The patient could also tell the student researcher directly that they do not want to take part.	Patients	The student researcher will respect the patient's wishes and they will not be involved in the research. The student researcher will ensure that the patient's wishes are respected. The student researcher will ensure that she is receptive to signs that may signal that the patient does not want to participate in the research.		3	1	Low	The student researcher will be aware of the patient's body language and non-verbal signs of distress.	Ongoing
Fluctuating capacity to consent	Patients	The student researcher will be aware to the possibility that a patient's capacity to consent can fluctuate. Informal consent procedures will take place unless the student researcher thinks that the patient may have lost the capacity to consent. In this case, a framework to assess capacity will be used and the patients' capacity to consent assessed. The student researcher is aware the consent can fluctuate. If the student believes that a patient can no longer give informed consent, the interview will be stopped immediately and the patients capacity to consent		4	3	Medium	The student researcher will take consent	Ongoing

		determined. If a participant has asked to spread their interview across numerous days formal consent procedures will be applied each time.						
Participants may not be able to write.		Participants can give verbal consent. Consent will be voice recorded using an encrypted Dictaphone and transferred off at the earliest opportunity.		1	3	Low	The student researcher will be responsible for obtaining informed consent in an appropriate way	Before the commencement of the interviews.
Participants may want to participate in the research but not want to be recorded.	All participants	The participants will be informed that if they are not comfortable being recorded, notes will be taken instead.		2	2	Low	During the consenting process, the participant will be asked by the student researcher whether they mind being voice recorded.	Ongoing
Communication issues. In order to consent to participate, the participants will generally need to be able to communicate their decision with the researcher.	All participants	If the language deficit involves comprehension, then informed consent will need to be obtained through proxy consent. During the recruitment stage, the recruitment documents will ask the participants whether they would prefer the interview to be in English or Welsh. If communication issues are due to language barriers, a member of staff/postgraduate student with the appropriate skills will be asked to facilitate the interviews.		3	1	Low	The student researcher will ensure that the participants understand the information provided to them. If the communication barriers are due to language, this should be identified in the recruitment stage as participants will be asked which language they prefer the interview to be in.	Ongoing
Safe guarding of participants	All participants (informal carers and patients).	The participants will be made aware that confidentiality will be broken in the event of disclosures of professional misconduct, harm to the participant or harm to someone else.		5	2	Low	In the event of disclosures, the student researcher will inform her supervisory team	Ongoing

		Disclosures and/or any concerns the student research may have will be reported to the advisory team immediately. At time of disclosure, the interview will be stopped. Line of reporting established Chief Investigator has had DBS clearance. The student researcher has undergone safeguarding training. In the event of a disclosure the student research will keep an accurate record, and inform the student researcher immediately. Immediate, urgent or prompt response may be required						
Over-researching	All participants (informal carers and patients).	The student researcher will be in constant contact with each chief executive and hospice matron to ensure that the same groups are not being over-researched. If research is already being conducted at the hospice, the students' researchers' interviews will be postponed.		3	1	Low	The student researcher will contact the chief executive before recruitment packs are distributed.	Ongoing.
Confidentiality breaches	All participants	Pseudonyms will be used when using direct quotes in publications. Recordings of the interviews will be transferred off an encrypted Dictaphone at the earliest		5	1	Low	The student researcher will be responsible for ensuring the participants confidentiality is maintained.	Ongoing

		opportunity and transferred onto an encrypted laptop. Consent forms and consent to contact forms will be stored in a locked filing cabinet. The chief executives will be responsible for delegating the task of participant recruitment. If a participant would like to participate in the research, they can complete a consent to contact form and send directly to the student researcher, or leave with a member of staff. The student researcher will also ensure that participants are aware that confidentiality may be broken if they disclose information that raises serious concerns about their well-being or the safety of another person. Confidentiality will also be broken in the event that disclosures of professional misconduct occur. The student researcher will aim to maintain participants' confidentiality and anonymity and will not reveal the identity of any participant, nor any information which may lead to their identification.						
Data protection breach	All participants	Data collection sharing agreement agreed between the North Wales hospice group and Bangor University.	The student has undertaken data protection training	5	1	Low	The student researcher will ensure that the principles of data protection are adhered to.	Ongoing

		Access to data will be restricted to the direct project team. Encrypted devices will be used. Patient names will not be recorded on the encrypted Dictaphone. Interview recordings will be stored on an encrypted laptop. Consent to contact forms and consent forms stored in a locked filing cabinet. Interviews conducted in a mutually convenient place. Potential participants will not be contacted unless the student researcher receives a consent to contact form. Caldecott guardian at each research site Any possible breaches to confidentiality will be disclosed immediately	The student research had undertaken Good Clinical practice training.				Any breaches will be disclosed immediately	
Unexpected guests	All participants	Participants will be offered joint interviews. If the unexpected guest would like to participate in the research. Informed consent will be taken.		1	3	Low		
Lone working		The student researcher will follow the Bangor University policies. The		3	1	Low	The student researcher will be responsible for ensuring	Ongoing

		fieldwork policy standard and procedures handbook (2015) and Social and Community Based Field work Handbook (2015).Supervision and support of researchers, including debriefing following interviews. The student research will ensure that her academic supervisors are aware when she is travelling to a participants home to conduct an interview- ‘a buddy system’ For home visits, the student researcher will contact the nurse/gatekeeper prior to arranging the interview to check that a home visit is appropriate. The student researcher will identify safe exists The student researcher will complete a risk assessment before each interview conducted at a participant’s home, which will be reviewed by the supervisory team.					that she follows the procedures and policies set out by Bangor University. The student researcher has extensive experience with lone working	
Researcher emotional distress	Researcher	The student researcher experienced in dealing with sensitive topics. Appropriate model of supervision and support built into research plan.		3	1	Low	If the student researcher feels overwhelmed she will inform her supervisory team	Ongoing
Deviation from the protocol		If the student researcher believes that there is a need to deviate from the original protocol, discussions will		3	3	Low		

		ensue with the supervisory team and advisory team. If changes to the protocol are needed the appropriate ethical bodies will be notified and amendments made.						
Anonymized patient level data								
Potential risk to participants privacy	Patients	Signed data sharing agreement between Bangor University and the North Wales Hospice Group Caldecott Guardian at each hospice site. Patient level data will be anonymized before it reaches the student researcher- therefore falling outside the Data Protection Act.		4	1	Low	The student researcher and Caldecott guardian will be responsible for ensuring the privacy of participants is maintained throughout the research. The student researcher will ensure any breaches are disclosed immediately.	Ongoing
Over-arching issues associated with the research								
Finishing within the designated time frame		Gantt chart has been developed to help direct the project. Regular meeting with supervisors 6 monthly advisory team meetings		1	2	Low		
Finance implications		Finance already in place. Fully funded project. To return completed consent to contact forms, a pre-paid envelope will be included within the recruitment packs. These pre-paid enveloped will be provided by the		n/a	n/a	n/a		

		student researcher. The hospices will not incur these costs.						
Disengagement of the partners		The student researcher will ensure that she organizes regular meetings with the company partners to ensure that everyone is up to date, and to ensure that any questions or worries they may have are addressed.		2	1	Low		
Lack of communication within the organization		The student researcher will ensure that each department at the hospice is aware of the research by organizing group meetings when different parts of the project begin.		2	2	Low		
Cost implications associated with the production of recruitment material.	The charity	Funding available to ensure all documentation is produced bilingually. The student researcher will be responsible for getting all of recruitment documentation printed.		n/a	n/a	n/a		

Appendix 4.3: Participant letter of information (MRes)

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Version 1: 11.07.2016

A Social Value Exploration of Hospices in North Wales

Nicole Hughes, a Masters student at Bangor University, is conducting research which will explore the social value of Hospices across North Wales. The purpose of this study is to understand the impact (positive and negative) of Hospices clinical and non-clinical activities from the perspective of key stakeholders. The information gathered here will help improve the existing evidence already collected by hospices and develop a clearer understanding of the intangible effects of hospice activities and their impact on the wider community. In addition, the evidence collected during this study could assist in the strengthening of hospice cases for re-funding.

The researcher (Nicole Hughes) is sending you this email to invite you to take part in the study. The study will involve participation in an interview. Your understanding of the experiences you have had will be a valuable additional source of information and may well help to enrich the interpretation of findings. These interviews are expected to last no longer than 90 minutes. Any information shared during this process will be anonymised and you will be unidentifiable from the outputs produced.

If you are interested in participating then please read the attached information sheet and email Nicole Hughes (sop80c@bangor.ac.uk) to declare your interest. A mutually convenient time for the interview can then be arranged. If you have any questions or would like to know more about the study, please contact Nicole Hughes at sop80c@bangor.ac.uk.

Please respond to this study invitation before …………….

Thank you for taking the time to read this letter

Cronfa Gymdeithasol Ewrop
European Social Fund

Knowledge Economy Skills Scholarships (KESS) is a Pan-Wales higher level skills initiative led by Bangor University on behalf of the HE sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.

Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

Appendix: 4.4: Participant information sheet for hospice personnel

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Participant Information Sheet

Title of study:

A Social Value Exploration of Hospices in North Wales

Introduction:

I would like to invite you to take part in a research study for a Masters project, which will explore the social value of hospices across North Wales. Before deciding on whether or not you would like to participate in this study, it is important that you understand why the study is being undertaken and what it will involve. Please do not hesitate to ask any questions if anything you read is not clear or you would like more information. Take your time to decide whether or not you would like to participate.

The purpose of the study

The purpose of this study is to understand the impact (positive and negative) of Hospice clinical and non-clinical activities from the perspective of key stakeholders. The information gathered will help improve the existing evidence already collected by hospices and help to develop a clearer understanding of the intangible effects of hospice activities and their impact on the wider community. In addition, the evidence collected during this study could assist in the strengthening of hospices cases for re-funding.

Why have I been chosen to take part?

You have been chosen to take part because you work within a palliative care setting.

Do I have to take part?

It is up to you to decide if you would like to participate in this study. If you decide to participate, we will then ask you to sign a consent form. I would like to emphasise that you are free to withdraw from the study at any point without prior notice.

What will happen if I decide to take part?

If you decide to participate within the study, you will then be invited to attend an interview lasting up to 90 minutes. There are no right or wrong answers and you choose what you wish to disclose. With your consent, the interview/focus group will be recorded using an encrypted Dictaphone. The project is a yearlong study and you may be asked to attend one or more interview however, you do not have to agree to attend any interview if you do not wish.

Will disclosed information be kept confidential?

Yes, however with your consent information will be anonymised and may be used in a quote within the final report. Full anonymity will be utilised throughout the study and your identity will not be identifiable within any of the reports or the final publication. All data obtained will be kept on a Bangor University shared drive which will also be subject to a number of stringent safeguards such as encryption, limited access to individuals outside of the research team and password protection. In addition, all devices which hold any of the collected data will be fully encrypted and password protected to prevent unauthorized use of the device and unauthorized access to the information held on the device.

The Data Protection Act applies equally to personal data held on paper files. Paper records and files containing personal data will be handled in such a way as to restrict access only to those persons who have ties to the research. This will entail the operation of a policy whereby paper files containing such data will be locked away when not required. Paper records will not be held longer than necessary and will be destroyed using the cross cut shredding method to ensure that any information cannot be reconstructed.

What will happen if I don't want to continue with the study?

You are free to withdraw from the study at any point without needing to disclose a reason. There is a specific informed consent right to withdraw from research at any point.

What are the benefits and risks of taking part in this study?

Although participation within this study is unlikely to display immediate results and may not directly affect you however, it will aid hospices and the care they provide. Your understanding of the experiences you have had will often be a valuable additional source of information and may well help to enrich the interpretation of findings. Whilst I do not anticipate any high risk factor, the topics explored within the interviews or focus groups could potentially be distressing.

What will happen to the results of the study?

The findings of this project will be included with a Masters Research project and may be published in an academic journal.

Who is organising the research?

The project is being organised by Nicole Hughes, as part of a master's project at the University of Wales, Bangor.

About the research team

The researcher is myself, Nicole Hughes. I am a postgraduate student within the College of Business, Social Science and Law and I am currently studying for a masters in research following the completion of my BA in Criminology and Criminal Justice. My supervisor for the project is Dr Lindsay Eckley who specialises in health and social care research. Furthermore, Lindsay has strong interests in Social Value Research and the application of the Social Return on Investment Framework.

Approvals granted

This study has received ethical approval from the College of Business, Social Sciences and Law, Ethics Committee, Bangor University.

Next steps

If you would like to participate in this study, please email the researcher Nicole Hughes at sop80c@bangor.ac.uk expressing your interest. Following this, a mutually agreed upon time and location will be arranged in order to conduct the interview.

What happens if I have concerns about this project?

If at any point you have concerns regarding any aspect of the project or if you would like to make a complaint, please contact Professor Jane Noyes.

E-mail: jane.noyes@bangor.ac.uk

Address: Professor Jane Noyes,
Bangor University,
Neuadd Ogwen,
LL65 2DG.

Telephone: 01248 388519

Any questions

If you would like to know more about this project, please don’t hesitate to contact me, Nicole Hughes (sop80c@bangor.ac.uk).

Knowledge Economy Skills Scholarships (KESS) is a Pan-Wales skills initiative led by Bangor University on behalf of the HE sector in Wales. It is part funded by the Welsh Government’s European Social Fund (ESF) convergence programme for West Wales and the Valleys.

Appendix: 4.5: Consent form for hospice personnel

PRIFYSGOL
BANGOR
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Consent form for participant

Title of study: A Social Value Exploration of Hospices in North Wales

(Please initial box)

I confirm that I have read and understood the information sheet for the above study and the nature and purpose of the research project has been explained to me ☐

I have been advised that I am free to withdraw my consent and to discontinue participation in the project at any time without prejudice ☐

I understand that I will be recorded during the interview ☐

I understand that while the information gained during the study may be published, I will not be identified and my disclosures will remain confidential ☐

I understand that you will not use my name when you report the study findings ☐

I understand that confidentiality may be broken if I mention information that raises serious concerns about my well-being or the safety of another person ☐

I agree to allow the information I provide during the interview to be used for educational purposes in the future ☐

I agree to allow anonymised quotations from my interview to be used in publications ☐

I understand that I may contact the researcher or supervisor if I require further information about the research ☐

I have been given satisfactory answers to my enquiries concerning project procedures and other matters ☐

I agree to take part in the above study ☐

____________________	__________	____________________
Name of participant	Date	Signature of participant
____________________	__________	____________________
Name of researcher	Date	Signature of researcher

1 copy for the participant
1 copy for the researcher

Cronfa Gymdeithasol Ewrop
European Social Fund

Knowledge Economy Skills Scholarships (KESS) is a Pan-Wales higher level skills initiative led by Bangor University on behalf of the HE sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.

kess 2
Ysgoloriaethau Sgiliau Economi Gwybodaeth
Knowledge Economy Skills Scholarships

Appendix 4.6: CBLESS Approvals for PhD research

COLEG BUSNES,Y GYFRAITH,ADDYSG A GWYDDORAU CYMDEITHAS
COLLEGE OF BUSINESS, LAW, EDUCATION AND SOCIAL SCIENCES

PRIFYSGOL
BANGOR
UNIVERSITY

17/08/17

Annwyl/ Dear Nicole

Yng/ Re: A social value exploration of hospices in North Wales

Diolch am eich cais diweddar i Bwyllgor Ymchwil Moeseg CBLESS.

Mae’r pwyllgor wedi ystyried eich cais, ac fe wyf yn awr mewn sefyllfa i roi caniatâd, ar ran y Pwyllgor Ymchwil Moeseg CBLESS, i chi gychwyn eich prosiect ymchwil.

Dymunaf yn dda i chi gyda’ch ymchwil.

Thank you for your recent application to the CBLESS Research Ethics Committee. The Committee has considered your application and I am now able to give permission, on behalf of the CBLESS Research Ethics Committee, for the commencement of your research project.

I wish you well with your research.

Yb gywir iawn/ Yours sincerely

Marguerite Hoerger

Dr. Marguerite Hoerger
Chair, CBLESS Research Ethics Committee
Cadair, Pwyllgor Ymchwil Moeseg CBLESS

Cc:Goruchwyliwr/Pennaeth Ysgol
Supervisor/Head of School

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YR ATHRO/PROFESSOR PHIL MOLYNEUX BA, Mphil, PhD
DEON Y COLEG/DEAN OF COLLEGE

Registered charity number: 1141565

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Appendix 4.7: REC 4 Research Ethics Approval for PhD

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 4
Wrexham

Mailing address:
Health and Care Research Wales Support Centre
Castlebridge 4
15-19 Cowbridge Road East
Cardiff, CF11 9AB

Telephone: 02920 785736
Email:
Tracy.biggs@wales.nhs.uk
Norbert.ciumageanu@wales.nhs.uk

Website : www.hra.nhs.uk

19 December 2017

Miss Nicole Hughes
Bangor University
Bangor
LL57 2DG sop80c@bangor.ac.uk jane.noyes@bangor.ac.uk

Dear Miss Hughes

Study title: **What is the Social, Economic and Environmental impact of hospice related care? V2**
REC reference: **17/WA/0399**
IRAS project ID: **232423**

Thank you for your letter of 18 December 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 11 December 2017

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Interview Participants Recruitment Poster]	2	11 December 2018

Letters of invitation to participant [Letter of Information for Qualitative Interview Participants]	2	18 December 2017
Letters of invitation to participant [Letter of Information for Consultees]	2	18 December 2017
Other [Personal Consultee Information Booklet]	2	18 November 2012
Other [Consultee declaration form]	1	18 November 2012
Participant information sheet (PIS) [Participant Information Booklet for Qualitative Interviews]	2	18 December 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Interview Participants Recruitment Poster]	2	11 December 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Bangor University Insurance Certificate]		01 August 2017
Interview schedules or topic guides for participants [Topic guide for hospice inpatients]	1	08 November 2017
Interview schedules or topic guides for participants [Topic guide for hospice at home patients]	1	08 November 2017
Interview schedules or topic guides for participants [Topic guide for Daycare Patients]	1	08 November 2017
Interview schedules or topic guides for participants [Topic guide for Informal Carers]	1	08 November 2017
IRAS Application Form [IRAS_Form_17112017]		17 November 2017
Letters of invitation to participant [Letter of Information for Qualitative Interview Participants]	1	19 July 2017
Letters of invitation to participant [Letter of Information for Consultees]	1	19 July 2017
Letters of invitation to participant [Letter of Information for Qualitative Interview Participants]	2	18 December 2017
Letters of invitation to participant [Letter of Information for Consultees]	2	18 December 2017
Other [Approval Letter from Bangor University agreed by the College of Business, Law, Education and Social Sciences Ethics Committee]	N/A	
Other [Consent to Contact form for Participants]	1	23 June 2016
Other [Consent to Contact form for Participants Personal Consultee]	1	23 June 2016
Other [Personal Consultee Information Booklet]	2	18 November 2012
Other [Consultee declaration form]	1	18 November 2012
Participant consent form [Participant Consent form for Qualitative Interviews]	1	19 July 2017
Participant information sheet (PIS) [Participant Information Booklet for Qualitative Interviews]	2	18 December 2017
Research protocol or project proposal [PhD protocol]	1	27 September 2017
Summary CV for Chief Investigator (CI) [Chief Investigator Interview Schedule]		08 November 2017
Summary CV for student [Summary CV for chief investigator]		08 November 2017
Summary CV for supervisor (student research) [First Supervisor CV]		08 November 2017

Summary CV for supervisor (student research) [Second Supervisor CV]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

17/WA/0399	**Please quote this number on all correspondence**

Yours sincerely,

Leon Ciumageanu

Norbert Leon Ciumageanu Research Ethics Service Administrative Assistant

On behalf of Mrs Tracy Biggs, Research Ethics Committee Manager

e-mail: norbert.ciumageanu@wales.nhs.uk

Appendix 4.8: Recruitment poster

11.12.2017 Version 2 Participant Recruitment Poster

PATIENT AND CARER PARTICIPANTS WANTED

THE RESEARCH RECRUITMENT PROCESS

Bangor University is working in collaboration with four hospices across North Wales- St.David's Hospice, Nightingale House Hospice, Hospice at Home Gwynedd and Anglesey and St. Kentigern Hospice. The aim of this research is to explore the social, economic and environmental impact of hospice related care.

This research will contribute to a PhD thesis

01 Are you a patient or carer receiving support from St. Davids hospice?

02 Would you like to take part in this research project?

03 I am inviting patients and carers to take part in a voluntary and confidential face to face interview lasting approximately 1 hour.

04 I will explore what you value from hospice services.

Cronfa Gymdeithasol Ewrop
European Social Fund

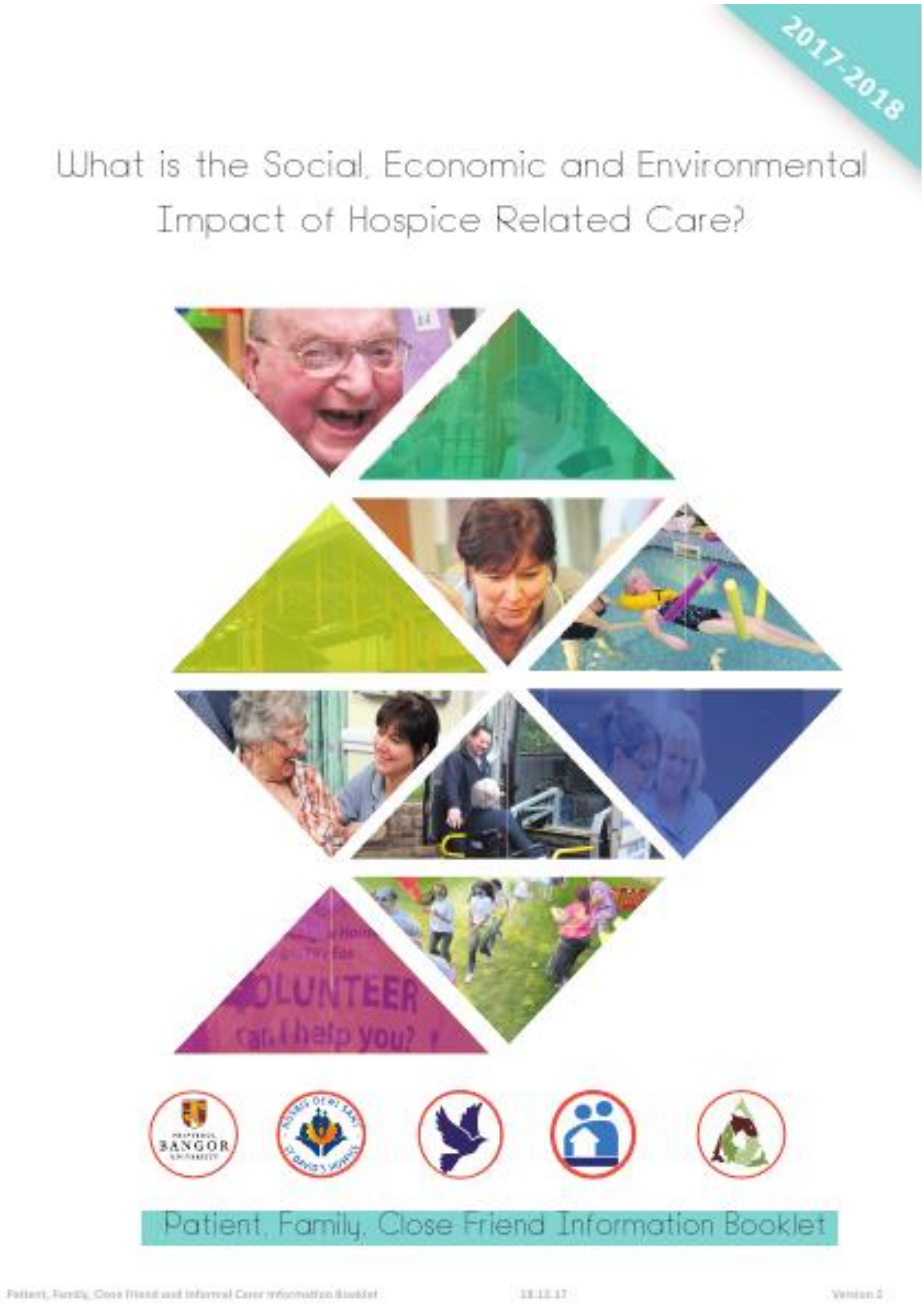
CONTACT DETAILS

For more information please contact me, Nicole Hughes

sop80c@bangor.ac.uk

07814246685

Appendix 4.9: Participants information booklet



2017-2018

What is the Social, Economic and Environmental Impact of Hospice Related Care?

Patient, Family, Close Friend Information Booklet

Patient, Family, Close Friend and Informal Carer Information Booklet 18.12.17 Version 2

Introduction

I would like to invite you to take part in a research study for a PhD project, which will explore the social, economic and environmental impact of hospice related care. Before deciding on whether you would like to participate in this study, it is important that you understand why the study is being undertaken and what it will involve. Please do not hesitate to ask any questions if anything you read is unclear or you would like more information. Please take your time to decide whether you would like to participate.

The purpose of the study

The purpose of this study is to understand the impact (positive and negative) of hospice activities from your perspective. The information gathered will help to improve the existing evidence already collected by hospices and help to develop a clearer understanding of the effects of hospice activites and their impact on the wider community. In addition, the evidence collected during this study could assist in the strenghtening of hospices case for funding. The hospices involved in this project include: St David's hospice (Llandudno), St Kentigern hospice (St Asaph), Nightingale House hospice (Wrexham) and Hospice at Home (Gwynedd and Anglesey).

Why have I been invited to take part?

You have been invited to take part because you are either a patient, family member, close friend or informal carer associated with one of the aforementioned hospices involved in this study.

Do I have to take part?

It is up to you to decide if you would like to participate in this study. If you decide to participate, you will be asked to take part in an interview. I would like to emphasise that you are free to withdraw from the study at any point without prior notice.

What will happen if I decide to take part?

If you decide to participate in the study, you will be invited to attend a confidential interview which could last up to 60 minutes. A range of questions will be asked regarding your experiences of hospice care. You are free to refuse to answer any question. There are no right or wrong answers. The interview will be conducted in either English or Welsh, depending on your preferences and, with your consent, will be voice recorded. Voice recording is not mandatory, and if you choose not to be recorded, notes will be taken instead.

Will disclosed information be kept confidential?

Yes, the information you share will be treated in confidence however, with your consent, the information you provide will be anonymised and may be quoted in reports or publications. Full anonymity will be utilised throughout the study and your identity will not be disclosed within any of the transcripts, reports or final publications. All data obtained will be kept on a Bangor University shared drive which will also be subject to a number of safeguards such as encryption, limited access to individuals outside of the research team and password protection to prevent unauthorized use and access of the information held on the device. If you disclose information that is suggestive of serious risk or harm to yourself or others, or instances of professional misconduct, confidentiality will be broken.

What will happen if I don't want to continue with the study?

You are free to withdraw from the study at any point without needing to disclose a reason. However, any information obtained up until that point will be retained.

What are the benefits and risks of taking part in this study?

Your understanding of the experiences you have had will often be a valuable additional source of information and will aid hospices with understanding the impact of the care they provide. Whilst I do not anticipate any high risks the topics explored within the interviews could potentially be upsetting or distressing.

What will happen to the results of the study?

The findings of this project will be included in a PhD thesis and may be published in an academic journal. It is anticipated the findings may also be used to develop an impact report for the hospices.

Approvals granted

All research in the NHS is reviewed by an independant group of people called Research Ethics Committee to protect your interests. This study has been ethically reviewed by REC 4. The study has also been approved by the College of Business, Law, Education and Social Sciences Ethics committee at Bangor University.

Funding

Funding for this project has been provided by Knowledge Economy Skills Scholarship (KESS), a major European Convergence programme which offers collaborative research projects linked with a local company partner.

Do you want to take part?

If you would like to take part in this study please return your 'consent to contact' form using the pre-paid envelope provided.

For more information please contact me (Nicole Hughes) at:

✉ sop80c@bangor.ac.uk

☎ 07814246685

Cronfa Gymdeithasol Ewrop
European Social Fund

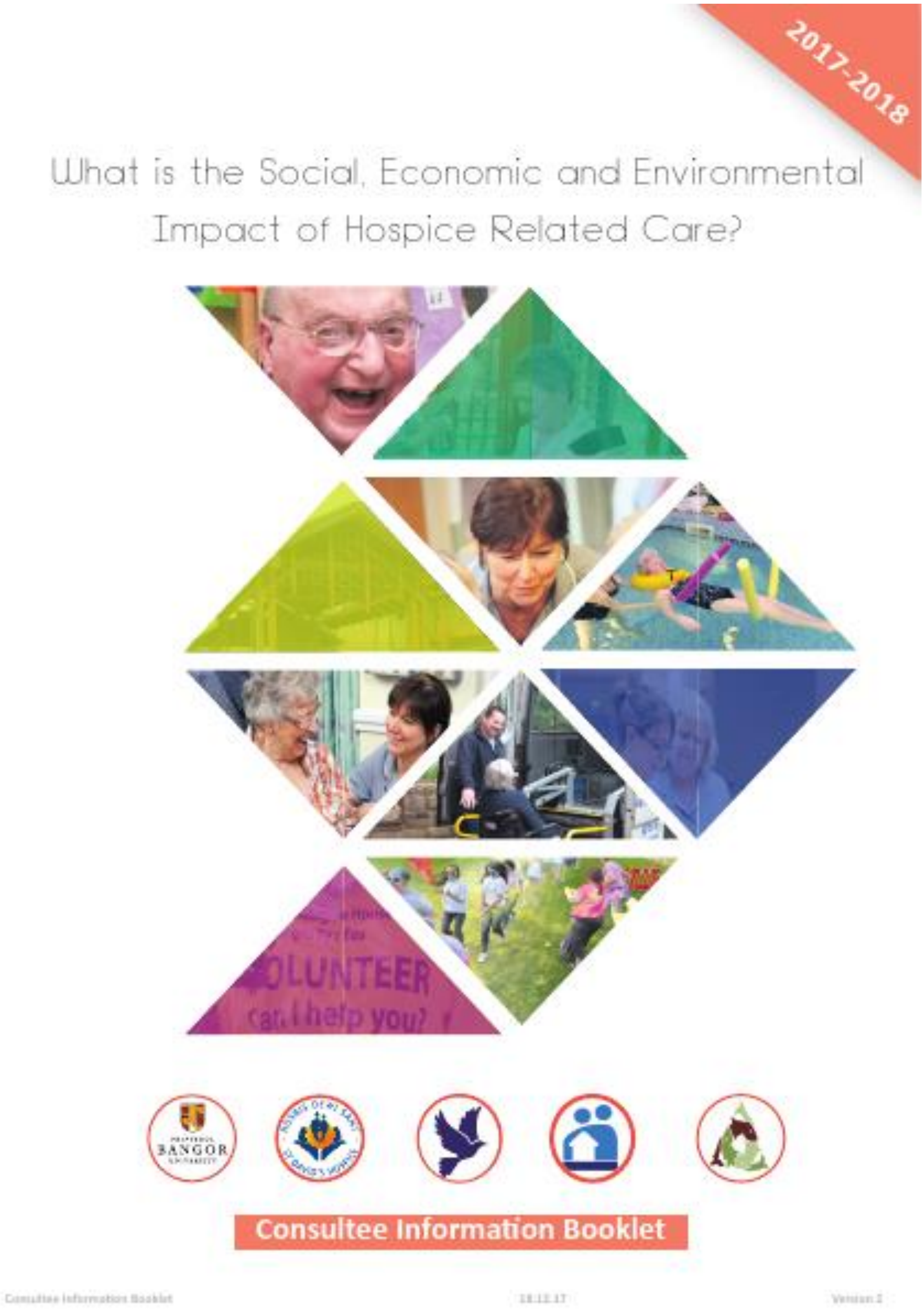
If you have any concerns about this project that the research team cannot resolve and would like to speak to someone outside of the research team, please contact Dr Martina Feilzer, Head of School, Social Sciences, Bangor University, Bangor, Gwynedd, LL57 2DG.

Telephone: 01248 388171

Email: m.feilzer@bangor.ac.uk

kess

Appendix 4.10*:* Consultee information booklet



2017-2018

What is the Social, Economic and Environmental Impact of Hospice Related Care?

Consultee Information Booklet

Consultee Information Booklet 18.12.17 Version 2

Introduction

The aim of this PhD project is to explore the social, economic and environmental impact of hospice related care. I would like to invite your partner/ relative/friend to take part. Their participation in this study will be completely voluntary. The purpose of this study is to understand the impact (positive and negative) of hospice services. The company partners involved in this project includes: St Davids's hospice (Llandudno), St Kentigern hospice (St Asaph), Nightingale house hospice (Wrexham) and Hospice at home (Gwynedd and Anglesey).

Why have I been handed this information?

You have received this information pack because you have been invited to act as a 'personal consultee.' We feel that your partner/relative/friend does not have the capacity to decide whether to participate in this research study. To help decide if they should join the study we would like to ask your opinion on whether they would wish to be involved. Please consider what you know about their wishes and feelings, and consider their interests. Please also let us know about any advance decisions they may have made about participating in research. These will take precedence.

What is a personal consultee?

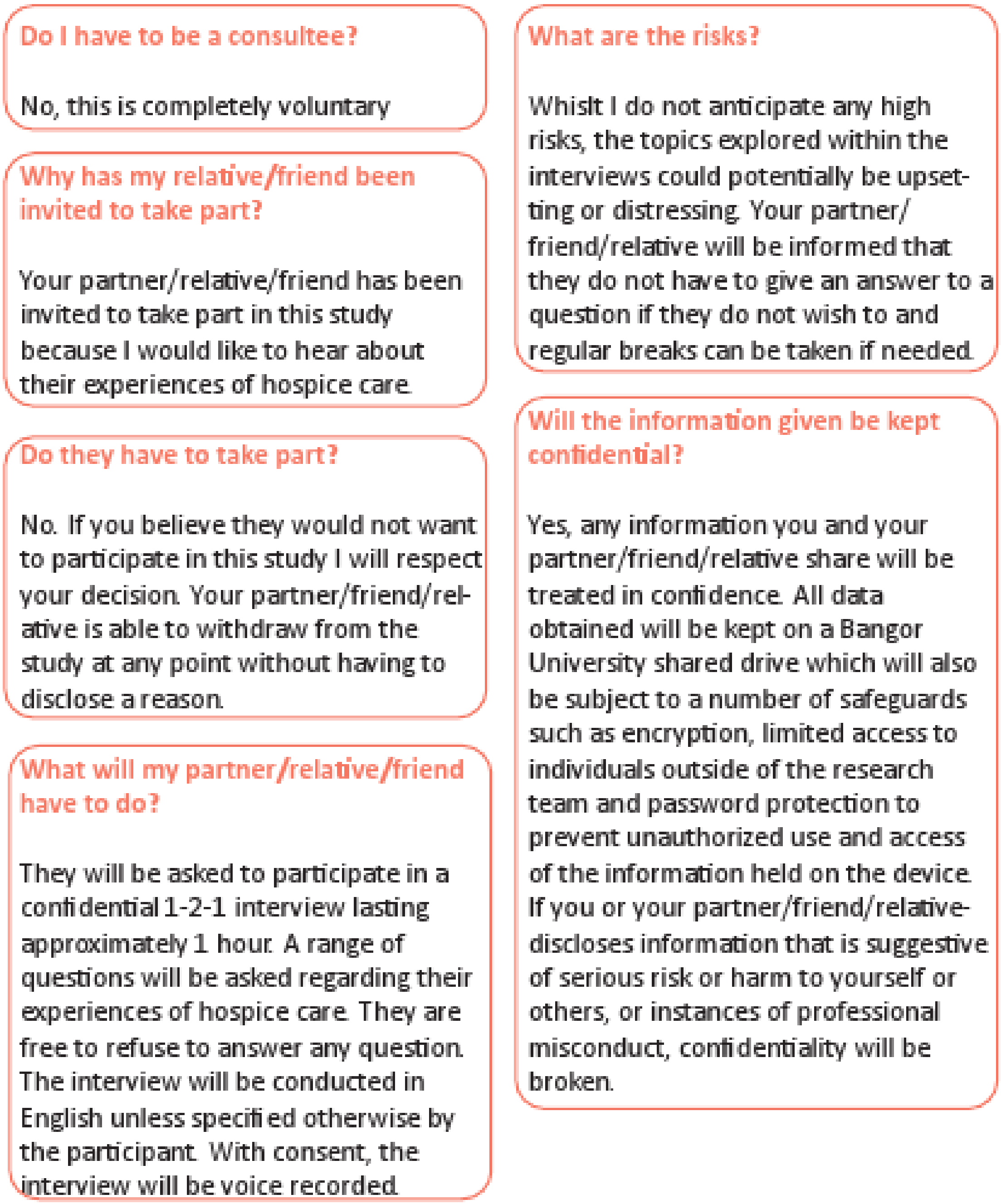
A personal consultee is someone who knows the person who lacks capacity in a personal way , who is able to advise me about what their wishes and feelings would be in regards to their participation in this project.

Why is a consultee needed?

The Mental Capacity Act (2005) developed a framework aimed at protecting the rights of individuals who lack capacity to make a decision for themselves. This act ensures that the feelings and wishes of the person who lacks capacity are taken into account. All decisions must be made in your partner/friend/relatives best interest.

Consultee responsibilities

If you agree to be a consultee, you must be prepared to be consulted about your friend/relative/partners involvement in the project. I will seek advice from you about whether your partner/relative/friend would want to take part. You may also be able to tell us how they may communicate that they no longer want to participate. This is to ensure that your partner/relative/friends current and previously expressed wishes and feelings are respected.



Do I have to be a consultee?

No, this is completely voluntary

Why has my relative/friend been invited to take part?

Your partner/relative/friend has been invited to take part in this study because I would like to hear about their experiences of hospice care.

Do they have to take part?

No. If you believe they would not want to participate in this study I will respect your decision. Your partner/friend/relative is able to withdraw from the study at any point without having to disclose a reason.

What will my partner/relative/friend have to do?

They will be asked to participate in a confidential 1-2-1 interview lasting approximately 1 hour. A range of questions will be asked regarding their experiences of hospice care. They are free to refuse to answer any question. The interview will be conducted in English unless specified otherwise by the participant. With consent, the interview will be voice recorded.

What are the risks?

Whislt I do not anticipate any high risks, the topics explored within the interviews could potentially be upsetting or distressing. Your partner/friend/relative will be informed that they do not have to give an answer to a question if they do not wish to and regular breaks can be taken if needed.

Will the information given be kept confidential?

Yes, any information you and your partner/friend/relative share will be treated in confidence. All data obtained will be kept on a Bangor University shared drive which will also be subject to a number of safeguards such as encryption, limited access to individuals outside of the research team and password protection to prevent unauthorized use and access of the information held on the device. If you or your partner/friend/relative discloses information that is suggestive of serious risk or harm to yourself or others, or instances of professional misconduct, confidentiality will be broken.

What will happen to the results of the research study?

The overall results of this study will be published in a PhD thesis. We may use quotes however pseudonyms will be given so that your partner/friend/relative cannot be identified.

What will happen if I decide to withdraw from being a consultee?

You are free to withdraw from being a consultee at any point without needing to disclose a reason. I will take reasonable steps to locate another personal consultee. If another personal consultee cannot be found, your partner/relative/friend will be withdrawn from the study. However, we will retain and use the data provided up to the point of withdrawal.

Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people called a Research Ethics Committee which helps to protect your interests. This study has been reviewed by Wales (REC 4). The study has also been approved by the College of Business, Law, Education and Social Sciences Ethics committee at Bangor University.

How can I find out more about the project?

Please read the enclosed participant information booklet for more details. Alternatively, you can contact me, Nicole Hughes via email (sop80c@bangor.ac.uk) or phone (07814246685) to discuss the project further.

What's next?

If you think your partner, friend or relative would be interested in taking part and you would like to be their consultee, please complete the 'consent to contact form' provided in this recruitment pack and return using the pre-paid envelope provided. Once I have received this, I will contact you via your preferred mode of contact and you will subsequently be asked to sign a declaration form. You will be kept fully informed during the study so that you are able to inform me of any concerns.

Appendix 4.11: Participant letter of invitation

What is the Social, Economic and Environmental Impact of Hospice Related Care?

Dear Sir/Madam,

I am a PhD student at Bangor University, conducting research in collaboration with St Davids Hospice, Nightingale House Hospice, St Kentigern Hospice and Hospice at Home, Gwynedd and Anglesey. This research will explore the social, economic and environmental impact of hospice related care. The information gathered here will help improve the existing evidence already collected by hospices and assist in the strengthening of hospice cases for funding.

I am sending you this letter to invite you to take part in the study. If you are interested in participating, please read the attached information sheet and complete the 'consent to contact' form enclosed in this pack and return using the pre- paid envelope provided. If you have any questions or would like to know more about the study, please do not hesitate to contact me (Nicole Hughes) at sop80c@bangor.ac.uk or via phone at 07814246685

Please respond to this study invitation before:

Thank you for taking the time to read this letter

Yours faithfully,

N Hughes

Nicole Hughes,
PhD Student
Bangor University.

Letter of Information for participants 18.12.2016 Version 2

Appendix 4.12: Letter of information for consultees

What is the Social, Economic and Environmental Impact of Hospice Related Care?

Dear Sir/Madam,

I am a PhD student at Bangor University, conducting research in collaboration with St Davids Hospice, Nightingale House Hospice, St Kentigern Hospice and Hospice at Home, Gwynedd and Anglesey. This research will explore the social, economic and environmental impact of hospice related care. The information gathered here will help improve the existing evidence already collected by hospices and assist in the strengthening of hospice cases for funding. You have been sent this information pack as I would like you to be a personal consultee on behalf of ………………… . A consultee is someone who represents the views of someone who lacks mental capacity.

If you believe ………………… would be interested in participating, please read the attached information booklets and complete the 'consent to contact' form enclosed in this pack and return using the pre- paid envelope provided. More information about this study and information on what a consultee entails has provided to you in this pack. Alternatively, you can contact me via e-mail at: sop80c@bangor.ac.uk or via phone at: 07814246685 for further information.

Thank you for taking the time to read this letter

Yours faithfully,

N Hughes

Nicole Hughes,
PhD Student
Bangor University.

Letter of Information for consultees 18.12.2017 Version 2

Appendix 4.13*:* Participant consent to contact form

Participant Consent to Contact Form

I am a PhD student working in collaboration with four hospices across North Wales to try to understand the social, economic and environmental impact of hospice related care. I would really appreciate the opportunity to speak to you in person to gather your first hand perceptions of what you think about hospice services and how they have impacted your life. If you would like to participate in this study please fill in your contact details below and return to me in the pre-paid envelope. I will contact you within 7 working days of receiving the form. If you have any questions please do not hesitate to contact me via email at: sop80c@bangor.ac.uk

Full Name: ______________________________

Email Address: ____________________________

Home Address: ____________________________

Home Telephone Number: _________________

Mobile Telephone Number: __________________________________

Which Hospice do you receive support from? _____________________

Would you like the interview to be conducted in: English ☐ Welsh ☐ No preference ☐

Preferred mode of contact: Home Phone ☐ Mobile Telephone ☐ Email ☐

Preferred contact time: Morning ☐ Afternoon ☐ Evening ☐

Has anyone helped you to complete this form?

If yes, please provide their contact details

Cronfa Gymdeithasol Ewrop
European Social Fund

Participant Consent to Contact Form 23.06.2016 Version 1

Appendix 4.14: Consultee consent to contact form

Consultee Consent to Contact Form

I am a PhD student working in collaboration with four hospices across North Wales to try to understand the social, economic and environmental impact of hospice related care. I would really appreciate the opportunity to speak to you in person about the potential involvement of   in this research project. The participant will be asked to partake in a 1-2-1 interview which will aim to gather first hand perceptions about how the hospice has impacted theirs and their loved ones lives. If you believe   would like to take part, I would like to discuss this with you further. Please fill in your contact details below and return to me in the pre-paid envelope. I will contact you within 7 working days of receiving the form. If you have any questions please do not hesitate to contact me via sop80c@bangor.ac.uk

Your full Name: ______________________________

Email Address: ______________________________

Home Telephone Number: ____________________

Mobile Telephone Number: ____________________

Relationship to Patient: ______________________

Preferred mode of contact: Home Phone ☐ Mobile Telephone ☐ Email ☐

Preferred contact time: Morning ☐ Afternoon ☐ Evening ☐

Has anyone helped you to complete this form?

If yes, please provide details

Cronfa Gymdeithasol Ewrop
European Social Fund

Consultee Consent to Contact Form 23.06.2016 Version 1

Appendix 4.15: Participant consent form

Participant Consent Form

Study title: What is the Social, Economic and Environmental Impact of Hospice Related Care?

(Please initial box)

I confirm that I have read and understood the information sheet provided for the above study and the nature and purpose of the research project has been explained to me ☐

I have been advised that I am free to withdraw my consent and to discontinue participation in the project at any time without prejudice but information obtained up until that point will be retained ☐

I understand that I will be voice recorded during the interview ☐

I understand that while the information gained during the study may be published, no identifiable details will be shared ☐

I understand that you will not use my name when you report the study findings ☐

I understand that confidentiality may be broken if I mention information that raises serious concerns about my well-being or the safety of another person or in the event that disclosures of professional misconduct occur. ☐

I agree to allow the information I provide during the interview to be used for educational purposes in the future ☐

I agree to allow anonymised quotations from my interview to be used in publications ☐

I understand that I may contact the researcher or supervisor if I require further information about the research ☐

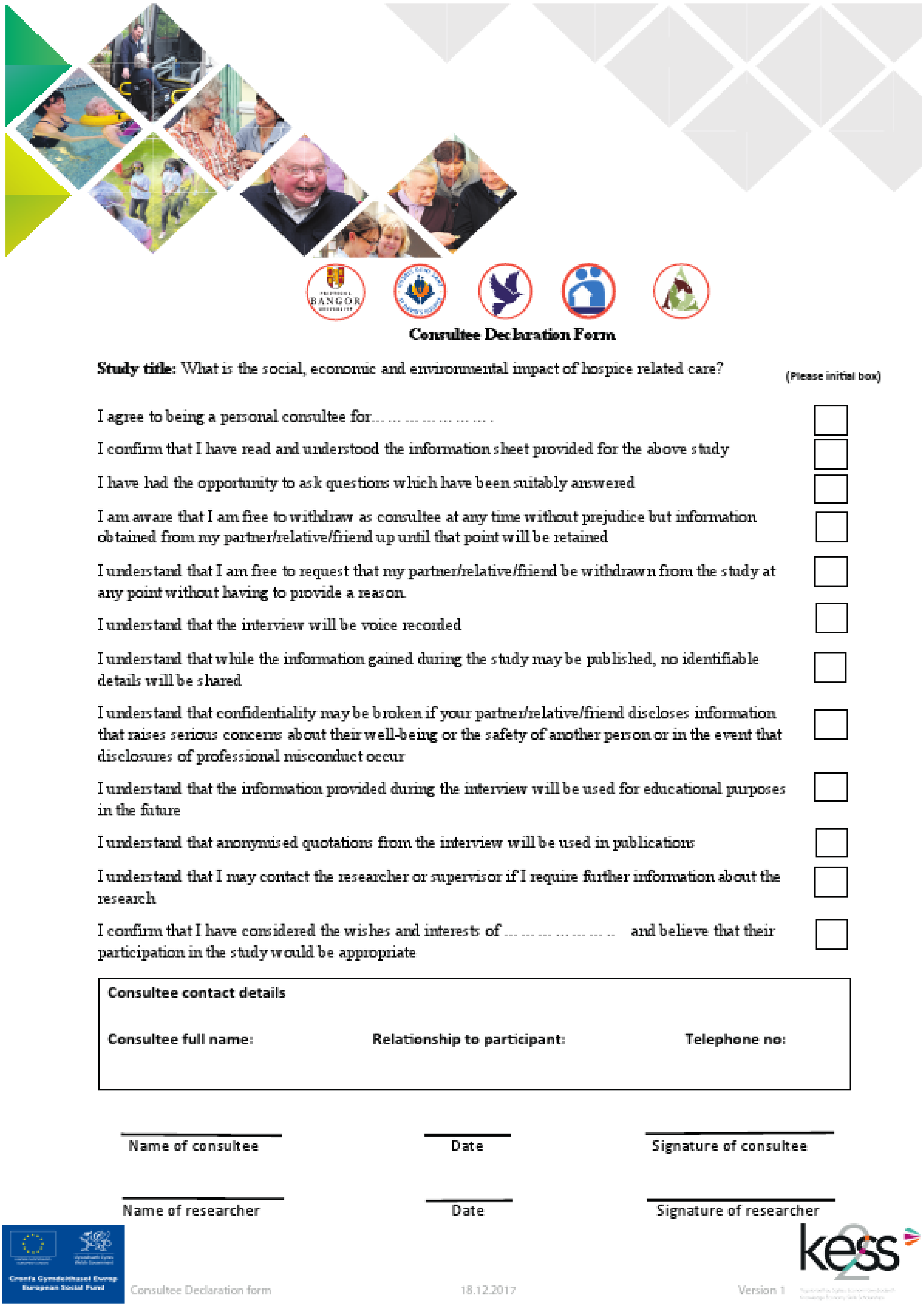
I have been given satisfactory answers to my enquiries concerning project procedures and other matters ☐

I agree to take part in the above study ☐

Name of participant	Date	Signature of participant
Name of researcher	Date	Signature of researcher

1 copy for the participant
1 copy for the researcher

Appendix 4.16: Consultee Declaration Form



Consultee Declaration Form

Study title: What is the social, economic and environmental impact of hospice related care?

(Please initial box)

I agree to being a personal consultee for……………………… ☐

I confirm that I have read and understood the information sheet provided for the above study ☐

I have had the opportunity to ask questions which have been suitably answered ☐

I am aware that I am free to withdraw as consultee at any time without prejudice but information obtained from my partner/relative/friend up until that point will be retained ☐

I understand that I am free to request that my partner/relative/friend be withdrawn from the study at any point without having to provide a reason ☐

I understand that the interview will be voice recorded ☐

I understand that while the information gained during the study may be published, no identifiable details will be shared ☐

I understand that confidentiality may be broken if your partner/relative/friend discloses information that raises serious concerns about their well-being or the safety of another person or in the event that disclosures of professional misconduct occur ☐

I understand that the information provided during the interview will be used for educational purposes in the future ☐

I understand that anonymised quotations from the interview will be used in publications ☐

I understand that I may contact the researcher or supervisor if I require further information about the research ☐

I confirm that I have considered the wishes and interests of ……………… and believe that their participation in the study would be appropriate ☐

Consultee contact details

Consultee full name: **Relationship to participant:** **Telephone no:**

Name of consultee Date Signature of consultee

Name of researcher Date Signature of researcher

Consultee Declaration form 18.12.2017 Version 1

Appendix 4.17: Family-caregiver topic guide

Press record: *"The interview is now being recorded…"*

Begin by stating date/ time/ location/

Topic 1: Introductory

- How long has your loved one been at the hospice?
- What were your first impressions of the hospice?
- When did you first find out about the hospice?
    - How did you find out about it?

Topic 2: The overall support from the hospice

- What is the physical and emotional impact of being a carer?
- How does your caring role impact upon your life/well-being?
    - What does the hospice do to support you personally?
- What support does the hospice provide you with?
    - What else do you wish the hospice could do to support you?

- In relation to the care provided by the hospice, would you describe your satisfaction with the service as Very high, high, medium, low or very low?
    - Why is this so high for you?
    - What could make it better?
    - Has it always been high?
- What do you value the most about the hospice?
- What do you value most from the hospice for yourself (not the patient)?
    - Can you put these in order from most to least important?
    - Why do you value these?
- If your loved one was not at the hospice where would they be?
- How likely is it that you would feel the same satisfaction if your loved one was cared for elsewhere? (e.g. very likely, not likely).
- How do you personally benefit from your loved one being at this hospice?
  - Has the hospice helped improve your quality of life?
- Think back to before your loved one first attended the hospice/ first obtained support from the hospice- how did you feel?
    - How has the hospice helped you to improve your quality of life?
    - What do you believe are the reasons behind these changes?

- Can you tell me how yours and your family's life has changed as a result of your loved one being cared for by the hospice?
    - Would any of this have happened if it wasn't for the hospice?
- What are some of the first things that begin to change for you and your family when you first started coming to the hospice? (I.e. improvements in health, social improvement etc.)
    - How did these changes make a difference in your life?
    - Are you able to tell me in a bit more detail about how the hospice has helped you personally?

- What improvements do you see and hope to see for yourselves and/or your family as a result of the work the hospice does in the:
  - Short term
  - Medium term
  - Long term
- Which of the improvements that you have just mentioned are the most important/significant to you and your family (i.e. put them in order)
  - How long do these improvements last?
  - Why is …… so important for you?
- Have you formed any new relationships whilst at the hospice?
  - Is the ability to socialise valuable to you? Why?
  - How is this encouraged within the hospice?
- Overall do you feel that you and your family get as much help and support from the hospice as you need.
  - What emotional support have you received from the hospice?
  - What practical support have you received from the hospice?
  - What spiritual support have you received from the hospice?
  - Did you value this?

Topic 3: What would happen without the hospice?

- What do you think would have happened to you and your loved one if your loved one hadn't attended the hospice?
- Would you be able to support your loved one if it wasn't for hospice the hospice/hospice at home?
- Where do you think your loved one would be if they weren't at the hospice?
  - How would they feel about this?
  - How would you feel about this?
- Has your loved one been in a NHS setting before?
  - How does the care and support compare?
  - Are these differences important?
- How would your life be different if hospices didn't exist?
  - What sort of services and support would they have received?
  - What are you able to do now because of the work the hospice has done that you weren't able to do before?
  - To what extent do you think your loved one would have been able to achieve the things you have seen them do, if hospices didn't exist?

Topic 4: The value of hospice services/ activities

- What support services have you accessed? (e.g. chaplaincy, OT, Bereavement)
  - Were these beneficial? Why?
  - Ask why they have accessed certain services
- Do you take part in any activities/therapies offered by the hospice?
  - Why did you decide to take part in these specific activities/therapies?
  - Would you have been able to do this in another care setting?
- Do the staff encourage you to take part? How do they encourage you?
  - What are the personal benefits from taking part in this activity?

- How do you feel about the flexible visiting hours?
- Has your social life been affected by your caring role?
  - What does the hospice do to support you socially?
- Have you ever contacted the hospice by telephone for support or advice?
  - Was it beneficial?
  - What would have happened if you couldn't contact the hospice
  - How did it make you feel knowing you could contact the hospice if you were worried?
- Can you think of any little things that the hospice does which creates added value?
- Do you feel that staff at the hospice are aware of your needs?
  - In what ways do they show that they are aware of your needs?
  - In what ways does this benefit you?

Topic 5: Volunteers specific question

- Do you have much involvement with the hospice volunteers?
- What do you value most about the volunteers?
  - Why do you value this?
- What effect would it have on you if there weren't any volunteers at the hospice?
- What do you believe is the added value of having volunteers?
- Can you think of an example of where the volunteers went above and beyond their role?

Probe and prompt as appropriate

Topic 6: Staff specific question

- What do you value most about the hospice staff?
- Do you feel staff are aware of your needs?
- Can you think of an example of where the staff went above and beyond their role?
- Do you spend much time with the staff at the hospice?
  - Is this of value to you?
  - Do you think staff in a hospital would be able to spend the same amount of time?
- How do you think the staff treat you as a carer?
- Do you feel that staff at the hospice take the time to explain things to you?
- Are you aware of which staff roles have been involved in the care of your loved?
  - Are you aware of the staff member roles that have helped you personally?
- Are you kept informed by staff of what to expect during your loved one's illness trajectory?
  - Is this of value to you?
  - Why is this important to you?

Topic 7: Hospice at home specific questions

- If you are worried or need advice which medical service are you most likely to contact?
- Why have you and your loved one chosen hospice at home as opposed to the inpatient unit at the hospice or hospital?
- Are you aware of which organisations are involved in the care of your loved one?
  - Which organisations?
- Have you had access to the hospice night aid?
  - If no, why?
  - Was this beneficial to you?

    - Why was it beneficial?
    - Did this provide you with respite? Was this important to you?
- How often did the hospice staff visit?
    - Would you have liked more or less visits?
    - What support did they provide for the patient?
    - What support did they provide to you?
- Do the staff members spend enough time with you and the patient?
- Are the staff members consistent?
    - How did this make you feel?
- Do you feel that you are given enough information and training to care for patients at home?
- How does it make you feel knowing that you can access 24/7 support.

Signal disengagement and end of interview coming up

Topic 8: Finishing questions

- Do you have any suggestions for how the hospice could improve the care that they provide?
- How will you feel when you are discharged from the hospice?
- Is there something you would change about the way the services/ activities are offered?

Debriefing

The digital recording device will now be switched off and the interviewee will be asked if they have any questions or concerns. Contact details will be left in case interview participants would like more information at any point.

Appendix 4.18: Day therapy topic guide

Press record: *"The interview is now being recorded…"*

Begin by stating date/ time/ location/

Topic one: Initial questions

- Can you start by introducing yourself and tell me about why you started attending day care?
- How often do you attend day care?
  - How long have you been attending day care?
- How did you hear about day care?
- Is day care what you expected it would be?
- Can you characterize the atmosphere within the day care setting?
  - Is the atmosphere important to you, why?

Topic two: The overall support from the hospice

- How do you personally benefit from being here?
- Name four things you value most about daycare?
  - Why
  - Which of the things you have mentioned are most valuable to you?
- In relation to day care, would you describe your satisfaction as Very high, high, medium, low or very low?
  - Why is this so high for you?
  - What could make it better?
  - Has it always been high?
- What aspects of day care provides you with the most satisfaction?
  - Why does this provide you with satisfaction?
- Whilst you're at day care what will your family/informal carer be doing?
- Have you formed new relationships whilst being at the hospice?
  - How does this make you feel?
  - Would this have happened without the support of the hospice?
  - Will you stay in contact once you have left the hospice?
- Think back to before you first attended day care- how did you feel?
  - How do you feel now? Have there been improvements?
  - What do you believe are the reasons behind these changes?
- Can you tell me how yours and your family's lives have changed as a result of the support provided by the hospice?
  - How can you tell? Can you give me some examples?
  - Would any of this have happened without the hospice?
- What are some of the first things that begin to change for you and your family when you first started coming to the hospice? (I.e. improvements in health, social improvement etc.
  - How did these changes make a difference in your lives?
  - Are you able to tell me in a bit more detail about how the hospice has helped you personally
- What improvements do you see and hope to see for yourselves and/or your family as a result of the work the hospice does in the:
  - Short term

  - Medium term
  - Long term
- Which of the improvements that you have just mentioned are the most important/significant to you and your family (i.e. put them in order)
  - How long do these improvements last?
  - Why is …… so important for you?
- How likely is it that [factors identified above] would happen if it wasn’t the hospice?

Topic Three: The value of hospice services/ activities

- Can you tell me a little bit about what you do whilst you’re at day care?
- Do you take part in any activities here at the hospice?
  - Why did you decide to take part in these specific activities?
  - Would you have been able to do this in another care setting?
  - Do the staff encourage you to take part? How do they encourage you?
  - What are the personal benefits from taking part in this activity?

- Did you come to daycare for the social or medical benefits?
- What is your favourite service/activity in day care?
  - Why is this your favourite?
  - Did you do this before you attended the hospice? (If not why?)
- Do you enjoy the different therapies?
  - Which is your favourite and why?
  - Do you think there is enough choice?
  - Do you notice a difference in your general well-being after a therapy (i.e. improvements in mood)
- What happens if you don’t want to take part in the activities, do staff respect your wishes?
- What mode of transport do you use to get to day care?
  - Why don’t you/why do you use hospice transport?
  - Why is hospice transport valuable to you?
  - If hospice transport wasn’t available how would you get to the hospice?
- How does the hospice meet your spiritual and emotional needs?
- How do you feel after a day at day care?
  - Why do you feel this?
- Have you ever contacted the hospice by telephone for advice or support?
  - Why was this beneficial to you?
  - How did it make you feel?
  - What would you have done if you couldn’t contact the hospice?
- Do you feel that day care is tailored to your individual needs?
- How do you feel about the food provided to you by the hospice? (i.e. taste, availability, choices).
- Can you think of any little things that the hospice does which creates added value?

Topic Four: What would happen without the hospice?

- If you couldn’t come to day-care do you know where else, you would go?
- How likely is it that you would feel the same satisfaction if you were cared for elsewhere? (e.g. very likely, not likely)

- Can you tell me how yours and your family's life has changed as a result of receiving support whilst at day care?
  - Would any of this have happened if it wasn't for the hospice?
- Has any other service or person contributed to these changes?
  - What other services/support are you aware of participants accessing at the same time they are accessing support from the hospice?

- Are you aware of any other services that offer activities similar to that of hospices?
  - How do these services compare with the services provided at hospices?
  - What sets hospices services apart from other projects?
  - Is there anyone you affect negatively?

- What do you think would have happened if you hadn't started attending day care?
- How would your life be different if hospices didn't exist?
  - What sort of services and support would they have received?
  - What are patients and carers able to do now because of the work you do that they weren't able to do before?
  - To what extent do you think he/she would have been able to achieve the things you have seen them do, if hospices didn't exist?

Prompts

Tell me more about?
Can we go back and talk further about?
You mentioned xxx, could you expand on this a little?

Topic Five: Volunteers specific question

- Do you have much involvement with the hospice volunteers?
- What do you value most about the volunteers?
  - Why do you value this?
- What effect would it have on you if there weren't any volunteers at the hospice?
- What do you believe is the added value of having volunteers?
- Can you think of an example of where the staff went above and beyond their role?

Probe and prompt as appropriate

Topic Six: Staff specific question

- What do you value most about the hospice staff?
- Can you think of an example of where the staff went above and beyond their role?
- Do you spend much time with the staff at the hospice?
  - Is this of value to you?
  - Do you think staff in a hospital would be able to spend the same amount of time?

Signal disengagement and end of interview coming up

Topic Seven: Finishing questions

- Do you have any suggestions for how the hospice could improve the care that they provide?

- How will you feel when you are discharged from the hospice?
- Is there something you would change about the way the services/ activities are offered?

Debriefing

The digital recording device will now be switched off and the interviewee will be asked if they have any questions or concerns. Contact details will be left in case interview participants would like more information at any point.

Knowledge Economy Skills Scholarships (KESS) is a Pan-Wales higher level skills initiative led by Bangor University on behalf of the HE sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.

Appendix 4.19*:* Hospice at Home patient interview schedule

Press record: *"The interview is now being recorded…"*

Begin by stating date/ time/ location

Topic one: Initial questions

- How long have you received support from Hospice at Home?
- What made you choose Hospice at home?
- Is the support you get from Hospice at Home what you expected it would be?

Topic two: The overall support from the hospice

- How do you personally benefit from receiving care from Hospice at Home?
- Name four things that you value most from the Hospice at Home service?
- In what ways has Hospice at Home helped you?
    - Relating to health
    - Relating to general well- being
    - Relating to social
    - Relating to equipment
    - Relating to practicality
- In relation to the care and support provided by Hospice at Home would you describe your satisfaction as Very high, high, medium, low or very low?
    - Why is this so high for you?
    - What could make it better?
    - Has it always been high?
- Which aspects of the support provides you with the most satisfaction?
    - Why does this provide you with satisfaction?
- Think back to before you first start receiving support from Hospice at Home- how did you feel?
    - How has the hospice helped you to improve?
    - What do you believe are the reasons behind these changes?
    - How long do you think these changes will last?
- Do you feel that care provided to you by the hospice is tailored to your individual needs?
    - How?
- Can you tell me how yours and your family's life has changed as a result of receiving support from Hospice at Home?
    - Would any of this have happened if it wasn't for Hospice at Home?
    - How can you tell? Can you give me some examples?
- What are some of the **first** things that began to change for you and your family when you first started receiving care from Hospice at home? (I.e. improvements in health, social improvement etc.
    - How did these changes make a difference in your lives?
    - Are you able to tell me in a bit more detail about how the hospice has helped you personally?
- Has any other service or person contributed to these changes?
  - What other services/support are you accessing at the same time you are accessing support from the hospice?

- What improvements do you see and hope to see for yourselves and/or your family as a result of the work the hospice does in the:
  - Short term
  - Medium term
  - Long term
- Which of the improvements that you have just mentioned are the most important/significant to you and your family (i.e. put them in order)
  - How long do these improvements last?
  - Why is …… so important for you?
- Has the support from Hospice at Home helped you to maintain good relationships?
- Have you ever contacted the hospice by telephone for advice or support?
  - Why was this beneficial to you?
  - How did it make you feel?
  - What would you have done if you couldn't contact the hospice?

- Overall do you feel that you and your family get as much help and support from the hospice as you need?
  - What emotional support have you received from the hospice?
  - What practical support have you received from the hospice?
  - What spiritual support have you received from the hospice?
  - Did you value this?
- How likely is it that [factors identified above] would happen if it wasn't for the hospice?
- In your opinion how does the care provided by the hospice differ to the hospital?
  - Are these differences important?
  - Why are they important?

Topic three: What would happen without the hospice?

- What do you think would have happened if you didn't receive care and support from Hospice at Home?
- How would your life be different if hospices didn't exist?
  - What sort of services and support would you have received?
  - What are you able to do now because of the work the hospice has done that you weren't able to do before?
  - To what extent do you think your would have been able to achieve the things you have seen them do, if hospices didn't exist?
- Are you aware of any other services that offer activities similar to that of hospices?
  - How do these services compare with the services provided at hospices?
  - What sets hospices services apart from other projects?
- How likely is it that you would feel the same satisfaction if you were cared for elsewhere? (e.g. very likely, not likely).
  - Have you been cared for in an NHS setting before?
  - How does the care and support compare?

Topic four: The value of hospice services/ activities

- Are you offered any therapies or activities by the staff from Hospice at Home?
  - Why did you decide to take part in these specific activities/ therapies?
  - Would you have been able to do this in another care setting?

  - Do the staff encourage you to take part? How do they encourage you?
  - What are the personal benefits from taking part in this activity/therapy?

- What is your favourite service/activity at the hospice?
  - Why is this your favourite?
  - Did you do this before you attended the hospice? (If not why?)
- Do you enjoy the different therapies/activities?
  - Which is your favourite and why?
  - Do you think there is enough choice?
  - Do you notice a difference in your general well-being after a therapy (i.e. improvements in mood)
- Have you ever contacted the hospice by telephone for advice or support?
  - Why was this beneficial to you?
  - How did it make you feel?
  - What would you have done if you couldn't contact the hospice?

- Can you think of any little things that the hospice does which creates added value?

Prompts

Tell me more about?
Can we go back and talk further about?
You mentioned xxx, could you expand on this a little?

Topic five: Hospice at home specific questions

- If you are worried or needed advice which medical service are you most likely to contact?
- Why have you and your loved one chosen hospice at home as opposed to the inpatient unit at the hospice or hospital?
- Are you aware of which organisations are involved in the care of your loved one?
  - Which organisations?
- Have you had access to the hospice night aid?
  - If no, why?
  - Was this beneficial to you?
  - Why was it beneficial?
- How often did the hospice staff visit?
  - Would you have liked more or less visits?
  - What support did they provide for the patient?
  - What support did they provide to you?
- Are the staff members consistent?
  - How did this make you feel?
- Do you feel that you are given enough information and training to care for patients at home?

Topic six: Staff specific question

- What types of support do the staff provide you with? (e.g. practical, emotional, social)
- What do you value most about the hospice staff?
- Can you think of an example of where the staff went above and beyond their role?
- Do you spend much time with the staff at the hospice?
  - Is this of value to you?

  - Do you think staff in a hospital would be able to spend the same amount of time?
- How do you think the staff treat your carer?
- How does the hospice staff, honour your wishes?
- Does the hospice staff regularly discuss and routinely evaluate pain control and symptom management with you?
  - How quickly does the hospice staff respond to requests for additional pain medication?

Topic seven: Volunteers specific question

- Do you have much involvement with the hospice volunteers?
- What do you value most about the volunteers?
  - Why do you value this?
- What effect would it have on you if there weren't any volunteers at the hospice?
- What do you believe is the added value of having volunteers?
- Can you think of an example of where the staff went above and beyond their role?

Probe and prompt as appropriate

Signal disengagement and end of interview coming up

Topic Eight: Finishing questions

- Do you have any suggestions for how the hospice could improve the care that they provide?
- How will you feel when you are discharged from the hospice?
- Is there something you would change about the way the services/ activities are offered?

Debriefing

The digital recording device will now be switched off and the interviewee will be asked if they have any questions or concerns. Contact details will be left in case interview participants would like more information at any point.

Appendix 4.20: Inpatient unit topic guide

Inpatient interview schedule

Press record: *"The interview is now being recorded…"*

Begin by stating date/ time/ location

Topic one: Initial questions

- How long have you been attending this hospice?
- What brings you to this hospice today (Respite, symptom management)
- How did you hear about the hospice?
  - How did you feel when it was first suggested to you?
- Is the hospice what you expected it would be?
- Can you characterize the atmosphere within the hospice?

Topic two: The overall support from the hospice

- How do you personally benefit from being here?
- In what ways has the hospice helped you?
- What was the best thing about for you about the service?
- In relation to your care at the hospice, would you describe your satisfaction as Very high, high, medium, low or very low?
  - Why is this so high for you?
  - What could make it better?
  - Has it always been high?
- What aspects of the hospice provides you with the most satisfaction?
  - Why does this provide you with satisfaction?
- Think back to before you first attended the hospice- how did you feel?
  - How has the hospice helped you to improve?
  - What do you believe are the reasons behind these changes?
  - How long do you think these changes will last?
- Do you feel that care provided to you by the hospice is tailored to your individual needs?
  - How?
- Can you tell me how yours and your family's life has changed as a result of being at the hospice?
  - Would any of this have happened if it wasn't for the hospice?
  - How can you tell? Can you give me some examples?
- What are some of the **first** things that began to change for you and your family when you first started coming to the hospice? (I.e. improvements in health, social improvement etc.
  - How did these changes make a difference in your lives?
  - Are you able to tell me in a bit more detail about how the hospice has helped you personally?
- Has any other service or person contributed to these changes?
  - What other services/support are you accessing at the same time you are accessing support from the hospice?

- What improvements do you see and hope to see for yourselves and/or your family as a result of the work the hospice does in the:
    - Short term
    - Medium term
    - Long term
- Which of the improvements that you have just mentioned are the most important/significant to you and your family (i.e. put them in order)
    - How long do these improvements last?
    - Why is …… so important for you?
- Have you formed any new relationships whilst at the hospice?
    - Is the ability to socialise valuable to you? Why?
    - How is this encouraged within the hospice?

- Overall do you feel that you and your family get as much help and support from the hospice as you need?
    - What emotional support have you received from the hospice?
    - What practical support have you received from the hospice?
    - What spiritual support have you received from the hospice?
    - Did you value this?
- Does the hospice staff regularly discuss and routinely evaluate pain control and symptom management with you?
    - How quickly does the hospice staff respond to requests for additional pain medication?
- How likely is it that [factors identified above] would happen if it wasn't the hospice?
- In your opinion how does the care provided by the hospice differ to the hospital?
    - Are these differences important?
    - Why are they important?

Topic Three: What would happen without the hospice?

- What do you think would have happened if you didn't attend the hospice?
    - How do you feel about that?
- How likely is it that you would feel the same satisfaction if you were cared for elsewhere? (e.g. very likely, not likely).
    - Have you been cared for in an NHS setting before?
    - How does the care and support compare?

- How would your life be different if hospices didn't exist?
    - What sort of services and support would you have received?
    - What are you able to do now because of the support you have received from the hospice that you weren't able to do before?
    - To what extent do you think your would have been able to achieve the things you have seen them do, if hospices didn't exist?
- Are you aware of any other services that offer activities similar to that of hospices?
    - How do these services compare with the services provided at hospices?
    - What sets hospices services apart from other projects?

- Can you tell me about any changes you would recommend that could enhance your experience of the hospice?

Extra Questions

Topic four: The value of hospice services/ activities

- How does the hospice meet your spiritual and emotional needs?
- Do you take part in any activities here at the hospice?
  - Why did you decide to take part in these specific activities?
  - Would you have been able to do this in another care setting?
  - Do the staff encourage you to take part? How do they encourage you?
  - What are the personal benefits from taking part in this activity?

- What is your favourite service/activity at the hospice?
  - Why is this your favourite?
  - Did you do this before you attended the hospice? (If not why?)
- Do you enjoy the different therapies?
  - Which is your favourite and why?
  - Do you think there is enough choice?
  - Do you notice a difference in your general well-being after a therapy (i.e. improvements in mood)
- How do you feel about the flexible visiting hours?
- How do you feel about the food provided to you by the hospice? (i.e. taste, availability, choices).
- Can you think of any little things that the hospice does which creates added value?

Prompts

Tell me more about?
Can we go back and talk further about?
You mentioned xxx, could you expand on this a little?

Topic five: Staff specific question

- What types of support do the staff provide you with? (e.g. practical, emotional, social)
- What do you value most about the hospice staff?
- Can you think of an example of where the staff went above and beyond their role?
- Do you spend much time with the staff at the hospice?
  - Is this of value to you?
  - Do you think staff in a hospital would be able to spend the same amount of time?
- How do you think the staff treat your carer?
- How does the hospice staff honour your wishes?
- Do you feel that staff at the hospice take the time to explain things to you?
  - Is this valuable to you? Why?

Topic six: Volunteers specific question

- Do you have much involvement with the hospice volunteers?
- What do you value most about the volunteers?

- Why do you value this?

- What effect would it have on you if there weren't any volunteers at the hospice?
- What do you believe is the added value of having volunteers?
- Can you think of an example of where the volunteers went above and beyond their role?

Probe and prompt as appropriate

Signal disengagement and end of interview coming up

Topic five: Finishing questions

- Do you have any suggestions for how the hospice could improve the care that they provide?
- How will you feel when you are discharged from the hospice?
- Is there something you would change about the way the services/ activities are offered?

Debriefing

The digital recording device will now be switched off and the interviewee will be asked if they have any questions or concerns. Contact details will be left in case interview participants would like more information at any point.

Appendix 4.21: Consolidated criteria for reporting qualitative studies (COREQ):32-item checklist [201]

No	Item	Guide questions/description	Page no.
Domain 1: Research team and reflexivity			
Personal Characteristics			
1	Interviewer/facilitator	Which author/s conducted the interview or focus group?	122
2	Credentials	What were the researcher’s credentials? E.g. PhD, MD	217
3	Occupation	What was their occupation at the time of the study?	217
4	Gender	Was the researcher male or female?	N/A
5	Experience and training	What experience or training did the researcher have?	217 - 218
Relationship with participants			
6	Relationship established	Was a relationship established prior to study commencement?	217
7	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	217
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	217 - 218
Domain 2: study design			
Theoretical framework			
9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	117 - 118
Participant selection			
10	Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	118 - 119
11	Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	119 - 120

12	Sample size	How many participants were in the study?	129 - 130
13	Non-participation	How many people refused to participate or dropped out? Reasons?	129
Setting			
14	Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	122
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	122
16	Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	130 - 131
Data collection			
17	Interview schedule	Were questions, prompts, guides provided by the authors? Was it pilot tested?	122
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	126
20	Field notes	Were field notes made during and/or after the interview or focus group?	123
21	Duration	What was the duration of the interviews or focus group?	129 - 130
22	Data saturation	Was data saturation discussed?	119
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	N/A
Domain 3: analysis and findings			
Analysis			
24	Number of data coders	How many data coders coded the data?	128
25	Description of the coding tree	Did authors provide a description of the coding tree?	126 - 129
26	Derivation of themes	Were themes identified in advance or derived from the data?	126 - 127
27	Software	What software, if applicable, was used to manage the data?	127
28	Participant checking	Did participants provide feedback on the findings?	N/A
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. participant number	134 - 147

30	Data and findings consistent	Was there consistency between the data presented and the findings?	134 - 147
31	Clarity of major themes	Were major themes clearly presented in the findings?	134 - 147
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	147 - 148

Appendix 5.1: IPOS Patient Version

IPOS Patient Version

Patient name : ………………………………………………
Date (dd/mm/yyyy) : ………………………………………………
Patient number : ………………………………… *(for staff use)*

Q1. What have been your main problems or concerns <u>over the past 3 days?</u>

1.
………
…..

2.
………
…..

3.
………
…..

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick <u>one box</u> that best describes how it has <u>affected</u> you <u>over the past 3 days</u>.

	Not at all	Slightly	Moderately	Severely	Over-whelming
Pain	0☐	1☐	2☐	3☐	4☐
Shortness of breath	0☐	1☐	2☐	3☐	4☐
Weakness or lack of energy	0☐	1☐	2☐	3☐	4☐
Nausea (feeling like you are going to be sick)	0☐	1☐	2☐	3☐	4☐
Vomiting (being sick)	0☐	1☐	2☐	3☐	4☐
Poor appetite	0☐	1☐	2☐	3☐	4☐

Constipation	0☐	1☐	2☐	3☐	4☐
Sore or dry mouth	0☐	1☐	2☐	3☐	4☐
Drowsiness	0☐	1☐	2☐	3☐	4☐
Poor mobility	0☐	1☐	2☐	3☐	4☐
Please list any <u>other</u> symptoms not mentioned above, and tick <u>one box</u> to show how they have <u>affected</u> you <u>over the past 3 days</u>.					
1.	0☐	1☐	2☐	3☐	4☐
2.	0☐	1☐	2☐	3☐	4☐
3.	0☐	1☐	2☐	3☐	4☐

Over the past 3 days:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*
Q3. Have you been feeling anxious or worried about your illness or treatment?	0☐	1☐	2☐	3☐	4☐
Q4. Have any of your family or friends been anxious or worried about you?	0☐	1☐	2☐	3☐	4☐
Q5. Have you been feeling depressed?	0☐	1☐	2☐	3☐	4☐
	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*
Q6. Have you felt at peace?	0☐	1☐	2☐	3☐	4☐

Q7. **Have you been able to share how you are feeling with your family or friends as much as you wanted?**	0☐	1☐	2☐	3☐	4☐
Q8. **Have you had as much information as you wanted?**	0☐	1☐	2☐	3☐	4☐
	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*
Q9. **Have any practical problems resulting from your illness been addressed? (such as financial or personal)**	0☐	1☐	2☐	3☐	4☐
	On my own	*With help from a friend or relative*			*With help from a member of staff*
Q10. How did you complete this questionnaire?	☐	☐			☐

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse

Appendix 5.2: Staff Version

IPOS Staff Version

www.pos-pal.org

Patient name : ……………………………………………………

Patient number : ……………………………………………………

Date (dd/mm/yyyy) : ……………………………………………………

Q1. What have been the patient's main problems or concerns <u>over the past 3 days?</u>

1. ………

2. ………

3. ………

Q2. Please tick <u>one box</u> that best describes how the patient has been <u>affected</u> by each of the following symptoms <u>over the past 3 days</u>?

	Not at all	Slightly	Moderately	Severely	Over-whelmingly	Cannot assess (e.g. unconscious)
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

Please list any <u>other</u> symptoms and tick <u>one box</u> to show how you feel each of these symptoms has <u>affected</u> the patient <u>over the past 3 days</u>.						
1.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
2.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
3.	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐

<u>Over the past 3 days:</u>

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*	*Cannot assess (e.g. unconscious)*
Q3. Has s/he been feeling worried about his/her illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q4. Have any of his/her family or friends been anxious or worried about the patient?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q5. Do you think s/he felt depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*	*Cannot assess (e.g. unconscious)*
Q6. Do you think s/he has felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as much as s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
Q8. Has the patient had as much information s/he wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	☐
	Problems addressed/ No problems	*Problems mostly addressed*	*Problems partly addressed*	*Problems hardly addressed*	*Problems not addressed*	*Cannot assess (e.g. unconscious)*

Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0☐	1☐	2☐	3☐	4☐	☐

Appendix 6.1: Day Therapy Base Case

STAGE 1		STAGE 2			STAGE 3								STAGE 4				
Stakeholders	**Inputs**		**Outputs**	**The Outcomes (what changes)**									**Deadweight %**	**Displacement %**	**Attribution %**	**Drop off %**	**Impact**
Who do we have an affect on? Who has an effect on us?	What do they invest?	What is the value of the inputs in currency *(only enter numbers)*	Summary of activity in numbers	Description	Indicator	Source	Quantity	Duration	Outcomes start	Financial Proxy	Value in currency	Source	What would have happened without the activity?	What activity did you displace?	Who else contributed to the change?	Does the outcome drop off in future years?	Quantity times financial proxy, less deadweight, dis placement and attribution
				How would the stakeholder describe the changes?	How would you measure it?	Where did you get the information from?	How much change was there?	How long does it last after end of activity? *(Only enter numbers)*	Does it start in period of activity (1) or in period after (2)	What proxy would you use to value the change?	What is the value of the change? *(Only enter numbers)*	Where did you get the information from?					
Day therapy patients (n=89)		£0.00	89 patients attended an average of 8 day therapy visits each. There is no charge to patients for using the hospice day therapy service.	Improved relationships with close family	Patients were asked if they felt that the hospice had helped improve their relationships with others	Qualitative interview with patients at 2 time-points	8	0	1	Can rely on family	£5,386	HACT	25%	25%	25%	100%	£18,177.75
				Improvements in physical symptoms such as pain, breathlessness and nausea	% of patients reporting no deterioration (no change or an improvement) in their pain post hospice admission	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	35	0	1	Good overall health, any age	£15,992	HACT	25%	25%	25%	100%	£236,131.88
				Increased feeling of autonomy and control over their life/personal environment	Patients were asked if they felt that they had control over the care that they receive and whether they felt that they had the freedom to make their own decisions	Qualitative interview with patients at 2 time-points	15	0	1	Feel in control of life	£12,620	HACT	25%	25%	25%	100%	£79,860.94
				Provided with information and advice which enhanced ability to address practical and financial issues	% of patients reporting no deterioration (no change or an improvement) in their ability to address their practical issues	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	32	0	1	Able to obtain advice locally, any age	£1,951	HACT	25%	25%	25%	100%	£26,338.50
				Improved friendships/ Increased social support network resulting in the reduction of loneliness and isolation and feeling less alone in their situation	Participants were asked whether they felt lonely since arriving at the hospice. Participants were asked whether their sense of loneliness had improved since being at the hospice	Qualitative interview with patients at 2 time-points	24	0	1	Feel belonging to neighbourhood	£2,980	HACT	25%	25%	25%	100%	£30,172.50
				Improvements in patient functionality, mobility and physical health	% of patients reporting no deterioration (no change or an improvement) in their mobility post hospice admission	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	35	0	1	Walking	£4,193	HACT	25%	25%	25%	100%	£61,912.27

				Reduction in feelings of anxiousness about their illness or treatment resulting in improvements in psychological well-being	% of patients reporting no deterioration (no change or an improvement) in their anxiety post hospice admission.	A survey aimed at patients, embedded into routine hospice data collection across varying time-points- baseline/other. IPOS (Patient version).	29	0	1	Relief from depression/anxiety (adult), any age	£29,192	HACT	25%	25%	25%	100%	£357,145.88
Day therapy Family/carers		£0.00	There is no charge to family-caregivers for using the hospice day therapy service.	Improved relationships with close family	Participants were asked if they felt that the hospice had helped improve their relationships with others	Qualitative interview with patients at 2 time-points	12	1	1	Can rely on family	£6,784	HACT	25%	25%	25%	75%	£34,344.00
				Provided with information and advice which enhanced ability to address practical and financial issues	Participants were asked whether they had received advice from the hospice which helped to address practical issues.	Qualitative interview with patients at 2 time-points	6	1	1	Able to obtain advice locally, any age	£2,457	HACT	25%	25%	25%	75%	£6,219.28
				Improved friendships/ Increased social support network resulting in the reduction of loneliness and isolation and feeling less alone in their situation	Participants were asked whether they felt lonely since arriving at the hospice. Participants were asked whether their sense of loneliness had improved since being at the hospice	Qualitative interview with patients at 2 time-points	4	1	1	Feel belonging to neighbourhood	£3,753	HACT	25%	25%	25%	75%	£6,333.19
				Reduction in feelings of anxiousness about the patients illness or treatment resulting in improvements in psychological well-being		A survey aimed at patients, embedded into routine hospice data collection across varying time-points- baseline/other. IPOS (Patient version)	31	1	1	Relief from depression/anxiety (adult), any age	£36,766	HACT	25%	25%	25%	75%	£480,830.34
Staff	Care, time, expertise (all values have been accounted for in chapter 3.	£0.00											0%	0%	0%	0%	£0.00
Volunteers	Care, time, expertise (all values have been accounted for in chapter 3.	£0.00		Care and support skills									0%	0%	0%	0%	£0.00
NHS: Pharmacy services [1 organisation]*	Medicine management	£0.00		Improved health, less reliance on other services									0%	0%	0%	0%	£0.00
NHS: BCUHB [1 organisation]*	Funding	£0.00		Cost savings for end of life and palliative care									0%	0%	0%	0%	£0.00
Hospices*	Funding via fundraising, staff, buildings, service models	£155,928											0%	0%	0%	0%	£0.00
Local authority*		£0.00											0%	0%	0%	0%	£0.00

Total	£1,337,466.52

Stage 5							
	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5	
Present value of each year	£1,337,466.52	£509,880.98	£0.00	£0.00	£0.00	£0.00	
Total Present Value (PV)							1,847,347.49
Net Present Value							1,691,419.49
(PV minus the investment)							
Social Return							**£11.85**
Value per amount invested							

Appendix 6.2: Inpatient Base Case

STAGE1		STAGE 2			STAGE 3								STAGE 4				
Stakeholders	**Inputs**		**Outputs**	**The Outcomes (what changes)**									**Deadweight %**	**Displacement %**	**Attribution %**	**Drop off %**	**Impact**
Who do we have an affect on? Who has an effect on us?	What do they invest?	What is the value of the inputs in currency *(only enter numbers)*	Summary of activity in numbers	Description	Indicator	Source	Quantity	Duration	Outcomes start	Financial Proxy	Value in currency	Source	What would have happened without the activity?	What activity did you displace?	Who else contributed to the change?	Does the outcome drop off in future years?	Quantity times financial proxy, less deadweight, dis placement and attribution
				How would the stakeholder describe the changes?	How would you measure it?	Where did you get the information from?	How much change was there?	How long does it last after end of activity? *(Only enter numbers)*	Does it start in period of activity (1) or in period after (2)	What proxy would you use to value the change?	What is the value of the change? (*Only enter numbers)*	Where did you get the information from?					
Inpatient patients (n=90)		£0.00	90 patients attended an average of 15 inpatient nights each. There is no charge to patients for using the hospice inpatient service.	Improved relationships with close family	Patients were asked if they felt that the hospice had helped improve their relationships with others	Qualitative interview with patients at 2 time-points	2	0	1	Can rely on family	£1,906	HACT	25%	25%	25%	100%	£1,608.19
				Improvements in physical symptoms such as pain, breathlessness and nausea	% of patients reporting no deterioration (no change or an improvement) in their pain post hospice admission	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	61	0	1	Good overall health, any age	£5,660	HACT	25%	25%	25%	100%	£145,656.56
				Increased feeling of autonomy and control over their life/personal environment	Patients were asked if they felt that they had control over the care that they receive and whether they felt that they had the freedom to make their own decisions	Qualitative interview with patients at 2 time-points	5	0	1	Feel in control of life	£4,466	HACT	25%	25%	25%	100%	£9,420.47
				Provided with information and advice which enhanced ability to address practical and financial issues	% of patients reporting no deterioration (no change or an improvement) in their ability to address their practical issues	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	19	0	1	Able to obtain advice locally, any age	£690	HACT	25%	25%	25%	100%	£5,530.78
				Improved friendships/ Increased social support network resulting in the reduction of loneliness and isolation and feeling less alone in their situation	Participants were asked whether they felt lonely since arriving at the hospice. Participants were asked whether their sense of loneliness had improved since being at the hospice	Qualitative interview with patients at 2 time-points	3	0	1	Feel belonging to neighbourhood	£1,055	HACT	25%	25%	25%	100%	£1,335.23
				Improvements in patient functionality, mobility and physical health	% of patients reporting no deterioration (no change or an improvement) in their mobility post hospice admission	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	49	0	1	Walking	£1,484	HACT	25%	25%	25%	100%	£30,677.06

				Reduction in feelings of anxiousness about their illness or treatment resulting in improvements in psychological well-being	% of patients reporting no deterioration (no change or an improvement) in their anxiety post hospice admission.	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version).	49	0	1	Relief from depression/anxiety (adult), any age	£10,331	HACT	25%	25%	25%	100%	£213,561.14
Inpatient Family/carers		£0.00	There is no charge to family-caregivers for using the hospice inpatient service.	Improved relationships with close family	Participants were asked if they felt that the hospice had helped improve their relationships with others	Qualitative interview with patients at 2 time-points	1	1	1	Can rely on family	£6,784	HACT	25%	25%	25%	75%	£2,862.00
				Provided with information and advice which enhanced ability to address practical and financial issues	Participants were asked whether they had received advice from the hospice which helped to address practical issues.	Qualitative interview with patients at 2 time-points	2	1	1	Able to obtain advice locally, any age	£2,457	HACT	25%	25%	25%	75%	£2,073.09
				Reduction in feelings of anxiousness about the patients illness or treatment resulting in improvements in psychological well-being	% of patients reporting that their family had experienced no deterioration (no change or an improvement) in their anxiety post hospice admission.	A survey aimed at patients, embedded into routine hospice data collection across varying time-points-baseline/other. IPOS (Patient version)	41	1	1	Relief from depression/anxiety (adult), any age	£36,766	HACT	25%	25%	25%	75%	£635,936.91
Staff	Care, time, expertise (all values have been accounted for in chapter 3	£0.00											0%	0%	0%	0%	£0.00
Volunteers	Care, time, expertise (all values have been accounted for in chapter 3.	£0.00		Care and support skills									0%	0%	0%	0%	£0.00
NHS: Pharmacy services [1 organisation]*	Medicine management	£0.00		Improved health, less reliance on other services									0%	0%	0%	0%	£0.00
NHS: BCUHB [1 organisation]*	Funding	£0.00		Cost savings for end of life and palliative care									0%	0%	0%	0%	£0.00
Hospices*	Funding via fundraising, staff, buildings, service models	£602,100.00											0%	0%	0%	0%	£0.00
Local authority*		£0.00											0%	0%	0%	0%	£0.00
Total		£602,100.00															

STAGE 5							
	Year 0	Year 1	Year 2	Year 3	Year 4	Year 5	
Present value of each year	£1,048,661.44	£619,200	£0.00	£0.00	£0.00	£0.00	
Total Present Value (PV)							1,667,861.44
Net Present Value							1,065,761.44
(PV minus the investment)							
Social Return							**£2.77**
Value per amount invested							

Appendix:6.3: SROI Assurance Process and Assessment Criteria

Assurance Process and Assessment Criteria

For anyone wishing to apply for report assurance

Social Value UK provide assurance that tests reports for a good understanding and application of Social Value principles and process.

The criteria set out in this document can be applied to any social value/impact report. However, to assure an SROI report principle # 3 “value what matters” requires the use of financial proxies.

Process/Scope

This report assurance process seeks to assess whether or not a report shows a good understanding of the Social Value principles. **A report must meet all of the assessment criteria set out in this document in order to demonstrate a good understanding of the Social Value principles.**

These assessment criteria will be used by assessors in order to produce a final assurance statement for a report. The assurance statement forms part of the report. If a report does not fully meet the assessment criteria then the assurance statement will identify the extent to which an understanding of the Social Value principles has been demonstrated (see page 2 for more information on the Assurance Statement).

Eligibility

To submit a report for assurance the applicants will need to ensure the following:

- that their membership of Social Value International or affiliated national network is current
- provide proof that the permission of the organisation to submit the report has been granted
complete the assurance application form

The assessment will be based on two documents:

- Value Map and
- written report based on the information in the Value Map.

Multiple value maps with a composite report will not be accepted for assessment without prior discussion with Social Value UK. Applicants will need to ensure that both the value map and report contain sufficient evidence to meet the assurance criteria.

The assessment criteria set out in this document are based on the Guide to SROI and any supplements to the guide published by Social Value UK.

The Assurance Statement:

A Social Value UK approved assessor will use the assessment criteria to produce an assurance statement.
The statement can be one of the three set out below:

"The Value Map and Written Report are consistent with and show a good understanding of SROI principles"

Or:

"The extent to which the Value Map and Written Report demonstrate an understanding of the SROI principles and process is set out below"

Principle	Meets criteria? *Please delete*	Commentary
Stakeholder involvement	All, ~~Majority, Minority, None~~	
Understand change	All, ~~Majority, Minority, None~~	
Value what matters	~~All~~, Majority, ~~Minority, None~~	
Only include what is material	~~All~~, Majority, ~~Minority, None~~	
Do not overclaim	All, ~~Majority, Minority, None~~	
Be transparent	~~All~~, Majority, ~~Minority, None~~	
Verify the result	~~All, Majority, Minority,~~ None	

Or:

"The Value Map and Written Report do not provide sufficient understanding of SROI principles"

Involving stakeholders

The important issues are:

- **identification of stakeholders and a rationale for those that have been included and excluded from involvement in the process**
- **evidence of involvement of the included stakeholders in the application of the other principles.**

Stakeholders are those people or organisations that experience change as a result of the activity and they will be best placed to describe the change. This principle means that stakeholders need to be identified and then involved in consultation throughout the analysis.

Ref.	***Criteria***
1.1	*Have representatives of all stakeholder groups considered likely to experience material outcomes been consulted about what changes for them?* *(this is also a criteria for forecast reports even though those representatives may not become involved in the activity)*
1.2	*Is there information on how many stakeholders from each group were involved?*
1.3	*Is there evidence to support the number involved as providing a reasonable basis for determining outcomes?*
1.4	*Does the report describe decisions about whether or not changes should be analysed for sub-groups of stakeholders where different outcomes are or may be experienced?*
1.5	*Are judgements to analyse, or not, stakeholders into separate subgroups, based on evidence that subgroups do, or do not, experience materially different outcomes?*
1.6	*Where a stakeholder group cannot be involved, does the report include evidence why this has not been possible?*
1.7	*Does the report include evidence that reasonable avenues of involvement have been considered (including involving another group to act as a proxy)?*
1.8	*Does the report clearly describe how stakeholder involvement has taken place, recognising that different groups or organisations require different approaches?*
1.9	*Is there evidence on how the involvement process has reduced the risk that those involved are not representative of the group?*
1.10	*Does the report clearly describe how qualitative data from stakeholder involvement has been gathered and recorded?*
1.11	*Are the questions presented to stakeholders included in the report?*
1.12	*Do the questions reflect an open approach to identifying outcomes, including positive and negative outcomes?*
1.13	*Is there evidence that stakeholder groups have been consulted about the value (relative importance) of outcomes to them?*
1.14	*If not are reasons included?*
1.15	*Is there evidence that stakeholder groups have been consulted about how they would evidence and measure change?*
1.16	*If not are reasons included?*
1.17	*Is there evidence that stakeholder groups have been consulted about the duration of outcomes?*
1.18	*If not are reasons included?*
1.19	*Is there evidence that stakeholders groups have been consulted about which other organisations or people contributed to the outcome?*

1.20	*If not are reasons included?*
1.21	*Is there evidence that stakeholders have been consulted about what might have taken place if the activity under analysis had not taken place?*
1.22	*If not are reasons included?*
1.23	***For a forecast report**, are there plans and recommendations in the report to ensure ongoing involvement of stakeholders in producing actual information to compare with forecast information?*

Understand what changes

The important issues are:

- **inclusion of a clear explanation of the theories of change or chains of events for included stakeholders**
- **statement of which outcome in each theory of change will be valued and why**
- **evidence to support causality in the theory of change**
- **the experience of all stakeholders in stakeholder groups is included**

Ref.	***Criteria***
2.1	*Has the author made clear that the analysis is either a forecast or evaluative study?*
2.2	*Are the activities for which the social return is being analysed clear?*
2.3	*Is the period over which the activities occur clear?*
2.4	*Is the theory of change, input, output and outcomes, which result from stakeholder involvement, supported by reasoning to show how the results of involvement have informed the theories of change for each stakeholder group?*
2.5	*Is third party research or organisation’s documented evidence that supports causality in the theory of change included?*
2.6	*If not is a reason included?*
2.7	*Have the outcomes been recorded against the stakeholder group that will experience the outcome?*
2.8	*Have unintended and negative outcomes been included in the analysis?*
2.9	*If not is the evidence that they do not take place included?* *(This would include evidence from other evaluations or research on similar activities. A statement that this is a forecast report is not evidence)*
2.10	*Are the outcomes in the Value Map consistent with the report?*
2.11	*Is there evidence to support the included duration of each of the outcomes after the end of the activity?*
2.12	*Is there evidence for the relevance of the indicators to the outcomes?*
2.13	*Where an indicator by itself does not give sufficient confidence about the amount of outcome that has or will occur, a combination of indicators should be used. Is there evidence that the indicators used are sufficient to give confidence about the amount of change created?*
2.14	*Is there evidence that the sample of stakeholders used to derive how much change is experienced by the stakeholder group is reasonable?*
2.15	*Is the amount of change included based on the difference between a baseline situation for the stakeholder group at the start of the activity and the position at the end of the activity?*

2.16	*If not are reasons included?*
2.17	***In a forecast report** is the quantity of expected change supported by proposals for how actual data will be collected to compare against the forecast?*
2.18	***In a forecast report** has evidence to support the forecast quantities of change being included? (this can include results from previous years, from other similar activities of a similar scale, from market research with people who share characteristics of expected future stakeholders)*
2.19	*Are the outcomes for all the stakeholders in a group included so that it is clear what happens to any members of a group that do not experience an included outcome?*
2.20	*Are all the outcomes in the Value Map consistent with the report?*

Value things that matter

The important issue is that the financial proxies should reflect the value of the outcomes to the stakeholder group

Ref.	***Criteria***
3.1	*Have all relevant inputs made by stakeholders been included?*
3.2	*Is there evidence to support the value of each input?*
3.3	*Where an input has not been valued has a reason been included?*
3.4	*Is the calculation of the total input or investment accurate?*
3.5	*Have all the material outcomes been given a value?*
3.6	*Is there evidence to support the choice of valuation methodology?*
3.7	*Where stakeholders have not been directly involved in determining value is there evidence that the values used are nonetheless representative*
3.8	*Is each financial proxy used relevant to the stakeholder group for which value is being claimed?*
3.9	*Is there evidence to support the choice of financial proxies for each outcome?*
3.10	*Does the calculation of the value avoid double counting, especially where more than one indicator has been used?*
3.11	*Is the calculation of the value of each outcome accurate?*

Only include what is material

The important issues are:

- **is there evidence to support decisions to exclude outcomes identified from stakeholder involvement and other research?**
- **does the evidence show why the stakeholder group would not be expected to make a different decision in relation to the activity had the information been included?**

Ref.	***Criteria***
4.1	*Does the report clearly explain that any decisions to include and exclude stakeholders are based on expected or actual outcomes?*
4.2	*Are judgements to exclude stakeholders prior to involvement based on evidence that a stakeholder group will or did not experience material outcomes from previous year’s research on the same activity?*
4.3	*Where judgements to exclude stakeholders prior to involvement are based on third party research is there evidence that the third party research was consistent with these assurance criteria?*
4.4	*Where outcomes have been excluded from the calculation of total value is there evidence that the outcome is not relevant?*
4.5	*Where outcomes have been included as relevant but subsequently excluded from the calculation of total value is there evidence that the outcome is not significant based on value, quantity and causality?*
4.6	*Where an organisational theory of change or mission described in the report dominates the outcomes included is there evidence to support this?*
4.7	*If so is there evidence to support the case that other outcomes, positive and negative, experienced by stakeholders are not material?*
4.8	***In a forecast report**, where there is more risk of the outcomes focusing on the organisation’s theory of change, is there evidence that other research that might highlight other outcomes is not available?*
4.9	***Is there any reason, in the experience of the assessor, that the activity would have other material outcomes that have not been included?***

Do not over claim

The important issue is that the analysis does not overstate the value claimed as caused by the activity;

Ref.	***Criteria***
5.1	*Is the approach used to assessing ‘what would have happened anyway’ clear (counterfactual, deadweight)?*
5.2	*Is there evidence to support the proportion of what would have happened anyway based on this approach?*
5.3	*Is there consideration of the risk of over claiming using the chosen approach?*

5.4	*Is there evidence to support the calculation of the activity's contribution to the value claimed (or attribution to other organisations or groups of people)?*
5.5	*Is the risk of displacement considered?*
5.6	*Where there is displacement has the relevant stakeholder group affected by displacement been recognised?*
5.7	*For outcomes that last more than one period more than the activity (e.g. for a one year activity lasting for two or more years) is there evidence to support decisions on how the level of outcome may drop off over time?*

Be transparent

The important issue is that all decisions relating to stakeholders, outcomes, indicators, values, and counterfactual; the sources and methods of information collection; the difference scenarios considered and the involvement and communication of the results to stakeholders should be explained and documented.

Ref.	***Criteria***
6.1	*Is there a summary of which stakeholders and outcomes have been excluded?*
6.2	*Is the Value Map clear and transparent and is the report completely consistent with Value Map contents?*
6.3	*Is there a summary of a sensitivity analysis that tested for quantities, values, counterfactual, attribution, displacement and drop off for each outcome?*
6.4	*If the sensitivity analysis did not cover all these is there a reason given?*
6.5	*Are all data sources in both the Value Map that do not relate to stakeholder involvement but to other sources of evidence referenced in a way that would enable the reader to refer and verify?*
6.6	*Is the data derived from stakeholder involvement related back to the process and results of involvement?*
6.7	*Are all calculations set out in a way that makes it possible for the calculation to be replicated and to arrive at the same result of social return?*
6.8	*Is the final calculation of the range of values included correct?*
6.9	*Are risks of errors discussed?*
6.10	*For a forecast report are there plans for assessing actual results to compare against the forecast?*

Verify the result

The important issue is that stakeholders have had an opportunity to review the information in the report

Ref.	***Criteria***
7.1	*Is there evidence on the extent to which stakeholders have been involved in reviewing and verifying the claims in the analysis?*