MSc Digital Transformation for the Health and Care Professions

BMDS7005

Feasibility of a prognostication aid to promote advance care planning.

Dissertation submitted in partial fulfilment of the award of

Master of Science in Digital Transformation for the Health and Care Professions

Dr Andrew Shuler

Declarations

I confirm that generative AI has not been used to produce any part of this dissertation.

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed

5th May 2025

ABSTRACT

Background: Advance care planning is a process which supports individuals in anticipating future care needs and being able to contribute to those decisions. By identifying those more likely to deteriorate, and require healthcare support, they can be empowered by having their preferences recognised. An improved patient experience will provide less moral distress, better communication and more efficient use of resources. However, the interface between palliative care and digital insights has had very limited consideration.

Aim: The aim of this study was to explore the feasibility of identifying a cohort where promoting advance care planning is more timely. The existing wealth of digital data provides the opportunity to explore how this can provide such a prompt.

Methods: A prevalent cohort study was carried out to ground the relevance of this research focus. The inpatients on a census day were followed for 12 months to identify the likelihood of death.

The second aspect was a qualitative phenomenological study using semi-structured interviews as to the perceived feasibility of a prognostication aid. Six interviews took place in person. The in-depth perspectives were then thematically analysed.

Results: The quantitative study identified that 19.3% of the cohort population died within six months of the census date. There was an increasing correlation between age and dying within six months. 13.0% of the cohort who were 60-64 years of age died within the following six months (odds ratio 18.41; $p<0.0001$); compared to 28.4% of the cohort who were 85 years of age or older. (odds ratio 4.79; $p<0.0001$);

Themes that arose from the semi-structured interviews were: i) its utility, ii) uncertainty of prognostication, iii) capacity of clinician, and, iv) ethical considerations. The concept of prognostication to support advance care planning was positively received. Concerns focused on medicine being an art rather than an algorithm and whether clinicians had the time and skills to fulfil the intent of this proposal. There was also a recurrent focus on the topical Assisted Dying Bill.

Conclusion: The in-depth perspectives supported the feasibility of a digital prognostication aid to aid the promotion of advance care planning. Further qualitative studies could engage with a larger group, including patients, to appreciate the breadth of opinions. These would be necessary to inform appropriate change management with application of any such prognostication aid.

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CHAPTER 1

Introduction

1.1 What – setting the scene

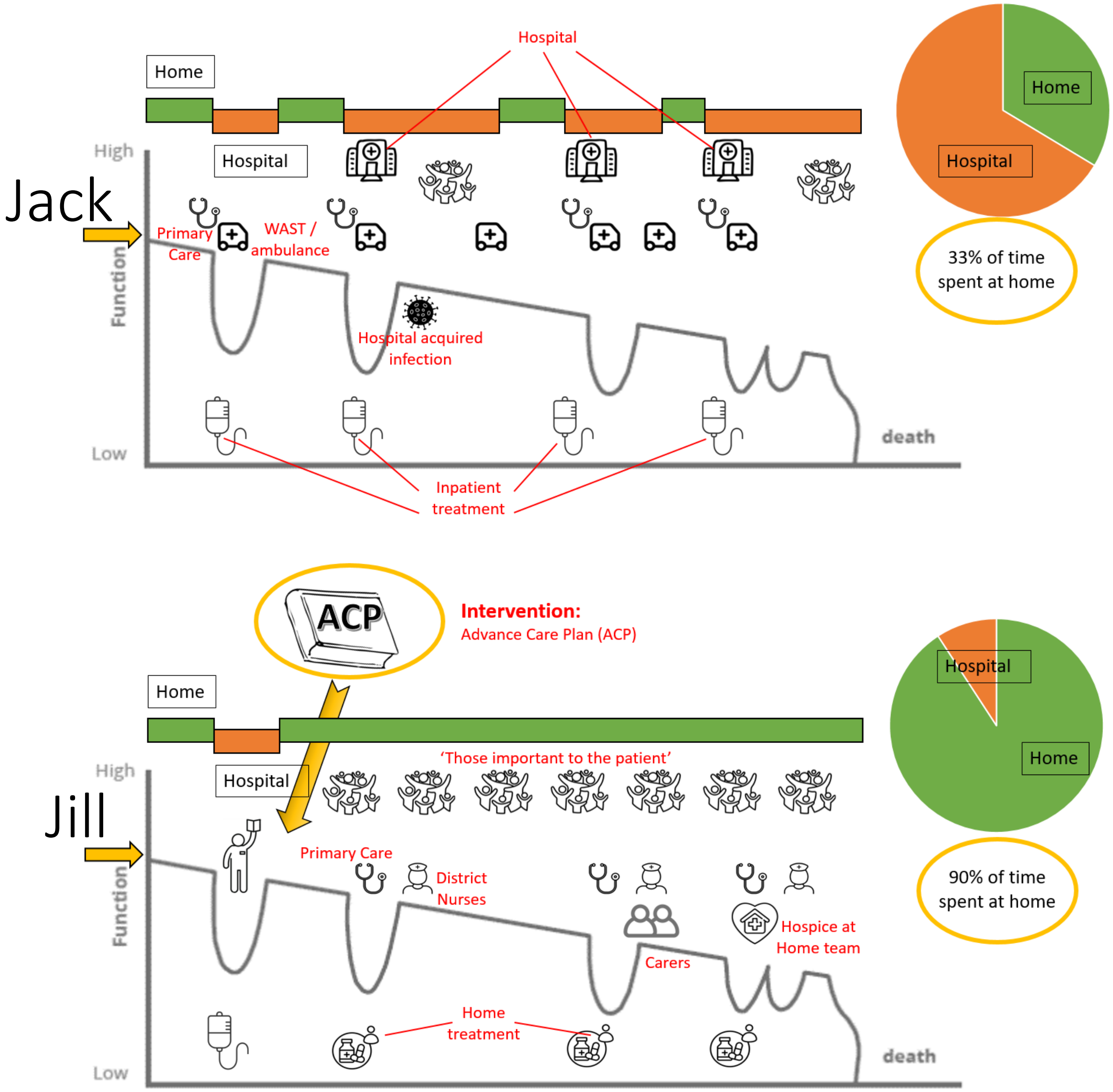


Figure 1.1: Rich picture illustrating the potential impact of an advance care plan

The rich picture, in figure 1.1, illustrates the disease course for two (hypothetical) individuals. Jack and Jill both have chronic medical conditions that bring them to hospital, but this is where their paths deviate.

Jack has treatment in hospital, recovers and gets home again. There are further exacerbations of his condition and there are repeated episodes of care in hospital. With every admission his level of independence on discharge is never as great as it was. The hospital experience can best be described as nomadic with the movement from ward to ward and sporadically edible food. ‘Visiting times’ limit his contact with his family. Jack dies in the hospital having spent only a third of his time at home.

Jill also has treatment in hospital, recovers and gets home again. The intervention, having recognised that further exacerbations and deterioration were possibilities, is that there is opportunity to reflect forwards. She can consider what her priorities are and make her decisions regarding future care – an ‘advance care plan’. The definition is considered in section 2.2; but, in short, is “a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care” (CQC, 2021). So, when further exacerbations occur they are managed at home, in the community setting. Similar to Jack, there is an underlying change in her level of function. However, her quality of life, with ongoing support and connection, is higher. Jill dies at home. She has managed to experience the end of life on her terms, with the majority of time spent at home.

1.2 So what – why it matters

The immediate reflection is what is the benefit of time at home over time in hospital.

There is an orthodoxy that home is the preferred place of care for the majority of people (Pollock, 2015). That generalisation is somewhat oversimplified in that the studies included opinions from the general public. The experience, to note, is that preferences can change over time; whether care needs or social factors. There is also the practical component to consider, as the preference may be valid but the logistics are not feasible (the author’s preference to be in the Caribbean is unlikely to be facilitated). Without debating the practicalities, and realities, of the intervention options (whether medical treatments or the realistic immediacy of nursing and carer support); time at home does bring a number of benefits, for example:

- a smaller team of professionals, rather than multiple teams on multiple wards across multiple admissions, enables better continuity of care.
- communication will be more open and consistent.
- the locus of power rests with the patient rather than the professional.

So ultimately, there can be more chance of dignified care at home.

‘Home’ is a measurable outcome of the intervention in this scenario. It is a surrogate indicator that precipitates from the opportunity to have open conversations about the trajectory of their illness. Welsh Government had an aspiration (2012) that a similar marker could be the “number of individuals in Wales who die intestate”. ACP, as an intervention, similarly provides a prompt for individuals to write their wills. Welsh Government’s outcome measure has been found wanting to date. The application of ACP will not precipitate universal changes, but the trends in the consequences can be captured and measured. The acknowledgement from looking at the ‘outcomes’ is that they are proxy markers following the stimulus of the offer of discussion regarding future care plans. This emphasizes the patient’s own role in the situation - having an accurate understanding of their stage of disease and giving them authority to share their priorities of care. Or as Atul Gawande, author of Being Mortal, would phrase it:

> “Whenever serious sickness or injury strikes and your body or mind breaks down, the vital questions are the same:
> What is your understanding of the situation and its potential outcomes?
> What are your fears and what are your hopes?
> What are the trade-offs you are willing to make and not willing to make?
> And what is the course of action that best serves this understanding?”
> (Gawande, 2015)

1.3 Now what – the challenge of digitalisation

The ‘advance care plan’ is an intervention which could draw on Atul Gawande’s reflections. This could facilitate a change in experiences for those (and those meaningful to them) at the end of their lives.

This dissertation considers how the wealth of digital data that is now available can be utilised to identify individuals approaching their final phase of life. Dr Ollie Minton (senior medical editor at Macmillan Cancer Support) asserts that “what we don’t routinely do is work out when we [specialist palliative care services] should be involved” (Minton, 2024) He describes what palliative care teams do as being “unconsciously competent”. Identifying those where there is an opportunity for intervention, as in the rich picture, provides empowerment to the professionals (not exclusively the unconsciously competent) in initiating a different focus of care. It also brings empowerment for individual patients in contributing to their choices regarding care.

Rather than exploring the research question through the ‘four stages of competence’ (De Phillips, Berliner and Cribbin, 1960) the lens of the Rumsfeld matrix (Krogerus, 2023) will be used. Digitalizing clinical processes and data can be very challenging due to a number of factors (Borges do Nascimento et al., 2023). These have been highlighted in table 1.1. In its entirety this aspiration, of accessing digitalised data to identify those on whom to focus discussions regarding advance care planning, would need a larger group and take a longer time. So, this dissertation explores a smaller (more manageable) step which will inform the larger project.

Table 1.1: Top seven identified barriers to adopting Digital Health Technologies (DHT) (Borges do Nascimento et al., 2023)

1. Healthcare professionals perceived that infrastructure and technical barriers were significantly crucial to using DHTs
2. Healthcare professionals perceived that psychological and personal issues directly affect the utilization of DHTs
3. Fear of increased working hours and workload hinder the adoption and broad use of DHTs
4. Healthcare professionals are aware and alert to legal and ethical features of using DHTs, factors that interfere with the success rate of any DHT
5. Lack of training and educational programs causes a negative experience for healthcare professionals using DHTs, decreasing their use
6. The structure of the healthcare system and lack of financial support limit the use of DHTs
7. Interoperability and data incompatibility are conflicting elements in using DHTs

In studying the ‘feasibility of a prognostication aid to promote advance care planning’, the objectives are:

- Specifically – to increase the stakeholder’s awareness of the association of dying within 12 months of being an inpatient.
- Measurable – to track the mortality rates for all inpatients from a census date over the following 12 months.
- Achievable – to schedule one-to-one semi-structured interviews with stakeholders in order to appreciate their perspectives about the perceived feasibility of this project.
- Relevant – to demonstrate the appropriateness of the timing of the intervention of advance care planning.
- Relevant – to establish the level of engagement and enthusiasm from stakeholders.
- Time – to provide a report (dissertation) by 5th May 2025.

Finally, returning to the Rumsfeld matrix: the literature review considers what known knowns there are, focusing on the existing knowledge and experience that has been published. This interface of technology with the specialty of Palliative Medicine is rather limited, but as chapter 2 demonstrates it is an area of expanding interest. The following chapter on methodology is the focus on what is not fully understood (yet) and the basis of this initial piece of research - known unknowns. The results chapter provides recognition of the intrinsic experience and expertise. It captures the details of what professionals are unaware of encountering in practice – unknown knowns. Finally, chapter 5 will bring the discussion – unknown unknowns – as the research findings are weighed, applications considered and future projects postulated.

> “There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don’t know. But there are also unknown unknowns. There are things we don’t know we don’t know.”
>
> (Donald Rumsfeld, 2002)

CHAPTER 2

Literature review

Known knowns

2.1 Introduction

The ‘Lancet Commission on the Value of Death’ (Sallnow et al., 2022) encouraged us globally to reimagine how death and dying could be; and how hospice care could develop to meet palliative care needs (Bailey and Talbot, 2024). Identifying the possibility that death is approaching is a key component of this global aspiration.

Weisman (1972), a renowned psychoanalyst, described “middle knowledge” as a concept where simultaneous but opposing views of death could be held. On the one hand resisting the finality of death, yet simultaneously making plans for death (for example, will writing and funeral plans). Weismann describes the benefit of “assimilating and accommodating death at a manageable pace”. An advance care plan is a component of that transition (or “middle knowledge”) which is a tool, as a conversation starter, for managing the anxiety that death can raise; and ultimately empowers the individual to express their perspective. The adoption of a prognostication aid (in concept, at least) is a means of triaging the population at large. There are limited resources of time and personnel to support every person, accepting the inevitability of death, so being able to focus the available resources is essential.

2.2 Definition

The first term to define for clarity is ‘advance care planning’ (ACP). The challenge is that it can be described in a wide context but is increasingly difficult to define at the detailed level. NHS England (NHSE, 2022) provided an overarching definition in response to the call for a “consistent national approach to advance care planning” (CQC, 2021):

> “Advance care planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care.”

The terminology of ‘advance care planning’ is a recent neologism. This early description highlights the principles have hardly evolved: “a process of communication that aims to ensure that clinical care is consistent with patients’ preferences for care” (Teno, Nelson and Lynn, 1994)

The most recent definition remains hugely inclusive and builds on Fleuren et al.'s work (2020). They sought to identify the underlying objectives of ACP given the breadth and diversity of the perceived benefits. Their systematic review distilled the themes to five underlying goals:

- respecting individual patient autonomy,
- improving quality of care,
- strengthening relationships,
- preparing for end-of-life, and,
- reducing overtreatment

The review also collated the objections to ACP that were in the literature. Although the benefits were twice as documented as the objections ("141 codes concerning goals… 70 codes about objections" (Fleuren et al., 2020)), there remains a need to acknowledge the limitations of the 'intervention' of advance care planning. Table 2.1, as an analysis of the complexity, provides some of the principal arguments regarding ACP. These are not for exploration within this dissertation but are worth holding in mind throughout this research.

Table 2.1: Underlying goals of ACP and corresponding objections (Fleuren et al., 2020)

Underlying goal	**Objections**
Respecting individual patient autonomy	Promises more control than is possible; ignores current interests of the patient; denies that decision making is engaged and emotional
Improving quality of care	Risk of ACP to be regarded as moral imperative
Strengthening relationships	Shifts focus away from the patient; risk that children take over too early
Preparing for end-of-life	Risk of ACP to be regarded as panacea
Reducing overtreatment	Pressure to refuse treatment; distrust of the health care system; against nature

The intentions of ACP are reasonable and prudent, even acknowledging the objections arising from misapplied (or misconceived) application. A specific plan will contain much nuance and personalisation; but there are a number of documents and tools under the umbrella of advance care planning. For example:

- 'advance statements', or 'living wills', provide an indication of wishes and preferences.
- an 'Advance Decision to Refuse Treatment' brings a legal obligation to respect what has been recorded (as long as it is specific enough to the scenario under consideration). This is rarely as categorical as it might appear, but does add weight to patient perspective when considering what they might have considered important.

- ‘Lasting Power of Attorney’ (specifically for health and welfare, in this clinical context) is another aspect of future care planning that can be considered. This also brings a legal authority to the attorney.
- ‘cardiopulmonary resuscitation’ decisions are a form of (not legally binding) advance care plan. Clearly there are many aspects of care that can be considered, or preferences weighed, before the heart stops beating and decisions about cardiopulmonary resuscitation need making.

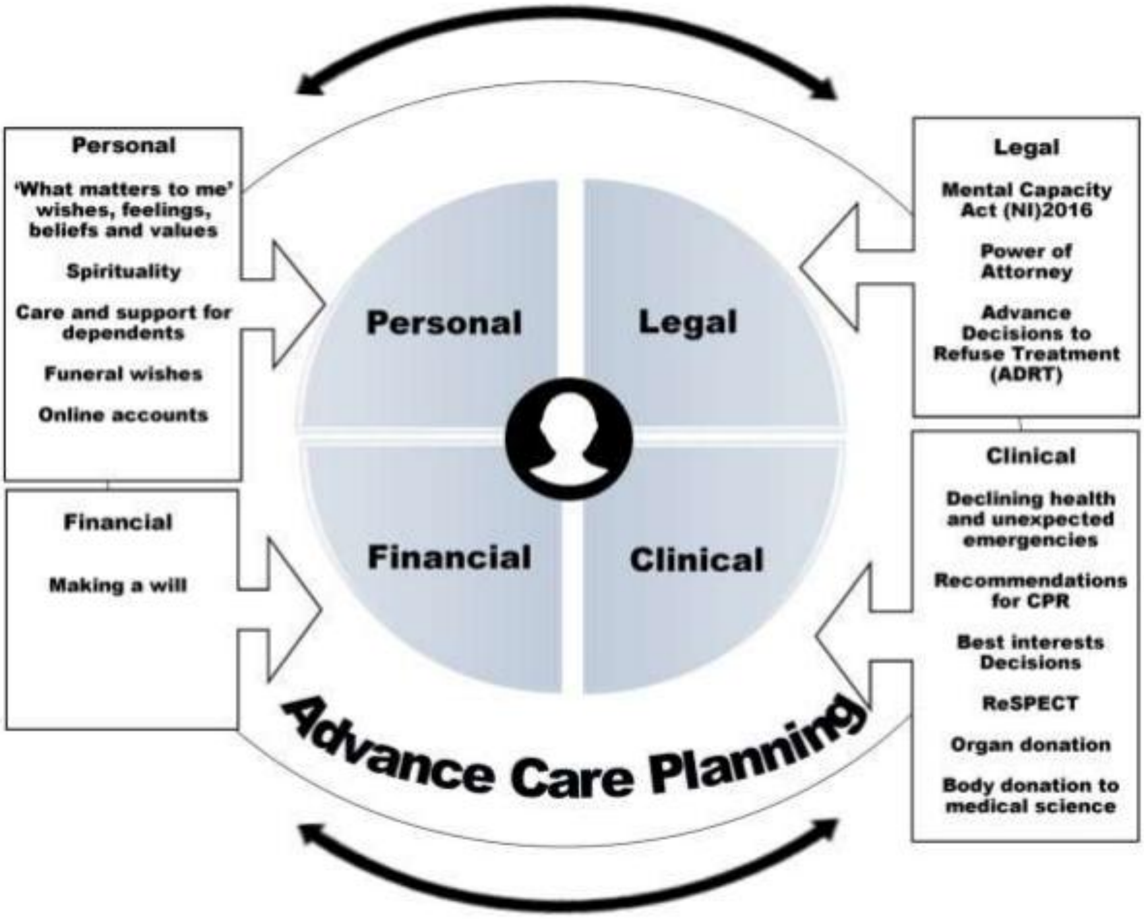


Figure 2.1: Components of Advance Care Planning (Department of Health, 2021)

Each aspect, and many others, could be characterised in their own contexts but the emphasis here is to consider the wider perspective.

One concern in the field is to identify those who will benefit soonest from having the opportunity to discuss and establish their preferences and priorities. Seeking to access digital resources in focusing effort on those within their last year of life aligns with the ‘prudent healthcare’ slogan of Welsh Government. Hence, identifying individuals with increasing burdens of illness, with, or without, declining functional abilities or those facing changes in their health and care needs enables that targeted approach. There is no compulsion to engage with this ‘planning’, but the aspiration – as with NHSE (2022) – is that individuals have, “a greater sense of involvement and the opportunity to reflect and share what matters most to them”.

Advance care planning is very much a process rather than an event. Discussions are often necessary over time with multiple actors contributing although the decisions about the plan rest with the individual. It is a dynamic process but one that raises the patient voice and empowers individualised care.

Figure 2.2: Advance care planning process

2.3 The Literature

Feasibility of a prognostication aid to promote advance care planning.

The application for ethical approval for this research is included in Appendix A. This provides assurance about compliance with ethical standards and the research's integrity. In addition, this is an emotive (and possibly contentious) topic, so it ensures that respect, trust and credibility are appropriately recognised.

The search strategy applied was to use the key words "palliative" AND "prognos*". This was cross-referenced with a search using the key words "deep learning" OR "machine learning" OR "artificial intelligence". The initial (scoping) search was simply through MEDLINE/PubMed; and only drew from the titles (mirroring Windisch's work, detailed below). There were no exclusion criteria, in order to maximise identification of potential research, given that this is a novel area of research (illustrated in figure 2.3). Specifically, given the evolution of this research area, there were no parameters to the timeframe (i.e., the search was performed across all years). This approach identified only one article, which was an editorial. The title actually posed a question – "Are prognostic predictions enough?" This cancer article started from the premise that continuing support from palliative care increased patient-reported and carer-reported outcomes (and experiences), better end of-life care communication and more chance of meeting preferences (Bakitas et al., 2009). The paper discussed in the editorial was by a Canadian group led by Jiang He (2024). They sought to explore the feasibility of machine learning as a method of using prognosis in order to optimise the (limitations in) palliative resources.

At least seven limitations were detailed in the discussion by He et al. This is where the challenge from the editorial arises ("Are prognostic predictions enough?"). An additional limitation is that the focus was on a cohort of cancer patients (appropriate to their remit – "machine learning to allocate palliative care consultations during cancer treatment"). Whereas, approaching this discussion from the palliative care perspective, patients with cancer are only a proportion of those needing support from specialist palliative care services.

As is acknowledged, in reality, there are multi-factorial components influencing care and decisions on all sides. He's group did boldly take on the challenge of including an assessment with their machine learning of moving from the retrospective realm to how it might perform in practice. Regardless of the limitations, the potential of the principle needs recognising. As an evolution of this thought, an interesting approach is being evaluated in cancer care – using machine learning to identify a subset of patients and prompting closer review by the clinicians. The result is “long lasting improvements in cancer care delivery”. The potential of extending this ‘nudging’ would be a valuable exploration across specialties. This single article illustrates the immediate and topical relevance of the question posed in this dissertation.

The earlier allusion to Windisch was due to their recent paper, ‘Leveraging Advances in Artificial Intelligence to Improve the Quality and Timing of Palliative Care’ (Windisch et al., 2020). Their approach was to review publications whose titles contain the word “palliative” and either of the terms “deep learning”, “machine learning” or “artificial intelligence”. This literature review is an extension of that starting point given the exponential interest in the clinical-digital interface. Indeed, Windisch’s work identified only four identified results through PubMed, up to 2020. The chart below illustrates the growth of interest in the subsequent four years.

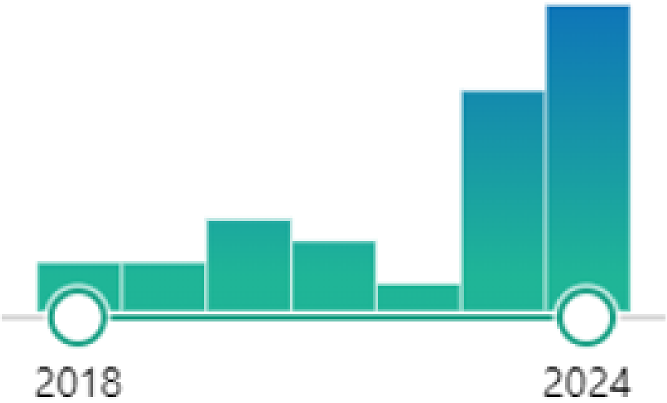


Figure 2.3: Windisch’s search, updated

Table 2.2: Search Strategy

Searches		**PubMed**	**Scopus**	**ScienceDirect**	**Cochrane Reviews**
1	“palliative”	33 765	42 670	11 577	32
2	“prognos*” (encompassing prognosis, prognostic and prognostication)	227 491	263 209	71 075	16
3	“deep learning”	29 177	135 487	19 888	0
4	“machine learning”	44 709	185 489	33 588	0
5	“artificial intelligence”	22 869	81 551	14 063	2
6	1 AND 2	411	449	147	5
7	1 AND 2 AND (3 OR 4 OR 5)	1	1	3	0
8	1 AND (3 OR 4 OR 5)	34	38	23	0

2.4 Discussion

The search strategy table identifies three further articles that were identified with the same approach as was used with the initial, exploratory, query discussed before. All three are published conference abstracts without associated papers. It is worth emphasizing here that as conference abstracts they will not have been peer reviewed in the same way that the other papers will have been. The oldest of these is from 2018 (Cho et al., 2018) where deep learning was harnessed to identify those with a prognosis greater than 3 months. The clinical intent was to guide where palliative oncology was appropriate compared to supportive care alone. Their accuracy was 0.70. Now, much could be considered, and deliberated upon, regarding that statistical summary; but the pertinent point is that this deep learning model was a step forward compared to traditional machine learning models, with potential to improve further.

The other two conference abstracts are identical, published in two different journals both from the European Society for Medical Oncology (Jung et al., 2023a; Jung et al., 2023b). They were able to show an area under the precision-recall curve (AUPRC) of 0.92. Without becoming distracted AUPRC, and ‘area under the receiver operating characteristic’ (AUROC), are recognised measures for comparing the performance of machine learning models. AUPRC has a reputation for being the better metric for ‘high-score mistakes’ and in scenarios where the population being considered is asymmetric. This would be relevant for prognostication as the extreme minority of people are going to die within the next week/month/year. There is a separate debate whether AUPRC is truly the superior metric (McDermott et al., 2024) but the potential of these digital tools is clearly developing.

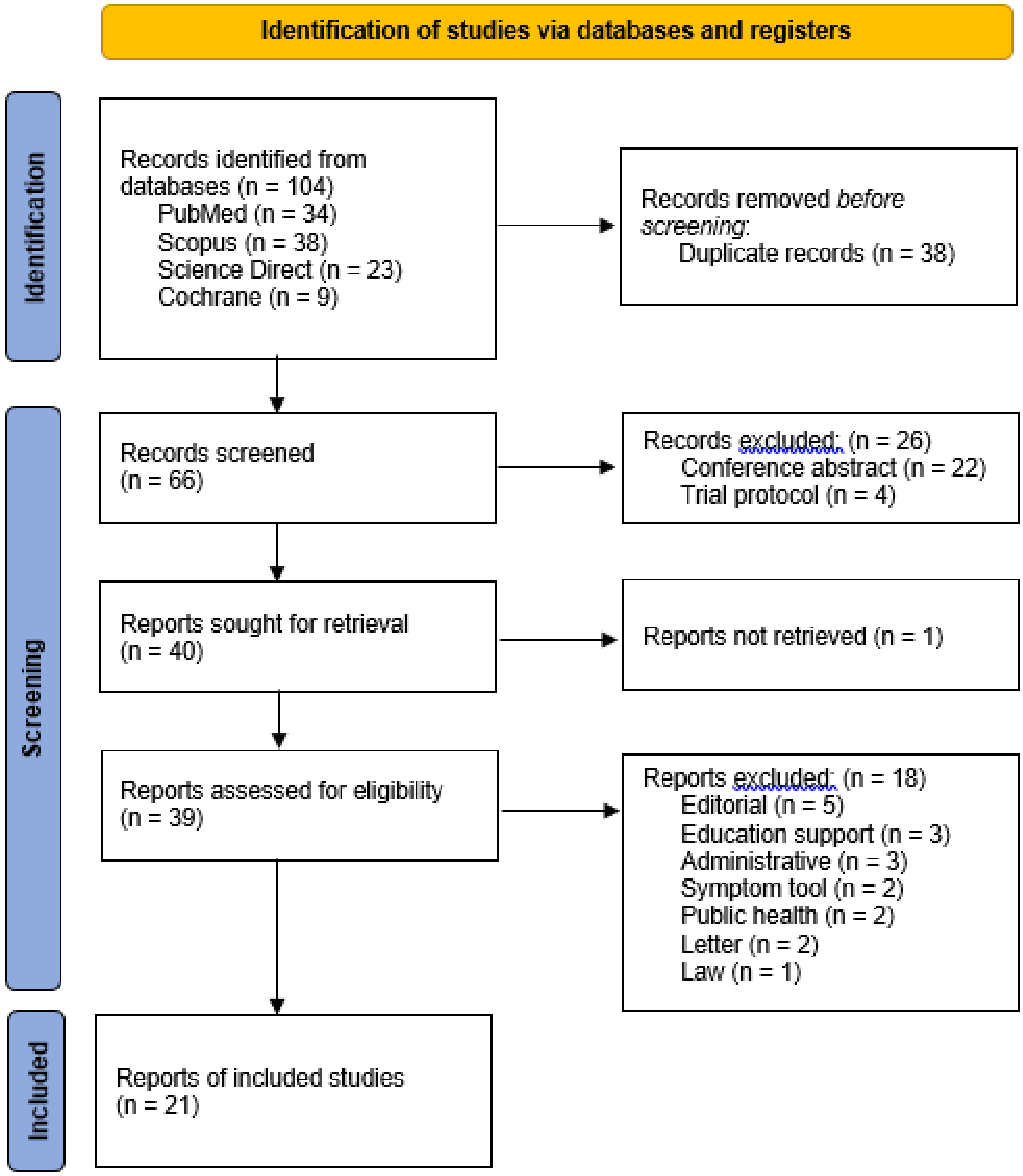


Figure 2.4: PRISMA 2020 flow diagram

Mendeley was used as the reference management system (Mendeley Reference Manager v2.52.0).

The concept of evaluating electronic health records to identify patients in need of palliative care has been a key objective since the earliest paper (Avati et al., 2018). The use of a mortality predictor, as the surrogate marker, is crude but does identify a number of patients for possible referral. The risk is that specialist palliative care becomes pigeonholed to end of life care rather than the spectrum of support it should, and does, provide. This first paper did lack detail, despite allusions to their "deep neural network". Moving forward, this chapter will seek to focus on the transferrable components of application. Early limitations, to declare, are that:

- The National Health Service is not as digitally advanced as other healthcare systems, limiting what is immediately achievable.
- Parallel care plans (active management and supportive care) are permissible; in contrast to the American system of choosing one or the other.

Shetrit, Daghash, and Sperling (2024) explored the ethical, societal, and legal challenges of implementing artificial intelligence in relation to the Israeli Dying Patient Act. No other identified studies have taken such a holistic and philosophical approach. While these are important considerations for the evolving technological landscape, they fall outside the scope of this dissertation.

The integration of digital health technologies within palliative care is absolutely a current worldwide conversation. A recent systematic review (Hamdoune et al., 2024) identified seven papers seeking to help with symptom management for cancer patients receiving palliative interventions. These seven papers arose from five countries. In addition to the 'first world' countries there was a contribution from Kenya and from Tanzania. Arguably the Kenyan intervention ("telephone monitoring" (Cornetta et al., 2023)) would be considered to be standard practice in this country, whereas the Tanzanian ("mobile palliative care link", a web application (Ho et al., 2022)) offers a novel opportunity. The concerns identified fell into two broad categories:

Table 2.3: Factors influencing adoption of digital health technologies in palliative cancer care (Hamdoune et al., 2024)

People	Technology
Professional commitment	Availability of technological resources
Perceived usefulness	Connectivity
Familiarity with technology	Software problems

These themes frequently arise at the intersection of digital technology and clinical practice and can help identify potential barriers. While both the British, through Dame Cicely Saunders, and the Americans, through Elisabeth Kübler-Ross, played pioneering roles in palliative care, valuable insights can be gained from global perspectives. Ideally, palliative care remains an inclusive and evolving field, rather than one confined to an academic or clinical 'ivory tower'.

As a final comment on the global experience; several groups in India have challenged the current technologies (specifically ChatGPT and Google Gemini) with palliative care scenarios (Gondode et al., 2024; Gupta and Gupta, 2024; Srivastava and Srivastava, 2024). Their intent is to empower generalist clinicians to improve patients' overall care in palliative medicine. However, the caveat is for "vigilant adoption" and an acknowledgement that "it should not be seen as a replacement for physicians' unique skills and decisions in providing patient-tailored care" (Gupta and Gupta, 2024).

Patel et al. (2024), published after the above searches were run, highlights the current interest in this topic. Starting from the recognition that "discussions about EOL [end of life] care are associated with earlier hospice enrolment, less aggressive care and improved quality of life." (Prigerson et al., 2023; Wright et al., 2008), this American study sought to target advance care planning discussions in patients with cancer. They applied technology to help identify those at high risk of dying having been admitted, as an emergency, to the oncology ward. The system triggered an alert to the clinicians about the mortality risk, who then could factor that in to the clinical management. The impact was that advance care planning conversations were documented for over 80% of patients following introduction of the alert, compared with only 2.3% initially. Extended observation of this patient cohort did not identify any differences in a number of quantitative parameters. The authors conclude that there was "a substantial increase in documented ACP conversations but did not impact EOL care". This paper focused on hospital-based outcome measures whereas the opportunity also rests with qualitative, experience measures; which were not assessed on this occasion. Although this considered a single ward at a single hospital, through the evaluation of electronic health records (acknowledging that undocumented conversations occur but recall is inconsistent), the authors highlighted the change in clinician behaviour that is possible and the potential for improving "downstream EOL care outcomes".

2.41 Mortality prediction in Oncology

Staying with the field of oncology, in addition to the most recent article (He et al., 2024), there have been two further papers published over 2024 using technology to stratify the mortality risk. The first (Cilla et al., 2024) seeks to use machine learning to aid prognostication for those receiving radiotherapy for bone metastases. A specific patient cohort but they did identify that, a "higher chance of 1-year survival is associated with low values of interleukin-8, higher values of hemoglobin and lymphocyte count, and the nonuse of steroids" (Cilla et al., 2024). None of these are novel parameters considering the wider oncological literature. The reflection is that these findings do not lend themselves entirely to screening outside of the research setting. The authors do postulate that, a traditional indicator of, performance status – a measure of one's abilities to carry out activities of daily living – was discounted by the learning model as it is more pertinent to short-term survival.

The other paper (Zhuang et al., 2024) studied a wider patient group; patients with any cancer at stage 3 or stage 4. These 'stages' are the more advanced stages of disease. Using "short-term mortality as a surrogate for identifying patients with high probability of palliative needs" enables appropriate focusing of individualised care. The findings were also presented in a different way: rather than a binary result (mortality risk or not), they illustrated the influence of the nine parameters for individual prediction in a "decision tree". Again, several are biochemical markers, but this group have drawn from standard blood results, which are more likely to be available. Regarding the real world this presentation, helpfully, recognises the spectrum of risk. The challenge is that the lack of definition will not enhance the immediacy of decision-making.

The most recent article (He et al., 2024) does conclude that, "prognostic machine learning systems could increase early PC [palliative care] despite existing resource constraints". This gives encouragement but appears to remove the human elements from the experience.

2.42 Mortality prediction outside Oncology

As an extension beyond the field of oncology the role of palliative care for those suffering traumatic brain injury (TBI) was also explored (Aude et al., 2024). The recognised starting point was the impact of a palliative care consultation on focusing care, (identifying goals, reducing unnecessary investigations and reducing the length of hospital stay (and the associated cost)), without affecting the mortality rate. The conclusion from the study, through machine learning, was of an inconsistent approach currently. For example, within the paper two of the ten most influential variables were identified, independently, as 'race: white' and 'race: black'. The authors finally put forward a challenge "for targeted strategies to ensure timely and equitable palliative care integration for this vulnerable population". This emphasizes the opportunity of 'advance care planning' style input across the wider medical environment.

A triaging approach has been attempted in several other medical environments. One of the earliest pursuits in applying a deep leaning algorithm in predicting mortality, in order to enable earlier palliative care support, was by Wang (Wang et al., 2019). They considered a subset of patients with Alzheimer's dementia. Their retrospective analysis showed that the top-ranked predictive topic for mortality at each of their endpoints (6 months, 1 year and 2 years) was the involvement of palliative care. Subsequent modelling has explored the different dementia subtypes. Whereas Wang originally considered 2500 patients, recent work (Zhang et al. 2024) analyses 45000 patients. The outcome from this wider analysis was that there were nine identified variables for multi-factorial computation for mortality risk with unspecified dementia. (Paradoxically some parameters, e.g., "more years of smoking", "became more associated with survival than with mortality"). These resulted in an AUROC of over 0.82 at the one-, three-, five- and ten-year time points. This is consistent with a "strong discriminative ability" (de Hond, Steyerberg and van Calster, 2022).

A surgical attempt was with digital prognostication (at 30 days and 1 year) for older patients with hip fracture (Cary et al., 2021). The AUROC for both of these time points was over 0.75. The starting point for this American group was the availability of an electronic medical record. The power to triage and then allocate (palliative care) resources effectively is a consequent opportunity. This does highlight the integrated dependency of digital systems, which brings additional complications for UK health services.

Demonstration of the potential is available. In Pittsburgh the electronic health record system was 'trained' to identify individuals hospitalised with intermediate, or high, risk for dying within 90 days (Oo et al., 2023). The outcome measure was "goals-of-care conversations" which is a synonym for the anticipatory care planning being discussed throughout this dissertation. The electronic alerts that were initiated resulted in a doubling of the conversations that were held, from 78 a month to 166. The foundational aspect, which is not transferrable, yet, is the established resource of the electronic health record. Oo's ability to interrogate half a million patient records, across five years is admirable; even if he was restricted to a single institution on this occasion.

2.43 Mortality prediction in Primary Care

These articles are all American, where electronic health records are established. It is interesting to consider the current activity and where this dissertation could extend to. The emphasis for this dissertation, as seen in the earlier rich picture (figure 1.1), is for an index hospital assessment being the trigger for conversations regarding advance care planning.

Firstly, to our American experts. As a concept in the settings where healthcare is paid for Zhang (2021) developed a "Generalized Machine Learning Pipeline". This intervened at the billing stage of medical care to identify those with perceived greater risks of mortality. This was only for patients with at least one of twelve chronic conditions more likely to predispose them to dying in the following year. Acknowledging that the American healthcare model is different, this approach still had a high false positive rate – that is those identified as likely to die within twelve months did not. As an evolution, Bowers et al. (2023) sought to identify features for predicting patient mortality in the American “older community dwelling” group. Despite drawing out a number of parameters, including some less acknowledged elsewhere (e.g., “pharmacy utilization”); the final model only correctly predicted 44.2% of patient deaths. Although an improvement on the previous model, with 24% predictive accuracy, the gap until clinical utility remains.

Although not the immediate focus, looking at ‘actigraphy data’ (that is activity measurement) (Huang et al., 2023) alongside clinical information to inform patient outcomes in palliative care has been considered. An increasingly technological future provides opportunities to harness common resources such as Apple watches in holistic reviews. This may be more suited to true assessment of performance status, and appropriateness to treat aggressively given the associated side effects, at an earlier stage of clinical management. However, an open mind needs to be kept given the breadth of technological potential.

An American analysis (Rotenstein et al., 2024) of a primary care population looked at the correlation of automated mortality tools with physician opinion regarding the need for advance care planning. (‘Serious illness conversation’ being the American terminology for, “discussions on a myriad of topics, such as prognosis, goals of care, advance care plans, cancer treatment decisions, and end-of-life care” (Bernacki and Block, 2014)). Although assessing risk as merely high or low at a one-year time interval there was a degree of correlation. (Again) The clinical utility of such a prompt in an unselected patient cohort is less clear.

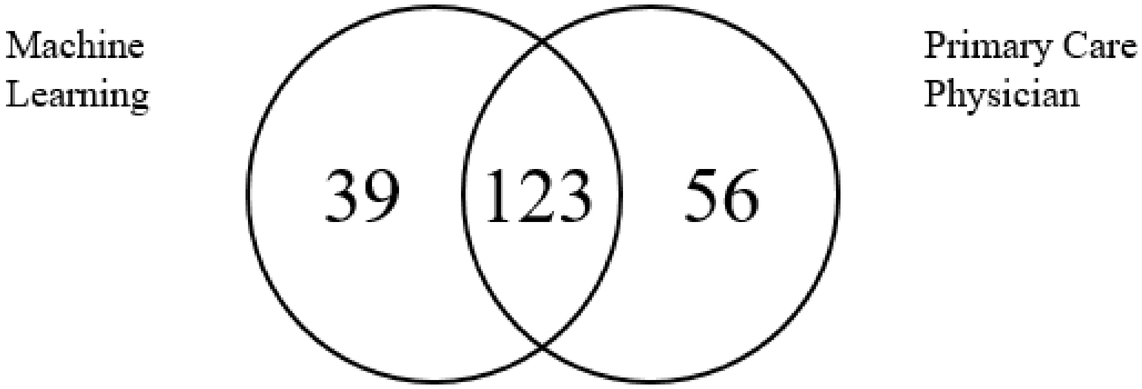


Figure 2.5: Venn diagram illustrating Rotenstein’s findings (2024)

Windisch’s aspiration seems challenging to extend, as has been highlighted throughout this chapter. A number of reservations in application have been identified (Courtright et al., 2019; Enguidanos et al., 2019). Heinzen’s team took on the challenge of “an outpatient-focused pragmatic clinical trial to examine the effect of machine learning on referral to palliative care” (Heinzen et al., 2023). This trial protocol from the Mayo Clinic is focused on primary care as the site of intervention. Following the algorithm’s identification of the ‘top 40’ (from 119 000) patients with the “highest predicted palliative care score”, the primary outcome is time to palliative care consultation. There is a dependence on accurate coding to exploit the benefits of electronic health records for this study given that palliative care may be possible by the usual care providers (i.e., no requirement for specialist palliative care input). Secondary outcomes, specifically number two: “number of advanced care planning notes documented in the electronic health record in each arm”, would be of interest to this dissertation. The timelines of reporting and publishing may limit this insight.

2.44 Mortality prediction at admission

Returning to this dissertation with its focus on hospital admission as a trigger point for evaluation, there are two additional publications to consider. A Swedish group looked at Emergency Department attendances and the likelihood of death in the 30 days after discharge (Heyman et al., 2021). Over 75% of deaths were "unsurprising" to the clinical team, so already identifiable. The reviewing panel noted that, "92% of visits were non-preventable". They simultaneously noted that, "23.0%, could have been avoided if preceded by a discussion of EOL prognosis and planning". The paradoxical commentary in this article also did not detail the false-positives identified through the machine-learning tool. Although several models were able to identify more deaths that subsequently occurred the clinical utility across healthcare services is limited. Rather than re-inventing the wheel; enhancing communication between primary care services and acute assessment services (ideally a digital step forward) would facilitate sharing of existing care planning.

Elsewhere, a Spanish team (Blanes-Selvaet al., 2021) designed a model for predicting 1-year mortality based on observations at hospital admission. This is more aligned to this dissertation's aspiration. They demonstrated that 36 features could create an AUROC of 0.9 at their hospital (single unit). This is the most robust model so far and better than the 13654 features necessary for Avati's model (Avati et al., 2018).

2.5 Conclusion

In conclusion, there has been limited progress since Storick's rapid review (Storick et al., 2019) of machine learning in the end-of-life care sphere concluded that "applications to policy and practice are formative". Where Windisch's systematic review (2020) identified four publications of potential relevance, the more recent reviews have greater focus (Vu (2023) identifying 15 publications considering machine learning for mortality prediction). Some commentators reflect that there is much more focus where there is "commercial potential". However, end of life care does not offer the profit margins the (largely American) literature seeks.

The limited research does focus on mortality prediction as the most dominant component between palliative care and the digital technology. It is reassuring that it has been recognised that, "predicting mortality…is a proxy problem for the need for palliative care, which is much harder to define" (Vu et al., 2023). The recurring themes from the literature are:

- there is a starting assumption of an electronic health record (albeit this is valuable with retrospective assessment and development of prognostic features, the contribution prospectively is less).
- the disease specificity of the developed prognostication tools.
- moving from the research environment to one of clinical utility is proposed as the next development.

This last point requires the contribution of clinical teams to complement the research and digital teams. Each of the articles concludes, in one way or another, that further engagement at the clinical interface is necessary. The importance of promoting advance care planning and anticipating care is embedded as good practice. The opportunity to recognise these individuals, using prognostication as a means of focusing resources, is the elusive goal. A cohesive approach will shape the development of digital opportunity into routine care. As part of that aspiration, this dissertation explores the feasibility of a prognostication aid (generically rather than disease specific) within the local healthcare service.

CHAPTER 3

Methodology

Known unknowns

3.1 Introduction

This chapter will consider the research onion. The research onion (figure 3.1) provides a template for a holistic approach to the methodology. It demonstrates the reliability and credibility of this research, ensuring its foundations are solid.

Without regurgitating the entire model, the six layers are:

1. Research Philosophy
2. Research Approaches
3. Research Strategies
4. Choices
5. Time Horizons
6. Data Collection Methods

These help to justify the approach in this research: from the broad aspects of the beliefs underpinning the interpretation of the research question (i.e., the philosophy) to the specifics of the data collection and analysis.

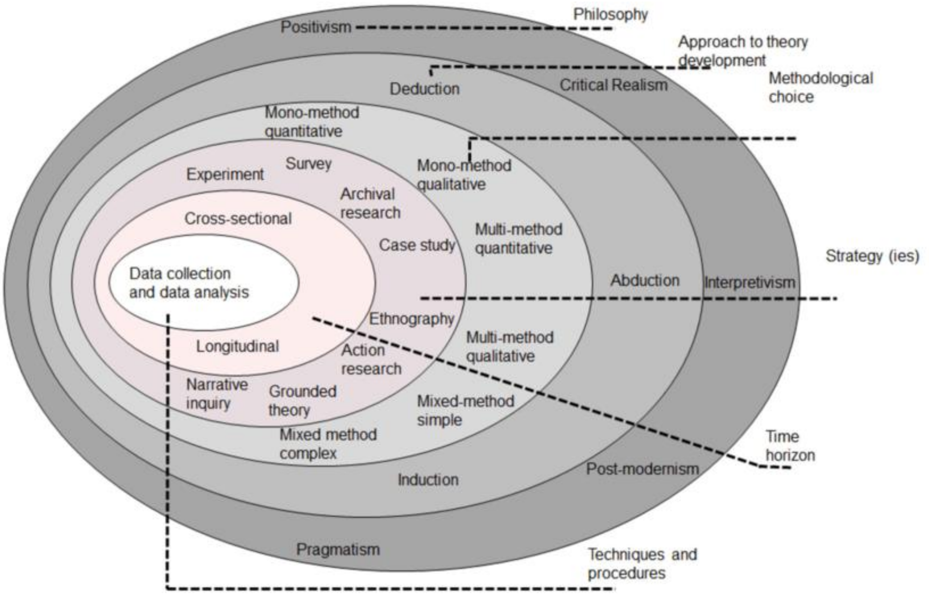


Figure 3.1: the research onion (Saunders, Lewis and Thornhill, 2019)

The research question posed - feasibility of a prognostication aid to promote advance care planning - requires some triangulation. Specifically, a quantitative component is essential to the later qualitative aspect as the published findings (Clark et al., 2014) appear implausible. Demonstrating the local profile of the hospitalised cohort will localise the subsequent discussion and add value in identifying where holistic support can be targeted.

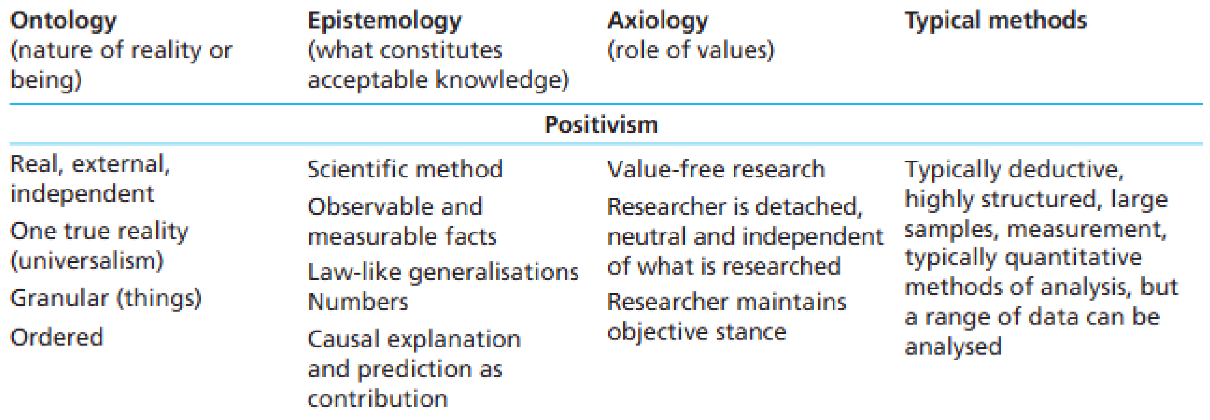
3.2 Justification for approach

This section will draw out the rationale behind three methods. The first is the narrow focus that is necessary for the quantitative component. Before consideration of the wider, interactive methods required to capture the lived reality (and perspectives) from the qualitative component. These two aspects will complement each other in understanding the feasibility of the use of a tool in identifying those in their last year of life that might be available. The final sub-section will introduce the tools being adopted for the data analysis. These methods, in combination, will enable appreciation of the feasibility of a prognostic aid in promoting advance care planning.

3.3 Quantitative

This aspect starts from a philosophy of positivism (in contrast to: critical realism, interpretivism, postmodernism or pragmatism (Saunders, Lewis and Thornhill, 2007)). Short of deviating to explore these philosophical starting points, table 3.1 draws out the pertinent points of positivism. The terminology has also been clarified, so the transparent and objective features will be evident.

Table 3.1: Defining positivism (Saunders, Lewis and Thornhill, 2007)



Ontology (nature of reality or being)	**Epistemology** (what constitutes acceptable knowledge)	**Axiology** (role of values)	**Typical methods**
	Positivism		
Real, external, independent One true reality (universalism) Granular (things) Ordered	Scientific method Observable and measurable facts Law-like generalisations Numbers Causal explanation and prediction as contribution	Value-free research Researcher is detached, neutral and independent of what is researched Researcher maintains objective stance	Typically deductive, highly structured, large samples, measurement, typically quantitative methods of analysis, but a range of data can be analysed

The reality of the outcomes for those admitted to hospital has been seen in Scotland (Clark et al., 2014). Despite publication, the figures remain at a point of incredulity. The intention is to simulate a similar study across North Wales to explore the local experience of hospital admissions. Having local data that can be ‘posited’ – that is put forward as fact or as a basis for discussion – will add credence (or not) to the subsequent qualitative discussions.

3.31 Prevalent cohort study

On a census date, what proportion of inpatients, in North Wales, will die within 7 days, 30 days, 3 months and 6 months?

A comprehensive purposive approach was possible. There are three district general hospitals across North Wales, all providing emergency care and acute admission. The inclusion criteria were being:

- at least 18 years of age at the time of admission
- a hospital inpatient on 1st July 2024 (that is that they had a date of admission 30th June 2024 (or earlier) and a date of discharge 1st July 2024 (or later)

Excluded were:

- Patients admitted to obstetrics
- Patients admitted to psychiatry

These were used in order to correlate, most accurately, with the published paper from Scotland (Clark et al., 2014). Community hospitals, 'geriatric long stay' units and elective operative sites were similarly excluded given their less acute profile. The observed measure was whether the census cohort were alive at the specified time points.

For absolute clarity, as detailed in the ethics submission (see Appendix A), there were no patient details necessary for this aspect of the project. The focus was at an epidemiological level so zero requirement for any individual identifiable information. The local informatics department ensured the shared data was summarised appropriately.

3.4 Qualitative

In isolation, this qualitative component would hold a philosophy of interpretivism. Interpretivism emphasizes the human component of research. It seeks a richer understanding acknowledging that the world is a place of non-conformity - that healthcare is an art and not a science (i.e., it is not comprised of universal 'laws'). However, in alliance with the outcomes from the quantitative research above, it is more akin to an approach of pragmatism. This philosophy would declare that, "pragmatism asserts that concepts are only relevant where they support action" (Kelemen and Rumens, 2008). This dissertation focuses on a clinical challenge and its research problem. Clinicians reside in applied reality (rather than the theoretical academic environment) and seek practical solutions. Hence the engagement necessary with this qualitative component to understand the feasibility of this practical solution and whether it might inform practice.

3.41 Semi-structured interview

Semi structured interviews were arranged with a range of professionals. A deliberate choice was to look beyond the specialty of Palliative Medicine and engage with clinicians palliating patients. (Specialist Palliative Care being involved with the complex minority rather than the clinician supporting their more generalised palliative, with a small 'p', population.) Approaches were made to several medical doctors and clinicians across several departments.

Time was set aside to protect these “conversations with a purpose” (Burgess, 1984). Initially details of the dissertation were shared alongside the rich picture (figure 1.1). An explanation as to the aspiration of the project, and specifically this phase of considering its feasibility. Consent was given for recording of the conversation in order that the details could be accurately recalled. The potential for review (or withdrawal of consent) by the interviewee was also made. The intention was that although there was a core of open questions these guided the interaction rather than forming a formal interview. The prompts ensured that the essential ideas and components were explored, typically according to the anticipated flow of the questions, but also provided the opportunity for some topics to be unpicked in greater detail. Face-to-face interaction enabled active listening (specific examples were: the reading of body language, clarifying nuances and reflection) and sensitivity in gaining a richer context in deviating (at times) from the script. This freedom to express views (or for the interviewer to probe and explore) brings added value in testing the feasibility of this research proposal. The output measure from the semi-structured interviews is the dialogue itself.

3.5 Data analysis

The quantitative data in this research is essentially a nominal variable. Therefore, for this study there is only consideration of a single outcome making univariate analysis appropriate. The categorical data results in the descriptive analysis focusing on the degrees of association rather than any central tendency. More specifically, it considers the degrees of dispersion in numbers and percentages, as the pertinent aspect – how mortality data (as categorical data) varies across time (as the range). (Bartley and Hashemi, 2021)

Statistical summaries for all the data was possible. Descriptive analysis will be the focus as the intent is to consider the trend of deaths over time. Statistically, given that there is no ‘intervention’ and that the data is non-parametric, a time series analysis is appropriate. Theoretically, the Mann-Kendall test could be used to assess whether a trend is present (Kendall and Gibbons, 1990). An upward trend would demonstrate that the number of those who died increased over time; but that is nonsensical given the same study population is being assessed. The binary observations (being alive or deceased) do not necessitate extensive statistical analysis.

The, second, qualitative component is dependent on familiarity with the data. Thematic analysis is appropriate for this small-scale exploratory study. Braun and Clarke’s (2006) framework of steps (as in table 3.2) was the approach adopted, using their caveat that the steps are not required to be linear.

The fourth step will be important in teasing out the subtleties of the discussions – whether the identified themes are too broad, their degree of overlap and /or presence of subthemes. Through review and iterative cycles, the themes will crystallise and be validated (even if time prevents a fuller peer review component to that process of validation). The credibility of this approach has been reinforced by asking for review by a more experienced researcher (albeit without the same investment of time) to ensure that no gross themes have been overlooked. (Ruona, 2005) Comparison of the semi-structured interviews was possible as there was the core of initial questions available. However, analysis was not so discrete.

Table 3.2: Six-phase framework for doing a thematic analysis (Braun and Clarke, 2006)

Step1: Become familiar with the data
Step 2: Generate initial codes
Step 3: Search for themes
Step 4: Review themes
Step 5: Define themes
Step 6: Write-up

3.6 Limitations

Even at this point, of methodology, there are evident constraints to this dissertation. Superficially, they appear inter-related, but these will be expanded within the discussion in chapter five. Language as a barrier is often identified as a limitation (Kakilla, 2021) within qualitative research. Regarding this research, the associated risk would be of technical jargon rather than language per se. In the medical context, acronyms are an example of such ‘jargon’ that can cause confusion and impact patient safety (Brunetti, Santell and Hicks, 2007). The pressing challenge for this piece of work is the time factor in order that it is available within the academic timeframe. There is inherent bias with the individuals approached to participate in this research. They are more engaged and have the required experience and confidence to talk. The consequence of this expediency is that the sample composition for the qualitative semi-structured interviews will not be generalizable. Another limitation is the experience of the researcher; or as Jansen (2024) reflects, “we don’t know what we don’t know”. Hence, it is appropriate to return to this topic within the discussion.

3.7 Discussion

The quantitative methodology is more objective, so this section will discuss the qualitative approach taken and the data analysis methodology. Qualitative research provides the tools to explore the complexities, and nuances, of healthcare. However, that is an encompassing term so the three principal approaches to qualitative research, (surveys, focus groups and interviews) will be considered. Following that, there will be some focused discussion as to the relevance of thematic analysis given the limited number of interviews possible and their inherent nuances.

3.71 Survey

Surveys, and particularly online surveys, offer a degree of ease through their design stage and distribution. There is the potential to garner a large amount of data quickly due to the relative ease of administration and circulation. In addition to this accessibility, surveys and feedback forms have become familiar to professionals requiring little introduction. However, this can also be a disadvantage; survey fatigue is an increasingly acknowledged limitation – even to the point of “undermining rigorously designed studies” (Brown et al., 2024). Technical aspects and computer literacy also continue to present barriers. Even with the current workforce, digital literacy must not be assumed – “7% of adults in Wales are not online” (Digital Communities Wales, 2023). This brings some bias but self-selection bias is a greater risk. This would be short-sighted and individuals may well exhibit other answer prejudices (such as acquiescence bias or courtesy bias), negating the nuance necessary here (Kalton and Schuman, 1982). This is the biggest barrier to using surveys for this dissertation research – a blinkered view lacks the richness and detail of other approaches. The novelty being considered in this feasibility study demands some reflectiveness and flexibility in moving towards its application.

3.72 Focus groups

Focus groups provide a forum for creative insights and developmental evolution. The dynamics within any group can promote discussion and debate. The multiple perspectives and shared experiences add colour to the initial template, elevating the development and application of a research project. Focus group studies are not a timesaving alternative to interview studies (OHID, 2020), but do bring the greatest challenge - the logistics. Being able to coordinate the relevant group at a mutually convenient time (within the constraints of this academic year) must not be underestimated.

Although focus groups enable more perspectives to be captured the nuance and exploration of these is limited. Within a group the dynamics should be manageable with an experienced facilitator (e.g., strong opinions should be mitigatable), but the potential for ‘groupthink’ remains. The “potential pitfall of censoring and conforming” (i.e., ‘groupthink’) is well-recognised (Carey and Smith, 1994) but management of it is elusive. Therefore, there is an inverse relationship - the depth of insight is lost as the breadth of opinion increases. One approach to mitigating ‘groupthink’ is to have groups facilitated by a professional in this area. This would need a larger project group, and is drawn out more in the discussion of limitations in section 5.6. This, current, research project seeks to understand the clinical utility of a tool so the greater the colour, the greater the degree of insight, the better.

3.73 Semi-structured interviews

Returning to semi-structured interviews, their strength (relevant for this project) is in providing depth and insights into experiences and perspectives. There is the opportunity to clarify anything unclear and to develop points of nuance. This flexibility in its structure facilitates authentic conversation leading to greater insights. It brings power through depth rather than by volume of data. The principal concern, as introduced above (section 3.3), is that bias undermines the validity of this approach. The interviewer’s preconceptions are going to be an influencing factor with the open conversation. (Ruslin et al., 2022)

Figure 3.2: Qualitative analysis methods (Timalsina, 2024)

3.74 Data Analysis

Figure 3.2, as an overview, illustrates the scope of qualitative data analysis methods available and the deviation that a comprehensive justification would necessitate. So, rather than critiquing each framework, this section will advocate why thematic analysis is going to be most productive and insightful. It is important to identify the similarities in individuals' perceptions of the feasibility of the application of this tool. In addition to identifying themes, there is the opportunity to spot the differences in responses (and potentially delve into why this is the case). A parallel strength with thematic analysis is that some interpretation of the thoughts and ideas is possible. The loudest or commonest opinions are not always the most insightful – giving authority to the quiet insightful observation adds to the richness of this approach to analysis. It adds to the ability to draw descriptive and explanatory conclusions.

As a method of analysis, there are some points of concern to highlight. With respect to the limitations of this sub-section, it is important to recognise that this dissertation is context specific, which will reflect into the research and analysis. The consequence of this specificity is that the generalisability is going to be limited. The additional challenge is that as this project's subject matter has some nuance to it, it brings potential complexity.

These challenges are best addressed through a 'theme and explore' approach. The (relatively) small data set, with its complex subject matter can be drawn out to identify the key concepts. Quotations will add colour, and relatability, to the subsequent discussion.

3.8 Conclusion

In summary, this project incorporates quantitative and qualitative strands. The quantitative aspect was able to take a comprehensive sample. It seeks to demonstrate the local profile of inpatients and their anticipated mortality indices. This then informed the qualitative component. Purposive sampling was used to draw out thoughts (from key stakeholders), through semi-structured interviews, regarding the feasibility of a tool to recognise those more likely to die within 12 months. This research is dynamic and interactive; hence, thematic analysis was the most appropriate way to distil the topics raised. The overarching limitation for this research was the restrictions of the timeframe. Stakeholders were limited by their availability; independent interviewers were not possible and there was minimal opportunity to revisit themes (akin to Delphi studies).

However, this dissertation does provide an insight into what might be achievable and its acceptability to clinical practice. It begins to build another bridge between the wealth of digital data being held and the utility of application. This is increasing the awareness and understanding of this interface, raising the profile and moving knowledge to the ‘known knowns’.

CHAPTER 4

Results

Unknown knowns

4.1 Introduction

This chapter draws out the pertinent features of the results in this research. The quantitative aspect is more structured aligning to the work by Clark et al. (2014). In contrast, the thematic analysis from the semi-structured interviews is more subjective. Inductive analysis (Naeem et al., 2023) enables an open-minded approach to identify the unexpected, outside of any theoretical constraints. These will provide the springboard for the discussion in the next chapter.

4.2 Mortality data

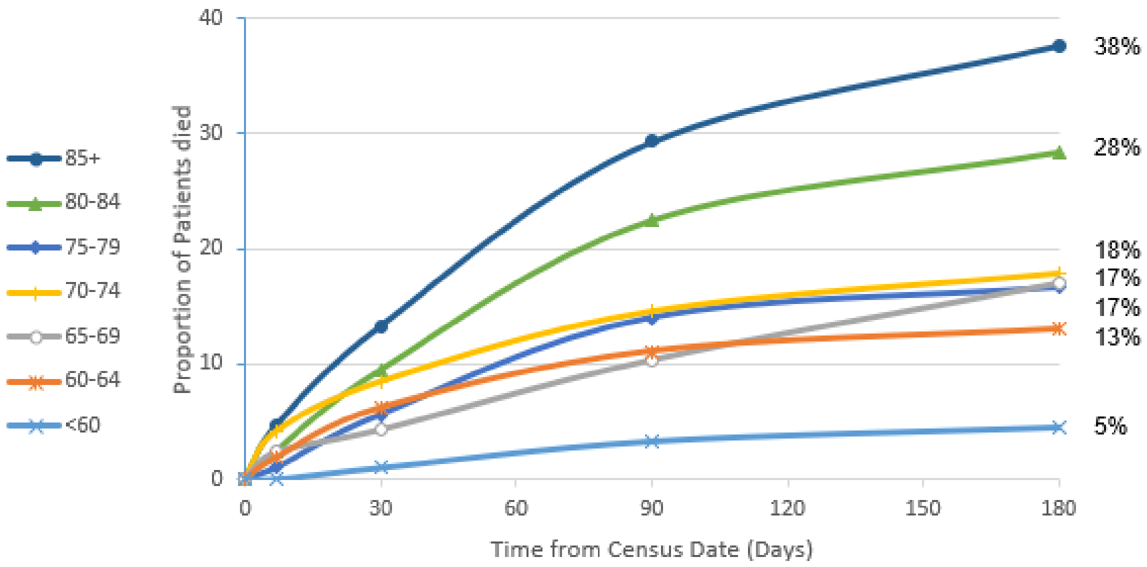
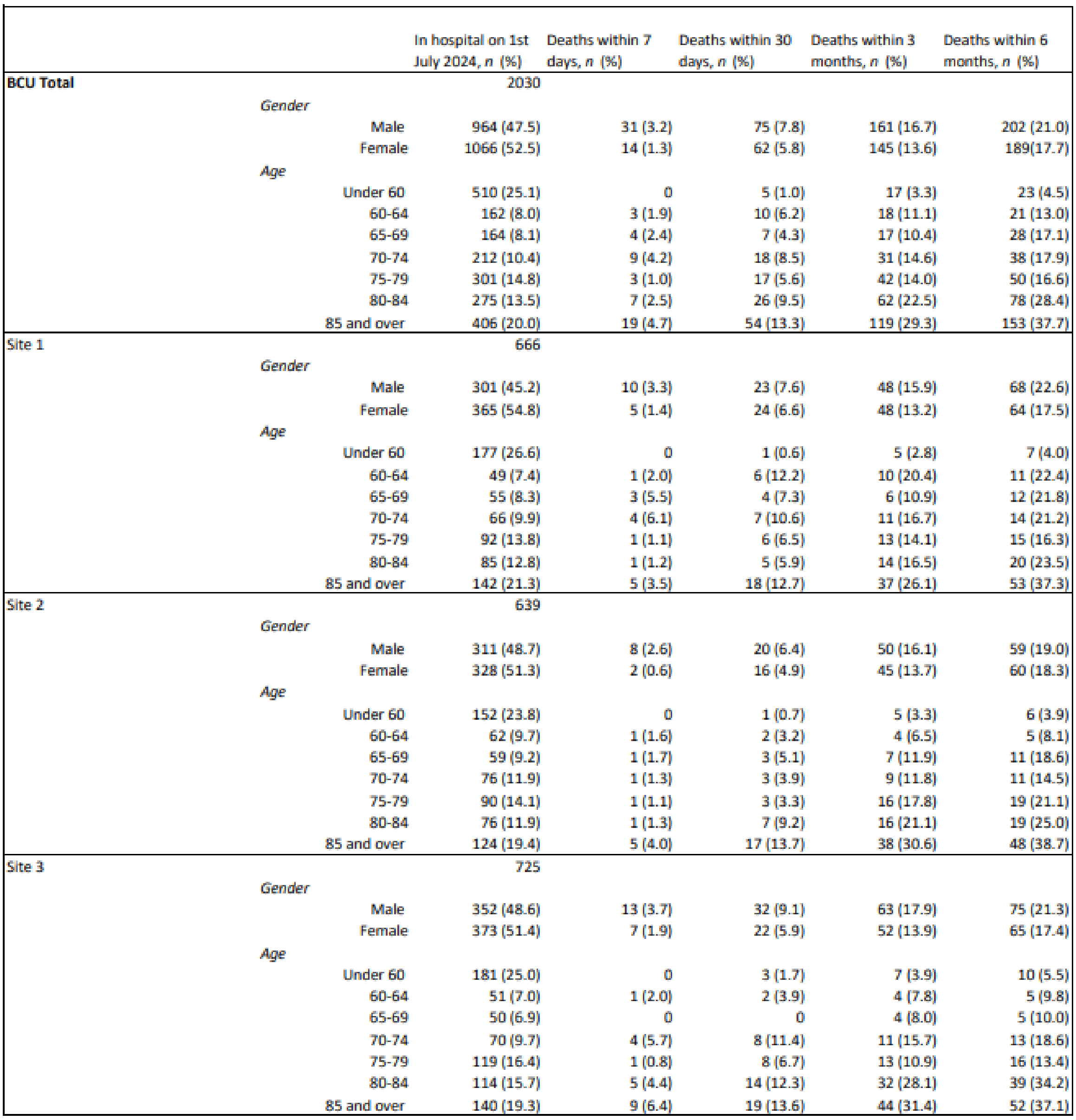


Figure 4.1: Mortality over time by age

2030 patients were identified on the census date. More were women (52.5%) than men (47.5%). A fifth (20%) were 85 years of age or older, and over two thirds (66.8%) were aged 65 years or older.

Table 4.1 shows the full raw data. Consolidating this information, it can be seen that 2.2% (45 of the 2030 patients) had died within 7 days of the census date, 6.7% (137 patients) by 30 days, 15.1% (306 patients) by 3 months and 19.3% (391 patients) by 6 months. At each analysis point, detailed in table 4.1, men were more likely to have died than women. Figure 4.1 illustrates that the mortality rate increased with age. The mortality rate was over seven times higher for those over 85 years of age (37.7%) compared to those under 60 years of age (4.5%). Considering the odds ratio for mortality, they range from 4.68 for those under 60 years of age to 59.28 for those over 85 years of age using the crude death rate (Statista, 2025). Using older, age specific, mortality rates (ONS, 2015) the results show that the odds ratio for those aged 60 to 64 is 18.41 and for those over 85 years of age it is 4.79. The p values for each odds ratio, with either mortality rate, is less than 0.0001. The probability of this being a coincidental finding is one in ten thousand.

Table 4.1: Mortality data



			In hospital on 1st July 2024, *n* (%)	Deaths within 7 days, *n* (%)	Deaths within 30 days, *n* (%)	Deaths within 3 months, *n* (%)	Deaths within 6 months, *n* (%)
BCU Total			2030				
	Gender						
		Male	964 (47.5)	31 (3.2)	75 (7.8)	161 (16.7)	202 (21.0)
		Female	1066 (52.5)	14 (1.3)	62 (5.8)	145 (13.6)	189(17.7)
	Age						
		Under 60	510 (25.1)	0	5 (1.0)	17 (3.3)	23 (4.5)
		60-64	162 (8.0)	3 (1.9)	10 (6.2)	18 (11.1)	21 (13.0)
		65-69	164 (8.1)	4 (2.4)	7 (4.3)	17 (10.4)	28 (17.1)
		70-74	212 (10.4)	9 (4.2)	18 (8.5)	31 (14.6)	38 (17.9)
		75-79	301 (14.8)	3 (1.0)	17 (5.6)	42 (14.0)	50 (16.6)
		80-84	275 (13.5)	7 (2.5)	26 (9.5)	62 (22.5)	78 (28.4)
		85 and over	406 (20.0)	19 (4.7)	54 (13.3)	119 (29.3)	153 (37.7)
Site 1			666				
	Gender						
		Male	301 (45.2)	10 (3.3)	23 (7.6)	48 (15.9)	68 (22.6)
		Female	365 (54.8)	5 (1.4)	24 (6.6)	48 (13.2)	64 (17.5)
	Age						
		Under 60	177 (26.6)	0	1 (0.6)	5 (2.8)	7 (4.0)
		60-64	49 (7.4)	1 (2.0)	6 (12.2)	10 (20.4)	11 (22.4)
		65-69	55 (8.3)	3 (5.5)	4 (7.3)	6 (10.9)	12 (21.8)
		70-74	66 (9.9)	4 (6.1)	7 (10.6)	11 (16.7)	14 (21.2)
		75-79	92 (13.8)	1 (1.1)	6 (6.5)	13 (14.1)	15 (16.3)
		80-84	85 (12.8)	1 (1.2)	5 (5.9)	14 (16.5)	20 (23.5)
		85 and over	142 (21.3)	5 (3.5)	18 (12.7)	37 (26.1)	53 (37.3)
Site 2			639				
	Gender						
		Male	311 (48.7)	8 (2.6)	20 (6.4)	50 (16.1)	59 (19.0)
		Female	328 (51.3)	2 (0.6)	16 (4.9)	45 (13.7)	60 (18.3)
	Age						
		Under 60	152 (23.8)	0	1 (0.7)	5 (3.3)	6 (3.9)
		60-64	62 (9.7)	1 (1.6)	2 (3.2)	4 (6.5)	5 (8.1)
		65-69	59 (9.2)	1 (1.7)	3 (5.1)	7 (11.9)	11 (18.6)
		70-74	76 (11.9)	1 (1.3)	3 (3.9)	9 (11.8)	11 (14.5)
		75-79	90 (14.1)	1 (1.1)	3 (3.3)	16 (17.8)	19 (21.1)
		80-84	76 (11.9)	1 (1.3)	7 (9.2)	16 (21.1)	19 (25.0)
		85 and over	124 (19.4)	5 (4.0)	17 (13.7)	38 (30.6)	48 (38.7)
Site 3			725				
	Gender						
		Male	352 (48.6)	13 (3.7)	32 (9.1)	63 (17.9)	75 (21.3)
		Female	373 (51.4)	7 (1.9)	22 (5.9)	52 (13.9)	65 (17.4)
	Age						
		Under 60	181 (25.0)	0	3 (1.7)	7 (3.9)	10 (5.5)
		60-64	51 (7.0)	1 (2.0)	2 (3.9)	4 (7.8)	5 (9.8)
		65-69	50 (6.9)	0	0	4 (8.0)	5 (10.0)
		70-74	70 (9.7)	4 (5.7)	8 (11.4)	11 (15.7)	13 (18.6)
		75-79	119 (16.4)	1 (0.8)	8 (6.7)	13 (10.9)	16 (13.4)
		80-84	114 (15.7)	5 (4.4)	14 (12.3)	32 (28.1)	39 (34.2)
		85 and over	140 (19.3)	9 (6.4)	19 (13.6)	44 (31.4)	52 (37.1)

4.3 In-depth perspectives on feasibility

Seven semi-structured interviews were initiated, with six being completed. The participants were three medical practitioners (resident doctor in nephrology, resident doctor in oncology, consultant in care of the elderly) and three nursing professionals (clinical nurse specialist, chemotherapy nurse, advanced medical practitioner). A paramedic withdrew from this research.

The interviews were carried out in January 2025 at the convenience of the participant (and availability of the, single, interviewer). They ranged in duration from 22 minutes to 48 minutes. Story-telling, as in recollection of experiences, was a strong theme prompted to empower participants in conceptualising this potential prognostic aid. The surrounding, hypothetical, discussion provided a breadth of themes to delve into alongside their explicit thoughts and opinions. After familiarisation with the data a number of quotes were captured to represent the diverse viewpoints. The use of a word cloud, as an infographic, was one method to highlight the recurring phrases providing some weighting. This was more useful contextually as it did not particularly support the coding process. The emphasized phrases supported the development of the thematic analysis.

Figure 4.2: Keywords

In over 3 hours of discussion, there were a number of repeated themes with different professions and specialties using the same ‘keywords’. The thirty-one words and phrases in figure 4.2 are the crystallisation of this familiarisation with the data. This ‘raw data’ was then converted to manageable units through coding into elements supporting further analysis. This step is illustrated in figure 4.3. Here one can also see the final step into identification of themes – linking the data back to the question as to the feasibility of a prognostication aid to promote advance care planning. These themes are explored in the next chapter with ‘utility’ advocating its feasibility, ‘ethics’ bringing insightful observations and the remaining themes raising caution.

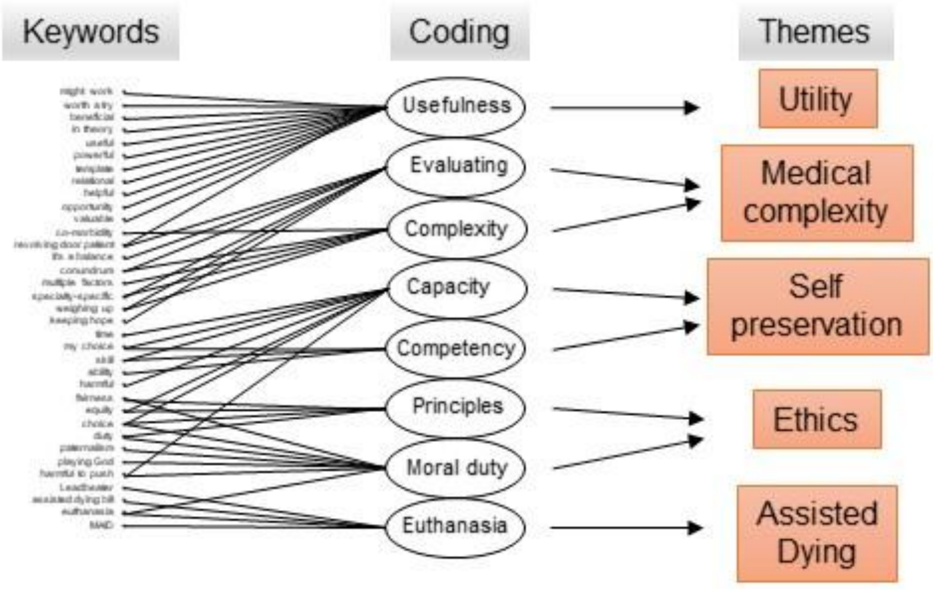


Figure 4.3: Thematic analysis

4.4 Conclusion

This results chapter provides the structure for the meaningful discussion in the next chapter. The results of the mortality data do align with the Scottish study (Clark et al., 2014) – that 19.3% of the inpatients on the census day had died within six months of that day. Localising these results adds credibility for the subsequent consideration of a prognostic aid. However, weighing up the feasibility of a prognostic aid does not provide a discrete, definitive outcome. The conversations regarding application of a tool elicited five principal themes – its utility, the relative medical complexity, staff resources, ethics (explicitly and implicitly) and, topically, ‘assisted dying’. These results are the framework for thoughtful exploration and constructive provocation in contemplating the unknown unknowns in the following chapter.

CHAPTER 5

Discussion

Unknown unknowns

5.1 Introduction

This chapter builds upon the reflective question proposed by Driscoll (1994), "So what?", to analyse the findings from the semi-structured interviews. It seeks to analyse the key themes identified through the integration of clinical perspectives. While the data presented is factual and offers limited scope for debate, it has served to ground the discussions in the context of local relevance, providing a clear outline of the real-world situation. The real colour of this research was then seen with the extended discussions about the feasibility of the adoption of a tool to aid recognition of those individuals ‘more’ likely to die within the next twelve months. Several themes were drawn out, as detailed in the last chapter, which are considered more deeply. The reflection regarding the ethical aspects is also included. There are many layers and nuances to that given the association, in this project, between the intervention and the end of life (even though they are independent components). The beginning of a conversation, again, but useful to frame some of the further considerations. The recognition of the limitations will similarly inform further research as well as understanding how change management might be optimised.

5.2 Interpretation of subjective and objective insights

Initially, to appraise the results, the interpretation of the objective components will be discussed. Unpacking the detail (even with this very limited dataset) provides plenty of content for consideration. The differing perspectives of the interpretations will be presented and weighed up. Dialogue, as the method, is the principal way to reconcile disagreement, embrace nuance and integrate ideas - “the truth is found by way of the conversation” (Ying, 2020).

This concept from Confucius extends into the following section. Here the subjective themes from the semi-structured interviews will be explored. These will be considered holistically, so that the positive as well as the less positive aspects can be contemplated. Furthermore, given that there is a balance of opinion, which influences these identified themes; counter arguments and responses will be part of the analysis.

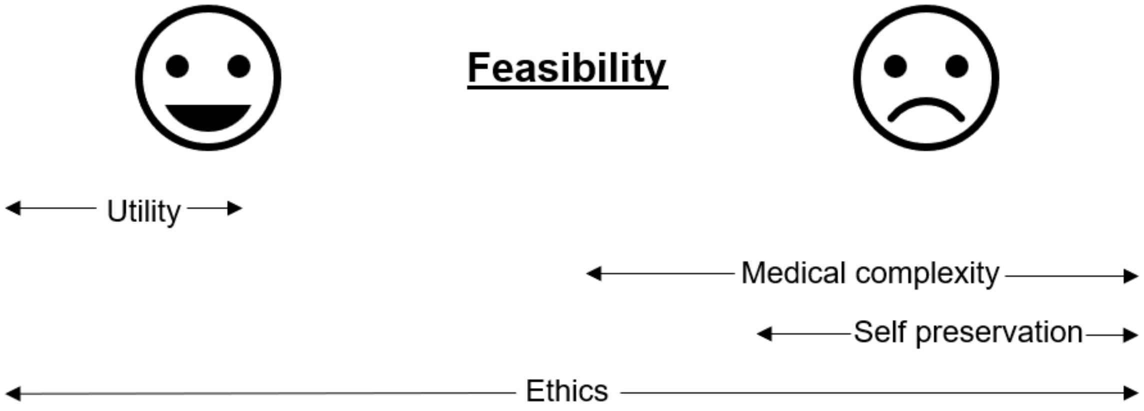


Figure 5.1: Likert (1932) representation of identified themes regarding ACP feasibility

5.3 Framework for discussion

This chapter builds on the explicit results presented in chapter four. The framework outlined in this chapter builds on the components identified in the previous chapter, incorporating a range of perspectives that contribute to a deeper understanding of the nuances involved. Figure 5.1 poses the themes identified in the last chapter as a Likert scale (1932). These perspectives are critically examined to explore areas of potential consensus, fostering a constructive dialogue. At this stage of the research, the framework aims to synthesise a collection of key discussion points, which serve as a foundation for evaluating the feasibility of this approach. This aligns with the project's stated objective from its inception. Furthermore, the evolution of this discourse not only advances the current project but also generates potential hypotheses for future research.

5.4 Discussion - Looking backwards

The retrospective quantitative component of this project was vital in setting the scene for the subsequent qualitative discussions. Stating the obvious, the data obtained was for six months rather than twelve. The informatics department misread the request and pulled data from 2024 rather than 2023. Regrettably, the time constraints of this project did not allow for further clarification. Having six months of data, comparison with Clark's group (2014) (as was the original intent) was still possible.

The chart (figure 5.2) compares the profile of hospital inpatients across Scotland, within their prevalent cohort study, (10743 patients) with the local scenario in North Wales. The subtleties of the variances between these two snapshots – for example, why the cohort of 75- to 79-year-olds fared better in North Wales – is beyond the scope of this research project.

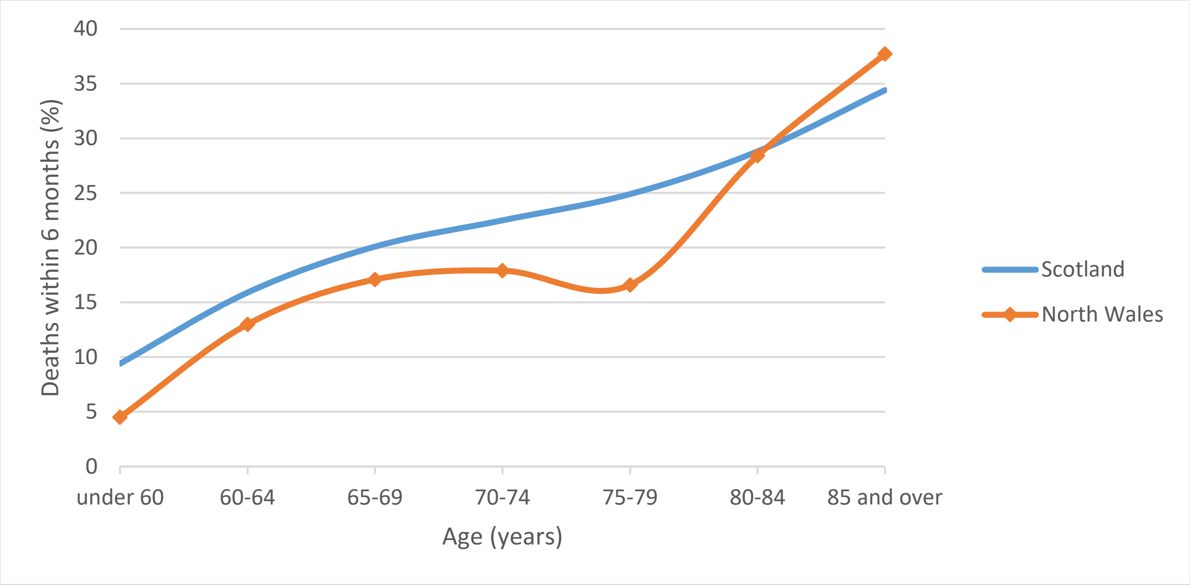


Figure 5.2: Comparison of percentage of patients dying, by age profile, within six months from the census date

Locally this data provides a number of highlights and headlines that warrant further consideration (e.g., the variations between the three acute hospitals). However, additional interpretation of the results is not pertinent to this dissertation. The purpose of this aspect of this research was to illustrate the experienced profile of the wider patient cohort locally. Demonstrating the validity of the "inconceivable" statistics raises the relevance of the advocacy that the recognition of these individuals would bring. Within the semi-structured interviews there was still incredulity that the proportion of deaths within six months of an admission were as high as they were.

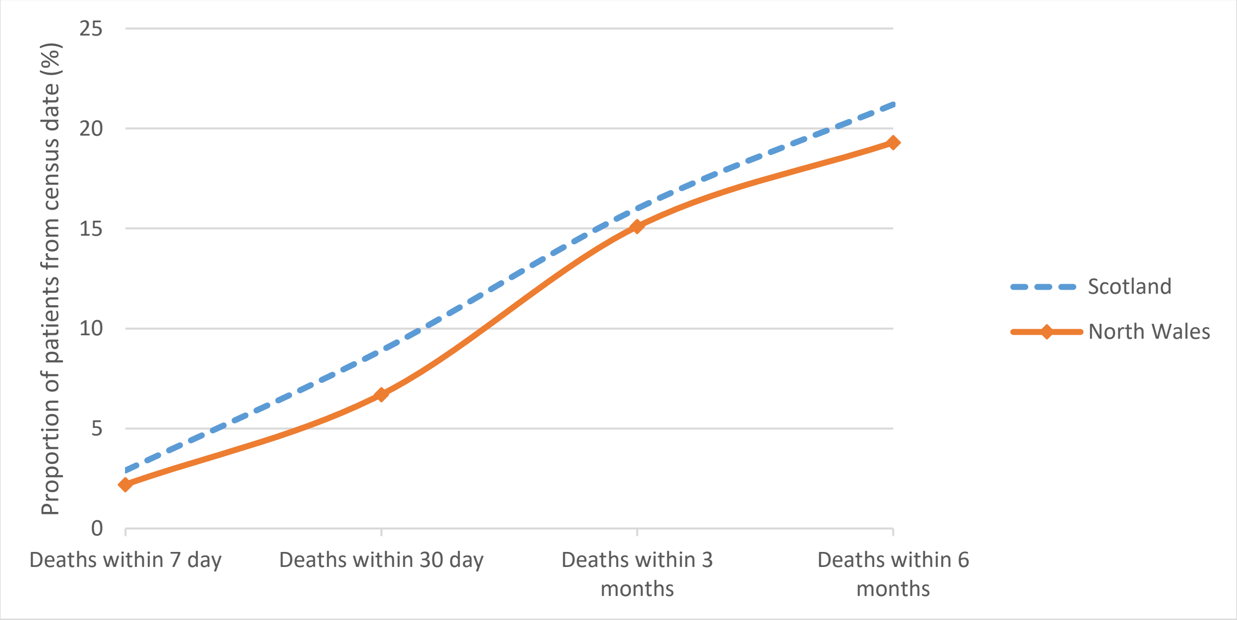


Figure 5.3: Comparison of percentage of patients dying longitudinally from the census date

The longitudinal data here has been taken at the simplest level. Figure 5.3 illustrates the cumulative mortality, which is comparable to the Scottish findings (Clark et al., 2014). The quantitative interrogation could have considered ‘indices of social deprivation’ (StatsWales, 2021) or ‘specialty of admission’ but they would have been tangential to this current study. The details about gender and age have been captured but do not add meaningfully to the current concern. Speculatively, an epidemiological multivariate analysis is an opportunity if this were to be pursued as a ‘Health Needs Assessment’ in informing service planning.

Returning to this research, the scale of the opportunity can be appreciated in the gradient of the line. Marie Curie commissioned a report – Public expenditure in the last year of life (Cummins et al., 2025) – which found that “of public funds spent on health care for people in their last year of life, 81% was spent in hospital”. The report provides plenty of figures, but distilling these down to a single person the hospital healthcare cost per adult who dies was £18020. Managers may appreciate the financial expediency that intervention could provide but the human component ought not to be undervalued (albeit less quantifiable).

> “Most devastatingly, too many people are dying in places where they don’t want or need to be.”
>
> (Dr Sam Royston, Executive Director of Policy and Research, Marie Curie)

If three in ten inpatients are in their last twelve months of life, then the relevant variables underpinning these figures are the medical profiles that influence the future. It is the feasibility of this identification step that is being tested. Clinical tools are available. Frailty scores (Moorhouse and Rockwood, 2012) are relatively crude, whereas the ‘Supportive and Palliative Care Indicators Tool’ (SPICT) (University of Edinburgh, 2025) helps identify individuals so they can be offered “timely palliative care and future care planning”. The data demonstrates that there is a population of patients that could be more proactively supported. One point of recognition of these individuals is with presentation to hospital (arguably there will be other opportunities short of acute intervention) and being able to embrace the wealth of digital data that this affords. Automated prompts, as was brought out in the literature review, can use the power of digital to enhance the clinical consultation.

5.5 Discussion - Looking forwards

Weighing the feasibility of a tool to identify those individuals approaching the end of their life does not present distinct themes. Discussions, and human thought, blends ideas. Earlier the metaphor was of adding colour, but more than that the blending of concepts is shading across the picture rather than colouring within the lines. This interplay has been teased out to a degree but the complexity of humans and healthcare will remain evident throughout this section.

5.51 Utility

The potential of this tool was acknowledged by all those interviewed. The rich picture helped personalise the concept and simply opened up the conversation. A number of wistful anecdotes were shared reminiscing about the consequences of missed opportunities. One reflection was that the team they worked with should already be being more proactive. This individual had previously worked on the dialysis unit and regularly supported the same cohort of patients. 'Regularly' being up to three times each week, given the nature of dialysis, alongside associated acute episodes necessitating hospital admission. With so much contact the clinician had been able to develop a relationship – primarily professional but they did recognise social aspects – and had had opportunity to reflect forwards. In conversation, it was the social relationship that limited them from introducing the challenge of future care needs. The feasibility of having a prompt – whether automated or following a trigger event – was a welcome consideration to flag the appropriateness of considering future needs more urgently.

> "…gives a prompt to discuss things. Almost the authority to start a conversation."
>
> (Participant 3, clinical nurse specialist)

> "Like getting a CT to prove what we know allows the doctors to stop treatment."
>
> (Participant 4, chemotherapy nurse)

References were shared to other tools and templates. The additional component that this proposal brings is that it seeks to identify individuals not currently being identified as within their last twelve months of life. Chronic conditions have a characteristic intermittent declining trajectory (Murray et al., 2005) which can be categorised with tools such as SPICT (2025).

> "We used to use TEPs [treatment escalation plans] as a way to make it easier to do the right thing."
>
> (Participant 2, resident doctor in oncology)

Treatment escalation plans are "a tool which records and communicates the personalised and realistic goals of treatment." (NHS Scotland, 2021) They are highly specific as they relate to a single episode of care at a single point in time. The relevance is that they are a form of advance care planning, reflecting an individual's values and preferences should they deteriorate.

Similarly, ‘Do Not Attempt Cardio Pulmonary Resuscitation’ (DNACPR) forms were brought up. These are also a form of advance care plan but have some common acceptance. This tool seeks to identify individuals earlier in their disease trajectories in order that generalised, and specific, plans can be considered. This is an opportunity to empower patients, to give them time to weigh their priorities in the calm before the storm.

The value of this intervention was highly respected. The two overriding sub-themes were:

1. its potential usefulness in catching patients sooner, especially those without regular healthcare interaction.
2. as a formulaic necessity within ongoing care, enabling professionals to hide behind process (whilst, simultaneously, accepting the right to expedite conversations when necessary).

Regarding the feasibility of its adoption several points for discussion were raised.

5.52 Medical complexity

A reservation that recurred in these conversations was individual professionals having enough confidence in the tool. This is in contrast to some of the thoughts (and quote above) which valued the objectivity of this process. It simply demonstrates that there is a multitude of opinions which need to be accommodated if this tool is to find a role to serve.

> “Medicine is just not that straightforward.”
>
> (Participant 6, consultant geriatrician)

> “We get it wrong all the time… With hindsight, I may be overly optimistic but what if we are too doom and gloom? I am not ready to let the computer tell me what to do.”
>
> (Participant 1, resident doctor in nephrology)

Another participant told an anecdote of a gentleman who was told he had three months left to live, but was still living independently twelve months later. The power of story-telling in undermining generalizable observations is high (Line et al., 2024) and it is recognised for “anecdotal evidence to be more persuasive than statistical evidence when emotional engagement is high” (Freling et al., 2020).

The digital scientific response is to focus on the potential for process mining. Process mining focuses on gaining insight from event logs (van der Aalst, 2012). The wealth of digital data available in the healthcare environment, at both the individual and population scale, provide a rich opportunity for pattern recognition and digital development. The concern of 'drowning in data' is less applicable to an inanimate analyser, so generalizable and specific modelling are both viable. The overriding concern, limiting large-scale development, is regarding data security. However, machine learning is a means by which data is already being interrogated, variables identified, parameters recognised and processes refined (He et al., 2024). Correlating the existing observations and investigations to distil the components most relevant to the outcome (of death, as the measure of prognostication, in this research) will inform good clinical care.

Medicine is an art rather than a science. The clinician makes the decisions, but these can be informed by the digital prompt. The utility of the tool has been acknowledged earlier but the adoption of it needs careful consideration. The feasibility of the tool necessitates that the credibility of the tool itself (not a focus of this research, per se) is established.

5.53 Self-preservation

Another theme that arose was resistance regarding the feasibility of application. Although identification of individuals was felt to be a positive opportunity, the subsequent requirement for time and effort to develop that opportunity was less tangible. The mind-set of 'not my job', or of protest at missed chances with earlier admissions (when discussing experiences), was evident.

> "I have had enough of doing other people's jobs."
>
> (Participant 5, advanced nurse practitioner, emergency quadrant)

> "It's all well and good finding these patients, but where is the time."
>
> (Participant 1, resident doctor in nephrology)

In expanding this point of reservation, there was enthusiasm if signposting were possible rather than it impacting the primary role of the clinician. That is an alert being triggered, but then having somewhere to pass that responsibility. The underlying concerns appear to be of having enough capacity to provide the necessary support. Capacity, here, is at least twofold:

- Having enough time, as highlighted in the quote above.
- Having adequate skills.

This second point was encapsulated by likening it to Pandora’s Box.

> “Once you open it, it is hard to close it again.”
>
> (Participant 4, chemotherapy nurse)

A response to these perspectives is that there is no single role carrying this responsibility. The duty for supporting patients stretches across the perceived silos of specialty. All professionals will have some ability to communicate. The skill, of sensitivity, does arise with the timing for initiating a conversation. Rather than permission to prevaricate, this brings a moral responsibility (unenforceable) for professionals to start the process. To introduce the concept of thinking ahead and advance care planning enables others to develop them. Patients need the time and space to reflect on what they might desire. There is also, inherently, an ethical obligation, as “no one knows your future self better than you do” (George and Harlow, 2011).

Staff and patient expectations need to be realistic. Akin to other clinical conversations, such as the appropriateness (or not) of cardiopulmonary resuscitation, timings for discussion are not always convenient or orderly. The challenge from surveying this scenario is whether discussions are initiated where identification has occurred.

5.54 Terminally Ill Adults (End of Life) Bill

Introduced by Kim Leadbeater, as a private members bill, this (at the time of writing) is at the committee stage of the process of being considered for legislation. In short, “the broad aim of the Terminally Ill Adults (End of Life) Bill is to allow adults aged 18 and over, who have mental capacity, are terminally ill and are in the final six months of their life, to request assistance from a doctor to end their life.” (Lipscombe et al., 2024)

Although this appears to be a tangent, it is warranted as a theme. It may be a topical concern, with significant media discussion, at the time the semi-structured interviews were happening throughout January 2025. However, the frequency of this area as a topic merited its identification for specific discussion. Albeit a largely hypothetical discussion at this point in time, the feasibility of identifying patients within their last 12 months and prognostication as a step for access to assisted dying (potentially) were too close to each other to avoid. All, but one, of the interviews ventured into this topic.

> “Prognosis is such an art form. It is like looking into a crystal ball.”
>
> (Participant 2, resident doctor in oncology)

> “[Prognostication] is mysterious but at the same time powerful and dangerous.”
>
> (Participant 3, clinical nurse specialist)

> “Having some objectivity brings some reassurance about my instincts.”
>
> (Participant 6, consultant geriatrician)

The comments pertaining to the feasibility of this tool and its consideration related to the theme here arose from seeing the quantitative figures. The detail reflected back was that if, following the data, one in five patients in hospital are likely to die within six months (setting aside the original twelve-month parameter), can these then be identified to enable objectiveness. Here the overlap of themes begins to become more evident. Individuals then have the (potential) option to consider assisted dying, even if it is not introduced explicitly; but without the onus of prognostication on clinicians.

In the interviews, clinicians did acknowledge that they have been surprised by both:

- patients ‘outliving’ expectations, and,
- patients dying sooner than anticipated.

Another comment was that an expected date of death was less reliable than the expected date of delivery for a baby. The reflection being that if the accuracy for the estimated date of birth is less than 5% (regardless of the dating method or timing of the dating) (Khambalia et al., 2013) with its more linear parameters, then what credibility does a doctor’s opinion add. This reinforces the value of the tool as an adjunct to clinical assessment.

This application would be an extension of advance care planning. Its use in this respect would present a significant challenge given the diverse positions regarding assisted dying. Its adoption would be constrained as the British Geriatrics Society (2024) and the Association of Palliative Medicine (2024) both oppose the legislation currently being considered.

5.55 Ethical dilemmas

Ethical concerns underpin a number of the hesitancies regarding application of this tool that were raised within these interviews. Not to say that they are insurmountable, but understanding these anxieties will help guide the further development of this project. The concept itself does not raise disquiet, but the feasibility of its use is less clear. These ethical considerations were implicit rather than explicit, even if sidestepping the conundrum regarding assisted dying. They will, briefly, be touched upon using the traditional (Gillon, 1994) principlist framework.

- Respect for autonomy

Even restricting this section to the two participants – the professional and the patient – there are knots to tie oneself in. Accepting that there is professional insight about prognosis, then the patient has a right to know. However, the patient may not want to know the details so imposing the conversation would be inappropriate. The extent to which the patient can then make informed decisions is debatable. Paradoxically the expectation of the professional's role and their autonomy are equal components to this conversation. This is not simply about having the necessary skills in communication, but rather respecting the professional relationship. The ethical challenge is that this approach promotes depersonalisation of care, or just practicing by numbers (or algorithm). The charge of 'paternalism' hangs heavily. Returning to the value of relationship, some of the emphasis moves from paternalism to maternalism. These are not gender specific labels – just as any clinician can be paternalistic, maternalism is not the preserve of the female. Succinctly, "to act maternalistically is to decide for another person based on a reasonable understanding of that person's own preferences." (Sullivan, 2016)

- Beneficence and non-maleficence

The good that might be available is greater patient empowerment. The opportunity to focus care, and the care environment, so that time is spent meaningfully (which is an individual interpretation, and not to be presupposed) and wider clinical management anticipated. Transparency between all those in the scenario is another (idealistic) benefit. And finally, similar to having a diagnosis, an 'answer' provides a tangible focus and clarity on which plans can be built.

There is also potential harm inherent in this conversation. The 'burden' of knowing time is short could limit the ability to live fulfilled. The psychological sequelae would not be reversible. So, although there is a tendency to 'bury heads in the sand' (61% of people in Wales do not have a will (Nation Cymru, 2023)), ignoring something does not change the inevitability of the future. There is an ethical responsibility for some awareness about the future.

- Justice

Resources bring their own ethical permutations at both the individual and societal levels. Although the focus is on the individual patient there will be implications for the wider health service. The consequence of supporting a patient to stay out of hospital is that there is one less inpatient. This will then be available for someone else. The associated costs of ambulance, investigation, medication, admission and staff time can be 'saved'. However, despite this 'saving', the reality is that there are not enough resources to fully support care in the community. Whether it is hands-on care needs, supporting equipment or access to medical review, the system is wanting. The ethical concern is that the ideal makes assurances that cannot be fulfilled.

The principlist approach to ethics provides a number of soapboxes to appreciate. It does not provide a resolution or guide as to how they may be navigated. This section highlights the debate that exists, and will continue to exist, with any aspect of healthcare. Different people (whether patient or professional) will have differing outlooks, which may well change over time. This will remain an unknown unknown.

5.6 Limitations (and delimitations)

Delimitations, initially, as conscious choices in this project were necessary to focus the scope of this research (Creswell, 2003). Assessing the inpatient population at a specific time point, as in this research, was an opportune conscious choice. Herein lies an opportunity, amongst several, for extending this potential tool. For example, considering a primary care population, or a cohort within that group, could identify additional foci where this tool might be utilised.

A further conscious choice was with the semi-structured interviews. These, however, simultaneously bring limitations as they introduce factors outside the researcher's control. There was convenience sampling (Edgar and Manz, 2017) which, by definition, removed any randomness and biased the representation of views – at least two limitations. Mitigation, by engaging more individuals and departments, would have been possible given a larger timeframe. Expanding the perspectives on the feasibility of the prognostication aid being proposed is already anticipated. The value of integrating such a tool clinically warrants further attention given the Welsh Government's priorities for 2025 (HEIW, 2025). In extending this project drawing on the experience and resources of the wider academic team will mitigate another limitation – the limited ability of the interviewer. Although a number of a physician's 'soft skills' are transferable (Moberly, 2016), there are professionals able to elicit greater depth within the research context. Independently optimising the input from those willing to invest is a duty as much as a service.

Underpinning several of these limitations is the constraint of time. Specifically, the constraint of time in accommodating the dissertation timetable within the academic year. Time constraints have:

- limited the ability to challenge discrepancies (such as data being drawn from 2024 rather than 2023, as requested);
- restricted the number and range of semi-structured interviews conducted;
- minimised the potential for review and refinement of the interview template;
- prevented clarification of interviewees points or phrases.

This section is an acknowledgement that the assessment of the feasibility of a prognostication aid to promote advance care planning is in its infancy. Its relevance with the ministerial priorities (HEIW, 2025) seeking to "deliver the Welsh Government Quality Statements for PEoLC [Palliative and End-of-Life Care] for Wales (2022)" is immediate. Recognising that "the quality and rigor of research is largely defined by its limitations" (Ross and Zaidi, 2019), this project does (and has) informed the consideration of ways to support advance and future care plans.

5.7 Conclusion

This chapter has reinforced the appreciation of the possibility that there is an increased risk that death will occur following hospital admission. The association of greater risk of death following hospital admission with greater age is, unsurprisingly, demonstrated. The professional perspective is that there is an opportunity to support the individual and counsel the family whilst being efficient with the healthcare resources. There is value (both human and financial) in identifying a cohort where focused input can generate better experiential outcomes.

The balance of discussion comes with a perceived responsibility to embrace this support (by the professional) against an individual's readiness to explore the future. The personalisation of this aspect has been touched upon but every encounter will be unique. There is plenty of scope to expound upon the duty of care, the duty to share the experience and wisdom from the professional vantage point. The moral dilemma of being truthful against the possible resulting distress. The ethical conundrum is developed in this chapter, but the detail will always be specific to a situation – it is analogous to 'breaking bad news' which is embedded in medical and nursing curricula. An associated, topical, point that arose was regarding assisted dying. This chapter cannot, and does not, provide an answer here either. Whether this prognostication aid would be an, accurate enough, objective means of assessing life expectancy has been left for discussion elsewhere. This point does reflect back to where the duty lies for discussing the professional insight about prognostication. Informed choices are dependent upon knowing the underlying information.

The other concluding recognition is that confidence and capacity were also raised as concerns. Given the semi-structured interviews were with individuals more open to establishing holistic support, this clearly needs further consideration. The degree to which these are generic skills and should be core competencies is another, ongoing, topical discussion. The usefulness of the prognostication aid is appreciated and the acceptance of the need to engage patients is present. The challenge to the feasibility of application appears to rest with existing busyness - "everybody blamed somebody when nobody did what anybody could have" (Osgood, no date).

CHAPTER 6

Conclusion

6.1 A useful prompt

The strength of this research is its localisation to North Wales, with its applicable data. It explores a novel interface between the digital and clinical environments and is highly clinically relevant. The recognition of the usefulness of identifying those more likely to be in their last year of life was confirmed. The feasibility of it as an opportunity to promote advance care planning was also appreciated. The semi-structured interviews did extend to consider the feasibility of adoption, rather than promotion. The current opinion regarding this was of a wariness about its feasibility. The proportion of inpatients who are within their last six months of life generated genuine surprise amongst clinicians. This blind spot reflected the taboo that is discussing death. Having an aid to recognise death, or to facilitate the ‘surprise question’ (“Would you be surprised if this patient died within the next 12 months?” (Lyon, 2005), was perceived to be a valuable adjunct to clinical instinct.

The potential for harnessing the digital data already being collected remains an unexploited opportunity. The processing power of machine learning seeking to identify more reliable indicators with multi-morbidity provides a research opportunity. The technical aspects for digital transformation will need further consideration, whereas the principle of feasibility at the level of the clinician is positive.

6.2 Value of recognising individuals

The value of having the option to discuss advance care planning is primarily owned by the patient – being able to take an active role in their care decisions. There may initially be associated distress but the opportunity to voice preferences and opinions is core to Western understanding of autonomy. Through the semi-structured interviews, the consequence of (potentially) initiating conversations about the future was that it would empower patients. Breaking down some of the barriers, and improving the professional relationship, between clinician and patient were also identified as positive consequences.

In addition to this relational benefit (which of itself facilitates further communication), another consequence is that the limited resources can be re-focused. Even in the intensivist setting a cluster randomised trial (Courtright et al., 2025) found that ‘nudging’ clinicians to consider prognosis and focus of care had effects. There was “a significant increase in discharge to hospice and earlier comfort-care orders”;

illustrating that the institutional resources (e.g., the intensive care support) could be focused and that the individual experience altered.

The value of earlier identification of these individuals and advance care planning discussion will facilitate greater likelihood that they are achievable. This supports dignified care as was the initial focus in section 1.2. The appreciated feasibility of a prognostication aid also provides prompts to support ‘multi-morbidity’ as an illness trajectory (Murray et al., 2024). This trajectory is more insidious being overlooked by professionals and dismissed by patients given the cumulative effects from their different conditions. It varies from the traditional trajectories (“short period of evident decline”, “long term limitations with intermittent serious episodes”, “prolonged dwindling” (Murray et al., 2005)) with a recognised reduction in life expectancy.

The value for clinicians is as a prompt to consider the wider context rather than focusing on the immediate situation. It can also be a reassurance regarding a clinician’s clinical instinct; or provide a point of reflection where opinions vary. It is a tool that will support a range of clinicians to improve their skills in holistic assessment.

6.3 Limitations

There have been limitations (as have been drawn out in sections 3.6 and 5.6). The main weaknesses arise from the necessary time constraints. This pressure required an efficiency of interviews that presented a sampling bias. The more interested clinicians have become involved; so, the depth of qualitative data has been at the expense of the breadth of the insights. Another limitation is the current level of digitalisation in NHS Wales - the infrastructure not yet being fully established. The literature review drawing more from worldwide experiences, rather than from the United Kingdom, is a reflection of this reality. One final acknowledgement is the lack of any patient involvement (influenced by the required ethical protocols within the academic year); but rather than a weakness this is an opportunity to step forward into further research.

6.4 Applying this research

The potential for larger scale (broader) qualitative research is an opportunity to build upon this groundwork research. This research is the first step of a larger project embedding a tool into clinical practice. This is an expanding field of interest as was illustrated in figure 2.3, with a further increase in published articles about digital aids relating to end-of-life care into the beginning of 2025. It is opportune as a priority for Welsh Government priority, in 2025, is to “increase patient-centred palliative end-of-life care… ensuring that the needs and preferences of patients are at the forefront of care planning and delivery” (HEIW, 2025).

Practically the transition from the conceptual discussion regarding feasibility to one of implementation will need significant change management. A further element of research which will be necessary as a preparatory step is to widen the consultation about this proposal. To appreciate the patient perspective and to increase the clinical conversation will, invaluably, broaden the understanding of this area. Generating an increased awareness of the potential, for better care from digital tools to aid prognostication to focus care appropriately, will build momentum and engagement with continued project development. Section 5.55 broached some of the ethical considerations which will be raised again with patient consultations. The ‘paradox of choice’ (Schwartz, 2005) – where although autonomy is seen as an ideal, the burden of decision making can be paralysing – is an unknown quantity. Hence the urgency for an understanding of patents’ preferences for discussions where expectation of death is shared.

In addition, this (novel) focus provides the potential to influence wider policies relating to healthcare. There is an opportunity, as electronic health records begin to become embedded in Wales, for integration of a digital tool such as this. The challenge is in building the collaborative team, with the technical and clinical skills, to take this forward; recognising that the subsequent change management to support this vision is an entire dissertation of its own.

6.5 Potential challenges

Change management presents the biggest threat as the resistance of clinicians should not be underestimated. The risk of misinterpretation, misrepresentation or misuse of this tool is also present. Section 5.54 (Assisted Dying Bill) illustrates one insight into this blurring of understanding; and the experience of the ‘Liverpool Care Pathway’ (Neuberger, 2013) continues to echo around the specialty of palliative care. In addition, the threat of data incompatibility and interoperability of current systems also present technical barriers. These need recognising even though there are ongoing projects to mitigate them. One last recognition is the legal and regulatory framework that is evolving across the digital horizon – most definitely an ‘unknown unknown’.

6.6 Conclusion

This research project has reinforced the apparent sense of the approach to identify individuals in order to promote advance care planning. Conversations with clinicians have raised aspects for further consideration. The realities of weighing multiple pathologies, and the practicalities of having adequate time and skills, indicate foci for research and application. There is scope to bring artificial intelligence into this aspect of healthcare but the clinicians remain vital for their empathy and face-to-face interactions - “seeing the person in the patient” (The King’s Fund, 2008).

A closing recognition that this research regarding feasibility is an initial foray into the possible. To borrow from Winston Churchill (1942):

> “Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.”

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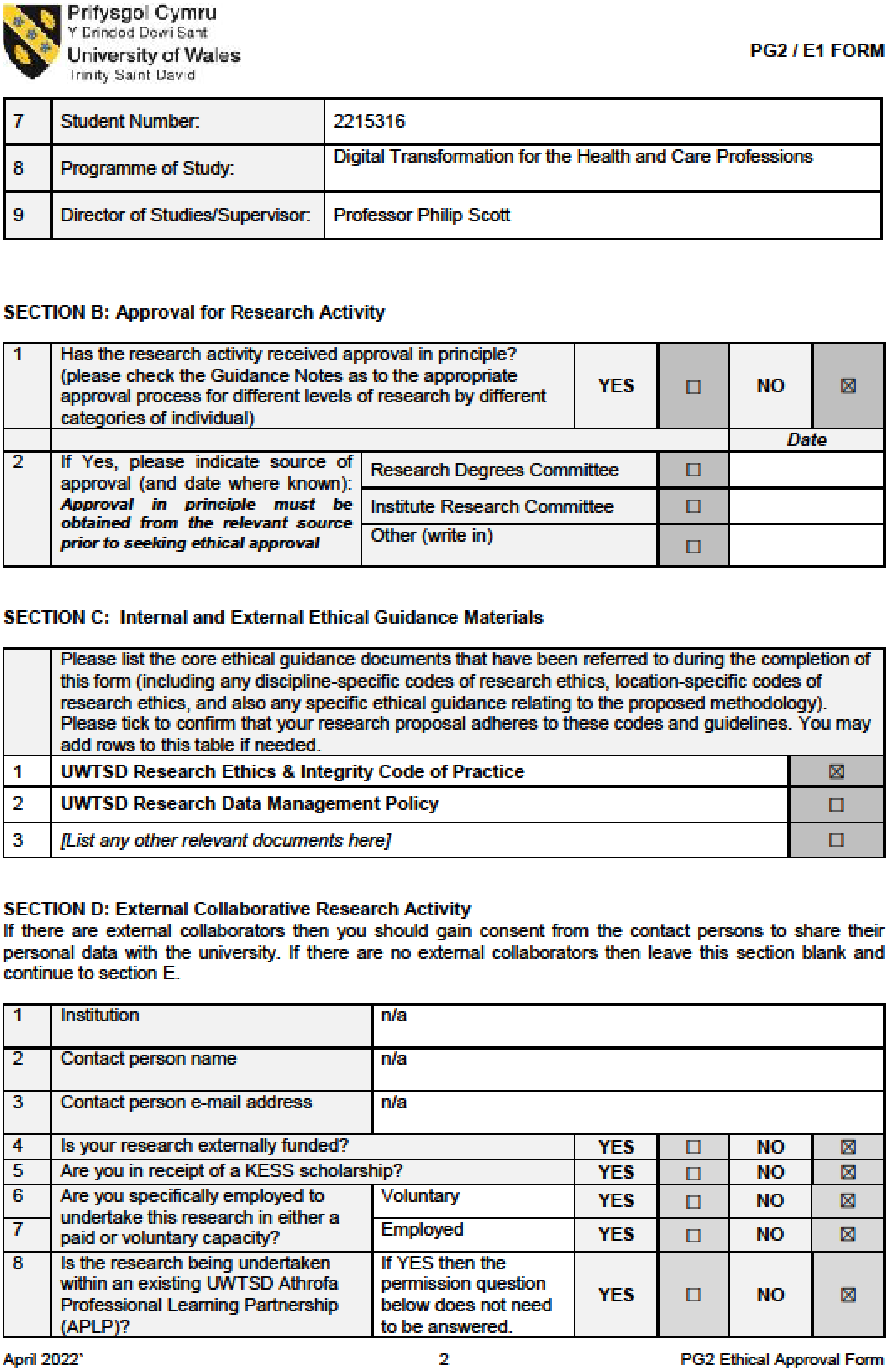

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7	Student Number:	2215316
8	Programme of Study:	Digital Transformation for the Health and Care Professions
9	Director of Studies/Supervisor:	Professor Philip Scott

SECTION B: Approval for Research Activity

1	Has the research activity received approval in principle? (please check the Guidance Notes as to the appropriate approval process for different levels of research by different categories of individual)	**YES**	☐	**NO**	☒
					Date
2	If Yes, please indicate source of approval (and date where known): ***Approval in principle must be obtained from the relevant source prior to seeking ethical approval***	Research Degrees Committee	☐		
		Institute Research Committee	☐		
		Other (write in)	☐		

SECTION C: Internal and External Ethical Guidance Materials

	Please list the core ethical guidance documents that have been referred to during the completion of this form (including any discipline-specific codes of research ethics, location-specific codes of research ethics, and also any specific ethical guidance relating to the proposed methodology). Please tick to confirm that your research proposal adheres to these codes and guidelines. You may add rows to this table if needed.	
1	**UWTSD Research Ethics & Integrity Code of Practice**	☒
2	**UWTSD Research Data Management Policy**	☐
3	*[List any other relevant documents here]*	☐

SECTION D: External Collaborative Research Activity
If there are external collaborators then you should gain consent from the contact persons to share their personal data with the university. If there are no external collaborators then leave this section blank and continue to section E.

1	Institution	n/a				
2	Contact person name	n/a				
3	Contact person e-mail address	n/a				
4	Is your research externally funded?		**YES**	☐	**NO**	☒
5	Are you in receipt of a KESS scholarship?		**YES**	☐	**NO**	☒
6	Are you specifically employed to undertake this research in either a paid or voluntary capacity?	Voluntary	**YES**	☐	**NO**	☒
7		Employed	**YES**	☐	**NO**	☒
8	Is the research being undertaken within an existing UWTSD Athrofa Professional Learning Partnership (APLP)?	If YES then the permission question below does not need to be answered.	**YES**	☐	**NO**	☒

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9	Has permission to undertake the research has been provided by the partner organisation?	(If YES attach copy) If NO the application cannot continue	YES	☐	NO	☒

Where research activity is carried out in collaboration with an external organisation

10	Does this organisation have its own ethics approval system?	YES	☒	NO	☐
	If Yes, please attach a copy of any final approval (or interim approval) from the organisation (this may be a copy of an email if appropriate).				

SECTION E: Details of Research Activity

1	Indicative title:	Exploring the feasibility of a prognostication aide for promoting advance care planning		
2	Proposed start date:	September 2024	Proposed end date:	May 2025

	Introduction to the Research (maximum 300 words per section) **Ensure that you write for a <u>Non-Specialist Audience</u> when outlining your response to the points below:** *Purpose of Research Activity* *Proposed Research Question* *Aims of Research Activity* *Objectives of Research Activity* Demonstrate, briefly, how **<u>Existing Research</u>** has informed the proposed activity and explain *What the research activity will add to the body of knowledge* *How it addresses an area of importance.*
3	**Purpose of Research Activity** 'Advance care planning' is poorly appreciated (Marie Curie, 2021) but can empower individuals with: • "parallel planning" • "support for personalised care and support conversations and advance care planning" • "support for end of life decision-making, including preferred place of care" (NHSE, 2023). This work considers a way of raising the profile of 'advance care planning' as a tool for making informed and timely decisions. The emphasis is on involving individuals with decisions relating to their (future) selves, or to use the Government's soundbite: "No decision about me, without me". (this box should expand as you type)
4	**Research Question** What are the measurable benefits with advance care plans for those identified as being in their last year of life? (this box should expand as you type)
5	**Aims of Research Activity** The aim is to improve care planning for the end of life. (this box should expand as you type)
6	**Objectives of Research Activity**

	• To confirm the proportion of the hospital inpatients, at a point in time, who are in their last year of life • To clarify the reliability of a (non-assessment dependent) prognostication tool • To identify appropriate outcome measurements to capture activity that is prevented (and those activities which occur as a consequence) • To explore the feasibility, and perceived usefulness, of such an aid with the clinical teams (this box should expand as you type)
	Proposed methods (maximum 600 words) Provide a brief summary of all the methods that may be used in the research activity, making it clear what specific techniques may be used. If methods other than those listed in this section are deemed appropriate later, additional ethical approval for those methods will be needed. You do not need to justify the methods here, but should instead describe how you intend to collect the data necessary for you to complete your project.
7	1. Quantitative. A retrospective analysis of existing, de-identified, electronic records. By reference to a census date, and any dates of death for those individuals up to 12 months. The data can be broken into cohorts to identify time frames in which death occurred, and whether part of the initial admission episode. 2. Quantitative. a. A retrospective evaluation, using the PREDICT prognostication tool, of prognostication. This tool does not require assessment or investigation parameters so should be extractable from the existing digital records. Validation of this approach can then be considered, with particular attention to its specificity and sensitivity. b. An indicative costing analysis will be explored through case scenarios. The psycho-social factors will not be quantifiable in the same way; nor some of the unpaid carer roles adopted by the family. 3. Qualitative. Interviews to elicit the clinical perspective of prognostication as an aid. These are likely to be limited by capacity of my time and the academic timeframe. Thematic analysis would be the method that follows on, although trialling the framework approach (even that is feasible as a non-specialist) warrants consideration. It is unlikely that repeating a cycle with an approach akin to Delphi would be possible in our given timeframe. (this box should expand as you type)
	Location of research activity Identify all locations where research activity will take place.
8	Betsi Cadwaladr University Health Board, North Wales. (this box should expand as you type)
	Research activity outside of the UK If research activity will take place overseas, you are responsible for ensuring that local ethical considerations are complied with and that the relevant permissions are sought. Specify any local guidelines (e.g. from local professional associations/learned societies/universities) that exist and whether these involve any ethical stipulations beyond those usual in the UK (provide details of any licenses or permissions required). Also specify whether there are any specific ethical issues raised by the local context in which the research activity is taking place, for example, particular cultural and/or legal sensitivities or vulnerabilities of participants. If you live in the country where you will do the research then please state this.
9	None. *(this box should expand as you type)*

10		NO	☐

	Use of documentation not in the public domain: Are any documents <u>NOT</u> publicly available?	YES	☒
11	Locally held health records will be required for this research project. No identifiable components will be necessary. The health board (through its Caldicott Guardian, SIRO and DPOs; along with the available policies) provides layers of governance to appropriately look after this information. The reality is that the informatics department will be able to provide the relevant information in an adequately anonymous way. *(this box should expand as you type)*		

	Does your research relate to one or more of the seven aims of the Well-being of Future Generations (Wales) Act 2015?	**YES**	**NO**
12	A prosperous Wales	☐	☒
13	A resilient Wales	☐	☒
14	A healthier Wales	☒	☐
15	A more equal Wales	☐	☒
16	A Wales of cohesive communities	☐	☒
17	A Wales of vibrant culture and thriving Welsh language	☐	☒
18	A globally responsible Wales	☐	☒
19	If YES to any of the above, please give details:		
	This project will support 'A Healthier Wales' through the reinforcement of: • patient-centred care • developing, and accessing, community-centred resources • use the latest technology and medicines to help people live the best life possible if they aren't able to get better. (this box should expand as you type)		

SECTION F: Scope of Research Activity

	Will the research activity include:	**YES**	**NO**
1	Use of a questionnaire or similar research instrument?	☒	☐
2	Use of interviews?	☒	☐
3	Use of focus groups?	☐	☒
4	Use of participant diaries?	☐	☒
5	Use of video or audio recording?	☒	☐
6	Use of computer-generated log files?	☐	☒
7	Participant observation with their knowledge?	☐	☒
8	Participant observation without their knowledge?	☐	☒
9	Access to personal or confidential information without the participants' specific consent?	☐	☒

10	Administration of any questions, test stimuli, presentation that may be experienced as physically, mentally or emotionally harmful / offensive?	☐	☒
11	Performance of any acts which may cause embarrassment or affect self-esteem?	☐	☒
12	Investigation of participants involved in illegal activities?	☐	☒
13	Use of procedures that involve deception?	☐	☒
14	Administration of any substance, agent or placebo?	☐	☒
15	Working with live vertebrate animals?	☐	☒
16	Procedures that may have a negative impact on the environment?	☐	☒
17	Other primary data collection methods. Please indicate the type of data collection method(s) below.	☒	☐
	Details of any other primary data collection method: Queries submitted through informatics department to generate datasets of information. The parameters will be generic and non-specific such that individual identification is not possible. (this box should expand as you type)		

If NO to every question, then the research activity is (ethically) low risk and may be exempt from some of the following sections (please refer to Guidance Notes).

If YES to any question, then no research activity should be undertaken until full ethical approval has been obtained.

SECTION G: Intended Participants

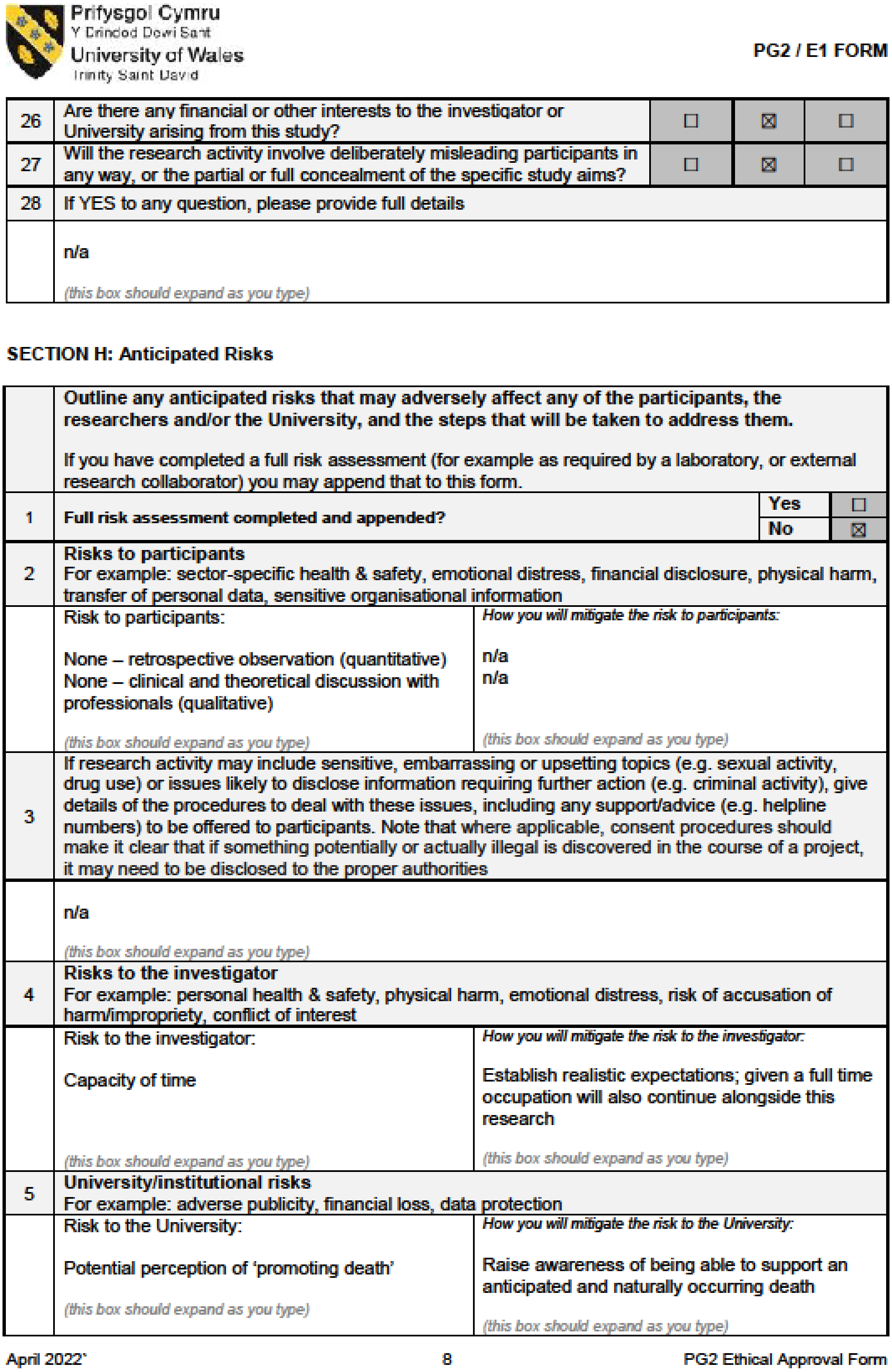
If there are no participants then do not complete this section, but go directly to section H.

	Who are the intended participants:	**YES**	**NO**
1	Students or staff at the University?	☐	☒
2	Adults (over the age of 18 and competent to give consent)?	☒	☐
3	Vulnerable adults?	☐	☒
4	Children and Young People under the age of 18? (Consent from Parent, Carer or Guardian will be required)	☐	☒
5	Prisoners?	☐	☒
6	Young offenders?	☐	☒
7	Those who could be considered to have a particularly dependent relationship with the investigator or a gatekeeper?	☐	☒
8	People engaged in illegal activities?	☐	☒
9	Others. Please indicate the participants below, and specifically any group who may be unable to give consent.	☒	☐
	Details of any other participant groups: Adults (over the age of 18 and unable to give consent (whether temporary delirium, established dementia or actively dying)) – any data will be anonymous with no identifiable, or personal, components. (this box should expand as you type)		

	Participant numbers and source Provide an estimate of the expected number of participants. How will you identify participants and how will they be recruited?	
10	How many participants are expected?	The quantitative aspects will be a comprehensive census; estimate of 500 anonymised datasets. The qualitative aspect will be dependent upon clinician availability given the tight academic timeframe; estimate of 10-12 participants (accept a minimum of 5-6). *(this box should expand as you type)*
11	Who will the participants be?	Professional colleagues; both medical and other senior clinicians. *(this box should expand as you type)*
12	How will you identify the participants?	Quantitative aspect – census of all eligible patients. Qualitative aspect – invitation to senior medical and clinical teams already supporting medical admissions. There will be a balancing from the volunteers to ensure that a spectrum of specialties can be represented. *(this box should expand as you type)*

	Information for participants:	YES	NO	N/A
13	Will you describe the main research procedures to participants in advance, so that they are informed about what to expect?	☐	☐	☒
14	Will you tell participants that their participation is voluntary?	☐	☐	☒
15	Will you obtain written consent for participation?	☐	☒	☐
16	Will you explain to participants that refusal to participate in the research will not affect their treatment or education (if relevant)?	☐	☐	☒
17	If the research is observational, will you ask participants for their consent to being observed?	☐	☐	☒
18	Will you tell participants that they may withdraw from the research at any time and for any reason?	☒	☐	☐
19	With questionnaires, will you give participants the option of omitting questions they do not want to answer?	☒	☐	☐
20	Will you tell participants that their data will be treated with full confidentiality and that, if published, it will not be identifiable as theirs?	☒	☐	☐
21	Will you debrief participants at the end of their participation, in a way appropriate to the type of research undertaken?	☒	☐	☐
22	If NO to any of above questions, please give an explanation			
	Retrospective analysis (especially where the outcome has been death) is not appropriate for written consent in the conventional way. Acceptable routes for consent in this context are 'personal consultees' and 'nominated consultees'. *(this box should expand as you type)*			

	Information for participants:	YES	NO	N/A
24	Will participants be paid?	☐	☒	☐
25	Is specialist electrical or other equipment to be used with participants?	☐	☒	☐



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26	Are there any financial or other interests to the investigator or University arising from this study?	☐	☒	☐
27	Will the research activity involve deliberately misleading participants in any way, or the partial or full concealment of the specific study aims?	☐	☒	☐
28	If YES to any question, please provide full details			
	n/a *(this box should expand as you type)*			

SECTION H: Anticipated Risks

	Outline any anticipated risks that may adversely affect any of the participants, the researchers and/or the University, and the steps that will be taken to address them. If you have completed a full risk assessment (for example as required by a laboratory, or external research collaborator) you may append that to this form.	
1	**Full risk assessment completed and appended?**	**Yes** ☐ **No** ☒
2	**Risks to participants** For example: sector-specific health & safety, emotional distress, financial disclosure, physical harm, transfer of personal data, sensitive organisational information	
	Risk to participants: None – retrospective observation (quantitative) None – clinical and theoretical discussion with professionals (qualitative) *(this box should expand as you type)*	***How you will mitigate the risk to participants:*** n/a n/a *(this box should expand as you type)*
3	If research activity may include sensitive, embarrassing or upsetting topics (e.g. sexual activity, drug use) or issues likely to disclose information requiring further action (e.g. criminal activity), give details of the procedures to deal with these issues, including any support/advice (e.g. helpline numbers) to be offered to participants. Note that where applicable, consent procedures should make it clear that if something potentially or actually illegal is discovered in the course of a project, it may need to be disclosed to the proper authorities	
	n/a *(this box should expand as you type)*	
4	**Risks to the investigator** For example: personal health & safety, physical harm, emotional distress, risk of accusation of harm/impropriety, conflict of interest	
	Risk to the investigator: Capacity of time *(this box should expand as you type)*	***How you will mitigate the risk to the investigator:*** Establish realistic expectations; given a full time occupation will also continue alongside this research *(this box should expand as you type)*
5	**University/institutional risks** For example: adverse publicity, financial loss, data protection	
	Risk to the University: Potential perception of 'promoting death' *(this box should expand as you type)*	***How you will mitigate the risk to the University:*** Raise awareness of being able to support an anticipated and naturally occurring death *(this box should expand as you type)*

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6	**Environmental risks** For example: accidental spillage of pollutants, damage to local ecosystems	
	Risk to the environment: None *(this box should expand as you type)*	***How you will mitigate the risk to environment:*** n/a *(this box should expand as you type)*

	Disclosure and Barring Service			
	If the research activity involves children or vulnerable adults, a Disclosure and Barring Service (DBS) certificate must be obtained before any contact with such participants.	**YES**	**NO**	**N/A**
7	Does your research require you to hold a current DBS Certificate?	☐	☒	☐
8	If YES, please give the certificate number. If the certificate number is not available please write "Pending"; in this case any ethical approval will be subject to providing the appropriate certificate number.			

SECTION I: Feedback, Consent and Confidentiality

1	**Feedback** What de-briefing and feedback will be provided to participants, how will this be done and when?
	Not necessary for the retrospective observation component. Discussions with colleagues will be within their professional roles. The findings and report will be shared with them directly as a courtesy for contributing to understanding this topic. *(this box should expand as you type)*
2	**Informed consent** Describe the arrangements to inform potential participants, before providing consent, of what is involved in participating. Describe the arrangements for participants to provide full consent before data collection begins. If gaining consent in this way is inappropriate, explain how consent will be obtained and recorded in accordance with prevailing data protection legislation.
	Verbal consent can be captured within the interviews for that component. The anticipation is that they can be recorded for transcription and reference. The retrospective analysis is more than service evaluation (and, hence, research) given it is looking with a fresh perspective. However, the framework for governance should permit access through this approach. *(this box should expand as you type)*
3	**Confidentiality / Anonymity** Set out how anonymity of participants and confidentiality will be ensured in any outputs. If anonymity is not being offered, explain why this is the case.
	Anonymous data will be accessed through the local NHS Informatics Department. *(this box should expand as you type)*

SECTION J: Data Protection and Storage

	Does the research activity involve personal data (as defined by the General Data Protection Regulation 2016 "GDPR" and the Data Protection Act 2018 "DPA")?	**YES**	**NO**
1	***"Personal data"*** *means any information relating to an identified or identifiable natural person ('data subject'). An identifiable natural person is one who can be identified, directly or indirectly, in particular by reference to an identifier*	☐	☒

	such as a name, an identification number, location data, an online identifier or to one or more factors specific to the physical, physiological, genetic, mental, economic, cultural or social identity of that natural person. Any video or audio recordings of participants is considered to be personal data.		
	If YES, provide a description of the data and explain why this data needs to be collected:		
2	n/a *(this box should expand as you type)*		
	Does it involve special category data (as defined by the GDPR)?	**YES**	**NO**
3	***"Special category data"** means sensitive personal data consisting of information as to the data subjects' –* *(a) racial or ethnic origin,* *(b) political opinions,* *(c) religious beliefs or other beliefs of a similar nature,* *(d) membership of a trade union (within the meaning of the Trade Union and Labour Relations (Consolidation) Act 1992),* *(e) physical or mental health or condition,* *(f) sexual life,* *(g) genetics,* *(h) biometric data (as used for ID purposes),*	☐	☒
	If YES, provide a description of the special category data and explain why this data needs to be collected:		
4	n/a *(this box should expand as you type)*		

	Will data from the research activity (collected data, drafts of the thesis, or materials for publication) be stored in any of the following ways?	**YES**	**NO**
5	Manual files (i.e. in paper form)?	☒	☐
6	University computers?	☐	☒
7	Private company computers?	☐	☒
8	Home or other personal computers?	☐	☒
9	Laptop computers/ CDs/ Portable disk-drives/ memory sticks?	☒	☐
10	"Cloud" storage or websites?	☐	☒
11	Other – specify:	☐	☐
12	For all stored data, explain the measures in place to ensure the security of the data collected, data confidentiality, including details of backup procedures, password protection, encryption, anonymisation and pseudonymisation:		
	This research will be carried out under the terms of my NHS contract. The laptop is my work machine and has encryption and protection to support my NHS role. Any manual files will be held in my office which is behind locked doors (as per any clinical notes that I have in my professional role). *(this box should expand as you type)*		

	Data Protection		
	Will the research activity involve any of the following activities:	**YES**	**NO**
13	Electronic transfer of data in any form?	☒	☐

14	Sharing of data with others at the University outside of the immediate research team?	☐	☒
15	Sharing of data with other organisations?	☐	☒
16	Export of data outside the UK or importing of data from outside the UK?	☐	☒
17	Use of personal addresses, postcodes, faxes, emails or telephone numbers?	☐	☒
18	Publication of data that might allow identification of individuals?	☐	☒
19	Use of data management system?	☒	☐
20	Data archiving?	☒	☐
21	If YES to any question, please provide full details, explaining how this will be conducted in accordance with the GDPR and Data Protection Act (2018) (and any international equivalents, where appropriate):		
	Adherence to the health board policies in these fields will ensure that compliance is achieved. *(this box should expand as you type)*		
22	List all who will have access to the data generated by the research activity:		
	Investigator only. *(this box should expand as you type)*		
23	List who will have control of, and act as custodian(s) for, data generated by the research activity:		
	Investigator only. *(this box should expand as you type)*		
24	Give details of data storage arrangements, including security measures in place to protect the data, where data will be stored, how long for, and in what form. Will data be archived – if so how and if not why not.		
	Data will be held within the NHS account (personal folders rather than shared). The firewalls and security are more robust than other systems I have access to as data protection is at a senior level. Health board systems exist to monitor and support best practice. Archiving will occur as with other NHS records, at 7 years as the default setting. Deposition in a data bank will be considered but will need to be contextualised as to the most appropriate repository. *(this box should expand as you type)*		
25	Please indicate if your data will be stored in the UWTSD Research Data Repository (see https://researchdata.uwtsd.ac.uk/). If so please explain. (*Most relevant to academic staff)*		
	No *(this box should expand as you type)*		
26	Confirm that you have read the UWTSD guidance on data management (see https://www.uwtsd.ac.uk/library/research-data-management/)	**YES**	☒
27	Confirm that you are aware that you need to keep all data until after your research has completed or the end of your funding	**YES**	☒

Appendix B Scheme of work

	Activity		Words	Pace	1st draft shared
1	Project brief			Oct	7 October 2024
2	Submit ethics approval			Oct	
3	Methods selection and justification			Nov / Dec	
4	Start primary data collection	Prognostic tool		Nov / Dec	
5	Draft introduction chapter			Nov / Dec	
6	Literature review chapter		4500	Nov / Dec	18 December 2024
				CHRISTMAS	
7	Methods chapter		2250	Jan	25 February 2025
8	Progress review			Jan	
9	Primary data analysis	Prognostic tool		Jan	
10	Carry out survey +/- interview	Feasibility		Feb	
11	Results chapter		750	Mar	24 March 2025
12	Discussion chapter		4500	Mar / Apr	24 March 2025
13	Conclusions chapter		1500	Apr	20 April 2025
				EASTER	
15	Introduction chapter		1500	Apr	20 April 2025
16	Final revisions			May	
17	Submit			6 May 2025	

Appendix C Supervision diary

21 September 2024	Residential, Swansea	
7 October	Supervision	E. Conley
23 October	Supervision	E. Conley
6 November	Supervision	E. Conley
19 November	Supervision	E. Conley
4 December	Supervision	E. Conley
CHRISTMAS		
13 January 2025	Progress review	E. Conley, and, S. Ferraraccio
29 January	Supervision	E. Conley
10 March	Supervision	E. Conley
4 April	Supervision	E. Conley
EASTER		
29 April	Supervision	E. Conley