A mixed methods approach to understanding the feasibility of the Integrated Palliative care Outcome Scale (IPOS) in two Palliative Care settings

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List of Abbreviations

APCA POS – African Palliative Care Association Palliative Outcome Scale
CEO – Chief Executive Officer
CMO – Chief Medical Officer
EMIS Web – Egton Medical Information Service
FY – Foundation Year
GP – General Practitioner
HIS – Healthcare Improvement Scotland
IHI – Institute for Healthcare Improvement
IPOS – Integrated Palliative care Outcome Scale
MDT – Multi-Disciplinary Team
NHS – National Health Service
PEOLC – Palliative and End Of Life Care
POS – Palliative Outcome Scale
PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analysis
PROM – Patient Reported Outcome Measure
SOMREC – School of Medicine Research Ethics Comittee
SPC – Statistical Process Control
SPPC – Scottish Partnership for Palliative Care
SQUIRE – Standards for Quality Improvement Reporting Excellence
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Finally, I would like to express my gratitude to Dr Deans Buchanan. You provided me with invaluable learning and research opportunities throughout this project. Your passion and commitment to teaching and engaging students is so inspiring.
**Declaration**

I, Catriona Grant, hereby declare that I am the author of this dissertation and that unless otherwise stated, all references have been consulted by myself. The work on which this dissertation is based, is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other University.

I empower the University to reproduce for the purpose of research, either the whole or any portion of the contents in any manner whatsoever.

Signature ...Catriona Grant...........

Date ........22.04.19........................
Abstract

**Background:** Outcome measures identify and quantify changes that a patient is experiencing and have been adopted in clinical care to support quality improvement efforts (1). Patient Reported Outcome Measures (PROMs) are considered a valuable way to measure health outcomes in a person–centred manner (2). NHS Tayside palliative care services have recently committed to implement a validated PROM, the Integrated Palliative Care Outcomes Scale (IPOS), into routine assessment practices (3). Although regarded as beneficial, the challenges of integrating the IPOS into clinical practice are many and little is known about the feasibility of the IPOS in routine care.

**Aim:** This service improvement project aimed to understand the barriers, facilitators and risks to integrating the IPOS into palliative care clinical practice in order to identify strategies to optimize uptake.

**Methods:** This project used a mixed methods ethnographic approach combining non-participant observation, semi-structured interviews and quantitative prevalence of completed IPOS forms. The project was based in two Tayside palliative care services – a hospital acute palliative care unit (in Ninewells) and a specialist inpatient unit (in Roxburghe House). Health professionals were purposively sampled from these settings and from the wider national palliative care community. Inductive thematic analysis was conducted.

**Results:** Prevalence of completed IPOS forms was 15% and 40% in Roxburghe and Ninewells, respectively. 18 interviews and 14 observations were conducted. Findings revealed varying compatibility with staff, patient and service needs between the two units. Barriers to IPOS uptake included: perceived lack of value and compatibility with staff assessment and person-centred care; frailty of patient group; lack of infrastructure, time and resources. Facilitators to uptake included: perceived value of the IPOS in enabling communication, facilitating holistic assessment and indicating service quality; development of electronic IPOS score systems and the current socio-political climate of person-centred care. Risks included potential for causing patient distress and burden, and staff fatigue.

**Conclusion:** The IPOS is unlikely to be sustainable in each unit for two different reasons. In Roxburghe, the IPOS doesn’t support the people in the system, as the clerking and ongoing holistic care often superseded the IPOS. In Ninewells, the system doesn’t support the people using IPOS, as system barriers such as time constraints, workload and infrastructure lowered the feasibility of the IPOS in routine practice. In order to integrate the IPOS, a shift in the process of care is required. Intrinsic motivation of staff must be mobilised through patient feedback and co-design of a process which fully meets stakeholder needs. Teams must be engaged through generating a shared ownership and purpose of the IPOS. Finally, services must be supported through funding and resources, to support the staff as they seek to improve healthcare delivery.
Chapter 1 | Introduction

1.1 Background

An outcome is defined as ‘the change in a patient’s current and future health status that can be attributed to preceding healthcare’ (4). Outcome measures identify and quantify changes that a patient is experiencing and have been adopted in clinical care to support quality improvement efforts (1, 5). As patients are the focal point of care, their perception of quality of care and quality of life are central. Patient Reported Outcome Measures (PROMs), which are self-reported questionnaires, are therefore considered a valuable way to measure health outcomes in a person-centric manner (6). Healthcare Improvement Scotland (HIS) recognise that PROMs ‘can help to monitor patient progress, facilitate communication between professionals and patients and/or health to improve the quality of health services’ (7).

Palliative care is described as the ‘active holistic care of people with advanced, progressive disease’ (8). This holistic approach, encompassing the identification and management of physical symptoms as well as psychological, spiritual and social needs, is a Scottish priority (9). Patients with advanced, progressive disease have unique healthcare needs, and assessing highly subjective health outcomes such as dignity and meaning can be challenging (1, 10). Recognising this, the previous Chief Medical Officer of Scotland identified that quality assessment measures in palliative care have tended to focus on resource or process measures such as admission rates, resource availability and health expenditure, which have limited value in determining care quality (11). On a national level, there has been a strategic commitment from commissioning bodies to improve the assessment of palliative care quality in Scotland, using PROMs (2, 12). NHS Tayside palliative care services have therefore committed to implement a validated PROM, the Integrated Palliative Care Outcomes Scale (IPOS), into routine care delivery (3).

The Integrated Palliative Care Outcomes Scale (IPOS) is a shortened, revised PROM derived from other validated tools (the POS, POS-S and APCA African POS). The IPOS comprises 10 questions designed to gather information about physical and non-physical needs. The format of the tool includes an initial open question followed by structured Likert-type scale, with domains scored from 0-4 (13). An example IPOS is shown in Appendix 1. It can be completed either by patients or by proxy (family or staff), however, patient reporting is gold standard (14). The IPOS should be repeated in order to monitor changes in patient burden (13). The frequency of PROM repetition and the inclusion of proxy measures are decisions made by individual services (1). Currently two versions of the IPOS exist: the 3-day recall and 1 week recall form. Recall period refers to the time period over which the results of the PROM are reported. Two Tayside settings are currently using IPOS: Roxburgh specialist palliative care unit and Ninewells acute palliative care unit.

The IPOS has undergone significant psychometric testing and several validation studies have been carried out (13, 15-17). Despite this, little is known as to whether the IPOS is practical and beneficial to healthcare professionals, families and patients in busy clinical practices which are markedly different from the ideal clinical conditions of research studies.
The 2017 collaborative report published by the Royal Academy of Engineering and Royal College of Physicians proposes a framework for service improvement using a four phase action plan: to understand, design, deliver and sustain (18). This project will focus on the first step in this improvement journey, to understand specifically the people, systems, potential designs and risks involved in IPOS integration within the two Tayside units.

1.2 | Aim and Objectives

1.2.1 | Aim
To understand the barriers, facilitators and risks to integrating the IPOS in clinical palliative care settings in order to identify strategies to optimize uptake.

1.2.2 | Objectives
1. To investigate the current IPOS work system in an acute and specialist palliative care setting.
2. To examine the barriers, facilitators and risks to IPOS integration.
3. To determine the changes that are needed to optimize uptake of IPOS, taking account of the full range of stakeholders
Chapter 2 | Literature Review

This chapter presents the review of literature on the integration of PROMs in clinical settings. The search strategy is presented, alongside the methodological gaps in identified papers and themes on the barriers and facilitators to introducing PROMs into clinical palliative care settings.

2.1 | Search Strategy

Four databases were searched between December 2018 and March 2019 (MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsychINFO and Psychology and Behavioral Sciences Collection) to identify studies reporting on patient reported outcome measures (PROMs) in palliative care settings. The search design was comprised of the population group (terms including ‘palliative care, hospice care, end of life care or terminal care’), the intervention (terms including ‘outcome measures or patient-reported outcome measures/PROMs or palliative care outcome scale’) and the strategy (terms including ‘implement* or introduce* or integrat*’). Search terms were chosen to locate all the literature describing the integration of PROMs in clinical settings, including literature reporting on factors inhibiting and driving PROM success. It is for this reason that ‘barriers and facilitators’ was not included as a search term.

Table 1: Search Strategy

<table>
<thead>
<tr>
<th>Search No.</th>
<th>Search term(s)</th>
<th>No. of papers</th>
</tr>
</thead>
<tbody>
<tr>
<td>#1</td>
<td>“palliative care OR hospice care OR end of life care OR terminal care”</td>
<td>168,125</td>
</tr>
<tr>
<td>#2</td>
<td>“outcome measures OR patient-reported outcome measures/PROMs OR palliative care outcome scale”</td>
<td>216,104</td>
</tr>
<tr>
<td>#3</td>
<td>“implement* OR Introduce* OR Integrat*”</td>
<td>764,471</td>
</tr>
<tr>
<td>#4</td>
<td>#1 AND #2 AND #3</td>
<td>472</td>
</tr>
<tr>
<td>#5</td>
<td>#4 (English language only)</td>
<td>464</td>
</tr>
<tr>
<td>TOTAL PAPERS</td>
<td></td>
<td>464</td>
</tr>
</tbody>
</table>

An initial search of studies published between 1985 and 2019 identified 284 papers after duplicates (n=180) were removed. Through hand searching of relevant review papers a further two articles were identified. Abstracts were screened and 27 papers were included for further analysis. Following in-depth evaluation of this literature, fourteen papers were excluded. Thirteen papers met the inclusion criteria (Table 2) and are shown in Appendix 2. A PRISMA flow chart detailing this literature searching process is shown in Figure 1(19).
Table 2: Inclusion/Exclusion Criteria

<table>
<thead>
<tr>
<th>Inclusion Criteria</th>
<th>Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Primary research studies published between 1985 and 2019 (the earliest PROM literature appeared in the late 1980s)</td>
<td>1. Editorials and review papers</td>
</tr>
<tr>
<td>2. Studies conducted in a clinical palliative care setting</td>
<td>2. Studies outside the clinical setting and the publication years</td>
</tr>
<tr>
<td>3. Studies assessing PROM integration or implementation</td>
<td>3. Research reporting the development, validation or psychometric testing of PROMs</td>
</tr>
<tr>
<td>4. Studies conducted in English in any part of the world</td>
<td>4. Studies implementing complex interventions alongside PROMs</td>
</tr>
<tr>
<td></td>
<td>5. Studies in languages other than English</td>
</tr>
</tbody>
</table>

Figure 1: Flow chart based on PRISMA recommendations
These 13 studies reported the use of PROMs in hospital, hospice or care-home settings and provided a set of pointers for introducing and implementing PROMs. Most studies were designed to investigate a pilot implementation of outcome measurement and subsequently discussed little of the routine daily challenges of using PROMs.

Two studies examined the IPOS as a measure. One explored the success of the IPOS-dem, a tool specifically developed for dementia patients (20). The other, by Lind et al. (21), investigated an IPOS implementation strategy in three acute care settings in Sweden.

2.2 | Methodological gaps

Several studies examined perspectives of staff using outcome measures but did not research the broader organisational and socio-cultural barriers which are crucial to the success of PROM implementation (22, 23). Bausewein’s (24) use of a quantitative survey tool to understand the challenges of using PROMs may have introduced bias due to non-coverage and non-response. Hughes et al. (23) argued that attitudes towards outcome measurement and the challenges of implementation may be significantly different for experienced staff compared with professionals unfamiliar with PROMs. Such factors weaken the power of the reported results.

Many of the early studies investigating the use of PROMs in clinical practice were carried out through sampling across a range of settings. Two early studies conducted by Hughes et al. (23) and Slater et al. (22), call for further research to investigate these contextual influences, to optimise integration of outcome measures. Hughes et al. (23) acknowledge that although common facilitators and barriers form a useful platform for understanding mechanisms of implementation, outcome measures ‘should not be developed in a vacuum’.

Recent studies have sought to improve this gap in knowledge by examining the contexts in which PROMs have been integrated (20, 21, 25, 26). The feasibility study by Lind et al. (21) provided a detailed analysis of the context and examined the degree of preparedness of the setting to accept the outcome measure. The authors utilised Moore’s (27) service evaluation approach to describe a lack of readiness due to feelings of “change fatigue”. This concept was congruent with a study conducted by Krawczyk et al.(25) in 2018 in which participants expressed burnout and cynicism due to continuous change.

Of the two studies specifically exploring the IPOS, neither fully interrogated the challenges of sustaining its use in routine clinical settings. Both studies tested an implementation strategy developed by the researchers who provided support for the training and facilitated the IPOS integration. The challenges of coordinating training and engaging staff in clinical, rather than research settings, are powerful barriers to PROM success.
2.3 | Literature Findings

This section explores findings from the literature regarding the barriers and facilitators to integrating PROMs and the recommended strategies for promoting uptake.

2.3.1 | Barriers Identified from the Literature

Several common themes emerged from the literature on the factors that acted as barriers to implementation.

The perceived burden of PROMs

A multi-site survey conducted by Daveson et al. (28) highlighted reasons given by health professionals for not using PROMs. These included concerns that the tool was burdensome for patients, families and staff to complete and that it did not accurately reflect the patient’s situation (28). This finding was corroborated by Hughes et al. (10) as staff frequently expressed concerns that patients found PROMs time consuming and burdensome, despite the contrasting evidence reported by patients and families themselves (3). However, it has been reported that patients perceived PROMs negatively when staff did not respond to the information given (3). The relevance of PROMS to clinical practice is therefore an important consideration for both staff and patients.

Limited staff awareness and shared ownership

Several studies reported a lack of staff awareness of why PROMs were introduced, coupled with a lack of understanding of their importance in clinical practice (24, 28). A study by Pinto et al. (26) concluded it is essential to define the rationale for PROM implementation to engage stakeholders. Additionally, it was identified by Krawczyk et al. (25) that stakeholder understanding of the potential benefits of PROMs beyond the direct clinical processes, such as service improvement and additional funding, may not be transparent across stakeholder groups.

Lack of Training

Limited training in how to perform PROMs and interpret their data have been identified as major barriers to introducing them (29). Daveson et al. (28) noted that it was essential to involve all staff in the decision to introduce outcome measures and that an effective training process was crucial, as goals of practice were different for the range of clinical staff involved.

Time Constraints

Several studies highlighted the challenges of implementation relating to time constraints, namely resulting from increased work pressures, low staffing numbers and lack of scheduled time for professional development. PROMs have been reported as being time-consuming to perform and interpret (23, 29, 30). Evidence has identified time constraints as the leading barrier reported by doctors and the second highest scoring barrier for nurses (28). The issue of time may be particularly problematic in acute settings, due to the often unpredictable nature of work and competing task priorities (31). An early report by Dunckley et al. in 2005 highlighted that successful implementation required concerted effort and clinical teams should take into consideration the extra time required to do this (29). Further research has confirmed this finding (22, 26).
2.3.2 | Facilitators Identified from the Literature

Factors that facilitated the implementation of PROMs in the literature focused on stakeholder perceptions of their value (relevance and compatibility).

Relevance to clinical practice

Relevance is recognised as being influential in promoting PROM uptake (32). This concept is highly subjective and may be perceived differently by various staff groups (28). PROMs in palliative care have been regarded as relevant if they are used to enhance communication and relationships (22), inform clinical decision making (31) including care planning and provision, as well as facilitating comprehensive holistic assessment (20). Again, while seen in research settings, few studies explored whether these were evidenced in the routine experience of palliative care patients.

Compatibility with working practice

The ease of use and level of compatibility with stakeholder needs was strongly correlated with uptake by individual staff. PROMs which are perceived as flexible to use, valid, reliable and brief are more likely to be adopted (20, 26, 31). Technological advancements in PROM tools, especially through wireless tablets enhance efficiency of use but some studies have raised issues regarding accuracy and reliability of the collection processes, and data security (33).

2.3.3 | Strategies for Implementation

Several strategies to overcome the barriers and improve the implementation and uptake of PROMs in palliative care were described. These included:

1. Education and training, which improves confidence in the use of the tool and enhanced staff engagement (20, 22).
2. Embedding PROMs into clinical interactions, such as Multi-Disciplinary Team (MDT) discussions and daily handover processes. This mobilises teams to make use of PROM results (26).
3. A cascade approach to implementation, with collective ownership and shared decision making. Dunckley et al. (31) identified that decision making and diffusion strategy should be a collaborative effort involving all stakeholders, especially frontline PROM users (31).
4. Investing in leadership and supportive supervision. Ellis-Smith et al. determining the feasibility of the IPOS dementia version in the care home setting noted that uptake was maximised through leadership and supervision (20). Pinto et al describe the importance of active participation and support from senior leadership to set examples of good practice (26).
5. Allocating roles and responsibilities. Practical challenges of implementation can be improved by early division of roles, as noted by Tavares et al. (34) to ensure staff have manageable tasks and understand their part in the larger process.
6. Sharing PROMs data has value to service providers and service users as well as having potential economic value to attract funding (26). The ability to manage and
analyse this data through feedback sessions has also been proposed as a sustainability factor, although this is yet to be investigated.

2.4 | The Premise for this Study
No studies have yet been carried out to address the integration of IPOS within Scottish palliative care clinical settings. Furthermore, research has neglected to understand the routine barriers to PROM use outside of a research implementation context which is often accompanied by human and funding resources. The challenge highlighted in best practice guidelines (14), is to use contextualised results about the barriers and facilitators to PROMs to develop specific integration strategies within each setting(23, 25). As Krawczyk et al. (25) stated;

‘PROMs are not a neutral technology, and implementation into clinical practice is shaped by a range of considerations constituted by a polyphony of system contexts and differently enabled actors.’

This dissertation therefore aims to understand the challenges to using the IPOS in two different palliative care settings in order to propose strategies to improve the efficacy and uptake of the IPOS and to fulfil the service improvement guidance to integrate the IPOS in Tayside (3).
Chapter 3 | Methodology

“Research methods should follow research questions in a way that offers the best chance to obtain useful answers” (35).

This chapter describes the choice of research design, the process of data collection and evaluation and the rationale for this approach.

3.1 | Study Design

Drawing on extensive literature in improvement science, Goodman et al. (36) suggest that a mixed method design which brings together data from observation, interview and quantitative measurement can provide a way of reliably and comprehensively understanding improvement efforts. This study adopted a mixed method design. It combined quantitative and qualitative elements including semi-structured interviews, non-participant observation and a quantitative time series over a period of 4 months in two separate sites.

A mixed methods design was deemed particularly suitable because, as Peters et al. note, it provides ‘a practical way to understand multiple perspectives, different types of causal pathways, and multiple types of outcomes—all common features of implementation research problems.’ (37). There are several ways of conducting mixed methods research. In 2006, Creswell et al. (38) described four major types of mixed methods designs, namely triangulation, embedded, explanatory and exploratory design. This study followed a triangulation (often labelled ‘convergent’) design, the most common approach, and one which is based on the principle that gathering different types of data on a singular topic allows the researcher a better understanding of that topic in question - in this case the IPOS (38).

The next phase of design is dependent on the sequence of the methods, the weighting given to each method, and the purpose of integration of findings (39). A concurrent sequence was adopted, so that the researcher collects and analyses different data sets over the same time scale and with equal weighting(38). Data collection and analysis were carried out separately but concurrently in two units between January and April 2019. An additional observation study carried out in November 2018 was incorporated. Data analysis from each unit was conducted separately and brought together at the point of interpretation of findings in April 2019. Methodological triangulation, as a way of comparing, corroborating and integrating the richness of the findings was used to enhance the reliability of the results(40). An outline of the study process and project timeline is shown in figure 2 and 3, respectively.
The Standards for Quality Improvement Reporting Excellence (SQUIRE) guideline identify two objectives for researchers undertaking improvement studies: to understand ‘**whether** and **why** an intervention works’ (41). Measurement helps determine the outcomes of improvement, i.e. whether it works, but it can produce a reductionist evaluation of an improvement effort. To understand why an improvement works it is necessary to consider the influence of contextual elements, which are often most effectively understood through ethnographic methods (36, 42). This mixed methods ethnographic study allowed for a rich, in-depth analysis of the IPOS work system, the contextual elements and the systematic driving and inhibiting forces.
3.2 | Study Setting

The settings for the study were two palliative care services located in NHS Tayside, Roxburgh House Specialist Inpatient Unit, and the Acute Hospital Palliative Care Unit (APCU) at Ninewells Hospital, hereafter referred to as Roxburgh and Ninewells. Both are implementing the IPOS into clinical practice following recommendations from Tayside Managed Care Network for Palliative and End of Life Care for a rollout of IPOS across Tayside (3). The two units reflect the diversity of patient, family and staff needs as well as the different organisational structures of coordinated palliative care services. Context details are presented in Table 3.

<table>
<thead>
<tr>
<th>Table 3: Study Setting Characteristics</th>
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<table>
<thead>
<tr>
<th>Roxburgh</th>
<th>Ninewells</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Service Type</strong></td>
<td>Specialist Inpatient Unit</td>
</tr>
<tr>
<td><strong>Size</strong></td>
<td>24 bed unit</td>
</tr>
<tr>
<td><strong>Team</strong></td>
<td>Multi-disciplinary team (MDT) : specialist palliative care doctors, nurses, allied health professionals, chaplains and social and family support workers</td>
</tr>
<tr>
<td><strong>Location</strong></td>
<td>Attached to Macmillan day care centre and community palliative care offices</td>
</tr>
<tr>
<td><strong>Services</strong></td>
<td>Provides short term care, rehabilitation or relocation and end of life care.</td>
</tr>
<tr>
<td><strong>Central Staff office</strong></td>
<td>Based in the Roxburgh centre adjacent to the Unit</td>
</tr>
<tr>
<td><strong>Staff Interactions</strong></td>
<td>Verbal handovers, Daily ward rounds and weekly MDT meetings</td>
</tr>
<tr>
<td><strong>Record keeping of IPOS</strong></td>
<td>Paper form only – inserted into Patient paper notes</td>
</tr>
</tbody>
</table>
### 3.3 | Qualitative Methods

An ethnographic approach was adopted in the qualitative arm of this study. Ethnography is an established method to understand complex systems and the social practices and interactions that occur (43). It allows researchers to explore views and actions in the location in which they are based without influencing the outcomes (44). Observation, a commonly used ethnographic method, can be either participant or non-participant. A non-participant observation was chosen so that the researcher was present but not participating in the clinical environments (45). It was pivotal in understanding the role of staff and the workflow processes.

Semi-structured interviews provide space for participants to express their own views in their own terms within a more defined conversation direction (45). This method was determined to be a valuable way of exploring why the system works the way it does, providing a gateway to understanding the facilitators and barriers to IPOS integration.

#### 3.3.1 | Data Collection

**3.3.1.1 | Non-Participant Observation**

Thirteen staff members (see Table 4) were shadowed across the two units throughout February and March 2019. In Ninewells staff were also shadowed in November. Observations of routine processes such as clerkings, daily ward rounds and handovers, MDT meetings, documentation and interactions between staff were collected with attention paid to specific IPOS processes. These included the explanation, interpretation, data collection and information sharing of IPOS as well as the process of completing the tool by patients. Clinical leads were approached to gather contact information from MDT members, thus ensuring a comprehensive list of staff groups and contacts was obtained. Purposive sampling of each professional group within the MDT was carried out with the goal of understanding individual roles and interactions in the system. Handwritten notes were taken in the field, typed up and transcribed for coding. Informed consent was obtained from those being shadowed prior to shadowing (Appendix 3) Field notes were not taken in situations involving individuals who did not consent to observation and all data was anonymized.

**3.3.1.2 | Participant Semi-Structured Interviews**

Purposive sampling was used to ensure participants came from different professional groups. A total of 18 interviews were conducted. The sampling frame included clinical, and managerial professional groups within each unit and four external stakeholders involved in national palliative care. A comprehensive list of study participants is shown in Table 4. Contacts were gathered through clinical leads and observation practice. Participants were contacted via email or face to face through conversations within the unit.

Interviews were carried out throughout February and March 2019 and each was structured using a topic guide (see Appendix 4). This topic guide was derived from recent quality improvement literature, with topics chosen based on emerging themes from the literature review (18). Topics explored staff perspectives about the purpose and process of the IPOS introduction, the barriers and facilitators to routine use of IPOS and the opportunities for improvement. This exploratory method of data collection is particularly important in
understanding staff motivation and attitudes towards the IPOS, aspects which have been identified as key drivers in change psychology (46) and IPOS success (1).

Table 4: Study Participants

<table>
<thead>
<tr>
<th>Observation</th>
<th>Roxburghe</th>
<th>Ninewells</th>
<th>External sources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2 Junior Doctors</td>
<td>1 Specialty doctor</td>
<td>N/A</td>
</tr>
<tr>
<td></td>
<td>1 Palliative care Registrars</td>
<td>2 Specialist palliative care Nurses</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 Senior Consultants</td>
<td>3 palliative care consultant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 spiritual care chaplain</td>
<td>1 APCU Junior Doctor</td>
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<td></td>
<td></td>
<td>1 Palliative care registrar</td>
<td></td>
</tr>
<tr>
<td>Semi-structured interviews</td>
<td>1 Senior Charge Nurse</td>
<td>1 Staff Nurse</td>
<td>1 Healthcare Improvement Scotland (HIS) clinical lead</td>
</tr>
<tr>
<td></td>
<td>3 consultants</td>
<td>1 Specialist palliative care nurse</td>
<td>1 Health and social care Policy worker</td>
</tr>
<tr>
<td></td>
<td>2 Junior Doctors</td>
<td>1 specialty doctor</td>
<td>1 CEO of Scottish Partnership for Palliative Care (SPPC).</td>
</tr>
<tr>
<td></td>
<td>1 GP trainee doctor</td>
<td>1 consultant</td>
<td></td>
</tr>
<tr>
<td></td>
<td>1 Clinical Nurse Co-ordinator</td>
<td>1 Junior Doctor</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1 Palliative care Registrar</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 EMIS Web Project Lead</td>
</tr>
</tbody>
</table>

3.3.2 | Qualitative Data Management and Analysis

With informed consent granted, all interviews were audio recorded and field notes hand recorded. Interviews were transcribed verbatim and field notes typed up, using NVivo 12 software to facilitate data management. Thematic analysis, a way of “identifying, analyzing and interpreting patterns of meaning (“themes”)” (47), is commonly used in healthcare research setting as a method for interpreting both interview and observation data as it allows flexibility for the researcher whilst ensuring data-driven findings are developed (47) Familiarization with the initial data was achieved by reading and re-reading the fieldnotes and interview transcripts.

Interview and observation data from the two settings were coded separately into a coding framework using a general inductive approach, that is, allowing patterns to arise from the data without a preconceived structure (48). Underpinning this decision to use an inductive approach was a desire to analyse the data organically, grounding the findings in the context as far as possible. Subthemes were identified, before bringing the data sets together for higher level theme concepts to be developed. This occurred through exploring patterns, sequences and relationships common to both and exceptions in the data sets. The coding framework can be found in Appendix 5.

3.4 | Reflexivity

I acknowledge that I am coming from a position of understanding that may favour the use of the IPOS due to my knowledge of the literature reporting positive patient, family and staff experiences and my prior experiences speaking with patients. Additionally, I recognise that
the decision to integrate IPOS was made by senior professionals with much greater knowledge and experience in palliative care. Although I sought to take a neutral, objective position, I recognised the individual bias we all carry. I sought to minimize the effects of bias through employing techniques of reflexivity outlined in the literature (49). I reflected on my experience of being in palliative care settings and my pre-existing perceptions of IPOS. I was conscious of the potential for my position to influence participant responses. Whilst I believe that participants wanted to tell their true experiences, they may also have felt a need to be more measured knowing that the system wanted IPOS to work. It was therefore important for me to state my position prior to the interview to ensure participants felt safe to share their true opinions.

3.5 | Quantitative Methods

The purpose of the quantitative component was to investigate the functional outcomes of IPOS implementation helping to build up a more reliable picture of the existing IPOS work system (50).

3.5.1 | Data Collection

The proportion of patients admitted to each unit with a completed IPOS form located in the notes was recorded. A 3-month period prevalence of IPOS completion was calculated for each unit to allow comparison of results. Each week, between 14th January to 8th April, data was gathered on number of admissions to each unit. For each patient admitted, paper and electronic notes were accessed to assess whether an IPOS was completed and whether this had been documented on electronic records.

3.5.2 | Quantitative Data Management and Analysis

Due to the higher number of admissions to Roxburgh, a weekly incidence proportion was also calculated. Incidence was then plotted on a P-chart, a type of statistical process control (SPC) chart. These charts use statistical methods to identify a range of normal variation allowing identification of common and special cause variation (51). An automated excel tool, created by the Information Services Division was used to analyse the P-chart (51). Measuring variation in a process over time is well known practice in improvement work and Bates et al. recommend this method for understanding the influence of contextual factors in a dynamic system (52).

For both units, period prevalence (expressed as a percentage) was calculated as follows:

\[
\frac{\text{No. Patients with a completed IPOS form in paper notes}}{\text{No. patients admitted to the APCU}} \times 100
\]
For Roxburghe only, weekly Incidence proportion was calculated as follows:

$$\frac{\text{No. Patients with a completed IPOS form in paper notes}}{\text{No. patients admitted to the unit}} \text{ per week}$$

### 3.6 | Analysis and Triangulation of Qualitative and Quantitative Data

A mixed method matrix technique detailed by O’Cathain et al. (53) was chosen to enable triangulation. This technique is based on the principle that qualitative and quantitative data can be drawn together and studied for individual ‘cases’, which in this context were two different palliative care settings. Understanding and situating findings within a specific context has been identified as a core task in implementation methodology literature both in the broader context of healthcare improvement and also specifically in the implementation of PROMS in palliative care (1, 54). To accomplish this case study of IPOS, integrated analysis of quantitative and qualitative data was carried out initially within each setting before being brought together at the final stage of analysis (see Figure 2). In each separate setting (case) the patterns of IPOS completion were interpreted in light of interview and observation findings and an annotated time series chart was created (55). Triangulation of the setting specific findings helped inform setting strategies for change. This contributed to the third objective of this project. As the IPOS is a collaborative tool intended for use across a range of palliative care providers, the common findings also serve to highlight issues with the IPOS as a tool.

### 3.7 | Ethical Considerations and Contingencies

A study protocol was submitted and approved by the University of Dundee School of Medicine Research Ethics Committee (SOMREC) (see Appendix 6). Caldicott approval was sought prior to collection of quantitative data. This study was determined to be low risk, however a number of ethical considerations were identified prior to initiation of the project. Table 5 summarises these considerations and how they were managed.

**Table 5: Ethical Considerations**

<table>
<thead>
<tr>
<th>Ethical consideration</th>
<th>Measures adopted</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confidentiality</td>
<td>Interview transcription data was anonymized, ensuring names were removed and only the participant’s job and setting were recorded</td>
</tr>
<tr>
<td></td>
<td>No identifiable staff features were recorded in the Fieldnotes</td>
</tr>
<tr>
<td></td>
<td>Data was handled on a secure password protected laptop</td>
</tr>
<tr>
<td>Consent</td>
<td>All participants received project information and consent forms prior to audio-recording and observation practices (see Appendix 3).</td>
</tr>
<tr>
<td></td>
<td>In October 2018, at the time of staff observation in Ninewells, verbal consent was sought as written consent forms had not yet been developed.</td>
</tr>
<tr>
<td>Access to patient information</td>
<td>Caldicott approval was sought prior to initiation of the project. Whilst access to patient written and electronic notes was needed to assess the prevalence of IPOS completion, no identifiable patient information was recorded. Patients were numbered 1 to 69 and the data recorded included: date of admission and whether an IPOS was completed.</td>
</tr>
</tbody>
</table>
Chapter 4 | Results for Objective 1

This chapter will incorporate quantitative and observation findings to present a discussion of the process of IPOS use and the functional outcomes of the IPOS in each setting.

4.1 | Representation of the IPOS Process

The process of IPOS distribution, collection and review is complex. A written and visual representation of the IPOS process in each unit is presented.

4.1.1 | Overview of the Process

In both units the process begins with the clerking doctor handing out the IPOS during the admission assessment. A prompt included in the clerking asks staff to document whether the IPOS has been considered, if it has been given and if not, why. The IPOS may be completed with the clerking doctor or later, by the patient with or without assistance from family or staff. The IPOS must then be collected, a process reliant on staff remembering those patients who received an IPOS. Neither unit has a dedicated staff member to collect the forms, so often they are forgotten or discarded. Collected forms should be stored in the patient notes for review by the medical and nursing team. IPOS review is ideally a collaborative process in which staff and patients discuss the results and management options. It is at this point that the process stops in Roxburghe.

In Ninewells an additional step has been added - the input of completed IPOS results into the electronic patient records (EMIS Web). This process must be completed on the ward, to allow the paper form to be returned to the patient paper notes. Repeat IPOS forms are intended to be given in Ninewells and the timing of this step is dependent on a clinical judgement from the team. Often it cannot be achieved as patients die or be discharged.

Although there is a common IPOS process between Units, the intricacies of this process are variable. As such, a flow chart of the process in Roxburghe and Ninewells is shown in Figure 4 and 6, respectively.
Figure 4: IPOS Process Map for Roxburghe

- Clerking doctor considers IPOS
  - Patient not suitable for IPOS
  - Reason for IPOS incompletion documented in clerking
  - IPOS given to patient to complete in own time
  - Patient doesn’t complete IPOS
  - IPOS completed there and then, with clerking doctor
  - Completed IPOS collected in and filed in notes by clerking doctor
  - IPOS reviewed by seniors on ward round

- IPOS collected and filed in notes
- IPOS reviewed by doctors on ward round

Figure 5: IPOS Process Map for Ninewells

- Clerking doctor considers IPOS
  - Patient not suitable for IPOS
  - Clerking doctor recommends ward team to give IPOS/IPOS given at a more suitable time
  - IPOS given to patient at later time
  - IPOS given to patient to complete in own time
  - Patient completes in own time
  - Completed IPOS collected in and filed in notes by clerking doctor
  - IPOS returned to notes

- Patient doesn’t complete IPOS
- Completed IPOS collected in and filed in notes by clerking doctor
- IPOS reviewed by seniors on ward round

- IPOS collected by ward team
- IPOS returned to notes

- IPOS reviewed with patient by HPCT
- HPCT input IPOS into EMIS
- IPOS returned to notes
4.1.2 | Observed barriers and facilitators

Through observation of the IPOS process, a number of barriers and facilitators specific to each unit were identified. These are set out in Table 6 and discussed further in Chapter 5.

<table>
<thead>
<tr>
<th>Stage in Process</th>
<th>Ninewells</th>
<th>Roxburghe</th>
</tr>
</thead>
<tbody>
<tr>
<td>IPOS Distribution</td>
<td>+ written prompt on clerking .  + FY (Foundation Years) have the time to do and keen to do job well  ≠ patients unwell / distressed  ≠ human memory (to bring IPOS with staff member)  ≠ difficulty locating IPOS  ≠ lack of time to explain or go through IPOS with patients  ≠ - only 3 patients on ward, IPOS difficult to make a habit</td>
<td>+ written prompt on clerking and physical form attached  + FY eager to do job well and have the time to do it.  + FY given an induction of their role in IPOS  ≠ patients often unwell and frail  ≠ senior doctors lack time and awareness of role of IPOS</td>
</tr>
<tr>
<td>IPOS collection</td>
<td>≠ paper lost amongst patient possessions/cleared away  ≠ ward awareness of IPOS  ≠ patient transferred elsewhere  ≠ lack of staff continuity, so awareness of completed IPOS may be low</td>
<td>≠ paper cleared away due to lack of awareness  ≠ patient not completed, due to illness or lack of awareness.</td>
</tr>
<tr>
<td>IPOS reviewed</td>
<td>+ IPOS easier to see due to separate medical notes, however, this exaggerated low awareness of IPOS amongst nursing team (-)  ≠ infrastructure to meet needs</td>
<td>≠ paper hidden amongst other paper forms due to shared nursing and medical folder  ≠ Lack of staff awareness of responsibility to view the IPOS  ≠ Lack of perceived relevance of tool.</td>
</tr>
<tr>
<td>IPOS input into EMIS</td>
<td>≠ accessibility to computers in the ward area  ≠ time and workload, other priorities of HPCT liaison team  ≠ EMIS difficult to navigate</td>
<td>≠ staff not aware of this stage  ≠ no audit in place</td>
</tr>
</tbody>
</table>

Legend:

(+) Facilitators
≠ Barriers

Table 6: Observations of the IPOS Process
4.3 | Functional Outcomes of the IPOS
This section presents the quantitative strand of this study – the prevalence of completed IPOS.

4.3.1 | Annotated Time Series: Roxburghe

*Figure 6: Annotated P-Chart of Incidence of IPOS Completion in Roxburghe*

**Explanation of P-chart and overview of results**

- There was a total of 62 admissions over the 11 weeks with 12 people completing IPOS forms.
- The variable control limits are derived from the varying sample size (patient admissions each week). Control limits were tighter on weeks with a greater number of admissions. There is also no Lower Control Limit (LCL) because the calculated limit is 0.
- The Upper Warning Limit (UWL) (at 2 standard deviations) and Upper Control Limit (UCL) (at 3 standard deviations) were not exceeded. Applying Shewhart Control Chart rules, this shows that there were no outliers over the 11 weeks. Additionally, no trends or shifts were identified.
- The process average was determined to be 22% although there was a wide range in the results.
- It is clear that the completion of IPOS is currently unreliable, varying from 0 to 50% over the weeks of observation.
Potential causes of Variation in Reliability of IPOS completion

During the study period IPOS use changed from being a patient and proxy measure to becoming a patient only form. This change happened on the 3rd February and may account for the higher rates of completion shown prior to this date. The patient only form process is shown in section 1 of this chapter.

From the 4th February to 8th April, there were 7 completed IPOS forms. On assessment of each patient’s admission clerking document, it was noted that a further 8 patients were given the IPOS however, this was not located in the notes. This suggests a key problem in the process of IPOS collection or a problem for patients completing the form without a staff presence.

Additionally, the FYs were noted to change rotation on the 25th March. Lack of confidence in the tool or lack of induction may have been a barrier for the new FYs administering the IPOS forms.

4.3.2 | Period Prevalence: Roxburge and Ninewells

In Ninewells, during the study period (14th January – 8th April), 7 patients were admitted to the unit, with 2 patients completing an IPOS. The prevalence was therefore calculated to be 28% over the 11-week period.

Table 7 and 8 present the prevalence of IPOS completion from the 4th February – 8th April. This is to account for the changes in the IPOS process in Roxburge from the 4th February, so that an accurate comparison could be drawn.

Table 7: Period Prevalence of IPOS Completion from 4th February 2019 to 8th April 2019

<table>
<thead>
<tr>
<th></th>
<th>Roxburge (4th February to 8th April)</th>
<th>Ninewells (4th February to 8th April)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>46</td>
<td>5</td>
</tr>
<tr>
<td>Patients with completed IPOS forms in their records</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Period prevalence (expressed as %)</td>
<td>15%</td>
<td>40%</td>
</tr>
</tbody>
</table>
Table 8: Period Prevalence of IPOS Completion for Individuals for whom the IPOS was Suitable

<table>
<thead>
<tr>
<th></th>
<th>Roxburghe (4th February to 8th April)</th>
<th>APCU (4th January to 8th April)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions</td>
<td>46</td>
<td>5</td>
</tr>
<tr>
<td>Patients with completed IPOS forms in their records (of patients suitable for IPOS) *</td>
<td>7 (15)</td>
<td>2 (2)</td>
</tr>
<tr>
<td>Period prevalence (expressed as %)</td>
<td>47%</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Note: the 'number of patients suitable' was determined as the number of patients who were given the IPOS to complete. There may have been occasions when a patient was potentially suitable, however, staff did not document that an IPOS was given or they may simply have left the document blank.

Summary of Prevalence Results

In Roxburge the prevalence of IPOS completion (15%) was lower than that observed in Ninewells (40%). This was most likely due to the frailty of the patient group, or as seen in Table 8, because patients in Roxburge were given IPOS forms, but these forms were not being collected or filled in by patients without staff assistance.

The period prevalence in Roxburge (15%) was lower than the process average (22.2%) displayed through time series. This was because the prevalence calculation levels out variation over time in the reliability of IPOS completion.
Chapter 5 | Results for Objective 2 and 3

This chapter presents combined findings from interviews and observation data. The purpose of this section was to understand the barriers, facilitators and risks to integrating the IPOS in clinical practice in order to identify strategies to optimize uptake.

The results are presented in three sections.

1) Stakeholder perspectives of the IPOS for a) patients and their families; b) the staff and c) the services.
2) Features of the inner context (the units) and the outer context (Scottish Palliative sector) enabling or restricting the use of the IPOS.
3) Stakeholder perspectives on the ideal IPOS system and how this could be achieved.

5.1 | Stakeholder Perspectives

New innovations are more likely to be adopted if there are clear, unambiguous and uncontested advantages for all stakeholders involved (56). This section presents participant perspectives on the advantages, barriers and the risks of integrating the IPOS for patients, staff and the system.

5.1.1 | Patients and Families

As the IPOS is completed by patients, staff perspectives on the impact of the IPOS was a determinant to integration. Two overarching themes emerged. These were that the IPOS enabled and facilitated more truthful, open conversation but that the IPOS also led to risks of distress, unmet expectations and burden for patients. From these two themes there were a series of subthemes.

Enabling communication and holistic care

Participants from both settings explained that the IPOS helped to normalise symptoms for patients “so they potentially think it is not just me going through this” (Interview 1, FY, Roxburghe) and it ‘made people feel they are being taken seriously’ (Interview 14, Registrar, Ninewells). The IPOS allowed patients to identify symptoms that they were unaware of, because the symptom itself had become so normal to them that it was no longer regarded as a “symptom”.

“\textit{It maybe highlights to them some of the symptoms areas that they maybe weren’t so aware of and that maybe allows us to maximise symptom control}” (Interview 7, Doctor, Roxburghe)

Patients often do not volunteer information such as their spiritual, social and psychological needs believing them to be irrelevant to the staff member (57). The IPOS can act as a prompt and give patients ‘permission’ to raise these difficult or sensitive issues with clinicians (57, 58). Patients focus on pain or physical symptoms, when the underlying unmet needs are non-physical in nature.
The following excerpt from observation data illustrates that IPOS results surprised both the researcher and the staff member involved in conversation, the IPOS brought a focus to the real issues the patient was experiencing:

Conversation started with general open questions about who they had seen and how they had been. Pain was talked about in detail, and consulting staff member was reassuring that this would try to be handled as best as possible. The patient wrote their top concerns as 'death and pain'. We had talked a lot about pain management and side effects of medications but concern about death was not talked about in such detail. Staff member said this was a 'stark' finding for her and helpful to consider both of these as equally important. (fieldnotes, Ninewells, 11.10.18)

These findings are congruent with a previous IPOS quality improvement project in Ninewells where patients believed IPOS “gave them a voice” (59). They reflected that the IPOS was a simple way for patients to communicate across time and place

Participants reflected on the ability of the IPOS to encourage family-centred care, helping family members and staff to better understand patient and family needs. They expressed how easy it was to become wrapped up in hidden agendas in healthcare and fail to understand what actually matters to families and patients.

“The IPOS helps you not miss out what is important to the family. Because what is important to the family may not be what is typically important on a normal ward-based environment” (Interview 13, FY, Ninewells)

In both settings the IPOS was identified as a tool for enabling conversation to flow from patient to healthcare professional, and potentially enabled teams to gain a deeper understanding of patients’ concerns (57).

Alongside these factors participants also identified a number of risks.
Risk of Distress and burden

In Roxburghe, due to the length of the clerking document and the time needed to complete it (1 hour), staff were concerned about the burdensome nature of the IPOS for patients, a commonly voiced concern across the literature (24, 26). It was seen as a cumbersome and tiring process for patients, especially given the frailty and limited capacity of the patient group.

“I think the admission process can be quite tiring. Asking the same questions over and over again can be tiring.” (Interview 6, Nurse, Roxburghe)

One concern voiced by participants in both units and observed in Ninewells, was the potential for the IPOS to cause distress. Patients and families may not be ready to think about these complex needs.

“You will maybe not ask the questions because you read the situation and you see that it is not maybe appropriate to go there yet and you will maybe give it time to build that rapport .... one of the concerns I have about IPOS is just that it is all there on day one or whenever you hand it to them.” (Interview 14, Doctor, Ninewells)

Short consultation with the doctor and patient. There was talk about discharge and arranging scans. Doctor asked patient if she had considered doing the IPOS that was given to her. Patient had forgotten about it and as she went through it became very tearful. The doctor had to take time to reassure patient. IPOS was left incomplete and ward were alerted about what had happened. (Fieldnotes, Ninewells, 22.10.18)

The following excerpt gathered through observation in Ninewells, supports this finding:

In Ninewells, staff expressed concerns about their inability to manage everything that the IPOS brought up, disappointing patients, or creating unrealistic expectations. In Roxburge, the accessibility of continuous palliative care support and the availability of complementary services and support, may allow these concerns to be handled more efficiently than in the busy and noisy ward environment. One staff member, with experience of working in both units, explained:

“We don’t have the same things that you can access in Roxburghe in the sense... a view, a pull down bed for families, flowers, complementary therapies, Macmillan day care. I think if you had a choice of where you wanted your palliative patient it would be Roxburghe just because it is geared towards palliative care. If you have a bed or a chair in here the room is squashed, there is no complementary therapies, no one coming round with home baking.” (Interview 9, Nurse, Ninewells)
While staff in both settings described common advantages to patients, the settings differed in how they saw the impact of the perceived risks, with Roxburgh staff concerned most about the burdensome nature of the IPOS because of their already comprehensive processes, and Ninewells staff concerned about their limited resources to respond to the issues that the IPOS raised. These worked as powerful barriers to the integration of the IPOS.

5.1.2 | Staff Perspectives
Views on the IPOS were not unanimously reported across the two settings and even within each setting there were differing perspectives. Staff attitudes were dependent upon the degree to which they saw the IPOS fulfilling their information needs, promoting communication with patients and supporting the person-centred ethos of the units.

Four themes emerged on the added value and the limitations of the tool for supporting staff needs:

1. Compatibility with and facilitating assessment needs,
2. Compatibility with person-centred care delivery,
3. Supporting information needs
4. Stakeholder Ownership

Compatibility with and facilitating patient assessment needs

To be compatible with the needs of the clerking doctors in both settings the IPOS needed to contribute to the assessment process and be valued as a way to understand more about the patient (28). Staff in both settings identified that the IPOS facilitated conversation and improved the information gathering process by acting as a prompt.

“when you clerk someone in it can be an emotionally draining task sometimes you know often you get quite wrapped up in people’s stories and can forget what the basics are so it’s quite good to give you a reminder of the basics to ask.” (Interview 1, FY, Roxburghe)

“Quite often new issues came out in the IPOS that we sometimes hadn’t identified in our routine consultation, so I think for the benefit of the patient and our service and for the individual patient to actually be able to target their care.” – (Interview 11, Doctor, Ninewells)

Participants in Ninewells described how the IPOS aligned with their value of holistic assessment and improved their ability to achieve this. It enabled them to prioritise the most concerning symptoms for individual patients and aided referral to other specialised MDT

“So, I think the benefit for them is actually just getting a better picture of what is the most troublesome symptom, especially if you go to somebody and you list off 6 symptoms that they are having. You can’t always deal with those six symptoms. So, you can assess what is the priority and deal with the most overwhelming symptom first of all.” (Interview 10, Nurse, Ninewells)

“So, you might have to involve the chaplain or the social work team. If they haven’t made funeral plans you can help them with pre-arrangements, the social work people can get the funeral directors involved. The earlier we involve the MDT the easier it is on the family, on the patient.” (Interview 13, FY, Ninewells)
services.

In contrast, in Roxburghe varying opinions emerged about whether the IPOS was supportive of assessment needs. Senior staff thought it beneficial especially for raising issues, whereas junior staff noted that the current admission clerking document was already comprehensive so completing the IPOS was repetitive. Not believing that the tool served to improve performance is a barrier of change uptake, noted by Greenhalgh (56).

“I feel like it is sometimes a repetition and actually we would ask most of the questions and it feels a bit silly sometimes and it feels a bit menial going through everything again.”

(Interview 1, FY, Roxburghe)

Observational findings resonated with these responses. The observer noted that the IPOS questions could be repetitive, but also a valuable prompt for sensitive issues.

FY took a detailed history and examined patient. The structure of the consultation followed the admission document covering topics e.g., depression, low mood, family and symptoms… . Patient was unable to read so FY went through the IPOS with patient. FY had covered lots of the IPOS questions already during the clerking. Unsure if the FY would bother to go through the form in instances where she thought that most of the info was already gathered. FY commented that things she usually misses out that the IPOS picks up on are the practical problems like financial and legal things. She noted these are incredibly important to think about at the end of life. They can be very distressing for patients. FY said it is also important to ask if these problems have been addressed because it gives some action points if not. (fieldnotes, Roxburghe, 07.02.19)
In both settings the frailty of the patient group was a significant barrier and even within the group who could complete it there was often a relatively small window. One participant with experience in both units, spoke of the differences in the patient cohort between the units and how this impacted the compatibility of the IPOS with the assessment process.

> “It is a different patient population in Roxburghe. It tends to be more patients who are at the end of life and you are thinking, ‘is it appropriate to be doing this?’ So in a way the population in Ninewells lend themselves better to the IPOS but the environment is worse. The practicalities of doing it in Roxburghe are easier but actually it is a patient group that are maybe less appropriate overall.” (Interview 14, Doctor, Ninewells)

Compatible with Person-Centred Care Delivery

During observations at Ninewells staff explained how medical referral reasons were often not the most pressing concern for the patient. The IPOS allowed staff to move beyond the immediate referral and explore other issues that matter to the patient in a holistic care way.

> “Definitely getting a better picture of what is important to them. Obviously they are fixed questions on the IPOS questionnaire, but it highlights what are the main symptoms. But it may not be just the physical symptoms that they care about...if you only just open the conversation you might find that this is something you might be able to help with. And if you do manage to help it makes such a huge difference to their quality of life.” (Interview 13, FY, Ninewells)

In Roxburghe, with its ethos of strong person-centred care delivery, staff felt that rather than supporting the holistic care the IPOS could detract from it, depersonalizing care rather than enhancing it.

> “We are there every day so patients usually once you get to know somebody and you build up that trust and rapport you maybe don’t have to, maybe depersonalises it slightly. I don’t know. I suppose it takes away from the human contact where you are just sitting and talking to patients and asking them about things. If you just say ‘here is a form. Fill it out’. I can totally see why that wouldn’t be a beneficial to the kind of patient-doctor –AHP –nursing relationship.” – (Interview 7, Doctor, Roxburghe)

The following extract also highlights the challenges of integrating the IPOS when relationships had been built up.

FY discussed challenging aspects of patient’s life exploring details of what was troubling them most. Conversation was very solemn. FY left IPOS to very end of consultation, after management had been discussed and rapport had been built. It felt unnatural leaving the IPOS there and not continuing the conversation as clearly there were troublesome questions on the form. FY was apprehensive to give it. (Fieldnotes, Roxburghe, 22.02.19)
The skill of building up relationships through active listening and compassionate conversation is pivotal in creating the trusting environment for patients to be able to share their worries. As observed and as expressed by staff, the act of using a scoring form may take away from the trust that is built up (25).

Supporting Information needs

The value of the IPOS is its ability to provide information which can be transferred into actionable knowledge for patients and the service (31). Staff in both sites described the complex nature of information sharing especially with the wide MDT and often exacerbated by verbal and written information mismatch. The existing processes in place to understand a patient's situation, - reading patient electronic or paper notes - was inadequate as a significant proportion of information was transferred through verbal handover and decisions were dependent on individual conversations. This is problematic due to the turnover of staff members in the settings.

“…In something like palliative care, there is so much that goes on outwith the paper notes or electronic notes… there is a lot of context that is maybe missed out of the paper notes, so quite often we get people that come across and the documentation doesn’t quite match with the picture we see. So something like the IPOS again would maybe just provide another extra dimension of what the symptom problems have been.” (Interview 7, Doctor, Roxburghe)

The IPOS had the potential to be an information sharing asset both in the units and also between the units and the community.
Acting as a barrier to the integration of the IPOS Roxburghe was a structural problem – the IPOS was not repeated. Staff explained that the 'Snapshot' information became irrelevant very quickly.

“*It's really helpful if you can see that you have made a difference, the patient is making an improvement in terms of quality of life*” (Interview 13, FY, Ninewells)

“*For most of the patients I haven’t found it useful. I think part of it is probably the fact that we only use it once and we don’t go back to review it.*” – (Interview 2, FY, Roxburghe)

In a unit with continuous specialist palliative care support and regular patient review, up to date and detailed information is essential. The following observational extract highlights the information needs observed during a ward round.

Following morning handover, and prior to first patient review, the doctor read the most recent note entre and studied the drug chart in detail in order to identify medication needs overnight. IPOS was not actively looked for. Upon prompting the doctor checked the notes from admission. The doctor justified not looking for the IPOS by stating that the IPOS would be useful to look back on only if the patient was deteriorating, to see what their main symptoms had been (Fieldnotes, Roxburghe, 02.04.19)

This lack of a repeat IPOS measure devalued the IPOS information and was barrier to success of the IPOS as staff didn’t look for the IPOS amongst more recent medical documentation. Relevance to practice and explicit utilisation of completed IPOS results are recognised in the literature as core qualities of a successful implementation approach (26). This disconnect between the views of the value of the IPOS and the actualization of it in practice meant that the service advantages which participants hoped for were not being realised fully in either setting. Observation data consistently evidenced the lack of human and time resources for using and auditing the IPOS.

Concerns about whether the IPOS was actually measuring the right information due to the subjective nature of patient burdens were expressed, mirroring concerns raised in the literature(10).

“*Sometimes in palliative care the things that are really important to patients are these intangible things which are hard to measure*” – (Interview 4, Doctor, Roxburghe)

“*My concern with the IPOS is that you hand someone a non-discriminatory piece of paper in that the sheet has everything on it which maybe has relevance or not relevance to certain patients*” – (Interview 14, Doctor, Ninewells)
While the IPOS provided a structure to collect information, staff felt it was not always able to pick up the complexity of patients' needs and in Roxburghe the one-off IPOS was not compatible with the Unit's information needs. Despite this, there was a consensus among all staff that measuring quality of life is necessary on a service level to ensure that quality can be assessed and improved.

**Stakeholder Ownership**

Different cadres of staff in the two units expressed different levels of commitment to IPOS distribution and consequently different levels of ownership. In both units, junior doctors were familiar with the IPOS as it was part of their clerking document. Observation data in Roxburghe showed that while junior doctors consistently completed the IPOS during clerking, senior doctors rarely did. Despite the inclusion of a prompt and a physical IPOS paper attached to the clerking document, senior staff were not aware of their role in the IPOS process. This was due to the lack of IPOS induction and poor visibility of IPOS in patient notes.

"I think the issue is just people knowing what they are supposed to do so that has been my issue, just that nobody told me about it when I started. I already knew about what IPOS was but didn’t know how it was used here and what my responsibilities were in completing it or encouraging others in getting it completed...."

This doctor then continued to explain how clarifying responsibilities would then facilitate the process.

"Knowing what it is and that it is part of your role, how you do it and when and then what you do with the completed form. I think if people know that it genuinely is not a big deal especially because we are not asking doctors or nurses to rate them, we are asking patients to do it."  

(Interview 4, Doctor, Roxburghe)

Lack of awareness about IPOS and its relevance among staff members meant that the IPOS forms were frequently discarded or cleared away.

"it just disappears and you don’t spend time looking for it or don’t know to look for it in most cases."  

(Interview 2, FY, Roxburghe)

So if the whole team is not aware of what they are and what they do, if it is just the medics, then potentially there is room for it to go unnoticed  

(Interview 7, Doctor, Roxburghe)

These challenges were observed during quantitative data collection as I struggled to locate the IPOS within the notes and across the unit, and through conversations with staff who were unfamiliar with the IPOS and unaware of its current role in practice.
In Ninewells, there was a greater understanding of the roles and responsibilities regarding the IPOS. The small size of the unit contributed to this, and the unit have collectively agreed to include the IPOS into a core data set for every patient. A shared sense of ownership has been

\[
\text{At our team meeting yesterday, we spoke about electronic systems, EMIS and spoke about IPOS and said that as a service we have agreed that we want to use that and we want that to be a part of data that we collect.} \quad \text{” (Interview 12, Doctor, Ninewells)}
\]

enabled by this communal commitment of all staff to the IPOS.

Yet despite this common ownership, the IPOS was not frequently administered, highlighting that other factors were at play. These included the challenges of remembering the IPOS in the busy and complex hospital system. As explored in the observations, the IPOS was not attached to the clerking document and staff had to remember to bring the paper form with them.

\[
\text{“I think especially for our team at the moment its staffing pressures, so if you have staffing pressure and a long list of patient to get round, it’s the one thing that is easy to forget.”} \quad \text{” (Interview 10, Nurse, Ninewells)}
\]
5.1.3 | The Service
Consistent assessment, benchmarking quality care and creating a ‘common language of improvement’ across palliative services are priorities for NHS Tayside. This section explores the compatibility of the IPOS in delivering to this service priority.

Potential Value of Organisational Data
Senior staff in both units believed the IPOS could be a quality indicator for their units, measuring the delivery of the service through providing evidence of the complexity of care needs. In the climate of limited funding within the NHS collecting data that pointed to effective, patient centred services with proven outcomes mattered:

“I also feel it has another value and that is just capturing quantitative data about the population of patients that are referred to palliative care services and we need that. We need to be able to demonstrate the kinds of needs that we are addressing as a service, the kinds of complexities that we are dealing with, the range of problems that people present with when they are referred so that we can tailor our service to those needs accordingly” – (Interview 3, Doctor, Roxburghe)

And by providing quantifiable evidence of the value of the service which could be translated into economic value.

“It provides the reassurance that we are focusing on what we should be...As well as being able to justify our worth so our service can continue and so we don’t face risks of cuts and budgets, because we know ultimately we need to be able to sit down at a table and say this is what we do, this is how we do it and this is the added value. “ (Interview 3, Doctor, Roxburghe)

“I think in the bigger picture by using IPOS we can demonstrate the value of our service so actually its hard data of what we do and the impact or goes some way to demonstrate what we can achieve which leads into issues to do with service development and funding for our service.” (Interview 12, Doctor, Ninewells)

Despite these advantages, staff in both settings raised different concerns that have not been adequately voiced in the literature on the IPOS. They expressed concerns that IPOS results could be taken out of context and potentially reflect poorly on the quality of the service. As an aim of the IPOS is to evidence good quality of care, this concern is significant and may underlie resistance to use
This section explored barriers, facilitators and risks to IPOS integration by examining how the IPOS was seen to meet or detract from the needs of patients, of staff and of the organisation. Integration was facilitated when the tool aided communication, supported a more patient centred service, and provided data to inform service changes. Barriers to integration were the potential distress and unmet patient expectations, the staff time needed, and the failure of the tool to enhance task performance.

*Sometimes I think it almost does you a disservice because it shows that patients are deteriorating and despite our best efforts that is happening. Sometimes it does show that things are getting better which is great but even if they are not I don’t think that it is a reflection of a poor service*” (Interview 4, Doctor, Roxburghe)

“we may see their IPOS gets worse and it is about for us how we interpret that. I think the bigger unintended consequence is how would that be interpreted outwith our service so for example if we were using IPOS to try and demonstrate the benefit of our service and peoples’ IPOS score got worse they might interpret that as not a good reflection on the care that we provide so I don’t know how you tease that out” (Interview 12, Doctor, Ninewells)
5.2 | Inner Context and Outer Context
While many of the advantages and the disadvantages presented in Section One impact stakeholder motivation to use the IPOS, a set of distinct characteristics of the inner context (the Units) and outer context (the social, technical and political environment outside the Units) shaped the way the IPOS was used, some facilitating and others hindering its uptake.

5.2.1 | Inner context
The preparedness of the service is important to consider when implementing change (22). This section explores the social and physical organizational factors that impact IPOS uptake.

Organisational Norms
One reason for the poor uptake in Roxburghe was the poor integration of the IPOS into organisational routines. Paradoxically this may have been due to the stability of the unit and its success as a person–centred service.

Members of Ninewells aimed to integrate a discussion of the IPOS into the morning handover, and staff spoke of how this helped them to remember the IPOS.

“There has probably been a small number of days when in our handover we have discussed patients and IPOS as part of our handover has meant that we have all openly discussed it there and said ok we are going to try and achieve IPOS and when that doesn’t happen it is maybe not in the forefront of your mind and I think where it has happened has been if we have thought about it at the start of the day and thought ok we are going to try and achieve that.” (Interview 12, Doctor, Ninewells)

Workload pressures, time constraints, lack of continuity of staff and low staffing meant that the feasibility of integrating the IPOS into these routines was challenging. As is illustrated below, the IPOS did not integrate easily into these discussions.

Attended the morning handover at 9.30 in the HPCT offices. Only 3 staff members present, due to unexpected circumstances. Staff talked about the mass of information to cover in one morning. The nurse who had been present the previous days took lead in the conversation and opened up the computer. Patients pain management was discussed, no reference to IPOS. (Fieldnotes, Ninewells . 16.10.18)

Infrastructure
A new electronic data collection system for the IPOS was launched in both settings in January 2019 as part of the existing Electronic Management System (EMIS) to facilitate the storage and management of data, something which staff in both units were highly supportive of. However, different barriers to making use of this infrastructure were observed in each setting.
Through conversations with staff in Roxburghe, it was apparent that not all staff were aware of the requirement to input electronic scores. As one junior doctor said:

“*The ideal system would then be online but we don’t have online notes so we have to use paper.*” (Interview 2, FY, Roxburghe)

In Ninewells integrating the paper IPOS form into a system of electronic based patient and department records challenging because of the dependency on electronic records for decision making. Paper records were not easily accessed as the palliative team offices are not adjacent to the ward. Therefore incorporation of IPOS into electronic notes was absolutely integral to achieving visibility.

“I can’t find an IPOS that was done for somebody in a readmission because I think there is a gap with integrating it into what we do so if I could look at EMIS and pick out IPOS that would be really useful.” (Interview 11, Doctor, Ninewells)

Computer access was also observed as problematic. There are only two computer stations at the doctor’s base on the ward, both of which are heavily used, thus preventing staff inputting data. A strategy was piloted where ward administration staff inputted IPOS scores into the EMIS. As illustrated in the excerpt below, there is a large degree of tacit knowledge to navigating the palliative care electronic records, making this a difficult task to complete.

HPCT member spoke to clerkess about her inputting it in future. But when I spoke to her she was quite confused about what had been said. She wanted someone to go through the process with her. She also need access onto EMIS system. She seemed happy to do the task but did not have enough information to go forward with it. (Field notes, Ninewells, 22.02.19)

Integrating new innovations such as IPOS into systems requires the system itself to be prepared, with the correct infrastructure, and capacity to use the innovation. Results showed that their were infrastructure barriers in both settings.

**Time and resources**

Time was reported as one of the greatest challenges by the senior team in both units.

“*Having the time to do it so it will come down to the day on the ward if you have got 20 other pressures. ….So, I think when things go well in our present circumstances it is usually because you have the luxury of time to be honest.*” (Interview 5, Doctor, Roxburghe)
A facilitator to using IPOS in Roxburghe was the slower pace of the unit, providing the opportunity to spend more time with patients. Time barriers were not presented as a core issue for FYs during clerking.

“I think it’s helpful in the sense that it’s not an acute setting so patient turnover isn’t high or anything like that and it’s better to take a slower paced approach to things and part of that can be getting the patients to write down what they are feeling as opposed to having to do it all within the sort of 30 minute clerking” (Interview 2, FY, Roxburghe)

“We have certainly got staffing time to go back over it with patients.” (Interview 7, Doctor, Roxburghe)

However, in Ninewells staff consistently expressed concerns about the lack of time available, due to the pace of the hospital system, heavy patient caseload and staffing constraints. Time with patients and families is treasured by the team and although the IPOS may be compatible

“I think it is very difficult because of staffing constraints and time constraints because it does take that little bit longer to do.” (Interview 10, Nurse, Ninewells)

with clinical practice, it may not be compatible with time restricted patient consultations.
5.2.2 | Outer context

Both units are part of the macrosystem of NHS Tayside Palliative Care, with socio-political influence from Scottish government policy and strategy and dependency on external informatics teams.

Socio-political context

The current socio-political climate in palliative care is centred on fulfilling the Scottish Government’s 2021 vision set out in the strategic framework for action (12). The framework goals specifically related to measuring palliative care outcomes and benchmarking are as follows:

‘Measurement and Monitoring - It is not currently possible to describe comprehensively how palliative care is being provided or experienced by those who receive it across Scotland. Measurement and monitoring are not yet embedded in routine clinical processes and practice. This makes it difficult to identify where to focus improvement support or describe the ways in which existing work is making a positive difference to individual and family outcomes’

‘Commitment 9. We will ensure that data and evidence – including people’s accounts of their experience of care – is used effectively to inform learning, improvement and the spread of high-quality care by supporting improvements in the collection, analysis, interpretation and dissemination of data and evidence relating to needs, provision, activity, indicators and outcomes in respect of palliative and end of life care in Scotland.’

This is potentially a significant facilitator to IPOS integration. However, the diffusion of this policy commitment in practice has not been achieved. It was recognised that:

“ There is not a good understanding in Scotland even in the Palliative Care community about IPOS. I know some areas are using it, but some are not using it at all.” (Interview 15, HIS Clinical Lead)

National Funding

Funding opportunities are limited, especially across health and social care boards. As identified by a Palliative Care Healthcare Improvement clinical lead, funding is key to embedding new improvements:
Tayside Information Services

The integration of IPOS into the Tayside EMIS is vulnerable to external services. Though those responsible for creating the electronic record platform were optimistic about the ability to evaluate data that is pulled from the IPOS, there is a lack of clarity on how this will be managed. Through observation of conversations in both units the co-ordination and communication between clinical and informatics teams was described as challenging. The advancement of the IPOS as an electronic input system has taken several months and a number of staff identified flaws in the data collected through EMIS. This is a huge barrier to ensuring uptake across both services. As was explored in section one discrepancies about the quality and reliability of the data renders the IPOS significantly less valuable for the staff and their services.

Although there are EMIS logistical challenges, the commitment from the Tayside Project lead for EMIS was inspiring.

“It’s about letting staff know that they are doing that amazing job and if this goes some way to doing that then that would be absolutely great.” (Interview 18, EMIS Project Lead)
5.3 | Ideal IPOS system

The third objective of this study was to identify strategies to improve the uptake of IPOS. The interviews provided rich data in understanding the vision of what an ideal IPOS system could look like.

Overview

In Roxburghe the ideal system needed to be meaningful for staff, patients and the service as a whole.

“If it’s going to be used successfully it needs to be something that informs and changes how we are managing patients.” (Interview 7, Doctor, Roxburghe)

Ninewells staff wanted to create a leaner, simpler and more supported IPOS system, which participants believed would enable the IPOS in practice.

“I Suppose it feels like added workload but yet if you take a step back you would realise in the whole coarse of someone’s care it is probably going to save you time but at that moment in time it maybe doesn’t feel like that.” (Interview 11, Doctor, Ninewells)

Across the different stakeholders interviewed with their different perceptions of the IPOS, a series of themes emerged which can be summarised as: the right person, time process and right resources.

Right person

In Roxburghe the FYs took ownership of the IPOS suggesting they would be the right people to distribute the IPOS as they are based on the ward day-to-day and know the patients well. This would make the IPOS more valuable for clinical interactions

“I think it is good that the juniors do it when they first clerk in the patients because we are the ones that are here Monday to first 8.30 to 6 so we are here most out of all the doctors which means technically we should see the patients the most often which means we get continuity,” (Interview 1, FY, Roxburghe)

It is important that the IPOS is done with someone whom the patient trusts in order for the information to be reliable. This level of continuity of FYs day-to-day is important in collecting reliable IPOS results.
Ninewells participants recommended that this ‘right person’ should be someone who has the time to hand out the IPOS, therefore dividing the IPOS responsibility to make it a more achievable goal.

“I definitely don’t think it should only be done by FYs. I think basically anyone who is able to sit down and talk to the patients about their thoughts and wishes.” (Interview 13, FY, Ninewells)

In both units participants suggested identifying a coordinator for all IPOS data, in charge of managing and reporting the results. The reality of this vision remains uncertain due to the lack of resources.

Right time

Timing was critical to maximise the opportunity for IPOS to contribute meaningfully to care. Roxburghe suggested giving out the IPOS at the first point of contact, as this would serve to improve the quality of the admission clerking.

“One of the junior doctors could sit with them and before we have even done any of their clerking and fill out the whole form to get a good baseline with something to work with and then you could say right there and then, right you are in pain so we can give you some pain relief before I could to clerk you in so you are a bit more comfortable” (Interview 1, FY, Roxburghe)

Similar findings were expressed in Ninewells as participants suggested that the integration of the IPOS into the admission clerking would make the task easier to implement.

Right Process

Staff in both sites acknowledged the need to embed the IPOS process into routine clinical interactions, such as the MDT meeting and handover processes, a practice recommended in the literature(26). In Roxburghe this was seen as a way to create ownership by making the information more valuable and accessible to all. In Ninewells it would act as a reminder for the team and help to clarify each patients’ IPOS status.
In Roxburghe, the IPOS was used as a once-off measure. Establishing a process for repeating the IPOS similar to Ninewells was suggested as a way to transform the IPOS results into valuable and actionable information.

**Right Resources**

The ability to draw meaningful data from the IPOS was a key requirement in both sites. Participants reported that this ideal system would involve an external facilitator of the information collected, undeniably a huge resource and one which is unlikely to be practical due to funding constraints.

In Ninewells, staff stressed the importance of having basic resources, like staffing and funding, in order to be able to test and roll out the IPOS.

What has been explored across all these results is that the ideal IPOS system requires a collective acknowledgement of the right person to take responsibility; the right time and processes to distribute, repeat and utilise the IPOS; and the right resources to maintain and sustain the process. In describing the ideal IPOS system participants thus reflected on the system changes needed to overcome system barriers.
5.4 | Results Table
The results from this chapter are presented in the tables below and a full summary of results is discussed in Chapter 6.

Table 9: Summary Results of Barriers, Facilitators and Risks to IPOS Uptake

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<td>Shared ownership – IPOS part of core data set</td>
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| Value of organisational data | Valuable for evidencing the quality of the service | Valuable for evidencing the quality of the service  
**Economic value of IPOS** |

**Inner context**

| Infrastructure | Electronic input system in place | Electronic input system in place |
| Organisational norms | Slower pace of unit  
Continuity of staff |

**Outer context**

| Socio-political climate | Strategic commitments to support measuring outcomes |
| Tayside information services | Informatics team optimistic about IPOS potential |
| | Informatics team optimistic about IPOS potential |

**Risks**

| Risks for Patients and families | Potential for distress  
Cumbersome and tiring process  
Depersonalized care interactions |
| Risks for Staff | Depersonalized care interactions |
| Risks for Service | IPOS data may fail to show the benefits of service |
| | IPOS data may fail to show the benefits of service |

**Ideal IPOS System**

| Right Person | Person whom the patient knows FY to distribute, to allow continuity in process |
| Right Time | IPOS done alongside, or prior to admission clerking |
| Right Process | IPOS integrated fully into clerking assessment |
| Right Resources | External facilitator of IPOS data to audit and feedback service results  
Sufficient staffing and funding |
Chapter 6 | Discussion

The findings reported in this dissertation have revealed several common barriers, facilitators and risks to using the IPOS in both settings.

6.1 | Summary of Results

The prevalence of completed IPOS forms was 15% and 40% in Roxburghe and Ninewells, respectively. This low completion rate was primarily due to the lack of patient capacity to complete forms, however, interview and observation findings pointed to additional barriers which impacted on staff willingness and ability to use the IPOS in routine care. Participants from both settings reported benefits of the IPOS in enabling and empowering patients in conversation, providing a way for them to voice their concerns. Staff also recognised the value of the IPOS to potentially identify unmet patient needs, helping to maximise management. Whilst the IPOS could contribute to evidencing the value of the service, concern were raised about the intrinsic tool properties such as the reliability and validity of the information collected. Professionals’ concerns about the sensitivity and subjectivity of the results have been noted in previous studies and there is evidence that having trust in the measure is influential in the decision to adopt the tool and take ownership of it (20, 23).

There were practical challenges in the process of IPOS distribution to, and collection from patients. This was due both to a lack of awareness and to challenges of coordinating a new tool in a dynamic work system. These practicalities were exacerbated by the tool being in a paper form, with a tendency to get lost or cleared away. The impact of practical considerations should not be underestimated. Evidence from a large systematic review has highlighted that inadequate technical or organisational infrastructure can cause PROMs to be disruptive to patient care and the work environment (32).

Due to the limited resources available, neither setting has been able to use the IPOS to improve more distal outcomes, such as service improvement goals. There is significant evidence in implementation research that having easily observable and noticeable benefits can improve the uptake of new changes (56). If staff are unable to see the day to day tangible impacts of using the IPOS (a concern which was raised in both settings), then the lack of routine IPOS feedback on service data to staff may be a threat to the sustainability of the IPOS.

6.2 | Contrasting Findings Across Settings

Whilst these common findings are useful, it is the contrasting findings which will enhance our understanding of the novel challenges to the use of IPOS and enable the development of a more focused strategy to overcome these. In each setting two very different IPOS stories have emerged throughout this study:

In Roxburghe the IPOS doesn’t support the people in the system

In Ninewells the system doesn’t support the people using IPOS
Greenhalgh et al. state that the outcome of any PROM can be conceptualized on a chronological spectrum, from the initial interaction with patients to the decision making outcomes, and finally to the longer term outcomes such as patient management and health outcomes (6).

The IPOS in Roxburghe:

The IPOS process did not meet the needs of the staff, patients or the service. Staff expressed concerns about the compatibility of the tool in fulfilling information needs and the subsequent ability or otherwise, to directly impact care decisions. While individual staff were positive about the IPOS, at the heart of the problem in Roxburghe was an inability of the collective body of staff to see the immediate benefits of the IPOS, and a subsequent lack of ownership. This lack of meaning and purpose at the most proximal phase, prevented the downstream benefits of the IPOS from being accessed. Staff expressed concerns about the IPOS detracting from the patient-centred interaction as the IPOS process was seen as potentially repetitive and depersonalizing. This is not in any way a criticism of the staff, rather an acknowledgment that the rigidity and structure of the IPOS - and many other PROMs (60) - may not fit with their organic holistic conversations.

This lack of ownership and limited downstream use of IPOS resulted from a chain of distinct yet closely related factors including a lack of IPOS visibility (due to the low numbers of patients able to complete the IPOS), a lack of awareness (due to staff not being aware of their roles regarding the IPOS) and a lack of compatibility (due to IPOS not fulfilling information needs). There was also the view that the IPOS did not add value to the already comprehensive in-depth clerking and patient care processes. Implementation strategies that encourage ownership enable PROM success (61) It is impossible to have ownership of something that is so invisible to staff and for which there is little perceived benefit to the delivery of patient centered services (whether proximal or distal delivery). The importance of being able to use PROM data to directly influence management is commonly cited in the literature (20, 31).

These findings have highlighted that we need to acknowledge the risks of distributing IPOS in a system in which it is not measurably improving the quality of conversations and not utilized to inform joint decision making. There is a risk in making this a patient feedback industry in which forms are collected with little downstream impact for patients. Essentially, creating a process centred, not patient-centred tool. This has been reported as a concern by patients (26) and highlights ethical concerns which should be taken into consideration prior to implementing the IPOS. Ethical implications of PROMS in palliative care have been significantly neglected as was highlighted in a recent systematic review (62).

The IPOS in Ninewells

In Ninewells findings revealed a very different story. All participants had ownership of the IPOS as they believed it had the capacity to enable a more patient-centred service, a core need of patients, staff and the service. The staff believed IPOS could encourage holistic assessment and enable conversations in a setting where it is often hard to do. But in reality the existing system with its practical challenges are incapable of supporting the IPOS. System barriers included timing constraints, workload and the seemingly cumbersome process of the paper IPOS distribution and collection. These challenges, resonate with findings from a recent study by Lind et al.(21) investigating the feasibility of IPOS implementation in an acute care setting. The authors noted that feelings of ‘change fatigue’ and a ‘constantly
increased workload’ prevented the success of IPOS (21). It was also reported that staff in the acute palliative care unit found there to be ‘nothing in it for us’ (21). This is markedly different from the findings from this project and highlight that although the practical challenges of daily workload and pressures make it difficult to implement the IPOS, there is still value for staff and patients in creating patient-centred care.

Alongside these practical system challenges, was a concern from staff that there is a lack of infrastructure to meet the needs the IPOS may bring up, creating false expectations of what can be achieved in an already stretched team. As reported by participants in both units, the IPOS may uncover or reveal distressing concerns which may have been neglected or normalized. With staff time constraints and the lack of a constant specialist palliative care consultant on the ward, there is a risk of causing unnecessary patient distress which cannot be managed by the existing system.

6.3 | Issues and Areas for Improvement
In 2018, the Institute for Healthcare Improvement (IHI) published a White Paper on the Psychology of Change. This model centres around the concept of agency, which is defined as ‘the ability of an individual or group to choose to act with purpose’ (46). Agency is driven by two component parts 1) the power, or the ability to act with purpose and 2) courage, or the emotional resources to act in the face of difficulty or uncertainty (46). Agency can be mobilised on three different levels: self, interpersonal and system.

Figure 7: Agency Levels

<table>
<thead>
<tr>
<th>Self: An individual’s agency to make his or her own choices. People feel an increased sense of agency when they exercise their power and courage to take action.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interpersonal:</strong> The collective agency of people acting together. People feel an increased sense of agency when they encounter positive experiences of other people exercising power and courage.</td>
</tr>
<tr>
<td><strong>System:</strong> The structures, processes, and conditions that support the exercise of agency within and across institutions and organizations. People feel an increased sense of agency when the structures within which they operate enable them to exercise their power and courage.</td>
</tr>
</tbody>
</table>

Agency can be created in each setting at individual, interpersonal and system levels to promote uptake of IPOS. In Roxburghie agency at the system infrastructure is there, however as individuals and as a team there was little perceived added value of the IPOS to their care. In Ninewells there is agency through motivation and movement within the team to overcome the barriers to implementation however, change must be activated on a system level to support the people working in it.
Through reference to the IHI change framework’s focus on creating agency for individual team members and the system (see figure 8) opportunities for change will be put forward. These suggestions are based on stakeholders’ needs and their vision of the ideal IPOS system.

**Figure 8: Psychology of Change Framework**

![Psychology of Change Framework](image)

In Roxburghe, staff - especially Foundation Year doctors - are most engaged in the IPOS, and most impacted by change. The process of designing the IPOS system could align with their needs and their vision of an ideal IPOS system (co-design).

The research findings suggest that it is more important to build momentum and motivation in staff by integrating the tool patient by patient rather than by an escalation of process approach. It is important for staff to determine the most meaningful process from the start rather than embedding an initial IPOS for everyone and trying to then repeat this. The IPOS is being reliably completed by FYs on the ward but this is not sustainable or ethical because the information from the IPOS is not being used. Creating change through small incremental changes based on patients, will allow the team to discover the feasibility of the upscaled process and will inform a decision as to whether the IPOS is more disruptive than it is helpful (Adapt in action).

Roxburghe participants spoke of time and space to discuss IPOS amongst the routine of the unit, reflecting the need for interpersonal agency. This requires a team motivation and dedication, something which can only be gained through IPOS champions and leadership to co-ordinate and which may require additional resource to facilitate.

Staff who pointed out the need for a data management system, were acutely aware of the resource challenges of doing this. An electronic system is in place, however, the success of this data management will depend upon education and joint decision making to ensure staff working on the ground know what their role is and how they can input scores electronically.
A shift in the implementation approach, a data management system and an educational component would take concerted effort to implement. Findings suggest that the tool may be redundant in Roxburghe due to the already very patient centred service. The deciding factor as to whether the IPOS should be taken forward will be patient feedback. The team need to hear from their patients about how the IPOS impacted their experience of care. Additionally, staff also need share stories of positive IPOS experiences. This reflects a key component of the psychology of change model - *unlocking intrinsic motivation* through patient and staff stories.

**In Ninewells**, system barriers made the IPOS unfeasible. Activating system agency is not a simple task and requires a shift in focus of organizational norms and support from macrosystem stakeholders, such as government policy makers, funding bodies and improvement advisors. Again, there is a need to *unleash intrinsic motivation*, not only for individuals but for teams and for the organisation as a whole. The value of patient, family and staff stories should not be underestimated as a way of mobilizing macrosystem change.

Without higher level support, the sustainability of the IPOS may be at risk, however, the IHI framework allows us to determine some smaller changes that can be made to tackle this feasibility issue. The distribution of power across systems may potentially reveal untapped human resources (*Distribute power*). Divisibility of tasks is also identified by Greenhalgh et al. as a facilitator of innovation uptake (56). Including the ward clerk in the electronic input of IPOS scores could overcome some of the current geographical and physical barriers highlighted in this study. It may also help to engage the ward team in the process, creating a shared purpose. Recommendations from the literature are clear about the need to involve staff in non-medical professions in order to enhance the impact of PROMs in improving care (6). Additionally, areas of good practice such as attaching the physical IPOS form to the clerking may remove obstacles such as staff forgetting to bring the IPOS to the admission interaction.

### 6.4 | Areas for Future Research

Further research is needed to explore patient and family perspectives on the IPOS as this has been neglected in the literature. Staff perceived the IPOS to have both advantages and disadvantages for patients and families and in depth qualitative interviews could provide more nuanced insights.

The ethical considerations of carrying out IPOS need to receive more attention in research. Findings showed that IPOS forms were completed but not reviewed, highlighting some of the ethical implications of using PROMs. The ethnographic approach would be a suitable method for investigating how staff are using the IPOS and if the information is being acted upon.

Initial findings showed that the sustainability of the IPOS is at risk due to the lack of resources, time and stakeholder engagement. Further studies to understand the core economic, infrastructural, social and educational support that is required to sustain the IPOS in practice are needed.

Finally, this study investigated two palliative care sites, both of which were inpatient units. A significant proportion of palliative care is delivered in the community. It is therefore
important to investigate the impact of the IPOS for GPs, community district nurses and community day care centres.

6.5 | Study Limitations

Whilst a mixed method design was chosen to minimise limitations, the researcher acknowledges that no research design is flawless when the research matter involves multiple perspectives. The subjective nature of interview data means that there is always interpretation of meaning. One method employed to minimise bias is to involve multiple investigators to overlook data coding and analysis(63). As this was a student dissertation coding and analysis of interview data was completed by the researcher alone though advice and support from experts in healthcare improvement, palliative care research and clinical practice was sought.

The most significant limitation was the exclusion of patients and families from the interview sampling frame. Given the time constraints of the project and the vulnerability of those receiving palliative care it was not considered appropriate that this student led project involve patient participants. Observation practice provided essential insight into the challenges and value of the IPOS for patients and families, highlighting the strengths of ethnographic research in gathering a broader view of IPOS barriers and facilitators.

Saturation of interview and observation data could not be guaranteed, due to the short time frame of the project and the variation in working hours of both staff and the researcher. Representative groups were chosen for the qualitative sampling frame in order to minimize the chance of reporter bias, however it was recognized that in improvement work and in PROM implementation, all stakeholder perspectives should be evaluated prior to the proposal of change strategies(1, 18).
Chapter 7 | Conclusion

This study provides an in-depth examination of the factors influencing the uptake of the IPOS. Findings from the literature review on time, compatibility, resources, and added value of the IPOS resonated with findings from this mixed methods study. For the IPOS to be integrated, it must be used to directly impact the care of patients and families. To achieve this, the IPOS must first meet the needs of both patients and clinicians in their specific organisation and setting (61, 64). This study concluded that in Tayside the IPOS was unable to meet these needs for two different reasons. In Roxburghe, the clerking and ongoing holistic care often superseded the IPOS. In Ninewells, system barriers such as time constraints, workload and infrastructure lowered the feasibility of the IPOS in routine practice.

There is no simple and quick way of embedding proms in practice but it is clear that a shift in the current processes of care is required. This is something that can change through individual agency, as the IPOS is a tool which is administered and reviewed by individuals. It also requires interpersonal agency, as the healthcare system is an inherently multidisciplinary group and the IPOS must be integrated into clinical team interactions to be useful (61). Finally, the success of the IPOS is dependent upon the system structures and processes supporting healthcare teams to use the IPOS. The resources needed to manage the data and to shift these barriers require funding, dedicated time and human resources on a system level.

With the changing population demographics, the constantly increasing burden on health services and the requirement for person- rather than process- centred care, NHS palliative care services must be prepared to adapt and change to meet the ongoing needs of a such a dynamic service. Across Scotland, there is a recognition that a robust approach to measurement in palliative care is key to sustaining services (12).

The IPOS carries enormous potential to improve services and provide valuable data. What is even more important is the intent and support behind the IPOS. It's success as a person-centred outcome measure is dependent on the preparedness of the setting, the processes of the service and the passion of the staff to see every person behind the paper.
Appendices

Appendix 1: Example IPOS

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**IPOS Patient Version**

**www.pos-pal.org**

**IPOS Patient** www.pos-pal.org Page 1 of 2

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**Over the past 3 days:**

| Q3. Have you been feeling anxious or worried about your illness or treatment? |
| --- | --- | --- | --- | --- |
| Not at all | Occasionally | Sometimes | Most of the time | Always |
| 0 | 1 | 2 | 3 | 4 |

| Q4. Have any of your family or friends been anxious or worried about you? |
| --- | --- | --- | --- | --- |
| Not at all | Occasionally | Sometimes | Most of the time | Always |
| 0 | 1 | 2 | 3 | 4 |

| Q5. Have you been feeling depressed? |
| --- | --- | --- | --- | --- |
| Not at all | Occasionally | Sometimes | Most of the time | Always |
| 0 | 1 | 2 | 3 | 4 |

---

**Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.**

**Not at all** | **Slightly** | **Moderately** | **Severely** | **Overwhelmingly**
--- | --- | --- | --- | ---

**Q2.** Pain

**Q3.** Shortness of breath

**Q4.** Weakness or lack of energy

**Q5.** Nausea (feeling like you are going to be sick)

**Q6.** Vomiting (being sick)

**Q7.** Poor appetite

**Q8.** Constipation

**Q9.** Sore or dry mouth

**Q10.** Dryness

**Q11.** Poor mobility

Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past 3 days.

---

**Q12.** How did you complete this questionnaire?

---

If you are worried about any of the issues raised on this questionnaire, then please speak to your doctor or nurse.
### Appendix 2: Table of Included Studies

<table>
<thead>
<tr>
<th>Author and Year of Publication</th>
<th>Title</th>
<th>Aim</th>
<th>Study Design</th>
<th>Geographical location</th>
<th>Palliative care setting</th>
<th>PROM used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bausewein C et al. (24) 2011</td>
<td>Implementing patient reported outcome measures (PROMs) in palliative care--users’ cry for help.</td>
<td>To describe professionals’ use and experiences with PROMs in European and African palliative care contexts.</td>
<td>qualitative: survey of clinicians</td>
<td>Europe and Africa</td>
<td>multiple settings</td>
<td>multiple</td>
</tr>
<tr>
<td>Daveson BA, et al. (28) 2012</td>
<td>Are we heading in the same direction? European and African doctors’ and nurses’ views and experiences regarding outcome measurement in palliative care.</td>
<td>To examine and compare doctors’ and nurses’ perspectives and experiences of using outcome measures in clinical palliative care.</td>
<td>qualitative: survey of clinicians</td>
<td>Europe and Africa</td>
<td>multiple settings</td>
<td>multiple</td>
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<tr>
<td>Dunckley M et al. (29) 2005</td>
<td>A research study to identify facilitators and barriers to outcome measure implementation.</td>
<td>To identify facilitators and barriers to implementing outcome measures and to identify strategies for improvement.</td>
<td>qualitative: semi structured interviews for clinicians</td>
<td>UK</td>
<td>hospice</td>
<td>POS</td>
</tr>
<tr>
<td>Ellis-Smith C et al. (20) 2018</td>
<td>How can a measure improve assessment and management of symptoms and concerns for people with dementia in care homes? A mixed-methods feasibility and process evaluation of IPOS-Dem.</td>
<td>To determine the acceptability, feasibility and implementation requirements to support comprehensive assessment of people with dementia</td>
<td>mixed methods qualitative: semi-structured interviews and focus groups, non-participant observation</td>
<td>UK</td>
<td>residential care home</td>
<td>IPOS-Dem</td>
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<tr>
<td>Hughes R et al. (30) 2004</td>
<td>It just didn’t work: The realities of quality assessment in the English health care context</td>
<td>To describe and evaluate the implementation of a PROM in non-specialist palliative care settings</td>
<td>qualitative - semi structured interviews with staff and patients</td>
<td>UK</td>
<td>non-specialist PC setting</td>
<td>POS</td>
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<tr>
<td>Hughes R, et al. (23) 2003</td>
<td>Professionals’ views and experiences of using outcome measures in palliative care.</td>
<td>To investigate professionals’ views and experiences of using the POS outcome measure.</td>
<td>qualitative - semi structured interview</td>
<td>UK</td>
<td>multiple</td>
<td>POS</td>
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<tr>
<td>Krawczyk M, et al. (25) 2018</td>
<td>Micro-Meso-Macro Practice Tensions in Using Patient-Reported Outcome and Experience Measures in Hospital Palliative Care</td>
<td>To understand clinicians’ experiences and perspectives of using PROMs ad PREMS through a micro-meso-macro analytical framework</td>
<td>qualitative analysis</td>
<td>Canada</td>
<td>acute palliative care using</td>
<td>electronic Quality of Life and Practice Support System (QPSS)</td>
</tr>
<tr>
<td>Lind S et al.(21) 2018</td>
<td>Implementation of the integrated palliative care outcome scale in acute care settings - a feasibility study.</td>
<td>To explore strategies to implement PROMS</td>
<td>Qualitative analysis</td>
<td>Sweden</td>
<td>Acute care and specialist palliative care units</td>
<td>IPOS</td>
</tr>
<tr>
<td>Pinto et al. (26) 2018</td>
<td>Perspectives of patients, family caregivers and health professionals on the use of outcome measures in palliative care and lessons for implementation: a multi-method qualitative study.</td>
<td>To understand the use of proms in specialist pall care services and strategies for implementation</td>
<td>Multi-method: semi-structured interviews and non-participant observation</td>
<td>UK</td>
<td>Specialist palliative care units</td>
<td>Multiple: IPOS, AKPS, Views on care, Caregiver bundle</td>
</tr>
<tr>
<td>Sawatzky R, et al.(65) 2018</td>
<td>Design and introduction of a quality of life assessment and practice support</td>
<td>To explore experiences of using a PROM amongst staff, family and patient</td>
<td>qualitative analysis : interviews and focus groups</td>
<td>Canada</td>
<td>inpatient palliative care unit and home care setting</td>
<td>electronic Quality of Life and Practice Support</td>
</tr>
<tr>
<td>Reference</td>
<td>Title</td>
<td>Abstract</td>
<td>Methodology</td>
<td>Setting</td>
<td>System</td>
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<tr>
<td>Slater A et al. (22) 2005</td>
<td>Is the Palliative Care Outcome Scale useful to staff in a day hospice unit?</td>
<td>To explore staff experiences with POS and the perceived usefulness of this tool</td>
<td>qualitative: focus groups</td>
<td>UK</td>
<td>POS</td>
<td></td>
</tr>
<tr>
<td>Stukenborg GJ et al. (33) 2014</td>
<td>Cancer patient-reported outcomes assessment using wireless touch screen tablet computers.</td>
<td>To assess the feasibility of collecting PROM data using an electronic system</td>
<td>qualitative: semi-structured interviews</td>
<td>USA</td>
<td>oncology palliative care clinics</td>
<td></td>
</tr>
<tr>
<td>Tavares APDS et al. (34) 2017</td>
<td>Implementing a patient-centred outcome measure in daily routine in a specialist palliative care inpatient hospital unit: An observational study.</td>
<td>To implement a PROM in clinical practice and evaluate the success of this intervention</td>
<td>observational prospective study</td>
<td>Brazil</td>
<td>Hospital palliative care unit</td>
<td>PROMIS touch screen tablet</td>
</tr>
</tbody>
</table>
Appendix 3: Participant Information Sheet and Consent Forms

PARTICIPANT INFORMATION SHEET - INTERVIEW

A Mixed Methods Approach to Understanding the Feasibility of the Integrated Palliative Care Outcome Scale (IPhOS) in two Palliative Care Settings

INVITATION TO TAKE PART IN RESEARCH STUDY

I am a female student undertaking a research study to understand the barriers, facilitators and risks to integrating the IPHOS in clinical practice in order to identify categories to understand aspects of this work. I would like to invite you to participate in this research in order to better understand your views about the use of the IPHOS in two palliative care settings, regarding current and potential use and a specialist palliative care unit. This project is supervised by Professor John Shepperd, Dr Daniel Bicharm and Samuel Grant.

WHAT TO EXPECT

The whole study will use qualitative and quantitative approaches including semi-structured interviews, non-participant observation, and analysis of the incidence of completed IPHOS.

All participants will receive a semi-structured interview using 10 semi-structured interview questions. There is no obligation to answer any of the questions and you can move on to the next question if the interview is at any time. The interview will be audio-recorded for analysis and transcribed onto a password protected computer. The interview day will be completely anonymous prior to coding and thematic analysis.

TIME COMMITMENT

The interview will last approximately 30 minutes.

TERMS FOR PARTICIPATION AND WITHDRAWAL

Participants in the study are entirely voluntary. The decision to take part will have no implications or negative consequences to your clinical practice. You may withdraw from the study at any stage. Your withdrawal will be respected and your personal details will not be shared.

BENEFIT, COST AND REIMBURSEMENT

There will be no direct benefit to you, however, the understanding gained from this research will hopefully enable ongoing improvements to the use of IPHOS as a clinical tool. There will be no financial compensation provided for participation in this study.

RISKS

There are no known risks involved in participating in this study.

CONFIDENTIALITY/ANONYMITY

No personal details will be recorded or accessed from participants. The data collected will be anonymised and stored securely. The study will be anonymous to the participants, and no identifiable details will be shared with any other parties. Any recording will keep the patient’s identity intact and will be released to the individual researcher. No personal details will be shared with the wider public and data will be used for the study and none other purposes will be included.


Semi -Structured Interview

CERTIFICATE OF CONSENT

A Mixed Methods Approach to Understanding the Feasibility of the Integrated Palliative Care Outcome Scale (IPhOS) in two Palliative Care Settings

This research project aims to determine the barriers, facilitators and risks to integrating the IPHOS in clinical practice in order to identify categories to understand aspects of this work.

Semi-structured interviews will be used to understand the perspectives of participants, patients and their families about the use of IPHOS in clinical practice in two different settings in the UK. The interviews will be audiotaped and no identifiable details will be shared with any other parties.

By signing below, you are indicating that you:

1. Have read and understood the participant information sheet.
2. Have asked any questions about the research.
3. Are willing to participate in this study and consent to the audio recording of this interview.

Name of Participant (given):

Signature:

Date:
Non-participant Observation

PARTICIPANT INFORMATION SHEET - OBSERVATION

A Mixed Methods: Approaching to Understanding the Feasibility of the Integrated Palliative Care Outcome Scale (IPSS) in two Palliative Care Settings

INVITATION TO TAKE PART IN A RESEARCH STUDY
I am a BSc(Hons) student undertaking a research study to understand the barriers, facilitators and risks to the use of IPSS in clinical practice in order to identify strategies to optimise uptake of this tool. I would like to invite you to participate in this research in order to better understand the purpose and process of using the IPSS in two palliative care settings, a hospital-based acute palliative care unit and a specialist palliative care unit. This project is supervised by Professor Peter Devlin, Dr. Dean Buchanan and Susanne Grant.

WHAT TO EXPECT
The whole study will use qualitative and quantitative approaches including semi-structured interviews, non-participant observation and analysis of the incidence of completed IPSS.

Non-participant observation is a qualitative technique that I will use to understand the work contexts in which the IPSS is used. This will involve shadowing healthcare professionals within both palliative care settings and recording field notes about the factors influencing the use of IPSS, specifically the environment, recognised and technical barriers and facilitators.

TIME COMMITMENT
I aim to shadow each participant for one morning or morning of clinical practice.

TERMS FOR PARTICIPATION AND WITHDRAWAL
Participation in this study is entirely voluntary. The decision to take part will have no implications on your role or clinical practice. You may decide to withdraw from this study at any point without explanation or penalty.

BENEFITS, COST AND REMUNERATION
There will be no direct benefit to you; however, the understanding gained from this research will helpfully identify strategies to improve the use of IPSS in clinical practice. There is no incentive or compensation provided for participation in this study.

RISKS
There are no known risks involved in participation in this study.

CONFIDENTIALITY/ANOYMITY
No personal information will be obtained from participant. The data collected will be password protected and stored on a password protected computer. This data will be viewed only by the researcher involved in this study. Information will not be shared with any other sources.

For further information about this research study
I am happy to answer any questions about this study. You may ask in person now, during or following the interview. Contact details are shown below.

Catherine Durt, t: 07756 231758, c: 07756 231758

The University Research Ethics Committee of the University of Dundee has reviewed and approved this research study.

CERTIFICATE OF CONSENT
A Mixed Methods: Approaching to Understanding the Feasibility of the Integrated Palliative Care Outcome Scale (IPSS) in two Palliative Care Settings

This research project aims to determine the barriers, facilitators and risks to the use of IPSS in clinical practice in order to identify strategies to optimise uptake of this tool.

Observations will be used to understand the context in which the IPSS is used in order to build a picture of the environment, contextualised clinical factors influencing the use of IPSS. By signing below, you are acknowledging that you:

1. Have read and understood the participant information sheet.
2. Have given your agreement to ask questions about the project.
3. Are willing to participate in this study and are willing to sign this certificate.

Name of Participant

Signature of Participant

Date

65
Appendix 4: Semi-Structured Interview Topic Guide

Introduction

1. What is your current role in this Palliative care setting and what is your involvement with PROMs so far?

Purpose of the IPOS

2. What were the main reasons why the IPOS was introduced into your setting?

3. What are the main outcomes that the IPOS is intended to measure?

Using the IPOS

4. Can you describe the process of using the IPOS in your setting?
   a. What tasks are involved and who is responsible for each?
   b. What is the timeline?
   c. What systems are in place to ensure that the IPOS is completed?

Barriers and facilitators

5. From your perspective
   a. What are the main advantages of the IPOS for patients, family and staff?
   b. What are the main disadvantages for patients, family and staff?

6. How far does the current use of the IPOS meet the original reason for its introduction?

7. What are some of the reasons why the IPOS is not completed by every patient? (refer to incidence data)

8. What challenges do you encounter when giving patients the IPOS and when interpreting and acting upon the information that is collected?
   a. Prompt: do any of these factors specifically impact your ability to use the IPOS?
      i. People involved, tasks, tools and technology, internal and external environment and organisation

9. What helps you to use IPOS?
   a. Prompt: do any of these factors specifically enable the use of IPOS?
      i. People involved, tasks, tools and technology, internal and external environment and organisation

Strategies for change

10. In your opinion, what would an ideal IPOS system look like?
    a. What information do you need from the IPOS to make meaningful improvements to care?
    b. Who should be involved in performing and interpreting the IPOS?
    c. When and how often should it be performed?

11. What systems can be put in place to make the collection, interpretation and handover of IPOS easy and to lower the burden of these tasks on other duties? (1)

Risk

12. What are some of the risks and unintended consequences of using the IPOS in palliative care?
## Appendix 5: Coding Framework

<table>
<thead>
<tr>
<th>Section</th>
<th>Theme</th>
<th>Definition of theme</th>
<th>Coding framework</th>
</tr>
</thead>
</table>
| **Stakeholder perspectives: Patients and Families** | Enabling Communication | The ways in which the IPOS helped or hindered communication flow between patients, their families and staff | • Family centred  
• Uncovering patient needs  
• Normalising symptoms  
• Gives patients a voice |
| | Risk for patients | Any ways in which staff perceived the IPOS cause discomfort for patients | • Emotionally distressing  
• Patients not ready  
• Burdensome  
• Creates unrealistic expectations |
| **Stakeholder perspectives: Staff** | Compatibility with assessment needs | The degree to which the IPOS fitted with and enhanced the assessment process | • Prompts staff  
• Aids holistic assessment  
• Enables prioritisation  
• Repetitive  
• Unnecessary  
• Brings up additional information  
• Patient group unwell |
| | Compatibility with person-centred care | The ability of the IPOS to enhance or detract from person centred care delivery | • Understanding what matters to patients  
• Depersonalising care |
| | Supporting information needs | The ways in which the IPOS either fulfilled or fell short of information gathering, sharing or interpreting. | • Sufficient information detail  
• Snap-shot vs monitoring measure  
• Impact on handover to MDT  
• Tool limitations  
• Information reliability  
• Too much information |
| | Stakeholder ownership | The factors influencing staff ability to identify with and take possession of the IPOS | • IPOS Invisible  
• Awareness of IPOS  
• Awareness of roles and responsibilities  
• Shared goals  
• Shared tasks |
| **Stakeholder Perspectives: Service** | Value of Organisational data | The perceived ways in which the IPOS data influenced the co-ordination and quality of the service | • Financial incentives  
• IPOS as a quality indicator |
| **Inner context (unit)** | Organisational norms | The routines and social structures in each unit which impacted IPOS use | • Pace of unit  
• Lack of IPOS in clinical interactions  
• Lack of IPOS routine or habit |
| | Infrastructure | The technical and physical structures in each unit and the interaction of staff with these structures | • Accessibility to computers  
• Reliance on paper vs electronic records  
• Geographical barrier  
• IPOS lost or discarded  
• Understanding of EMIS/IPOS interface |
| | Time and resource | Time and human resources impacting IPOS uptake | • Time constraints  
• Workload  
• Staffing constraints  
• Lack of IPOS champion |
<table>
<thead>
<tr>
<th>Outer context</th>
<th>Socio-political context</th>
<th>The influence of palliative care policy and strategy on IPOS uptake by staff and service</th>
<th>Strategic commitments common indicator across Tayside</th>
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<tr>
<td>National funding</td>
<td>The availability, or lack of funding for palliative care improvement</td>
<td>Lack of funding in health and social care Cost of improvement</td>
<td></td>
</tr>
<tr>
<td>Information services</td>
<td>The interactions with and dependence upon external information services to integrate the IPOS</td>
<td>Communication challenge Reliability of EMIS Web EMIS project committed to improving care</td>
<td></td>
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Appendix 6: Ethical Approval and Caldicott Guardianship

School of Medicine
University of Dundee

CW/PM
School of Medicine and Life Sciences Research Ethics Committee
University of Dundee

17/01/2019

Catriona Grant

SMED REC Application Number: 19/04
Title: A mixed methods approach to understanding the feasibility of the Integrated Palliative care Outcome Scale (iPOS) in two Palliative Care settings

Dear Catriona

I am writing to advise you that your application for ethical approval of the study named above has been reviewed and approved on behalf of the School of Medicine and Life Sciences Research Ethics Committee.

Approval is valid for the duration of the project as stated in the original application. Should you wish your study to continue beyond the stated project end date, you must request an extension to this approval a minimum of 3 months before the project end date.

Any changes to the approved documentation (e.g. study protocol, information sheet, consent form) must be approved by this committee before the changes are implemented.

Yours sincerely

Carlos Wigderowitz

Convenor, School of Medicine and Life Sciences Research Ethics Committee
CW/PM
22/01/2019

Caitriona Grant
University of Dundee

Dear Caitriona

SMED Caldicott Guardian Approval 15/07 – This is a healthcare improvement study to assess the feasibility of using a patient reported outcome measure (PROMs) in two different palliative care settings, specifically an acute hospital based palliative care unit (Nineveh) and a specialist palliative care unit (Troxburg House)... Thank you for your application for Caldicott Guardian Approval.

After careful consideration of the information you have provided to me, I pleased to approve your application.

It is important that you comply carefully with the project you submitted and that has been approved. Any further changes should be communicated to the Caldicott Guardian and that will be seen as amendment to the project.

You and your supervisor remain responsible for the safety of the data until the data is safely disposed of.

I hope your research project goes well.

Yours sincerely

Carlos Wigserson

UoD Caldicott Guardian & Honorary Clinical Senior Lecturer
References


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