# THE INNOVATION ACADEMY RESEARCH SERIES

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Dr Dan Rees

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Mr Ramakrishnan Gurumoorthy

Mr Edward Miller

# Foreword

It is with great pleasure that we present the second volume of **Innovation Academy: Advanced Management (Applied Innovation)**, an open-access collection showcasing the outstanding work produced by learners from the *PGCert Applied Innovation* programme at Swansea University. Building on the success of the previous edition, this volume continues to demonstrate how applied innovation can bridge academic inquiry and practical implementation to address contemporary organisational and societal challenges.

This publication highlights research outputs and practice-informed projects that embody the core principles of applied innovation: the purposeful integration of theory, evidence, systems thinking, and action. Through experiential learning opportunities and engagement with real-world organisational contexts, learners explore how innovation methodologies can be applied to support meaningful transformation across health, social care, public services, industry, and community settings.

The projects collected within this volume demonstrate how academically grounded approaches can:

- Enable innovation within complex and evolving systems
- Support transformation under operational and organisational pressures
- Deliver practical benefits for organisations, services, and communities

Collectively, these contributions reflect the productive relationship between scholarly inquiry and applied practice. Learners critically engage with contemporary issues relating to innovation management, organisational development, service redesign, digital transformation, leadership, and collaborative working. The result is a body of work that advances both conceptual understanding and context-sensitive solutions capable of informing real-world improvement.

The projects also align closely with national strategic priorities in Wales. They support the ambitions outlined in ***A Healthier Wales*** (Welsh Government, 2018), particularly around integration, prevention, collaboration, and sustainable system development. They also resonate with the ***Innovation Strategy for Wales*** (Welsh Government, 2023), which promotes mission-led innovation, translational research, and cross-sector collaboration to deliver social and economic benefit. Together, these projects contribute to Wales's broader ambition to foster a resilient, collaborative, and innovation-driven future.

The interdisciplinary composition of the 2025 cohort has significantly enriched this publication. Learners from health and social care, public services, industry, and the wider life sciences landscape bring diverse professional expertise and perspectives to their work. This breadth of experience strengthens knowledge exchange, encourages collaborative problem-solving, and reinforces the applied and practice-oriented ethos that defines the PGCert Applied Innovation programme.

This publication continues to offer value to a wide readership. For academics and researchers, it provides insight into emerging practitioner-led scholarship and applied innovation methodologies. For policymakers and organisational leaders, it offers evidence of innovation capabilities developing across sectors and examples of practice-informed transformation. For students and professionals, it presents accessible illustrations of inquiry-driven innovation in action and demonstrates how academic frameworks can be translated into meaningful organisational impact.

The *Innovation Academy Research Series* reaffirms Swansea University and the All-Wales Intensive Learning Academy for Innovation in Health and Social Care's enduring commitment to advancing innovation scholarship, promoting open-access knowledge exchange, and disseminating research that informs policy, strengthens practice, and supports future innovation across Wales and beyond.

Warm regards,

Editorial team

## Contents

# Could Morbidity and Mortality meetings be a tool for fostering a sense of belonging in Resident Doctors?

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**Abstract:**

Workforce wellbeing, retention, and inclusive cultures are central to innovation and sustainable transformation in health and social care systems. Resident doctors play a critical role in frontline service delivery and organisational learning, yet frequently report limited influence, reduced engagement, and a weak sense of belonging. These factors undermine innovation capacity and patient safety. This study examines whether Morbidity and Mortality meetings, which are long established as governance and learning mechanisms, can be reimagined as innovation enabling spaces that foster belonging, psychological safety, and inclusive participation among resident doctors. Using a qualitative case study design across two United Kingdom surgical units, data were collected through participant observation, unstructured interviews, document review, and a cultural survey. Thematic analysis identified system level enablers and barriers including organisational structure, time pressures, leadership behaviours, autonomy, emotional support, and links to quality improvement. Findings suggest that while Morbidity and Mortality meetings possess substantial potential as platforms for collective learning and innovation, prevailing practices often constrain resident doctors to passive or administrative roles. Aligning these meetings with innovation principles such as inclusive leadership, psychological safety, coproduction, and continuous improvement can strengthen organisational learning while enhancing belonging and professional identity formation. The study highlights practical pathways for redesigning routine clinical forums into innovation assets that support workforce wellbeing, capability development, and safer, higher quality care across health and social care systems.

**Keywords:** Health and Social Care Innovation, Organisational Learning, Morbidity and Mortality Meetings, Workforce Wellbeing and Belonging, Psychological Safety, Inclusive Leadership.

## Table of Contents

# 1 Introduction

## 1.1 Background and Context

The wellbeing and retention of resident doctors (formerly known as junior doctors) has been rising on the agenda for healthcare organisations over the past few years. The impact of junior doctor strikes, the COVID-19 pandemic and increasing service pressures have subsequently resulted in 61% of trainees considered to be at moderate or high risk of burnout (General Medical Council, 2025). Subsequently healthcare organisations and long-term workforce plans have highlighted the need to improve the working lives of National Health Service (NHS) staff, particularly resident doctors, recognising the need to sustain healthy workplace cultures and create a sense of belonging and value (General Medical Council, 2025), (NHS England, 2024). In Caring for Doctors (West & Coia, 2019), autonomy, belonging and competence were highlighted as core needs for the wellbeing of doctors with actions focused on building team working, giving trainees a voice and building cultures focused on learning and continually improvement, however the barriers and mechanisms to deliver this culture change remain poorly understood.

Morbidity and mortality (M&M) meetings represent a long-established method for medical teams to focus on organisational learning, having evolved in the early 20th century to help surgeons learn from complications (De Vos et al., 2023). In the UK, these meetings are often used to review the human, systems and patients factors that may lead to patient harm, and all are encouraged to participate in constructive discussions and identify patterns for wider learning (Royal College of Surgeons, 2018), with various policies relating specifically to how we can learn from deaths (NHS England, 2017). However, the effectiveness of these meetings can be highly variable (Beaulieu-Jones et al., 2023) with learning opportunities underutilised (Higginson et al., 2012) and barriers to success impacted by culture and format (De Vos et al., 2017). Anecdotally, participation and critical discussion from resident doctors have been particularly poor across units, with limited research into the obstacles faced regarding their involvement.

As a surgical trainee and resident doctor with a vested interest in burnout, an understanding of the organisational factors which feed into this, and the subsequent impact on patient safety, I have always been keen to understand how engaging resident doctors in organisational learning can help improve wellbeing and transform patient care. Adjacent to this project I was awarded the Averil Mansfield fellowship by the Associations of Surgeons of Great Britain and Ireland (ASGBI), which afforded me the opportunity to visit different surgical units across the UK and gain a wider understanding of how we learn. Therefore, this project aimed to utilise my experiences and opportunities to explore barriers to engagement in M&M meetings and investigate if they could be utilised as a tool to foster a sense of belonging, engaging resident doctors in wider organisational learning. By transforming the medical environment and creating a sense of purpose and belonging, resident doctors will be able to flourish and deliver compassionate and high-quality care suited to the needs of patients and the NHS (West & Coia, 2019).

## 1.2 Research Question and Aim

The aim of this project is to explore belonging in resident doctors and investigate how engaging resident doctors in activities of organisational learning (such as M&M meetings) can improve doctor wellbeing and patient safety. This report will explore the relevant existing literature for this study, outline the research design in observing 2 surgical units and their respective M&M meetings, and synthesise key findings and their subsequent impact on belonging in resident doctors.

Hypothesis: Could Morbidity and Mortality meetings be a tool for fostering a sense of belonging in Resident Doctors?

## 1.3 Definitions, Synonyms and Abbreviations

| Terminology | Definition |
|---|---|
| Resident doctor<br>Alternatively: Residents, Trainees | A non-consultant grade doctor including doctors in training who frequently rotate, as well as clinical fellows |
| M&M<br>Alternatively: Morbidity and Mortality meeting, Mortality conference | A regular departmental meeting to learn lessons from patient harm or death and drive improvement to maintain high standards of care (Royal College of Surgeons, 2018) |

| | |
|---|---|
| Belonging | A subjective feeling of connection and integration with our surrounding systems and communities (Allen et al., 2021) |
| Leader Inclusivity | Words and deeds by a leader that invite and appreciate others' contributions in discussions and decisions (Nembhard & Edmondson, 2006) |
| Autonomy | Having a voice and control over our working lives that reflects our values (West & Coia, 2019) |
| Psychological Safety | Shared belief within a group that it's afe to take interpersonal risks by asking questions and admitting mistakes without fear of punishment (Edmondson, 1999) |
| On call | Team responsible for managing emergency admissions and acutely unwell patients, typically involved a Consultant, 1-2 senior residents and 3-4 junior residents or foundation doctors. |

## 1.4 Literature Review

A preliminary literature review was performed to identify the existing body of knowledge relating to the role of resident doctors in organisational learning and the impact of this on their sense of belonging and wellbeing. This identified no studies looking at this niche of belonging; therefore, the scope was widened to explore firstly, belonging in resident doctors and secondly, resident doctors' role in the M&M and organisational learning. Details of the literature review methodology are detailed in section 2.1.

### 1.4.1 Belonging in resident doctors

Belonging has been recognised as one of Maslow's fundamental needs (Maslow, 1943) and has been defined as a subjective feeling of connection and integration within our surrounding systems and communities (Allen et al., 2021). Allen et al. (2021) also described that the state of belonging is influenced by our daily experiences and stresses and adapts to the environment around us. Their framework (Figure 1) shows the interplay between competency or skill, access to opportunity, perception and motivation, and enables us to link theoretical research with practical relevance, however there is little research exploring the relevance and importance of each aspect in a healthcare context and how this may change throughout our careers.

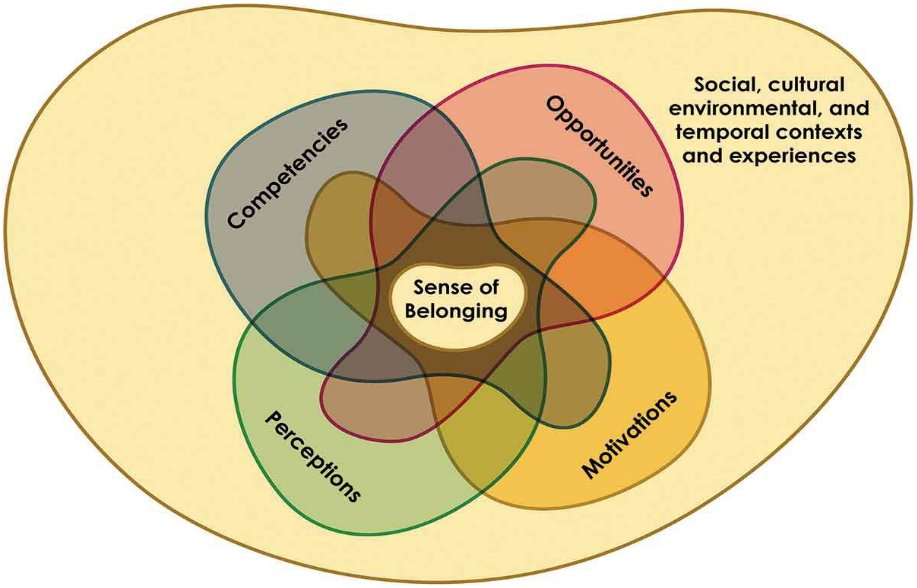

Figure 1. An integrative framework for fostering a sense of belonging (Allen et al., 2021)

For resident doctors, as they learn to understand the role of a doctor, both within society and in healthcare organisations, belonging helps formulate their professional identity (Sternszus et al., 2024) as well as a being a protective factor against burnout (Feng et al., 2024). The importance of belonging continues to be promoted by healthcare organisations (General Medical Council, 2025)(NHS England, 2024) but the challenge is identifying which factors foster a sense of belonging and which inhibit it.

Numerous studies have explored belonging in healthcare such as Haggins, (2020) whose survey of healthcare managers identified the role of culture, organisational structure and leadership in promoting belonging. With the importance of multi-disciplinary teamwork and a nurturing culture being echoed in the Caring for Doctors report by West and Coia (2019) supporting their synthesis of the literature with case studies, however these studies fail to identify how these processes promote belonging, over-simplifying the complexity of individuals and the impact of their environment and leadership. Beattie et al., (2017) noted in psychiatric teams, junior doctors who felt they had little autonomy and responsibility struggled to identify their role within the team, causing frustration and a disconnect from the wider team. They highlighted that doctors want to make a difference and have meaningful involvement to feel a sense of belonging and improve their morale, hence further research is required to identify additional mechanisms for resident doctors to contribute to decision-making and improving patient care.

Given the subjective nature of belonging, we must also consider the role of the individual, and the impact of personal experiences and professional identity. Autonomy and active engagement of residents is key to building meaning (Toubassi et al., 2023) but we also need to recognise the impact of emotions and experiences. Sternszus et al. (2024) have tried to capture the complexity of factors which contribute to perceptions of belonging as shown in Figure 2, as well as recognising the role of the individuals' emotions and identity.

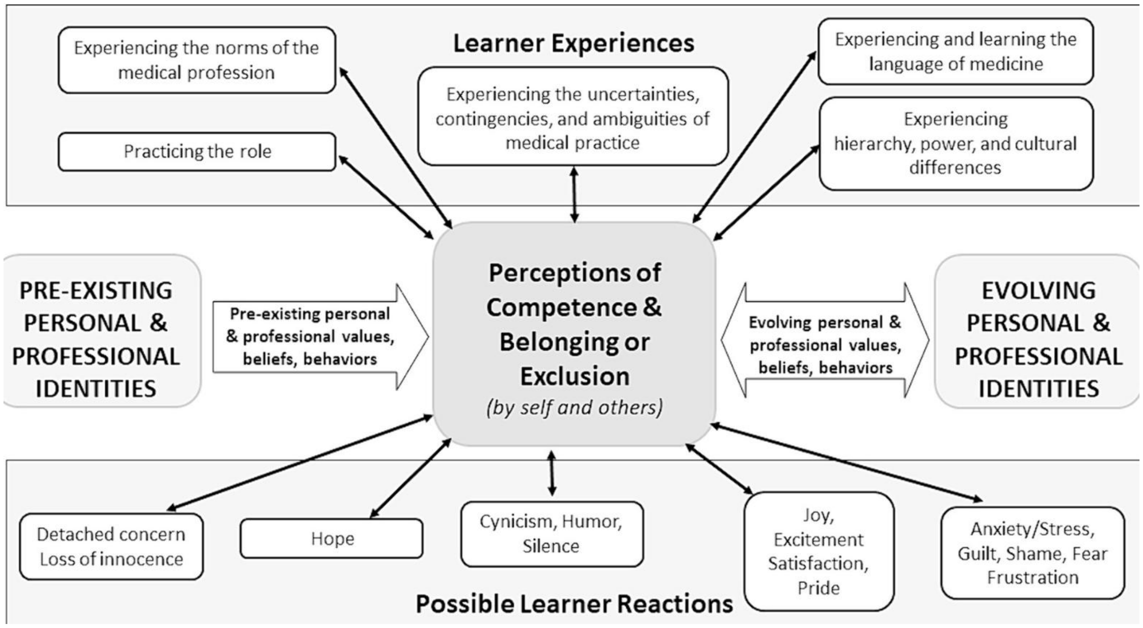

Figure 2. Perceptions of Competence and Belonging, taken from Sternszus et al. (2024).

The framework highlights the subjective nature of belonging and the impact of learner experiences and beliefs, with a particular emphasis on the experience of professional and cultural norms and the role of power dynamics and hierarchy. Additionally, they also noted how culturally dominant identities (typically white, male, middle-class) define what is perceived as "professional" and the cultural norm, leaving those who are different at increased risk of marginalisation and that they don't belong. Uys et al., (2023) is one of the few studies that applied a systemic approach to understand how the environment can shape our experience of belonging. They noted that informal spaces such as the doctors' mess, lunch clubs and coffee breaks, can provide a sense of connectedness and belonging among peers, with benefits emphasised in legitimate social spaces endorsed by senior colleagues. Role-modelling from senior colleagues plays a vital role in shaping residents' ability to form their professional identity and appreciate where they belong in the wider healthcare community. Broader research to understand the impact of generational differences on collaboration and how to reduce power dynamics could also supplement the literature and integrate into the framework. Additionally, there is also a lack of literature recognising how the wider socio-political environment feeds into the culture and perceptions of belonging at work, especially for resident doctors who are the Consultants and leaders of tomorrow's NHS.

In summary, to generate belonging in a rapidly changing healthcare system, we need a multifaceted approach which recognises the individuality of resident doctors, provides a collaborative culture and overcomes power dynamics and hierarchy to enable residents to influence decisions and shape healthcare services.

### 1.4.2 Resident doctors in M&M Meetings and Organisational Learning

Organisational learning can be viewed as a cycle of action and reaction that builds knowledge and understanding to build an effective organisation, and within healthcare this is typically done by learning from experience (Carroll & Edmondson, 2002). Yet numerous reports into patient safety highlight ongoing concerns with openness and responsiveness to reporting, reflecting and learning from issues (Martin et al., 2023), with resident doctors seen to have some of the lowest reporting of healthcare professionals (Hotton et al., 2014) and M&M meetings being highly variable and lacking formal governance processes for effective organisational learning (Higginson et al., 2012). Carrol and Edmondson (2002) highlighted that for effective organisational learning, organisations need to recognise potential opportunities and rethink assumptions, often without fully knowing the kinds of problems they will face or who is pivotal to those conversations for innovation and improvement. Therefore, engaging resident doctors, and understanding the barriers to their participation, is vital for organisational learning.

Despite significant workplace and cultural changes in the NHS over the past 30 years, resident doctors still report toxic work cultures with bullying, sexism and racism, with a lack of support following critical incidents, and reports they often feel blamed for systemic or organisational failings (Riley et al., 2021). A systematic review of factors that support psychological safety noted that those lower in the hierarchy, such as resident doctors, also feel less able to speak-up and assert themselves due to a lack of psychological safety and a perceived knowledge gap (O'Donovan & McAuliffe, 2020). Therefore, highlighting the role of positive and inclusive leadership behaviours to encourage those from all backgrounds and experience levels to have a voice. This echoes research into the effectiveness of high-quality M&Ms (Beaulieu-Jones et al., 2023) (Royal College of Surgeons, 2018)but these studies lack specificity regarding methodology and the role of resident doctors.

Research regarding specific activities to engage resident doctors in organisational learning is often based on local experiences. Kuper et al., (2010) performed an ethnographic study exploring learning in M&M rounds in Canada and found that senior staff doctors and residents had differing perceptions on learning within the meetings with many of the 'softer skills' not being appreciated by residents. This highlighted the need for further research into pedagogical changes to optimise learning within the M&M for residents. A few studies such as Garcia & Goolsarran, (2016) and Tait et al. (2023) noted that mortality reviews are often conducted by Consultants, but utilising a structured proforma can help resident doctors understand the whole patient journey as well as see the bigger picture and recognise organisational and systemic issue that may have contributed to patient harm. Additionally, although a small qualitative study, Gafson et al. (2019) explored educational barriers to raising concerns and suggested that improving induction and engaging them with educational activity targeted at raising concerns could help build stronger teams, foster a sense of belonging and improve organisational learning.

Overall, although studies (Beattie et al., 2017) (West & Coia, 2019) highlight the role of autonomy and involving resident doctors in decision-making and enable them to feel that they make a difference, no studies explore the interface between belonging and participation in M&M. The literature implies that resident doctors face numerous barriers to belonging and being engaged in organisational learning, however including them in the processes and having supportive leadership and a psychological safe environment may improve their sense of belonging and engagement in the learning process. Further research is required to understand the current learning culture and how this may be facilitated.

# 2 Methodology

## 2.1 Literature review methodology

A literature review of Pubmed, Embase and Google scholar was performed using truncation of key concepts and Boolean operator 'OR' and 'AND' to incorporate terms and concepts.

Concept 1 : “belong*”

Concept 2 : “resident” OR “junior” AND “doctor”

Concept 3 : “organisational learning” OR “M&M” OR “Morbidity AND Mortality” AND “meeting*”

Concepts 1 and 2 were combined to review Belonging in Resident Doctors. Concepts 2 and 3 were combined to review Resident Doctors in the M&M. All 3 concepts were combined to identify any studies relevant to the role of resident doctors in organisational learning and the impact of this on their sense of belonging. Titles were reviewed to identify their relevance. Additionally, reference lists of included articles were reviewed to identify additional relevant literature.

## 2.2 Research Design

There are numerous attempts to measure belonging (Allen et al., 2021), but no standardised scale that has been validated in healthcare workers has been developed. A mixed method, qualitative case study approach was utilised to provide a real-world in-depth study of the processes, relationships and experiences regarding the role of resident doctors in M&M meetings. Other benefits of this approach include being able to apply a holistic approach and utilise a variety of research methods to explore some of the intricacies of complex social situations, however it will also risk the observer effect impacting peoples’ behaviours (Denscombe, 2021).

As M&M meetings are frequent occurrences, two sites within the UK were selected as ‘typical instances’ to promote the generalisability of the findings. M&M meetings were focused on as the areas for theory building, but the wider interplay of the resident doctors and their local hospital team was also observed. The two sites chosen also offered convenience as they utilised contacts through ASGBI and supported the fellowship application. Site A was also in England and Site B in Scotland, which in combination with my personal experiences in Wales added a national perspective. A focus on surgical M&M was undertaken as this represented both the researcher’s specialty of interest and the literature suggestions that surgeons are more likely to discuss error than medics (Pierluissi et al., 2003.)

## 2.3 Data Collection

Data was collected via participation observation and taking field notes at the two sites, combined with unstructured interviews, and a review of relevant documents and policies. This was to minimise disruption and try to gain unique insights in to culture (Denscombe, 2021). Additionally, a cultural survey (appendix 1) was developed, adapted from Postgraduate Hospital Educational Environment Measure (Roff et al., 2005) with 50 rated on a 1-5 Likert scale with 1= strongly disagree and 5 = strongly agree, and additionally included a checkbox to identify leadership opportunities available and free text comment. Questions 7,8,11 and 13 were designed as negative questions so their corresponding Likert scores were reversed for the analysis. The survey (appendix 1) was disseminated to 14 resident doctors at site A via paper forms and Google survey.

## 2.4 Ethics

Participation was entirely voluntary, with all sites and participants aware of the study and observation. Verbal consent was taken for unstructured interviews, and consent was explicit for survey participation. Ethics approval was sought from the University Swansea ethics committee and approval granted (ethics approval reference: 1 2024 11575 10506). The study was also deemed not to require review by the NHS Research and Ethics Committee using their decision tool (Health Research Authority, 2020).

## 2.5 Data Analysis

Key notes were transcribed, and data was analysed using a thematic approach to group together data from observations and interviews (Braun & Clarke, 2006) after each site visit. Data was amalgamated with the survey responses which were grouped into themes as per the PHEEM survey (Roff et al., 2005) relating to service pressures, leaderships, wider culture and organisational learning. This then enabled further review and defining of themes.

# 3 Results and Discussion

The results and discussion of the study have been combined to facilitate commentary and reflection alongside the narrative. The initial themes that emerged are shown in Figure 3.

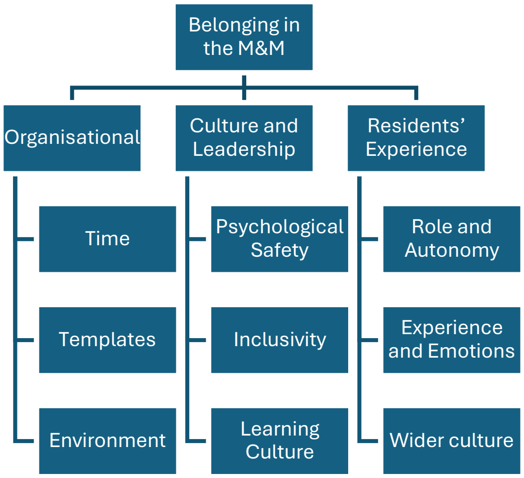

**Figure 3. Initial Themes**

The survey results are shown in Figure 5. The survey was divided into 4 keys sections detailed below with Figure 4 demonstrating a box and whisker plot of the results:

1. Perceptions of role autonomy
2. Perceptions of teaching
3. Perceptions of social support
4. Perceptions of learning culture

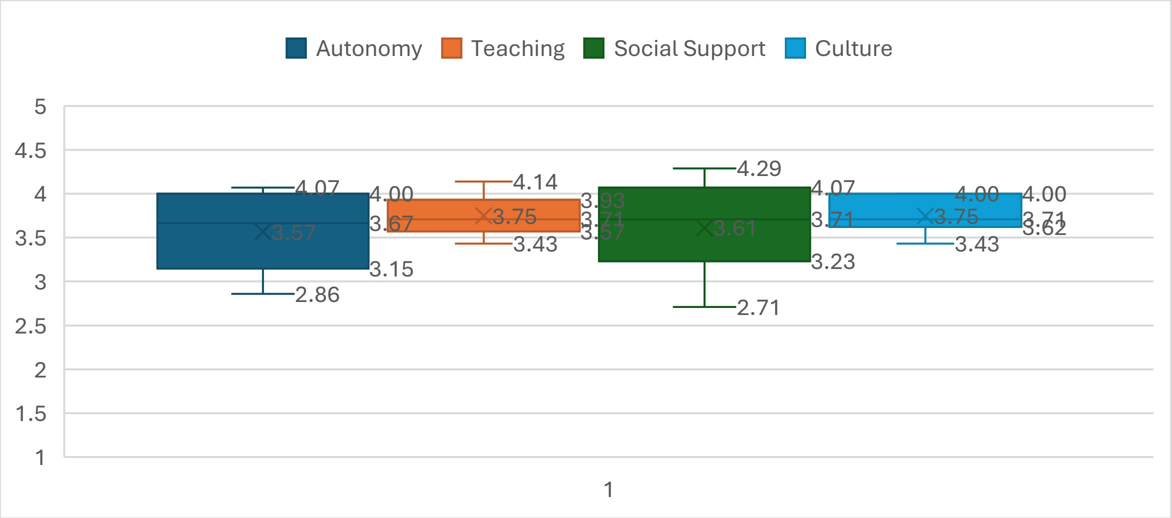

**Figure 4. Box and Whisker plot of survey results.**

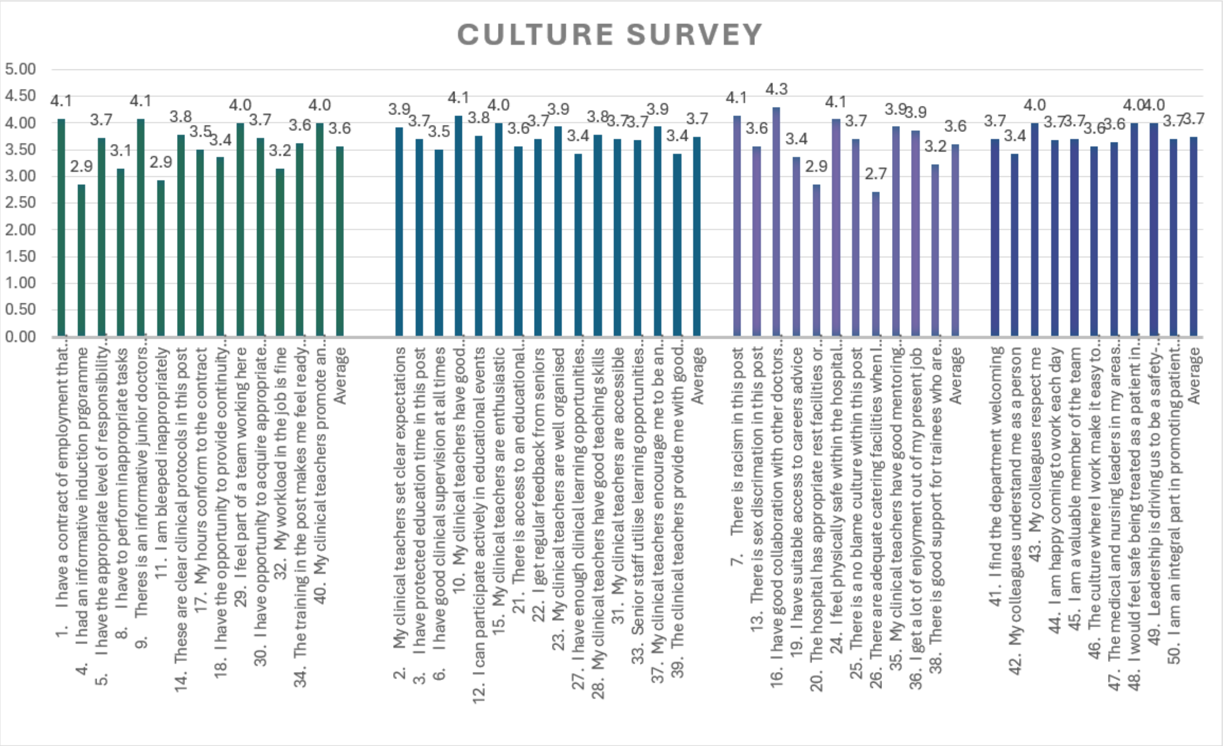

Figure 5. Survey Results

## 3.1 Organisational Structure of the M&M

### 3.1.1 Structure and Environment

To understand the wider context of the findings it is firstly essential to appreciate the structure and organisation of the M&M meetings. Both sites were busy tertiary hospitals and for their M&M would meet weekly for 1 hour, in hospital seminar rooms, the consultants – mostly in their shirts and ties, and resident doctors in their scrubs, would trickle in, often sitting with their peers and the resident doctors gathering towards the back of the room. Each site used a standardised proforma and PowerPoint template to review weekly department workload, key audit data, and discussion of individual M&M cases. As most resident doctors rotate every 4-6 months, the role and purpose of the M&M need to be regularly emphasised, yet the meetings had no introduction or clarification of roles. As highlighted by Beattie et al., (2017) role clarification promotes a sense of purpose and De Vos et al., (2017) noted that clear protocols and responsibilities are facilitators to effective M&M learning. Many residents rely on the local induction process to highlight key roles and a practical orientation, yet the survey results demonstrated that induction was rated poorly (mean 2.86) highlighting the lack of preparation, with many residents stating *"I just asked "X" who's done it before what to do"* highlighting the need to rely on colleagues for practical advice.

Structure alone doesn't create belonging and effective learning. For an M&M meeting to be effective Beaulieu et al. (2023) identified 4 key components of the meeting to include pre-meeting planning, a balance between structured presentation and learning points vs facilitated discussion, formal channels for quality improvement and creating a culture of safety with a focus on organisational development. However, the role of resident doctors in promoting this hasn't been defined, in both examples residents were utilised in the pre-meeting planning and structured presentation, yet the weren't actively involved in the facilitated discussion or quality improvement, creating a sense of being an administrative role. Additionally, Tait et al. (2023) found that using a structured proforma can support resident doctors in being involved in mortality reviews, understanding the whole patient journey as well as the wider systemic issues. Therefore, engaging resident doctors further in the reviews can supplement their own personal learning as well as feeding back to the wider group, but a clear structure must be provided to ensure meetings aren't just focused on governance processes and tick box exercises but are valuable tool for organisational learning. A balanced structure can facilitate the engagement of residents and provide pragmatic solutions in improving patient safety. This will also align with GMC requirements for doctors to show they actively participate in improving patient safety (General Medical Council, 2017).

### 3.1.2 Time Pressures

At site A, the M&M would occur on Thursdays at 1pm and chaired by the governance lead, whereas site B held their meeting at 8am on Wednesday mornings, chaired by the consultant from the previous week's on call. Attendance for all except those on call was mandatory and as it was a regular scheduled event although interruptions occurred most of the team was able to attend with agreement although a slightly better rating for 'I have protected education time in this post' (3.71).

The presentations would be prepared by one of the junior resident doctors who would arrive early to set up. Discussions with the resident doctors highlighted that this can be quite a time-consuming process with no dedicated administrative time, making the process quite stressful. Survey results demonstrated the high clinical demands with neutral score for 'My workload in the job is manageable' (average 3.15) and 'my hours conform to the contract' (3.5). Although time to attend the meeting was protected the impact of additional service demands was still felt and this can contribute to the feeling that residents are just there for service provision rather than valued members of the team. One resident stated "*I'm not really sure what I'm doing or when I'll do it, but one of the other trainees is going to show me later*" also noting that no formal training or protected time to develop the presentation was given, with residents feeling the pressure to produce a polished and well-structured review taking them away from the discussion and wider learning. Whilst many valued the opportunity to recap events and saw the importance of the meeting to their consultants, they also commented that their role was just to present the data quickly to enable the consultant to engage in discussion and press on with the meeting. The impact of time pressures was also observed during the meetings which were more relaxed initially, discussing cases in detail, and later rushing through cases to prevent the meeting overrunning. The effect of the time pressure resulted in less discussion, unless thought to be of high clinical importance, and therefore input from the residents was also sought less. The intention to involve residents and the impact of the time pressures was additionally reflected in the survey, with perceptions of teaching scoring higher (average 3.75) especially in areas such as my clinical teachers set clear expectations (3.92) and are enthusiastic (4.0) but less when asked about the relevance to their needs (3.43) or associated feedback (3.43) with learning opportunities being effectively utilised perceived slightly better (3.69). This highlights the impact of time and service demands on critical thinking and discussion and resonates with the wider literature that time can inhibit opportunities for research and learning (Chen et al., 2025). To facilitate resident doctor engagement in the M&M in addition to protected time to attend the meeting, each case needs appropriate time for all team members to be consulted and contribute, as well as time before and after meetings to reflect on wider learning. This remains challenging in an increasingly busy healthcare system, but making time to learn can drive innovation and transformation, enabling improvements for patient care and efficiency (Kenney & Berwick, 2011).

## 3.2 Leadership within the M&M

### 3.2.1 Psychological Safety

Both units are busy emergency and tertiary General Surgical departments with a very visible consultant presence for the on-call teams. This translated to their dominant presence in the M&M where they would take responsibility for chairing discussions, managing time and managing the infrastructure and environment for the meetings. Their leadership shaped the tone of the meeting and although they would utilise open questions, responses were often clipped and formal, with few responses from the residents in the room. As time progressed throughout the meeting it would also feel increasingly rushed to get through the agenda, further limiting open discussion. Further questions to expand on the situation would often only come from the consultants. In later discussions, the residents said, "*I felt I had nothing relevant to add*" and "*They (referring to one of the Consultants) are quite particular about how things are done, I wouldn't want to get on their bad side.*" Outside of meetings, despite friendly discussions, a professional barrier remained with residents always referring to consultants as "Mr X" or "Ms Y" rather than first names. Hierarchy can be vital in critical situations in healthcare to ensure responsibility and roles are appropriately allocated, but it can also inhibit speaking up as those more junior lack the confidence to challenge the norm (Umoren et al., 2022). To facilitate meaningful discussion and a culture of learning, residents must feel able to speak up without fear of repercussions ergo psychological safety must be present.

Factors that support psychological safety in medical education and the corresponding observations from the M&M are highlighted in Table 1. As shown, leadership availability and the focus on learning and patient care are noted as positive observations that can promote psychological safety. However, the lack of critical thinking, learner autonomy and persistence of social hierarchy remain as barriers for open discussion. To appreciate the behaviours of individuals within the M&M an understanding of the wider workplace culture is required Although the survey results demonstrated 'good collaboration with other doctors of my grade' (mean 4.29) and respect from colleagues (mean 4.0), feelings of being a valuable member of the team (mean 3.71), that they are working in a no blame culture (3.71) and are happy coming to work each day (3.69) was less. The consultant seemed aware of this and noted *" we have learnt from feedback in the past, we take on the responsibility and are quite hands-on, it's the right thing for the patients, and helps the juniors feel more supported"* and was reflected with a positive response to the question "Leadership is driving us to be a safety-centred organisation (mean 4.0). However, change in culture takes time, and what the Consultants deem as supportive isn't always translated to what the residents feel as supportive. This reflects the literature which highlights how those with higher status feel their opinion is valued more and they can voice their thoughts freely without fear of repercussions (Nembhard & Edmondson, 2006). Often it requires small and sustained changes in interpersonal behaviours such as open-questions, inviting dialogue and explicit expectations (McClintock et al., 2023) to reduce the hierarchy and subjective perceptions of power to create wider change in the team and organisation.

**Table 1 – Adapted from McClintock et al. (2023) Positive behaviours for psychological safety. Colour coding to represent behaviours observed across Site A & B. Red = Not observed, Orange = Partially Observed, Green = Observed.**

| | Positive |
|---|---|
| Organizational | 🟧 Time allotted for team formation, longitudinal design of teaching |
| | 🟥 Time to debrief |
| | 🟧 Create communities of practice |
| | 🟥 Support development of faculty development to provide skills to optimize climate |
| | 🟥 Use of near peer coaching in faculty development |
| | 🟩 Implementation of routines and predictability |
| | 🟧 Protection of time to learn |
| | 🟩 Lack of formal assessment |
| | 🟧 Remove competing factors (distractions, interruptions) |
| Team | 🟥 Team leadership structure without associated social hierarchy |
| | 🟧 Team member continuity |
| | 🟧 Downplaying power differentials |
| | 🟩 Embrace teaching as a core value |
| | 🟩 Patient care as a core goal |
| | 🟧 Explicit social contract for respect, allyship, or 'fiction contract' (for simulation) |
| | 🟧 Relationships and team cohesion |
| | 🟥 Coaching oriented leadership |
| | 🟧 Challenging team members in respectful ways |
| | 🟧 Invitation and appreciation for other's contributions |
| | 🟧 Team leader "love of profession' |
| | 🟩 Culture of accountability |
| Observed interpersonal behaviours | 🟧 Explicit statement of expectations or objectives |
| | 🟧 Encourage dialogue through stated invitation |
| | 🟧 Specific phrasing recommendations |
| | 🟧 Use of open-ended questioning |
| | 🟥 Questioning focused on critical thinking |
| | 🟧 Allowing learners time to answer questions |
| | 🟥 Providing learner autonomy |
| | 🟧 Explanations of clinical reasoning |
| | 🟩 Leadership physically available |
| Pre-existing personal attitudes, beliefs & skills | 🟧 Factors affecting position within the hierarchy (gender, attributes, learner stage) |
| | 🟧 Comfort with uncertainty |
| | 🟧 Coping strategies |

### 3.2.2 Inclusivity

At site A, all five consultants present were male, four of whom were white British, whilst the twelve resident doctors present was mostly female and more ethnically diverse. At Site B, one of the nine consultants present was female as opposed to over half of the residents, and both residents and consultants were predominantly white. One non-white female noted "the consultants are really friendly and approachable, but I don't think I would want to speak to them about personal issues". This highlights the professional barriers that remain and may be exacerbated by perceptions of the hierarchy and lack of diversity among seniors. Although the survey noted few had experienced racism or sexual discrimination, and one resident reported she felt allyship and support from a consultant after receiving racist comments from a patient, the lack of diversity and representation in the Consultant cohort may still create a barrier in residents feeling comfortable. As shown in table 1, behaviours such as using open-ended questions, focusing on critical thinking and giving time to learners to answer are key factors in providing psychological safety but are poorly observed. By inviting and encouraging resident doctors to challenge it helps build psychological safety as well as develop learner experience that build their sense of belonging and professional identity (Sternszus et al., 2024) . Inclusive and authentic leadership behaviours are associated with psychological safety (O'Donovan & McAuliffe, 2020) and having leaders that seek to listen without judgement and value the differing opinions of all team members, may be one mechanism to mitigate power imbalances and encourage open discussion. As with hierarchy, leader inclusivity is required to ensure residents feel their opinions are valued and they can build mutual trust and respect.

### 3.2.3 Learning culture

Assessment of learning in the M&M can be challenging to evaluate, especially when there are competing governance priorities with residents and consultant having varying perceptions on intended learning outcomes in M&M (Kuper et al., 2010). Beaulieu-Jones et al., (2023) found that effective M&M meetings are able to balance focused learning with facilitated discussion to guide quality improvement (QI) and education. This was echoed by De Vos et al., (2017) who found that clear planning, allocation of tasks with determined timelines and a strong focus on improvement also facilitated learning. Engaging in QI is a Generic Professional Capability for doctors of all levels (General Medical Council, 2017) with 12/14 of the residents surveyed stating they participate in QI but only 4/14 leading a QI, and further discussions highlighting that were data collecting for large group QI projects but unclear of the purpose. At site A, one Consultant did note that some of the discussions had could be a good idea for a QI project and asked which residents still wanted a project, but no further elaboration of improvement was explored. Site B had a more robust system in place, using electronic notes to feedback outcomes and any further actions and timelines to be undertaken, however resident doctors were not engaged in this process. Carroll & Edmondson (2002) noted that organisational learning focused just on 'learning from experience' is insufficient as it risks complacency and over-emphasise on the individual technical aspects rather than wider interests. By incorporating a diverse mix of opinions and collective feedback, departments can utilise residents and their frontline experience to rethink assumptions and generate new ideas for QI and system improvement.

## 3.3 Resident Doctors' Experience

### 3.3.1 Autonomy and Role

As shown in Figure 4, perceptions of autonomy, although positive showed a wide range of results and was less compared to other domains. Residents reported that sometimes the M&M is *"just a tick-box exercise"* and *"we're not really involved in the process, I just follow the proforma".* This was reflected in the survey with 'The culture where I work make it easy to learn from errors' having an average score of 3.57. This may be exacerbated by the lack of feedback from the M&M outcomes as *"no one tell us the outcome".* The lack of feedback is counterproductive to organisational learning and can result in residents disengaging as they feel the processes are largely performative. Mechanisms to engage residents in the M&M must focus on both engaging residents in the discussions and learning, whilst finding pathways to feedback outcomes to consolidate their learning, yet this can be challenging with frequent rotations and high turnover of trainees.

Furthermore, Table 1 highlights that providing learner autonomy was not observed, although they were given tasks these were highly prescribed and didn't give residents any control or influence. Traditionally learning in medical education is by observation, but active learning strategies are being further encouraged to engage participants and promote application of knowledge and understanding (Bucklin et al., 2021). Residents often struggle to recognise teaching, especially of non-technical skills that aren't explicit, but their knowledge and perceptions of learning is greater with active learning techniques (Boedeker et al., 2025), although planning to incorporate active learning can require further time and preparation. In America, they developed a 1-hour teaching workshop to educate residents on the role of M&M, patient safety and error reduction strategies using a real case, which they could then apply to future case reviews (Garcia & Goolsarran, 2016). Residents felt this was a unique way to improve the quality of care, giving them autonomy and enabling them to make a meaningful impact. Giving clear roles with opportunity for personal development and constructive input to meetings, either by; pre-meeting education, interactive case developments or active learning techniques may encourage residents' confidence to participate more effectively. To promote effective learning in the M&M Beaulieu-Jones et al., (2023) suggests that everyone must feel able to contribute for constructive conflict.

### 3.3.2 Experience and Emotions

Sternszus et al., (2024) noted how learner reactions can feed into perceptions of belonging as well as how they experience the uncertainties and norms of the profession. It can be easy to depersonalise the patient from the events and processes within the M&M, but pastoral support was appropriately observed with recognition that "we've had a few difficult cases recently" and regular check-ins outside the meeting to see how the residents were finding things. Following an additional meeting to discuss a complex death, when one of the residents joining virtually became visibly upset, she was later phoned by the consultant after the meeting to check in and reassure her that she'd done nothing wrong, but it was understandable to be upset. Although the section on social support had a wide spread of results ( figure 4), the poorest were related to rest and catering facilities rather than psychological support and if you exclude these datasets the mean increases to 3.80 with median 3.86, making this area the most positive results and this was echoed in residents reports of feelings of support outside of the meetings. Validating the complexity of emotions that M&M may bring up is useful in expressing vulnerability, which in turn reduces the hierarchy and promotes psychological safety, as well as being formative in the development of professional identity as per Figure 2. Kuper et al., (2010) noted in their study of learning in M&Ms, that residents agreed that dealing with the emotional impact of deaths could be a good use of the meetings but had yet to experience it, despite senior doctors highlighting the benefits of exploring psychotherapeutic aspects. Perhaps instead of reactive responses to emotions after meetings, a more integrative framework that addresses emotional wellbeing and psychological toll could be incorporated. Observing consultants role model emotions and appropriate behavioural responses can support trainees to feel less isolated and would be add further value to meetings.

### 3.3.3 Belonging outside of the M&M

As already alluded to, the wider culture and environment play a critical role in shaping whether resident doctors experience a sense of belonging within their teams. Both site visits occurred approximately 6 weeks after most resident doctors rotated to the department. This gave them time settle in but was still representative of the transient nature and short rotations resident doctors face. On ward rounds, most of the resident doctors felt able to approach the Consultants with clinical queries, but site A promoted a more open culture and a 'if you don't know, just ask' culture, creating psychological safety and making the doctors more active participants in their learning, contrastingly Site B was more task-orientated and would rely on questions being passed along the hierarchy and dealt with by peers. The impact of these differing cultures on belonging is difficult to ascertain as there was no difference in speaking up and questioning behaviours in more formal environments, such as M&M. This may reflect how clinicians switch to professional mode, become acutely aware of power dynamics and feel less able to be vulnerable in formal environments. Although acceptance from seniors is important, support from peers may also foster a sense of belonging and provide confidence as doctors bond over their shared experiences, share doubts and navigate challenges together. In the M&M, instead of just one resident presenting, having multiple may enable them to speak more freely.

Additionally informal spaces, such as coffee breaks, emerged as opportunities to build community, flatten hierarchies and share humorous stories or weekend plans, feeding into the resident doctors' experience of professional norms and therefore the perception of belonging. Informal interactions enable residents to see the vulnerable side of consultants and the authenticity in their leadership. The role of informal spaces in creating a sense of belonging was echoed by Uys et al., (2023), who found the opportunity for resident doctors to be 'unguarded' and able to connect outside the constraints of professional roles and hierarchies, enabling them to build trust and relationships and resolve disagreements. However, they also noted the opportunity for these informal and uninterrupted rest is reducing, therefore being able to mimic some of the informal atmosphere in formal meetings may help overcome service pressures to create connection in a more standardised way. When consultants demonstrate inclusive leadership—by actively inviting junior perspectives, acknowledging contributions, modelling openness about mistakes, or offering pastoral check-ins—they create powerful signals that residents are valued as colleagues rather than peripheral service providers. With fewer opportunities for team-bonding, meetings that bring the team together need to be effectively utilised to promote cohesion and belonging amongst doctors.

### 3.4 Limitations

This study was conducted across 2 sites which are busy surgical departments in teaching hospitals and may not be applicable to smaller or non-surgical departments, and by focusing just on M&M meetings there was less appreciation for the impact of other environments, especially clinical areas, on belonging and wellbeing. This study predominantly assessed perceptions of belonging from a resident doctors perspective and it would be useful to compare that with consultants who may feel similar barriers to meaningful engagement. The impact of any changes would need to consider impact on the whole team. As an observational study, we must also recognise the impact of the researchers' personal perspectives on interpretation of the data, although this was counterbalanced by having a wide range of sources. Additionally, this study must be recognised as the first to explore belonging within M&M meetings, with the aim to enhance understanding and guiding future research into suitable interventions.

## 4 Conclusion

Morbidity and mortality meetings have vast potential for being an opportunity for inclusive learning spaces that engage resident doctors in critical thinking, formation of their professional identity and developing a sense of belonging. They provide a regular, interdisciplinary gathering in a protected space to unite opportunity, skill development, and motivation to engage with their healthcare organisation, subsequently feeding into their sense of belonging(Allen et al., 2021). By recognising the residents' experiences, feeling and perceptions within the M&M, leaders can create meaningful opportunity for residents to speak up and have active input. However current practices are still entrenched in tradition with resident doctors' present but not active participants, especially in the discussion and learning. When resident doctors are given autonomy in their learning, encouraged to ask questions and challenge processes, it helps them feel part of the process and that their role is valued. M&M meetings can be re-designed to create a culture of learning, promote resident doctor participation and promote actionable change. By reimaging learning in M&M meetings, healthcare leaders can begin to transform how they engage the wider workforce in shaping a representative healthcare system that belongs to the workforce and is focused on learning to provide better patient care.

## 5 Key Recommendations

Morbidity and Mortality meetings may be an opportunity to engage resident doctors in organisational learning and foster a sense of belonging; however, the following recommendations must be incorporated to ensure meetings are effective and engaging for all attendees, particularly resident doctors:

### 5.1 Protection of time

To adequately prepare for M&M meetings and engage in discussions without distractions, resident doctors must have protected time away from clinical duties and responsibilities both prior and during the meeting.

### 5.2 Organised structure and clear role allocation

A structured framework and clear roles can provide the skills and competencies for learning and active participation in the M&M. For resident doctors, a framework can also provide autonomy and guide their understanding of organisational learning.

### 5.3 Create psychological safety

Clinical leaders must recognise and minimise the impact of hierarchy to encourage residents to speak up freely. Behaviours such as open dialogue, encouraging critical thinking and inviting residents to speak can be gateways to more open conversation.

## 5.4 Inclusive Leadership

Resident doctors are increasingly diverse, which may not always be represented in the consultant population and senior roles. Departments must make a concerted effort to seek out and value different perspectives and populations.

## 5.5 Link with Quality Improvement

Resident doctors frequently engage with quality improvement projects but often need ideas or support to align them with organisational needs. The M&M provides an opportunity to engage residents in QI by identifying system issues, developing solutions and feeding back. This can be an opportunity for residents to have autonomy within the healthcare system and develop a sense of purpose and belonging.

## 5.6 Recognise the emotional impact

Learning from morbidity and mortality provides pivotal learner experiences for developing professional identities as doctors. However, facing death, ambiguity and potential errors can take an emotional toll particularly in the formative years of a doctor's career. Recognising this emotional complexity, appropriately responding to reactions and role modelling vulnerability and compassion, can influence the connectedness residents feel.

## 5.7 Implementation of findings

To further develop these recommendations, we propose a trial of resident doctor focused M&M meetings in local units. This would require enthusiastic and engaged leadership with clear role allocation and clarification of expectations reinforced at each meeting. It would be vital to observe engagement, evaluate psychological safety and sense of belonging. If successful these results could then be spread and scaled to develop an inclusive and holistic approach to engagement within M&M meetings, improve outcomes for staff, patients and the wider healthcare system.

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# 7 Appendices

Appendices can be found in the following page:

https://cronfa.swan.ac.uk/Record/cronfa71902

# Public Involvement in Health Service Design: A service provider perspective.

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## Abstract:

Service user engagement is critical to the development of effective healthcare services that are both quality driven and patient centered. The literature is extensive and convincing yet despite Government direction there remains a gap between the theory and practice of effective public and patient engagement within the NHS. This paper explores the results of a questionnaire-based methodology targeted at service providers, exploring their perspective on the use of the public and patients to co-produce service change. With a satisfactory questionnaire return rate the results demonstrated that increased service user engagement attracted overwhelming support, however due to many factors the reality of achieving this is challenging. The study highlights good insight around these challenges, including inadequate service user knowledge, lack of a recognised protocol, and limited resource, which in turn provides a good foundation for further research, as well as a practical roadmap to increase service user engagement levels in practice.

**Keywords:** Service provider, Service user, Engagement, Co-production.

# Tables and Figures

## List of Tables

## List of Figures

## Table of Contents

# 1 Introduction

## 1.1 Background and Context

The National Health Service (NHS) is a product designed for yesterday. Increasing population size, patient complexity, and expectation has created unprecedented demand on an already over-subscribed system. With an untenable financial position, the health service is not able to simply throw money at the problem, which means service re-design is required (Department of Health, 2025). Whilst clinical and operational teams within individual NHS organisations recognise the need for efficiencies and are always looking for service improvement, they rarely involve the public in these discussions (Damas et al, 2022). The result is predominantly a service re-design that does not meet the full extent of patient needs and therefore its effectiveness (and efficiency) is limited.

## 1.2 Government Policy

Public involvement has been central to health service direction for many years and as such it holds public ownership in high regard, declaring that those who may need to use NHS services should be involved in its design and improvement (Department of Health, 2015). In addition, the Children Act (2004), Health and Social Care Act (2012), Care Act (2014), and NHS England's Patient and Public Participation Policy (Department of Health, 2017) all require local NHS organisations and local authorities to embed public involvement in service change decisions. NHS Wales and Llais (an independent public body established to give people a voice around Welsh health service change) dictate, through the Health and Social Care (Quality and Engagement) (Wales) Act 2020, that health organisations must seek the views and represent the interests of the public in health and social care in Wales. This supports the key principles of the Wellbeing of Future Generations Act (2015) and also enables the delivery of the Welsh Ministers vision for 'A Healthier Wales' (2021). However, despite organisational constitutions and government directives, public involvement rarely achieves the level of genuine co-production required for effective and meaningful change. It does however provide a strong foundation on which to build.

## 1.3 The importance of service user engagement.

Public and patient involvement in health service decision making is not a new concept. Tambuyzer et al (2014) stated that service user involvement is increasingly seen as essential, whilst Martin (2018) highlighted the need for public, patient and third sector collaboration to drive service modernisation. More recent papers (Sheldon et al, 2024); Scott et al, 2024) add further support suggesting academic acceptance and provide further insight into maximising impact. Ezaydi et al (2023) highlights the 'ladder of co-production', emphasising how maximum effectiveness will only be achieved through full co-production with the service user. Whereas the National Collaborating Centre for Mental Health (2019) in a paper that pre-dates Ezaydi et al (2023) describes 'Doing to', 'Doing for', and 'Doing with'. The paper proposes that most NHS organisations 'Do for' which is less effective than 'Doing with'. Further to this, many papers have explored co-production and how it needs to be separated from simple collaboration and become a priority within health-based organisations (Social Care Institute for Excellence, 2022). The body of evidence around co-production is wide ranging and extensive and will be explored further in Chapter 2.

## 1.4 Authors interest and service benefit.

The researcher is a strategic manager who is motivated to make sustainable service improvement. Their experience is that the public voice could be utilised more widely and more effectively when it comes to service change, and they are motivated to explore this opportunity further through this work-based research project.

## 1.5 Research question and objectives of the research

How can we improve public involvement in health service design? Objectives include:

- To increase awareness around the position of NHS employee's when it comes to utilising the service user voice in service re-design.
- To understand any barriers and enablers that exist in using the public voice.
- To understand the perceived impact of utilising the public voice.
- To create high level foundations for further research into this subject matter.

## 1.6 Summary and the structure of the paper

This chapter has introduced the topic that the research project will explore. It has briefly covered the need, Government and public body position, as well as the motivations of the researcher. Chapter Two will explore and review the existing literature around the subject matter, with Chapter Three highlighting the methodology and research design. Chapter 4 will present and analyse the findings, with Chapter Five synthesising the findings with the literature. Chapter Six will conclude the project and highlight the implications and recommendations, including opportunities for further research, and how the findings will influence and benefit local service change practice.

# 2 Literature Review

## 2.1 Introduction and search criteria

This section will review, demonstrate and analyse the available literature, exploring both past and present works to inform the paper. The literature search used the iFind facility via the Swansea University online library service. Criteria for the search consisted of the following;

SEARCH CRITERIA

↪ Title contains **Health service** AND Any field contains **public involvement**
↪ OR Any field contains **service design**
↪ OR Any field contains **service development**
↪ OR Any field contains **service improvement**
↪ OR Any field contains **patient invovlement** AND Any field contains **United Kingdom**

English language only.
2015-2025
Peer reviewed journals
Reputable collection sources
Open access

**Figure 1. Literature review search criteria**

It was found that the body of evidence used several terms interchangeably. These consisted of Public involvement, Patient involvement, Service user involvement, as well as Service improvement, Service design, service change and Service development. Therefore, in order to capture the relevant and important works all of these search terms were utilised. The searches were limited to English language papers from peer reviewed journals, initially from 2015-2025, however the volume of results was low and therefore the date range was extended until an adequate volume of quality papers was achieved.

## 2.2 The NHS perspective on service user engagement.

Public involvement in the design and improvement of the NHS has been central to public sector ambitions for many years (Scottish Executive Department for Health, 2000). Furthermore, The National Health Service Act (2006) places a legal duty on NHS organisations to consult and involve patients and the public in meaningful interaction when developing services. Additionally, through an international lens, many governments have developed health policy emphasising the need for patient and public involvement in not only the design but also the planning and delivery of health services (Finn et al, 2018). Most state that listening to the patient is critical as they are the individuals who are both the beneficiaries and funders of health care (Crawford et al, 2002). Others including Armstrong et al (2013) advocate patients are legitimate stakeholders of health care in a consumerist society, and as such are entitled to have their say on how it is delivered. Goodwin et al (2011) also add that in the current climate of higher patient expectations with the demand for a more personalised and responsive service, patients and the public absolutely need to be involved in its design and delivery. NHS England (Department of Health, 2017; Department of Health, 2018) add to this and suggest anecdotally that public involvement in all aspects of health care, patient safety and health outcomes is imperative if we are to ensure a fit for purpose service. NHS England were early implementors of patient involvement, stating that the NHS had a duty to work in partnership with the public, and that the service should be 'of the people, by the people, and with the people'.

## 2.3 Public sector policy

Public sector policy development has undoubtably instigated a drive to amplify the public and patient voice., with recent years experiencing a significant effort to improve the use of public forums, however uptake remains low (Sheldon et al, 2024). Over the years various papers have explored public involvement in health service change, with many drawing distinctions between engagement and participation (Wynne & Felt, 2007). This paper recognises the poorly defined nature of public engagement and public participation (as highlighted in the literature by Cohen et al, 2008; Rowe & Frewer, 2005) and therefore within the limited context of this study they will be considered interchangeable. Moreover, recent papers (Lewis et al, 2023; Sheldon et al., 2024) have debated public engagement and public participation and whilst definitions have developed somewhat (informing policy terminology), the two terms are largely still used (in the literature and in practice) interchangeable. Despite the lack of consistent definition of public engagement and participation in the literature, the fall out of a national (public body) push to increase public involvement in health service design (not to mention the legal duty) is that there has been a plethora of research in this area.

## 2.4 Underserved and diverse populations.

The literature has recognised the motivation, rationale and necessity of service user involvement in the development of the NHS, but it also recognises that service user uptake is low. Sheldon et al (2024) explored the engagement of underserved populations in a cohort of patients with inflammatory bowel disease. Their study used a community-based approach to inform a quality improvement programme, using workshops to engage people from various communities (including Roma, Afro-Caribbean, BAME) in South Yorkshire. The paper highlighted that several barriers to successful engagement existed (including language accessibility, staff attitudes and awareness, ease of access, and use of safe spaces), all of which contribute to low rates of engagement. Whilst Sheldon et al (2024) concentrated on a study population of inflammatory bowel disease patients, their findings appear representative of most service user cohorts. The paper proposes that the challenges identified (if overcome) can act as levers to improve the co-producing of health services, and therefore engaging with people from a range of communities is imperative if effective solutions are to be established. However, the cultural complexities of South Yorkshire may detract from the generalisability of their data.

Sheldon et al (2024) highlight the significant lack of representation of underserved populations and diverse groups in the evidence base, and this is supported by Sedano et al (2022) and Pathiyil et al (2023). Both siting a lack of adequate patient advocacy and social support, as well as mental health stigma as obstacles to effective patient engagement. They also explore the impact of cultural differences and power inequalities, both between staff and patients, but also between the patients themselves. Sedano et al (2022) highlight that overcoming these challenges is critical to the effective uptake and facilitation of meaningful service user engagement.

## 2.5 Socioeconomic factors

Tandon et al (2023) explore socioeconomic causes of poor engagement and highlight how resources and access to facilities are likely to affect the level of engagement received. However, the research by Tandon et al (2023) and Sedano et al (2022) concentrate on chronic disease patient cohorts, and as such the generalisability of their work beyond these cohorts is questionable. Furthermore, when analysing engagement levels consideration needs to be given to the cost of transport when attending in person engagement events, or the cost of acquiring equipment enabling people to join virtual meetings. Low-income communities or individuals with chronic disease (who may as a result have reduced income) are less likely to have the means to attend these forums (Afzali & Cross, 2016; Damas et al, 2022), and as a result are less likely to have their voice heard. Moreover, low-income communities typically have lower health status (Damas et al, 2022) and as such they should be the priority groups that engagement forums are targeting, more so, according to Egan et al (2024), given these are the communities most likely to require health intervention.

## 2.6 Chronic disease burden

Low uptake of engagement opportunities according to Egan et al (2024) is not only a result of factors such as socioeconomic status, but also largely influenced by other social determinants such as the context in which a person is born, raised and lives, as well as their occupation and access to health resources. Similar papers (Gautam et al, 2023; Akseer et al, 2020) describe the chronic disease burden and how disadvantaged adolescents are particularly prone to greater levels of chronic disease as a result of poor diet, alcohol and tobacco use (termed modifiable lifestyle risk behaviours). Egan et al (2024) highlights that preventing adolescents partaking in such modifiable lifestyle risk behaviours is critical for safeguarding their health and as such reducing health inequalities in society. Alliott et al (2022) support these observations and discuss the need to overcome social, structural and economic barriers, to enable and facilitate participation in preventative interventions such as service user engagement forums.

## 2.7 Minority groups

Ryan et al (2017) explored what good healthcare looks like from the perspective of the seldom heard groups consisting of Irish travellers, illegal drug users, migrant workers, and young males. Through focus groups, including a control group consisting of educated elderly individuals, the study found that the views of the various seldom heard groups did not differ significantly when exploring what good health care needs to look like. However, the views of the groups differed considerably when asked about their personal expectations of health services, and these views typically related to personal past experiences, with the drug user group reporting particularly poor experiences and low expectations. Ryan et al (2017) discuss how perceived differences in what is regarded as an entitlement in health care largely alter how services are experienced. The paper concludes that whilst care is similarly prioritised across different patient groups, including those who are seldom heard, the bigger outstanding challenge of how to provide equitable access for marginalized groups remains. Ryan et al (2017) holds consistencies with Alliott et al (2022) in that both studies explore specific segments of a given population and have found similar outcomes. Both studies conclude that there is a significant need to overcome economical but particularly social barriers if marginalised groups are to have their say in what good healthcare should look like.

## 2.8 Digital solutions to engagement

Alliott et al (2022) along with Vogels et al (2022) explore the use of digital mechanisms to improve the engagement of school aged individuals in health service improvement. Their work found that forums and interventions delivered via media platforms (mostly computers and smartphones) capitalised on adolescent frequent use of this technology. This is supported by data from the Australian Bureau of Statistics (2016-17) looking at adolescent utilisation of portable technology and willingness to communicate with surveys and other similar requests via technology-based medium. The work of Alliott et al (2022) and Vogels et al (2022), whilst focused on young adults and school-aged individuals, is generally representative of a large proportion of the population, particularly with the vastly increasing utilisation of mobile technology across all age spectrums, including primary school children and the elderly. Furthermore, with the elderly being another cohort of the population with a disproportionate demand on health services (similar to those with chronic disease), it is critical that service providers break down barriers to successful and meaningful engagement on service improvement for these groups. Importantly, according to the findings of Alliott et al (2022) and Vogels et al (2022) this may be possible through technology.

## 2.9 Barriers and facilitators

Hung et al (2023) produced an exploratory scoping paper into the barriers and facilitators of involving patients and public in the building of learning health systems. The paper highlights the essential need for active engagement and meaningful involvement of patients and communities, and stresses this level of participation ensures that the system design addresses the needs of those that it will ultimately serve. Hung et al (2023) highlight that previous literature has largely focused on data management whereas more attention needs to be paid to public and patient engagement. Furthermore, the term value-based healthcare is becoming increasingly prioritised in the current healthcare climate, yet it wasn’t as far back as 2019 when Menear et al (2019) linked its potential benefits to greater service user engagement. Both Hung et al (2023) and Menear et al (2019) use scoping methodologies to review the literature, and whilst the earlier paper by Menear et al (2019) focuses more on the critical individual components of a successful learning health system, Hung et al (2023) looks more toward the specific impact of service user involvement. However, both conclude that successful engagement is key, with both papers citing ‘core values’ as major facilitators to this type of work.

## 2.10 The power balance and professional protectionism

The literature reviewed thus far has largely focused on service user involvement in health service development and how enablers and barriers to a successful engagement process relate to the service user. However, it is important to consider that NHS staff can also be enablers and barriers to successful service user engagement. Meetoo (2013) wrote an early paper on public engagement in health service development and stressed the critical Government position. Meetoo (2013) describes public engagement as implying two-way exchanges between the public and those who have knowledge of, or power over, the particular issue. This is interesting, as the more recent literature including Finn et al (2018) and Sheldon et al (2024) imply that the public or the patient has as much if not more power (and equal appropriate knowledge) than those who manage and lead the service. Furthermore, in line with Crawford et al (2002) given the public funding the NHS they should be central to its development.

Meetoo (2013) highlights several early papers that clearly evidence a lack of public participation in health service development. The work of Ashton and Seymour (1988) significantly pre-dates Meetoo (2013) but argues similarly the lack of public involvement. Ashton and Seymour (1998) discuss professional protectionism, and how the general public do not understand the complexities of the health system enough to be involved in its development. They discuss how professional protectionism works against sharing power and demystifying knowledge within the NHS, and how there is a marked unwillingness of staff to really engage in the process. This is particularly challenging to accept given Government processes as early as the 1990 GP Contract (Department of Health, 1989) placed an onus on practices to evaluate services at user level. Moreover, eight years later under a new Government administration a new NHS Charter was promised (Department of Health, 1997), where the NHS would measure itself against the aspirations and experiences of its users.

Meetoo (2013) identifies the nursing role as ideally placed to support the public in influencing strategic and policy decisions, particularly given nursing is viewed as an empowering approach to patient care. However, whilst nursing may act as powerful advocates of the patient voice, Anderson et al (2006) describes how this often leads to conflict when the patient utilises their own voice. Tritter et al (2003) hypothesise how nurses may perceive patient participation in service development activities as a threat to their own professional status, and as a result may consciously avoid it. Furthermore, Wilson et al (2006) builds on the work of Tritter et al (2003) and suggests nurses may have a fear of losing the patient advocate role if patients are empowered to be their own advocate.

## 2.11 The model of co-production

More recent literature has discussed the theory of co-production as a model to deliver effective partnership engagement in health service change. Ezaydi et al (2023) explores the ‘Ladder of Co-production’ (Figure 2) and how the different rungs on the ladder represent different levels of service user decision making power, with the upper rungs offering more in the way of equal power between all involved. This is not a new theory as the work of Arnstein (1969) represents in his work ‘titled a ladder of citizen participation’. Arnstein (1969) found that the lower rungs on the ladder represented passive service user involvement or even levels of coercion, which directly correlated with a lack of success in the related projects. Both papers clearly state that successful engagement requires equal partnership at the highest level between service users and providers.

**Figure 2. Ladder of co-production (Ezaydi et al., 2023).**

Ezaydi et al (2023) heavily linked their work with the National Collaborating Centre for Mental Health (2019) in their paper Working well together: Evidence and tools to enable co-production in Mental Health. This paper identified six core principles of co-production (Celebrate involvement, Adaptable, Resources, Influence of power, Needs-led, and Growth) as well as describing three levels of involvement (Doing to, Doing for, and Doing with), with the report encouraging a shift toward 'Doing with'. Both Ezaydi et al (2023) and the National Collaborating Centre for Mental Health (2019) identified the barriers to this necessary change consisting of limited staff engagement, lack of resources, and confusion about expected contributions. The paper by Ezaydi et al (2023) set out to explore service level outcomes in Mental Health following a change using true co-production. They conducted a thorough Systematic Literature Review which returned 10,901 records. However, when applying strict co-production criteria, the search was reduced to only six studies. Whilst the search return alone highlighted an extremely low utilisation of true co-production, it also demonstrated that co-production-facilitated changes were associated with more positive and substantial service level improvements.

### 2.12Summary

The literature in this subject matter is extensive and explores barriers and enablers to service user involvement in depth. To a lesser extent it also provides good evidence and insight into service provider perspectives on service user involvement. Early work highlights the proposed psychological barriers of providers (nurses) as limitations to the success of service user involvement, whilst more recent work frames the positive impact that service user involvement can have if full co-production is adopted. The literature explores differences for different populations including age, socioeconomic, and disease status, and highlights the position of Government policy on the topic. The following chapter will focus on appropriate research design and will draw on some of the literature already reviewed to support the chosen data collection methodology used within this study.

## 3 Research Methodology

### 3.1 Introduction and Purpose

The purpose of this section is to present the chosen methodology and demonstrate how it is appropriate to answer the research question. It will take the reader through the main elements of the questionnaire design and will relate it back to the research topic. The chapter is structured using the research onion model (Saunders et al, 2023) as seen in Figure 3. It adopts an interpretivist philosophy using a deductive questionnaire design, which contains both qualitative and quantitative data capture across a cross-sectional sample of NHS employees.

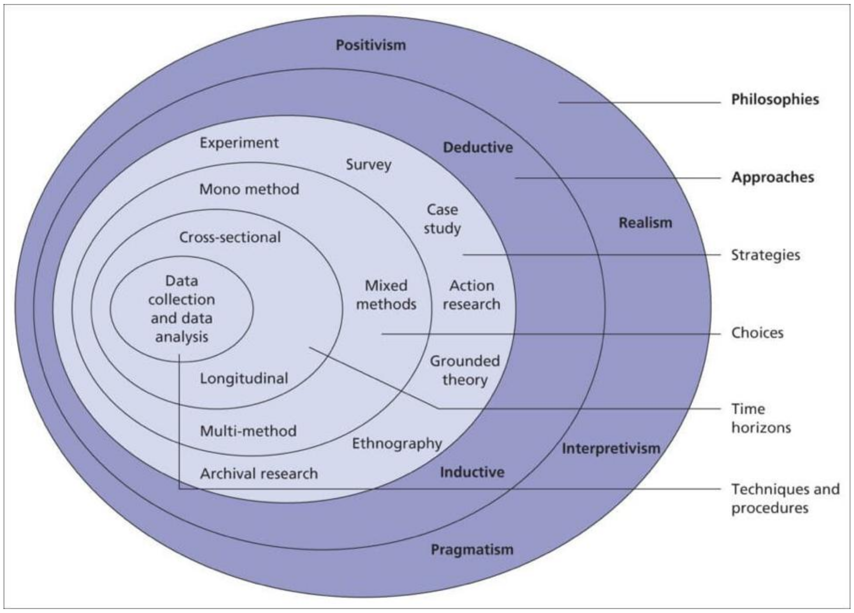


Figure 3. The Research Onion (Saunders et al., 2023)

## 3.2 Literature Review

Many studies were reviewed over the course of this work, both for their data and for their methodological approach. The main studies evident from the literature search used Interviews, Questionnaires, Focus Groups, or Systematic Literature Reviews. Some of the primary studies used a combination of these approaches. Lloyd et al (2024) set out to evaluate outcomes from public involvement in health service design, with a focus on barriers and enablers. They used semi-structured interviews conducted via a virtual platform and whilst potentially more accessible Lloyd et al (2024) stated this approach to data gathering was time consuming, with virtual platforms having psychological barriers to open and honest communication.

Finn et al (2018) used questionnaires to explore patient preferences for involvement in health service development. They contacted 229 patients with a return rate of 70%, however, whilst this is an exceptionally good return, the single largest limitation of a questionnaire design is the unpredictable rate of return, which can influence the validity and reliability of the findings.

Sheldon et al (2024) used enquiry-based focus groups to evaluate the involvement of underserved populations in health service improvement. The work identified several barriers that then became levers for co-producing service change. However, Sheldon et al (2024) had methodological limitations, including dominant personalities overshadowing less confident speakers, as well as a degree of conformity within their individual groups which potentially skewed their data. Additionally, focus groups tend to have limited sample size and thus limited representation, but this is often countered by the richness of the data gathered.

Ezaydi et al (2023) performed a Systematic Literature Review on service user involvement in mental health service change, with particular interest in outcomes of changes that were patient directed. Ezaydi et al (2023) used specific search criteria which returned over 10,000 studies. They then re-assessed the studies to a strict co-production criterion of which only six aligned. A concluding limitation of the work was that strict literature review criteria can extremely limit the return, however the individual return will be more relevant.

## 3.3 Questionnaire preference

A questionnaire methodology was determined the most effective study design in this case mainly due to the time-limited nature of the work. The questionnaire was designed and distributed through Microsoft Forms and can be seen in Appendix A It includes a combination of demographical questions as well as open and closed questions, some of which required a Likert Scale response.

## 3.4 Sample selection and questionnaire distribution.

Participant selection criteria were wide and consisted of the following:

- NHS Staff
- Position of leadership or leadership duties with their role
- Experience of service development / service change / service improvement

NHS staff were selected as the study sample target group given they were in plentiful supply and easily accessible by email. It was also considered important to grasp the perspective of service providers given the majority of papers on this subject matter have been service user centred. Questionnaires were sent to selected individuals who met the above criteria by way of an invite via email. The email contained a link to the Microsoft Form Questionnaire, as well as a Consent form (Appendix B) and Participant Information Sheet (Appendix C). Invites were sent out on the 1st August 2025 and participants had until the 31st August 2025 to complete the questionnaire.

### 3.5 Confidentiality and Data Protection

Confidentiality and Data Protection were adhered to as per the Data Protection Act 2018 and the UK General Data Protection Regulation (UK GDPR). All Microsoft Forms responses were stored on a password protected encrypted laptop, within a secure One Drive folder. Furthermore, the questionnaire purposely did not ask for any identifiable details and as such the data was completely anonymous from start to finish. The limitation of this was that participant was unable to withdraw their data at a later time as their data was not linked to any identifiable tracker.

### 3.6 Ethical Considerations and approval

This research is focused on service user perspectives and as such did not require NHS research ethics committee (REC) approval. However, despite this not being patient-orientated research, it was considered by the author that certain ethical issues may still arise. This research is focused on service provider perspectives of patient and public involvement in health service development and as such it might highlight negative attitudes of staff toward patients in this context. Certain questions might also place the participant in a perceived uncomfortable position. Furthermore, given the questionnaire used NHS staff work email addresses, and the NHS carries a caring and empowering persona, it may encourage staff to respond in a more positive light than they would if responding from a personal email address, potentially skewing the results.

The Health Research Authority webpage confirmed that the study was considered research (Appendix D), but that it did not require NHS REC review (Appendix E). The Swansea University research ethics approval was also awarded (Appendix F).

### 3.7 Summary

The literature revealed a multitude of options that would serve as an appropriate methodology to conduct this research and work toward answering the research question. The papers that the author explored adopted individual approaches most suited to answer their specific question and used varying study designs to achieve this. Given the short timescale for this research project a questionnaire methodology was adopted and designed to explore service user involvement through a service provider lens, and the following chapter will describe the findings of the questionnaire.

## 4 Findings

### 4.1 Introduction

The purpose of this chapter is to provide a review of the findings from the study. It will explore each element of the questionnaire and where appropriate use tables and charts to clearly highlight the data. The results will then be analysed with reference to the existing literature and evidence base in the following chapter.

### 4.2 Return rate

The study sent out 105 questionnaires and received 70 completed responses, providing a return rate of 66%. All returns provided consent and were fully anonymous.

## 4.3 Demographics

Figure 4 below demonstrates a varied age range within the sample, with the largest proportions of responses existing in the middle three categories (31-40 years, 41-50 years, and 51-60 years). Very few responses were provided by participants in the extreme categories including 21-30 years or 60 years and above, possibly demonstrating the typical age demographic of NHS staff.

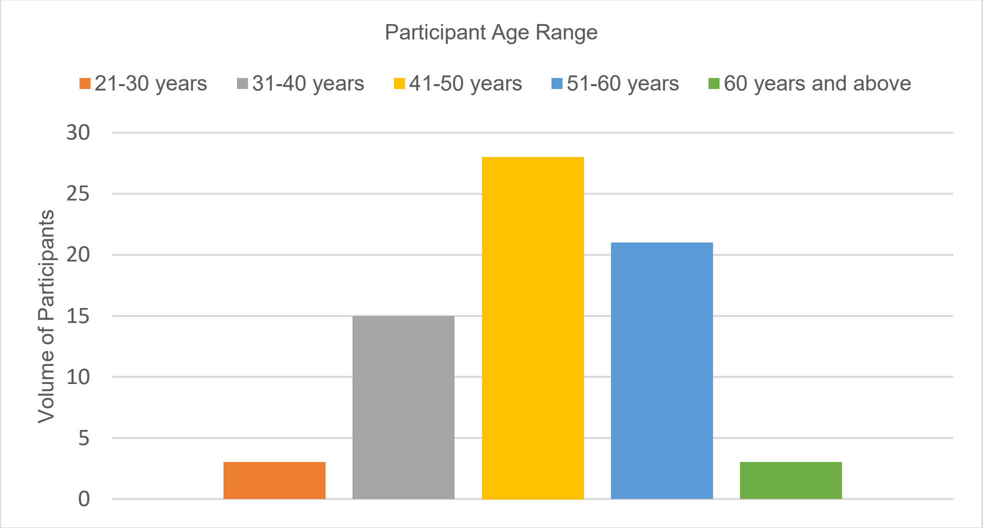


**Figure 4. Participant Age Range**

Figure 5 below details the gender spread within the sample, with predominantly ‘Female’ participants, followed by ‘Male’, and very few identifying in the remaining options. Whilst this is representative of typical NHS Wales employment patterns, it might also just be coincidental within the study. Furthermore, gender was not a consideration when selecting participants and as a result it might simply be a symptom of potentially asking more female than males to complete the questionnaire, therefore being proportionately representative of the original sample.

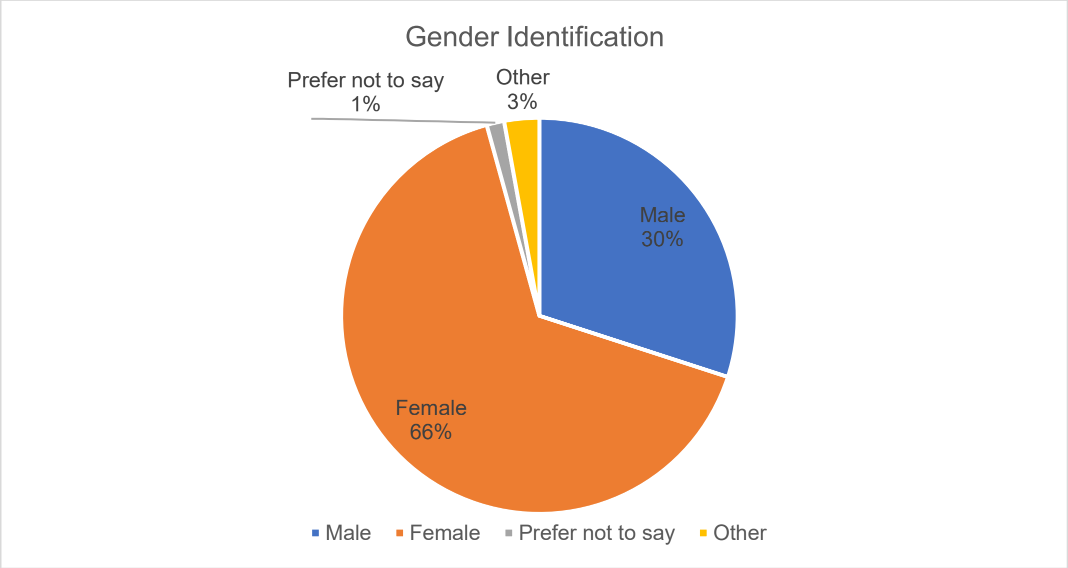


**Figure 5. Gender Identification**

## 4.4 Experience and Autonomy

Figure 7 below demonstrates that the majority of participants (47%) do not feel they have autonomy to involve the public in service design, with 14% responding ‘Don’t know’. Figure 6 shows that the vast majority of responses (68%) were from participants with 0-5 years of experience in their current post, possibly demonstrating an element of inexperience. The levels of inexperience correlate directly with the low levels of autonomy, however it recognised that the paper has derived levels of experience relating to current post only, and that participants may have significant experience in previous roles.

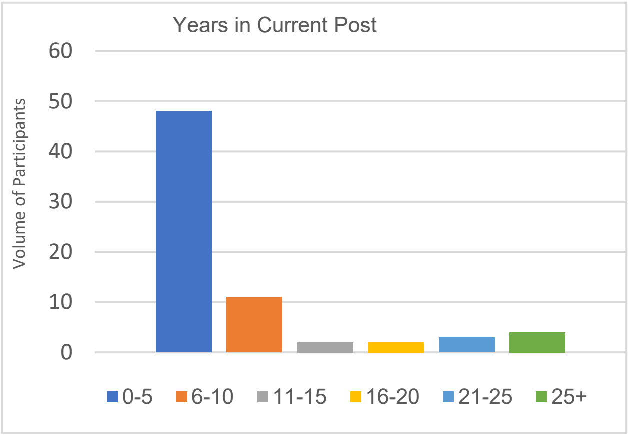


Figure 6. Years in current role

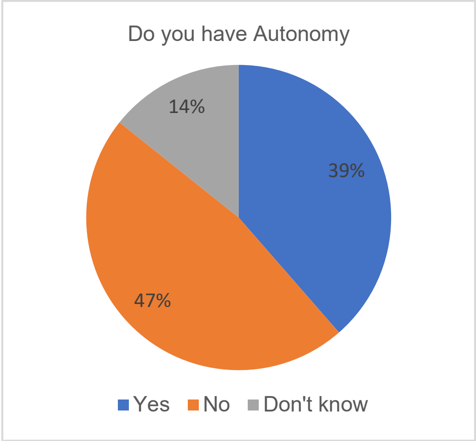


Figure 7. Perceived autonomy in role

## 4.5 Using the public in health service design

61 out of 70 (87%) of participants answered Yes (Figure 8) demonstrating good support for service user engagement. However, when asked to what extent did they involve the public in health service design (Figure 9) only three participants answered 'Most of the time' and ten 'At every opportunity'. These results suggest a gap between support 'in principle' and support 'in action' amongst the sample, confirming much of what has been found in previous studies and suggesting that significant barriers exist to the practical application of engagement with service users.

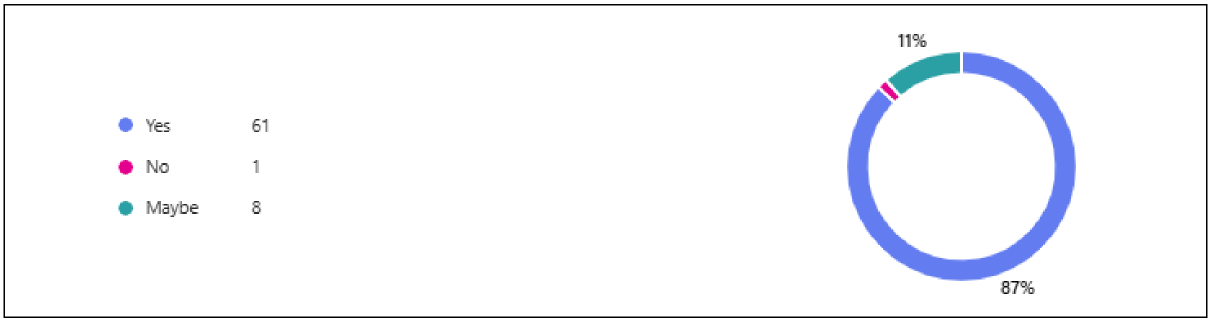


Figure 8. Agreeing with the use of the public in health service design

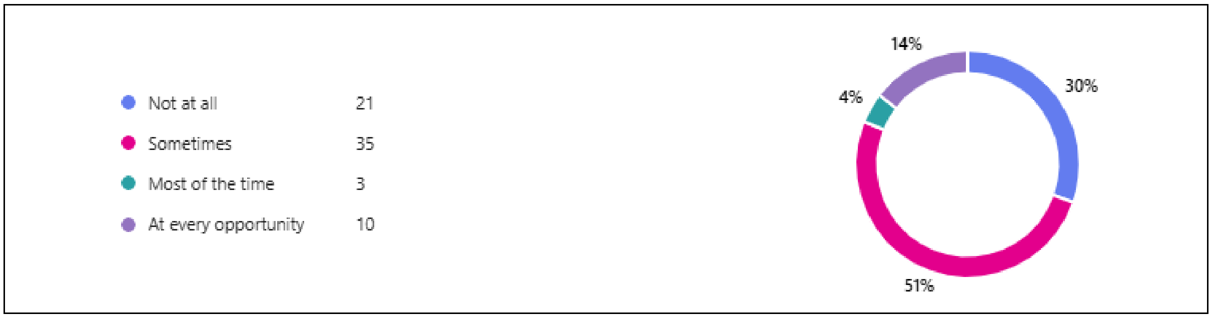


Figure 9. Involving the public in health service design

## 4.6 When to involve the public in health service design

Participants were asked ‘At what stage during a service design would they schedule public involvement’, with the option to provide more than one choice if appropriate. Figure 10 demonstrates participant awareness of the principles of good engagement and co-production, with most responses advising toward the beginning or at the start of a project. Critically, only a small proportion advise toward the end.

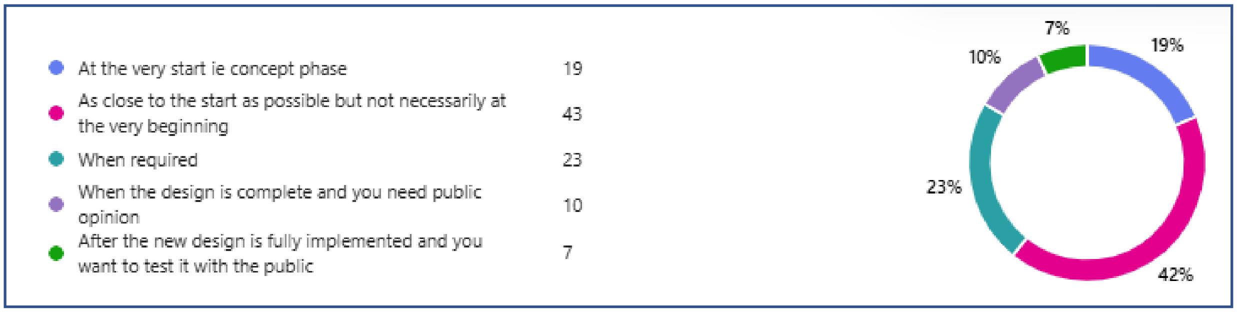


Figure 10. When to involve the public in health service engagement

## 4.7 Involving the public has had a positive impact on service designs.

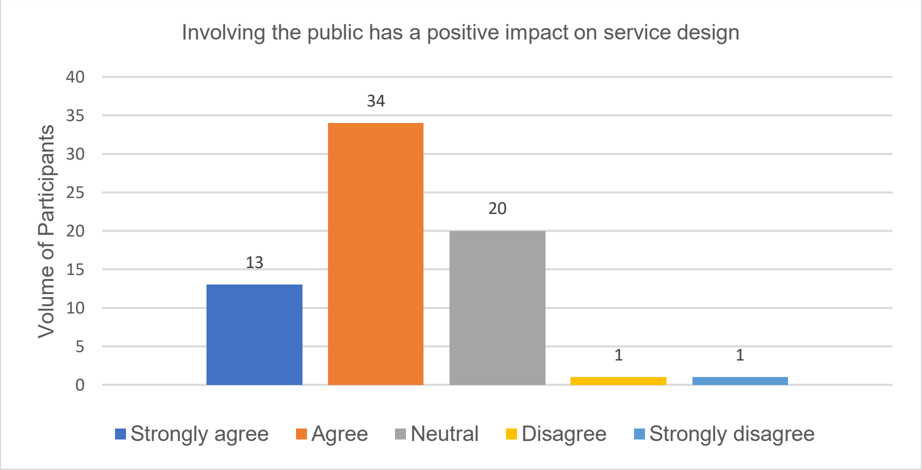
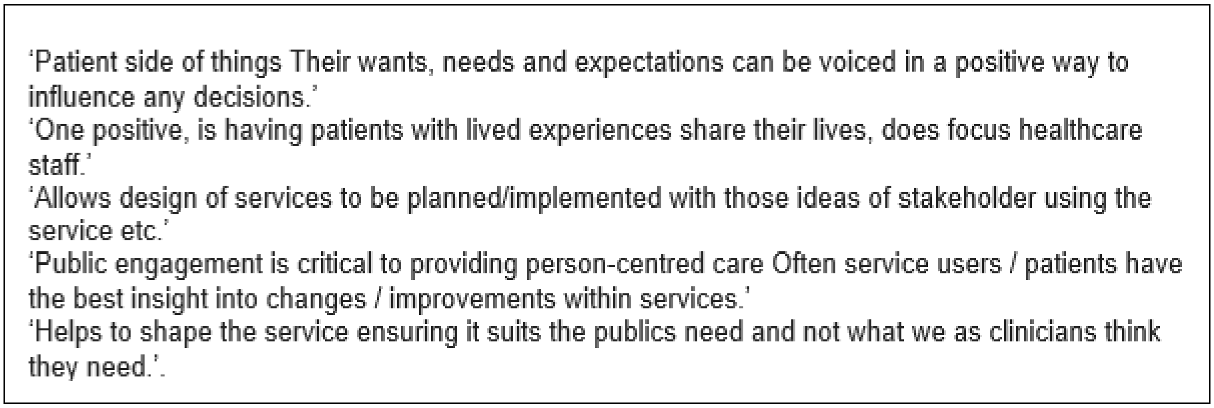


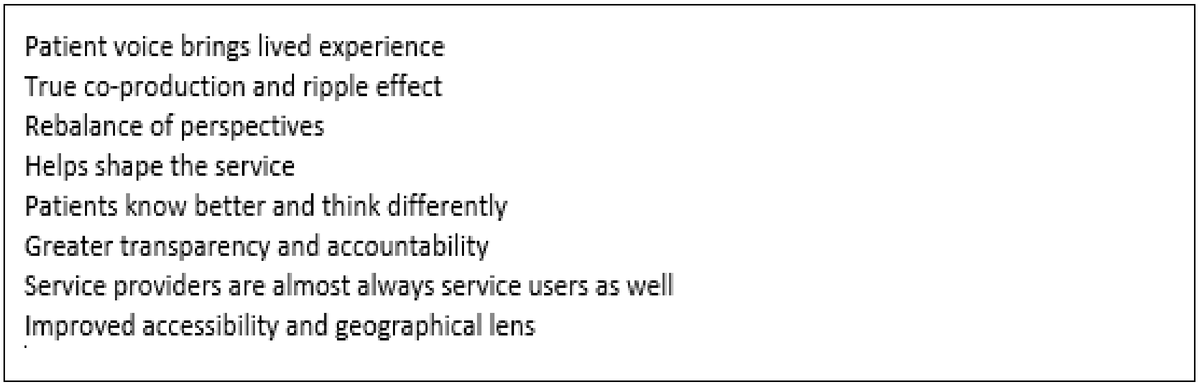
Figure 11. Positive impact of service user engagement

Figure 11 above demonstrates that the sample clearly favours service user engagement having positive impact, with only two participants ‘Disagreeing’ or ‘Strongly disagreeing’. Table 1 captures some of the key responses supporting the data in Figure 11, with Table 2 grouping the wider responses (provided by 49 participants) into common themes, which are all largely referenced in previous literature.



‘Patient side of things Their wants, needs and expectations can be voiced in a positive way to influence any decisions.’
‘One positive, is having patients with lived experiences share their lives, does focus healthcare staff.’
‘Allows design of services to be planned/implemented with those ideas of stakeholder using the service etc.’
‘Public engagement is critical to providing person-centred care Often service users / patients have the best insight into changes / improvements within services.’
‘Helps to shape the service ensuring it suits the publics need and not what we as clinicians think they need.’.

Table 1. Key responses to support opinion around positive impact of public engagement



Patient voice brings lived experience
True co-production and ripple effect
Rebalance of perspectives
Helps shape the service
Patients know better and think differently
Greater transparency and accountability
Service providers are almost always service users as well
Improved accessibility and geographical lens

**Table 2. Thematic representation of responses to support opinion around positive impact of public engagement**

## 4.8 Involving the public has had a negative impact on your service design.

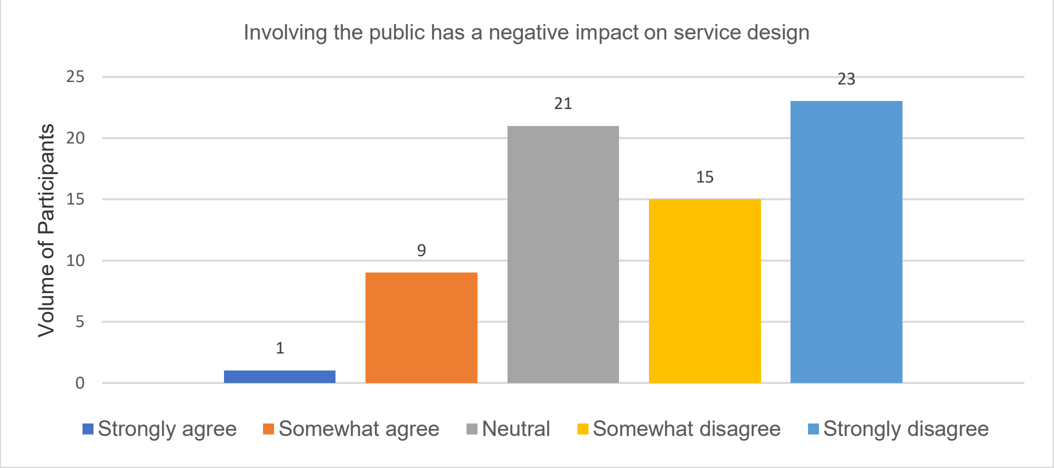
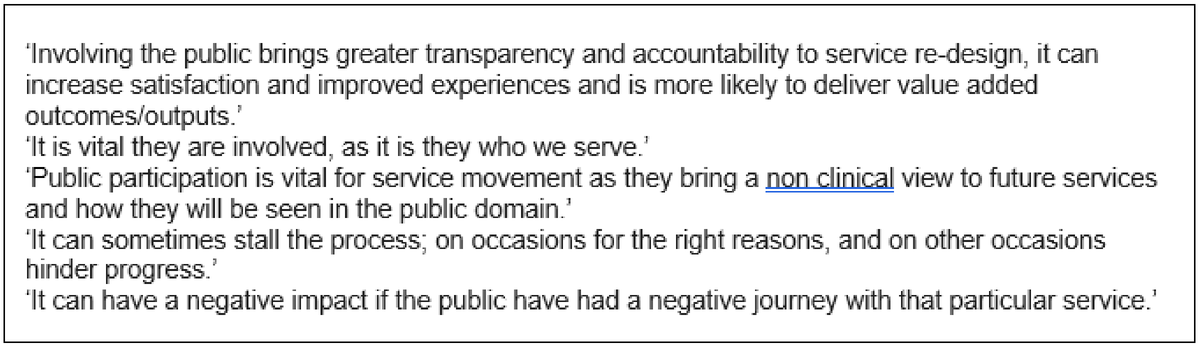


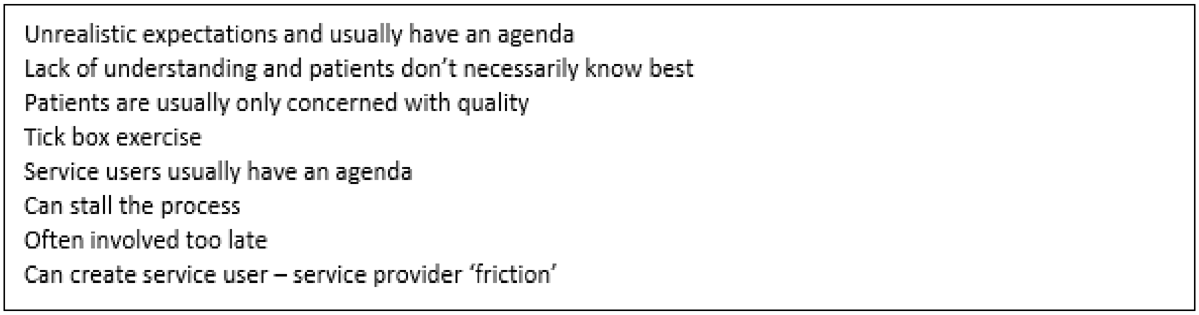
**Figure 12. Negative impact of service user engagement**

Figure 12 demonstrates a near opposite to Figure 11 in that only a minority support that public engagement has a negative impact. However, both Figure 11 and Figure 12 highlight a large proportion of responses in the neutral category. Whilst this acts as a test – retest measure, it also possibly demonstrates a lack of experience in the sample, correlating with Figure 6. Table 3 below documents a number of key responses supporting Figure 12, with the main themes (of the wider 41 responses) listed in Table 4. These appear to be more focused around the challenges to engagement, and it is assumed that this represents a misinterpretation of the question and a failure point within the study design.



'Involving the public brings greater transparency and accountability to service re-design, it can increase satisfaction and improved experiences and is more likely to deliver value added outcomes/outputs.'
'It is vital they are involved, as it is they who we serve.'
'Public participation is vital for service movement as they bring a non clinical view to future services and how they will be seen in the public domain.'
'It can sometimes stall the process; on occasions for the right reasons, and on other occasions hinder progress.'
'It can have a negative impact if the public have had a negative journey with that particular service.'

**Table 3. Key responses to support opinion around negative impact of public engagement**



Unrealistic expectations and usually have an agenda
Lack of understanding and patients don't necessarily know best
Patients are usually only concerned with quality
Tick box exercise
Service users usually have an agenda
Can stall the process
Often involved too late
Can create service user – service provider 'friction'

**Table 4. Thematic representation of responses to support opinion around negative impact of public engagement**

## 4.9 Deciding which service users for health service design projects

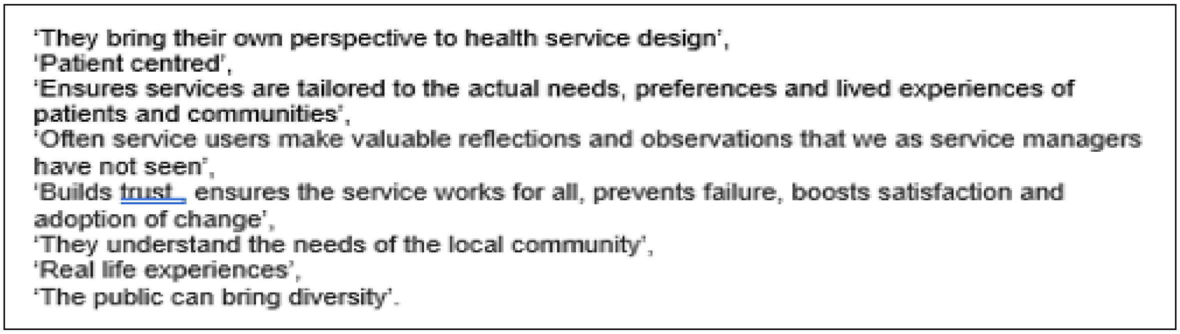
Table 5 below provides a list of the common responses with the data demonstrating a level of participant insight but also to some extent uncertainty, which could be interpreted as a lack of experience. Several themes also highlight delegation to other people, potentially suggesting low levels of autonomy or adequate experience to know that there are other departments available to assist the process.

'Focus Groups'
'Comms teams'
'Local groups'
'Via the appropriate service manager who is able to collaborate and make decisions.'
'Whoever can attend'
'Via the head of patient engagement'
'Usually people with lived experience'
'Stakeholder mapping'
'Unsure due to volume of patients that would want an input'
'Depends upon the project'

**Table 5. Which public to include in health service design projects**

## 4.10The benefits of utilising the public in health service design

68 people responded to the question providing a wide range of perspectives with Table 7 presenting a thematic representation and Table 6 highlighting some of the rich content. The responses provided data in keeping with the literature on good engagement principles, but also added elements such as 'diversity', 'builds trust' and 'patients can alter political perspectives', demonstrating good insight.



'They bring their own perspective to health service design',
'Patient centred',
'Ensures services are tailored to the actual needs, preferences and lived experiences of patients and communities',
'Often service users make valuable reflections and observations that we as service managers have not seen',
'Builds trust, ensures the service works for all, prevents failure, boosts satisfaction and adoption of change',
'They understand the needs of the local community',
'Real life experiences',
'The public can bring diversity'.

**Table 6. Benefits of engaging with the public on health service design**

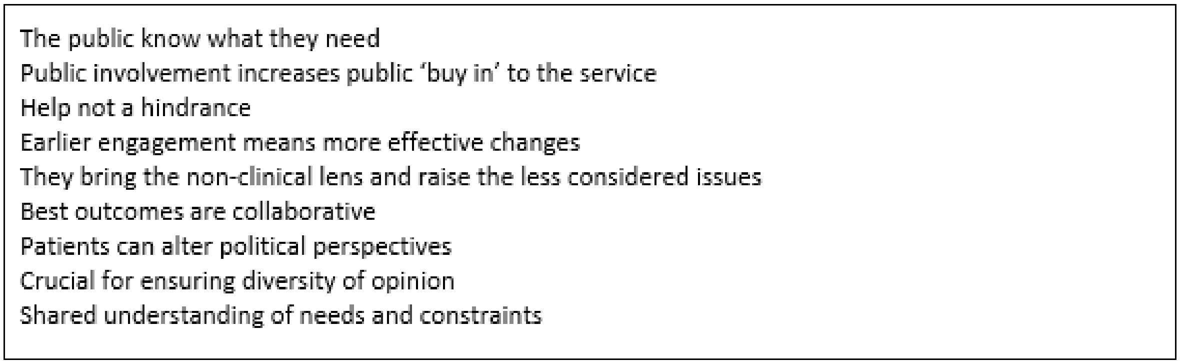

The public know what they need
Public involvement increases public 'buy in' to the service
Help not a hindrance
Earlier engagement means more effective changes
They bring the non-clinical lens and raise the less considered issues
Best outcomes are collaborative
Patients can alter political perspectives
Crucial for ensuring diversity of opinion
Shared understanding of needs and constraints

**Table 7. Thematic representation of responses to supporting the benefits of public engagement**

## 4.11 The challenges of utilising the public in health service design

19% of participants (n=13) answered N/A and 4% (n=3) responded with 'None', suggesting that 23% of the sample do not recognise any challenges to service user engagement. However, given the literature has highlighted a plethora of challenges this data is more likely suggestive of a lack of experience than lack of challenges. The majority of responses however were rich in content with some key challenges listed in Table 8 below and a thematic representation presented in Table 9. Aligned to the data in Tables 6 and 7, Tables 8 and 9 suggest good sample insight around the complexities of successful engagement. In hindsight the study would have benefited from follow up interviews or focus groups to gather deeper insight into the challenges with the aim of providing a more robust solution.

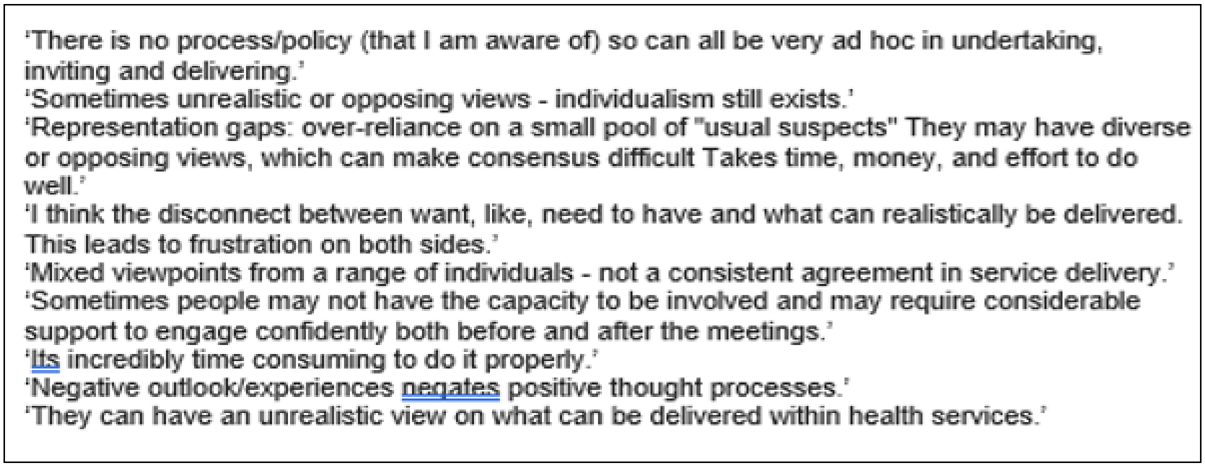

'There is no process/policy (that I am aware of) so can all be very ad hoc in undertaking, inviting and delivering.'
'Sometimes unrealistic or opposing views - individualism still exists.'
'Representation gaps: over-reliance on a small pool of "usual suspects" They may have diverse or opposing views, which can make consensus difficult Takes time, money, and effort to do well.'
'I think the disconnect between want, like, need to have and what can realistically be delivered. This leads to frustration on both sides.'
'Mixed viewpoints from a range of individuals - not a consistent agreement in service delivery.'
'Sometimes people may not have the capacity to be involved and may require considerable support to engage confidently both before and after the meetings.'
'Its incredibly time consuming to do it properly.'
'Negative outlook/experiences negates positive thought processes.'
'They can have an unrealistic view on what can be delivered within health services.'

**Table 8. Challenges of engaging with the public on health service design**

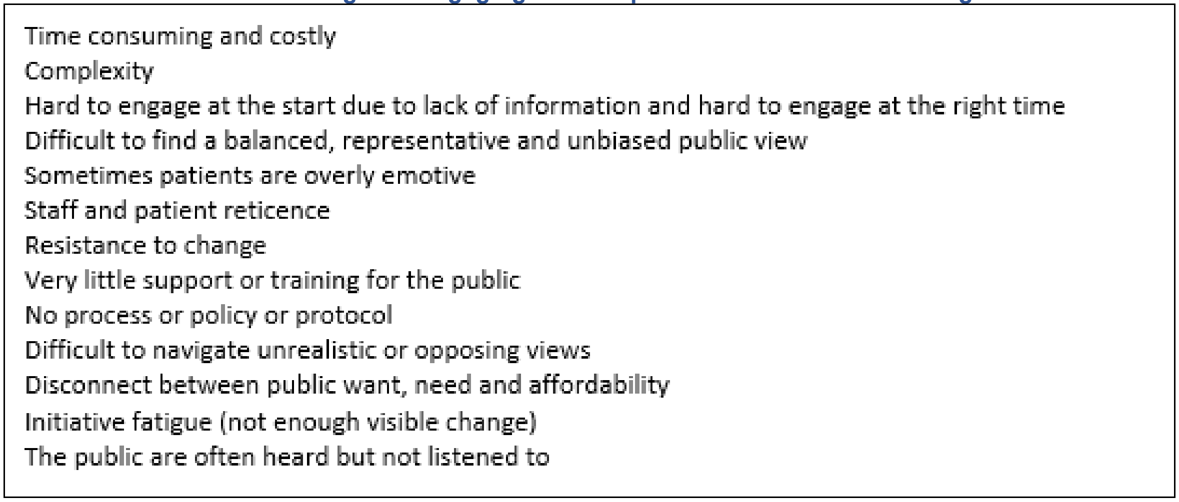

Time consuming and costly
Complexity
Hard to engage at the start due to lack of information and hard to engage at the right time
Difficult to find a balanced, representative and unbiased public view
Sometimes patients are overly emotive
Staff and patient reticence
Resistance to change
Very little support or training for the public
No process or policy or protocol
Difficult to navigate unrealistic or opposing views
Disconnect between public want, need and affordability
Initiative fatigue (not enough visible change)
The public are often heard but not listened to

**Table 9. Thematic representation of responses to supporting the challenges of public engagement**

## 4.12Recommending the use of the public in health service design

98% of participants (n=69) responded to this question and the responses demonstrated a wide spread of opinion across all options as can be seen in Figure 13, with only 10% (n=7) volunteering to having 'Never' recommended the public. This data demonstrates that only 10% are potentially against the notion of using the public in service change projects, however it could also mean that the same 10% are those in less of a leadership or role.

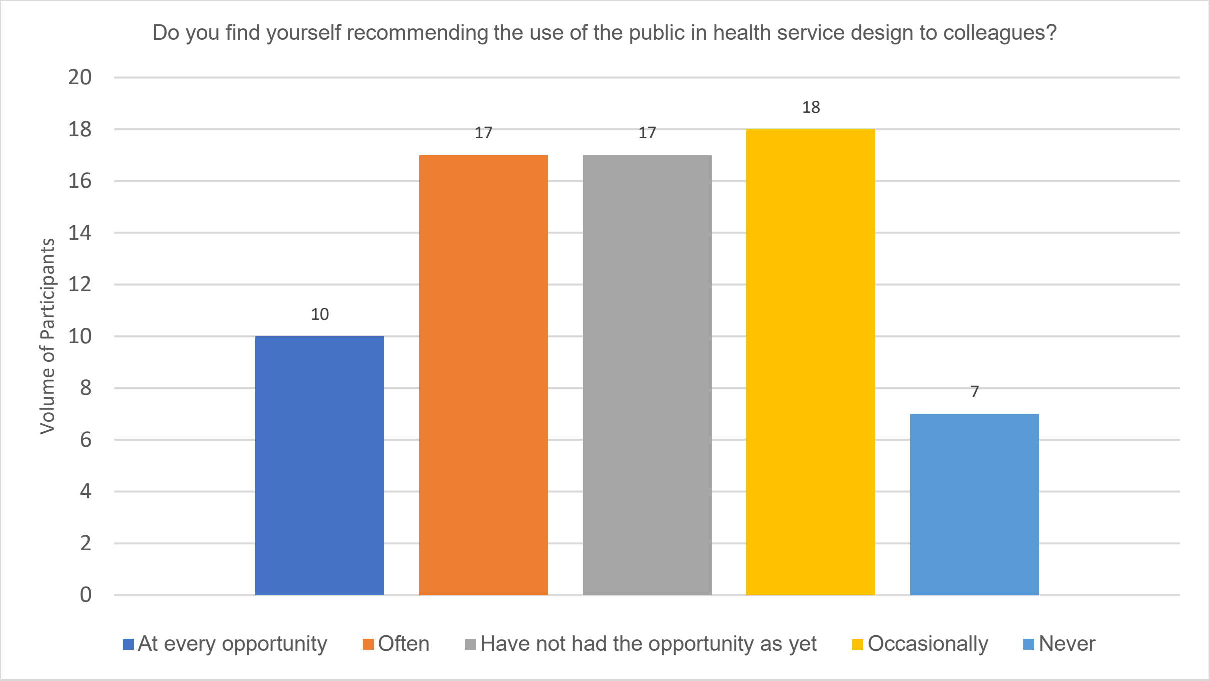


**Figure 13. Recommending public engagement in health service design**

## 4.13Reasons for not using the public in health service design

Participants were asked to rate their response on a Likert scale with the questions purposely phrased in a negative manner. Figure 14 shows the majority of responses as either 'Strongly disagree' or 'Disagree'. This was particularly the case for 'No added value' and 'Too little benefit'. This is in contract to 'I don't know who and / or how to contact the public for service design purposes', and 'We don't have the resource to support it', with results sitting more in the 'Agree' category. This suggests that whilst the participants support service user engagement the organisations do not necessarily prioritise it.

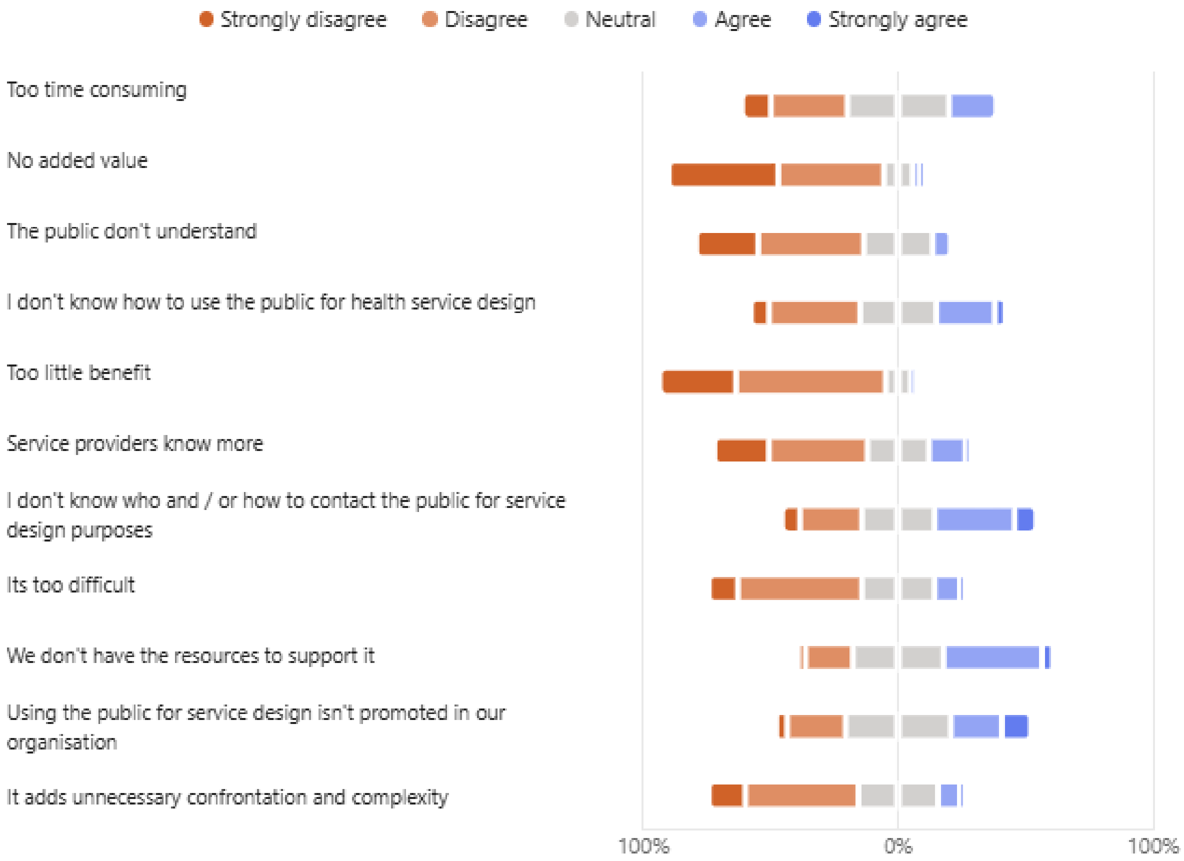


Figure 14. Reasons not to use the public in health service design

## 4.14 Summary

This chapter has presented the key findings of the study and has demonstrated a range of perspectives. With a representative NHS staffing sample, the vast majority of participants agreed with service user engagement, however with a significant number of barriers identified. These included low autonomy and inexperience which manifests in significant 'in principle' support, but little actual uptake in practice. Key themes identified include; Participant lack of self-knowledge; Lack of organisational process; Patient lack of service level understanding; And, unrealistic patient expectations. The common themes along with other identified barriers and enablers will be discussed further in the following chapter.

# 5 Discussion

## 5.1 Introduction.

This chapter will explore the study findings and link them back to the existing literature, drawing similarities and contrasts between previous data and that found within this study. It will draw on the motivations of the author and the benefits of researching this subject matter with the goal of answering the research question.

## 5.2 Findings in relation to Government direction.

The paper highlights the clear government drive for increased service user engagement in the design and improvement of health services. However, both the literature and the study findings clearly detail that service user engagement is not where the Government expects it to be. From a service provider perspective, the main reasons for this (confirmed by Finn et al, 2018; Damas et al, 2022; Egan et al, 2024) include a lack knowledge about specifically who to engage with, how engagement is supported within the organisation, as well as a perceived lack of self-autonomy. Other common reasons found in the study include inadequate service user knowledge, unrealistic service user expectations, and high levels of service user negativity and resistance to change.

## 5.3 Service user engagement and challenges

The findings demonstrated a clear preference for service user engagement with 68% responding with either 'Strongly agree' or 'Agree' when asked if involving the public had a positive impact. Conversely, the low volume of responses not supporting the positive impact further supported this outcome. This was re-tested by negatively framing the question, also demonstrating similar results. However, the not insignificant volume of 'Neutral' responses potentially demonstrates either a lack of knowledge or experience of how the public can (positively or negatively) impact service change. Furthermore, the limited experience reported within the sample also supports the lack of service provider uptake in practice, as demonstrated in the findings and supported by Hung et al (2023) and Martin et al (2018).

To gain deeper understanding the participants were asked to identify any challenges to engaging with public, with individuals frequently citing unrealistic expectations, conflicting views, disconnect between need and want, lack of organisational resource, amongst others. However, question 18 highlighted challenges commonly cited in the literature and asked participants to rate on a Likert scale how much they agreed or disagreed with each. Interestingly, whilst a minority of the identified challenges were not raised by the participants earlier in questionnaire (no added value, lack of process structure, lack of organisational support), all of the others were, demonstrating a level of test-retest reliability and good engagement insight in the sample. Additionally, with 23% not recognising any challenges it has to be questioned why the uptake in practice is still low.

## 5.4 Theory and reality gap

87% of responses in Question 7 stated they agreed with the use of the public to help inform health service change, with most stating they would choose to involve them early in the process. However, despite this, only a small proportion of participants advised they regularly use the public in this way. The results are somewhat conflicting in that whilst the vast majority favour the use of the public and highlight the positive impact, only a small proportion advise they use them 'At every opportunity' (14%) or 'Most of the time' (4%). This suggests 'support in principle' for service user engagement, however there must be barriers preventing wider uptake, creating a gap between 'theory' and 'reality'. Further complexity is added by Question 17, where 38% recommend public engagement ('Often' and 'At every opportunity') whereas 36% state 'Never' and 'Occasionally', despite earlier responses demonstrating clear support for the process. Question 10 however, clearly highlights an overwhelming majority in favour of service user engagement, further supported by the richness of the responses and thematic representation where participants listed many varied reasons for their positive outlook. The responses closely mirrored what was seen in the literature (Meetoo, 2013; Ezaydi et al., 2023) with notable examples being, 'True co-production', 'Lived experience input', 'Crucial to have stakeholder input', 'Better grasp of local community need', 'Provides a more patient-centred approach' and 'Rebalancing of perspective'. The paper considered that there might be a level of misinterpretation of Question 10, however, it was somewhat retested in Question 15, which also demonstrated a similar outlook and therefore providing a level of reliability confidence.

## 5.5 Selecting the service user

When the participants were asked 'how they decided who from the public to engage with the responses generally fell into three groupings; Regular engagers, Those most effected, and, The organisational process. The wide array of responses critically highlights the lack of knowledge, lack of recognised organisational process, and also possibly the low levels of experience within the sample. A good number of responses related to either selecting the service users most effected or selecting the regular (reliable) service users. Both opportunities have pros and cons and with careful planning and consideration the two can be merged into the same group. However, the third grouping (organisational process) is somewhat limiting. Most responses that referred to 'organisational process' referred to it in a restrictive sense and how there does not appear to be a documented policy or protocol to facilitate the service user engagement process. The fallback option (stated by several participants) was to refer the process to the patient engagement team (or similar), whose knowledge of specific service level engagement may also be insufficient. These results in particular demonstrate a challenge that is easily rectified (by developing a protocol) if a service is to increase its service user engagement levels.

## 5.6 Representation and generalisability

The chosen design and methodology were appropriate for this study, and this is partly confirmed by the questionnaire return rate of 66%, as well as the richness of the data within each return. The sample included a cross-sectional representation of NHS service provider opinion. However, the sample was targeted toward those in leadership roles and as such there is an argument (supported by Sheldon et al, 2024) to suggest that minority, lower socioeconomic status, and lower educational status groups may be under-represented in the sample. Recruiting participants from across NHS Wales and not localising to a single Health Board will have reduced any regional bias within Wales. However, given education levels and socioeconomic status in Wales is generally lower than England (Office for National Statistics, 2022), as well as fewer and smaller minority groups (Office for National Statistics, 2022), the data holds limited representation for the UK as a whole. It is important to highlight however that this paper was examining the service provider perspective and as such the age and gender spread of participants was representative of any given NHS organisation and as such (in this context) generalisable across the UK.

## 5.7 Leadership, autonomy and experience mismatch

The levels of autonomy demonstrated within the data were lower than anticipated, despite the sample being targeted toward those in leadership roles who are presumed to be more educated and economically stable. 47% stated they ‘did not’ feel they had autonomy to invite service users to engage and 14% stating ‘didn’t know’. This might be explained by 69% of participants spending five or less years in their current post, demonstrating a level of leadership and engagement ‘inexperience’ within the sample. The latter is also supported by a wide spread of responses (demonstrating a lack of uniformity) around the extent to which the participants engaged with service users, with the majority stating either ‘sometimes’ or ‘not at all’. However, when asked ‘at what stage of a service design would you schedule public involvement’, the majority answered ‘as close to the start as possible’, with significant volumes stating ‘when required’ and ‘at the very start’, demonstrating awareness of co-production (Ezaydi et al., 2023). Furthermore, this strongly correlates with 87% of responses ‘agreeing’ with service user engagement, however when exploring the ‘actual use of engagement’ the results are less convincing with only 14% stating ‘at every opportunity’ and 4% stating ‘most of the time’. This suggests a gap between theory and practice which is supported by the plethora of challenges identified within the responses and in the literature. Whilst this appears to be a negative finding, it is also significantly informative as we move toward establishing solutions to these recognised challenges.

## 5.8 Summary

The majority of the evidence base on this subject matter is about service user perspectives and service user related limitations, whereas this study has looked at the subject though the lens of the service provider. As a result, it has added to an existing but limited evidence base. However, none the less this is an important perspective to appreciate in order to better understand and overcome service provider related challenges to good engagement and co-production. The study has both supported and built on previous work but importantly it has allowed service providers to share personal perspectives on an important and necessary process which supports health service improvement. It is acknowledged by the author that some responses would have benefitted from further exploration, and that further work in this area should consider focus groups and interviews as opportunities to extrapolate more depth and detail as required. The author also acknowledges there was a degree of question repetition in the questionnaire design, particularly questions 10 and 15, as well as questions 12, 16, and 18. However, whilst this is somewhat inconvenient for the participant, it does provide a level of test – retest reliability. Finally, the study recognises the significant mismatch between ‘in principle’ support and that seen ‘in practice’, however what the findings also clearly demonstrate are the specific challenges, most of which can be rectified.

# 6 Conclusions, limitations and next Steps

The study set out to explore, through the lens of the service provider, the challenges and enablers to improve service user engagement in health service change. It has mostly answered the research question and fulfilled the objectives, providing additional data to add to the existing body of evidence, as well as highlighting several areas for improvement that will likely result in greater levels of service user engagement. These include the following: A clearly documented organisational process which is supported at all levels and informs the service change team how to engage and when. A clear (publicly visible) organisational narrative that invites, facilitates and appropriately resources service user interaction. Mandatory training (including use of appropriate technology) for all service providers on the importance and benefits of service user – service provider co-production. And finally, Organisational encouragement to facilitate a culture shift promoting a co-production. Whilst the four suggested improvements will move toward better levels of engagement, they are not exhaustive and possibly not universal and should be considered in line with individual organisational challenges. However, as a forward plan, these identified areas for improvement provide a roadmap as to what needs to happen next, if increased engagement and ultimately co-production is to materialise in practice.

It should be recognised that this paper, whilst representative of a Welsh NHS service provider population, might not extend beyond that due to the lower representation of minority groups and different representation of socioeconomic status and education levels to the UK as a whole, but particularly to NHS England. It is also acknowledged that the study would have provided significantly more insight if performed over a longer time period, affording the possibility of interview or focus group follow up to particular themes identified within the questionnaire. Also, involving a greater number of participants would have supported the use of more sophisticated quantitative statistical modelling, improving the reliability and validity of its findings. However, the paper does provide an evidenced foundation to explore the subject matter further.

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# 8 Appendices

Appendices can be found in the following page:

https://cronfa.swan.ac.uk/Record/cronfa71902

# Unscheduled Care in the Last Year of Life: Integrating Population-Level Digital Dashboards with Patient-Reported Perspectives to Inform Value-Based Health Care in Wales

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**Abstract:**

### Background

The number of people with palliative and end-of-life care (EOLC) needs in Wales is increasing, with around 32,000 affected annually. Unscheduled and emergency care use is highly prevalent in the last year of life (LYOL) and often poorly aligned with person-centred priorities for dignity, comfort and coordinated support.

### Aim

To examine unscheduled care use in the LYOL among people with dementia, heart failure, liver disease and lung cancer in Wales, integrating routine service data with patient reported outcome and experience measures (PROMs/PREMs).

### Methods

A retrospective observational study was conducted using the All-Wales LYOL Dashboard for adults who died between 2018 and 2024 with one of the four target conditions. Datasets included NHS 111, GP out-of-hours, ambulance service activity, emergency department attendances and hospital admissions. Findings were synthesised with OECD PaRIS survey data to provide a multi-perspective account of EOLC.

### Results

Unscheduled care use was extensive across all groups, with variation by condition. Dementia and liver disease were characterised by frequent crisis-driven admissions, limited specialist palliative care (SPC) and fragmented pathways. Heart failure patients showed repeated admissions with little anticipatory planning. Lung cancer patients who accessed earlier SPC had more extended hospital stays and were more likely to die at home or in hospice. PROMs/PREMs evidence highlighted persistent gaps in care coordination, communication and trust, with widespread unmet needs.

### Conclusion

Integrating service-use data with PROMs/PREMs offers essential insights into the quality of EOLC. Addressing inequities in palliative care access and embedding multi-perspective approaches could reduce avoidable unscheduled care while improving equity, dignity and person-centredness in the LYOL.

**Keywords:** End-of-Life Care; Palliative Care; Patient-Reported Outcomes (PROMs/PREMs); Health Data Integration; Value-Based Healthcare

## Table of Contents

# 1 Introduction

The demand for safe, high-quality palliative and end-of-life care in Wales is rising, with an estimated 32,000 people requiring support annually (Marie Curie, 2A024). Despite coordinated, person-centred end-of-life care being recognised as a priority by NICE (NICE NG142, 2019) and a key strategic ambition of the NHS Wales' Value-Based Health Care approach (NHS Wales, 2021), end-of-life care service delivery in Wales remains dominated by crisis-driven, unscheduled and emergency care. This pattern often results in fragmented pathways, poor alignment with patient values and inequities in access to specialist palliative care, particularly for those with non-malignant conditions such as dementia, heart failure and liver disease (French, Keegan, Anestis, & Preston, 2021).

This project was commissioned with Digital Health and Care Wales as the principal organisational client, in collaboration with NHS Wales Executive and local Health Boards. The client requirement is clear: to generate population-level insights that inform the redesign of services, reduce avoidable crisis-driven unscheduled care attendances and admissions and embed person-centred outcomes within operational planning. The specific task is to evaluate patterns of unscheduled care in the last year of life across four high-burden conditions: dementia, heart failure, liver disease and lung cancer, by integrating data from the All-Wales Last Year of Life Dashboard with patient-reported outcome and experience measures (PROMs/PREMs) from the OECD PaRIS survey.

This project introduces an innovative approach by integrating routinely collected service use data, which highlight care system exposure and utilisation, with patient-reported perspectives that capture care outcomes and experiences. The combination of these data sources enables a more comprehensive evaluation of system performance, identifying areas of success, shortcomings and opportunities to enhance care quality and equity at the end of life. The project operates at the intersection of digital health, service evaluation and value-based healthcare transformation.

The report is structured as follows:

5. The **Identification of Project Requirements** defines the client context, scope and success criteria.
6. The **Main Analysis** presents findings from the dashboard and PROMs/PREMs synthesis, with condition-specific insights and a critical appraisal of data quality.
7. The **Conclusion** distils overarching lessons about end-of-life care in Wales.
8. The **Key Recommendations** outline practical, evidence-based proposals for policy and service redesign, including ownership, implementation steps and suggested measurable indicators of success.

# 2 A Note on Main Analysis Methods

The methodological approach for this study comprised three structured stages, each selected for its capacity to provide both breadth and depth in understanding unscheduled care at the population level while considering its intersection with individualised patient-reported perspectives.

Initially, descriptive statistical techniques were employed to summarise key demographic variables and patterns of unscheduled care utilisation, including NHS 111 contacts, GP out-of-hours usage, ambulance service activities, emergency department visits, hospital admissions, bed days and length of stay. These analyses were stratified across the whole last year of life.

In the second stage, comparative subgroup analyses explored variation in service utilisation both between and within the four cause-of-death cohorts. This included stratification by comorbidities (as captured by the Charlson Comorbidity Index), care setting at time of death and access or timing of specialist palliative care input. This approach enabled the identification of contextual factors associated with care inequities and inefficiencies.

Thirdly, findings from routine service-use data from the dashboard were conceptually linked with PROMs/PREMs from the OECD PaRIS survey. Although direct individual-level data linkage was not feasible due to anonymisation, population-level synthesis sought to triangulate quantitative service use patterns with qualitative insights from patient perspectives. Illustrative patient journeys, derived from the Last Year of Life Dashboard's 'patient on a page' function, were integrated to demonstrate plausible intersections between service utilisation and patient-reported perspective, thereby enhancing interpretive validity.

Alternative methodological options were considered but ultimately disregarded for this project. For instance, a mixed-methods design incorporating primary qualitative interviews, case note reviews or linkage with prospective data collection could offer richer contextualisation but would demand additional ethical approvals, longitudinal access and greater resource allocation, which were not feasible within the timeframe for this PGCert Project. Similarly, while individual-level record linkage between PROMs/PREMs and service-use data would yield more granular associations, this option was precluded by governance constraints on patient-level identifiability and survey design. Furthermore, advanced statistical modelling (e.g., regression analyses or propensity score matching) was considered to account for confounding variables.

However, the heterogeneity in data completeness and the exploratory objectives of this service evaluation rendered these approaches less suitable for this project; however, they remain important considerations for future hypothesis-driven research.

Overall, the selected analytic pathway balances comprehensiveness, feasibility and governance requirements while positioning the study to inform practical, system-level improvements in end-of-life care in Wales.

# 3 Identification of Project Requirements

## 3.1 Nature of the Project

This project is a service evaluation and strategic analysis commissioned by Digital Health and Care Wales, with direct relevance to the NHS Wales Executive, local Health Boards and specialist palliative care providers. It focuses on the last year of life, a period characterised by high unscheduled and emergency care use, fragmented pathways and variable access to specialist palliative care. The project seeks to generate actionable insights that can inform service redesign, reduce avoidable hospital use and strengthen person-centredness in line with NHS Wales' Value-Based Health Care strategy (NHS Wales, 2021).

## 3.2 Client and Stakeholders

**Principal client:** Digital Health and Care Wales, as custodian of the All-Wales Last Year of Life Dashboard.

**System stakeholders:** include the NHS Wales Executive (for policy oversight), Welsh Ambulance Services NHS Trust (WAST), NHS 111 and GP out-of-hours services, hospital and community palliative care teams and Health Boards.

**End users:** patients and caregivers experiencing care in the last year of life. Their perspectives are central, captured through PROMs/PREMs.

## 3.3 Problem Definition

Unscheduled and emergency care use is prevalent for people in their last year of life in Wales. For example, almost 90% of patients with a palliative condition contact 999 in their last year of life and one-third do so in the last week of life (Better End of Life Programme, 2024). These encounters are often distressing, poorly coordinated and misaligned with patient values and priorities. Inequities in care also persist; patients with cancer are more likely to access timely specialist palliative care, while those with dementia, heart failure and liver disease often experience repeated crisis-driven emergency admissions and less anticipatory planning (NCEPOD, 2024).

## 3.4 Specific Task

The project task is to:

- Evaluate unscheduled care use in the last year of life across dementia, heart failure, liver disease and lung cancer using the All-Wales Last Year of Life Dashboard.
- Integrate these findings with PROMs/PREMs data from the OECD PaRIS survey to generate a multi-perspective view of care quality.
- Identify system inequities, gaps in anticipatory care and opportunities for redesign that could reduce avoidable emergency and unscheduled care use.

- Provide evidence-based recommendations for embedding PROMs/PREMs into national dashboards, standardising early palliative care referral and enabling policy and service transformation.

### 3.5 Success Criteria

**Equity:** Reduced variation in access to specialist palliative care between malignant and non-malignant conditions.

**EAiciency:** Measurable reductions in avoidable unscheduled and emergency admissions and hospital bed days.

**Person-centredness**: Improvements in the use of PROMs/PREMs indicators.

**Transformational value:** Demonstrated feasibility of linking digital dashboards with patient-reported perspectives as a scalable model for Value-Based Health Care.

### 3.6 Innovation and Value Proposition

The project introduces a multi-perspective digital framework that combines routine service data with PROMs/PREMs to provide a more comprehensive picture of end-of-life care in the last year of life. This approach offers transformational value by:

- Shifting the dashboard from a utilisation tracker to a quality and equity monitoring tool.
- Providing decision-makers with actionable intelligence to target anticipatory care, community-based interventions and earlier palliative care referral.
- Supporting NHS Wales in meeting its commitments to Value-Based Health Care, national end-of-life care policy and the OECD's international agenda for integrated system approaches (OECD, 2023).

## 4 Main Analysis

### 4.1 KEY MESSAGES What is already known on this topic

Unscheduled and emergency care use is highly prevalent in the last year of life and often misaligned with person-centred priorities. Evidence highlights inequities in access to specialist palliative care, particularly for non-malignant conditions, but population-level insights integrating service data with patient perspectives remain limited.

### 4.2 What this study adds

This study demonstrates extensive unscheduled care use across dementia, heart failure, liver disease and lung cancer in Wales, with marked variation between conditions. It shows that earlier specialist palliative care involvement, as in lung cancer, is associated with more coordinated and person-centred outcomes. Integrating routine service data with patient-reported measures provides a richer, multi-perspective understanding of end-of-life care.

### 4.3 How this study might affect research, practice or policy

The findings highlight opportunities to reduce avoidable crisis-driven hospital use through earlier specialist palliative care, as well as better coordination and integration of PROMs/PREMs into routine data dashboards. This multi-perspective approach can inform national policy, support service redesign and improve dignity, equity and person centredness at the end of life.

### 4.4 Key words

Unscheduled care, emergency care, end-of-life care, last-year-of-life, dementia, heart failure, lung cancer, liver disease, dashboard, routine data, PROMs, PREMs BACKGROUND

The number of people with palliative and end-of-life care needs in Wales is increasing. At present, around 32,000 people each year are living with a life-limiting illness that requires support during their last year of life (Marie Curie, 2024). This rising demand highlights the need to reassess how health systems respond to the complex needs of individuals nearing the end of life, particularly in unscheduled and emergency care settings.

In NHS Wales, a key strategic priority is the adoption of a Value-Based Health Care approach, which seeks to optimise population health outcomes by ensuring that care is equitable, efficient and centred on what matters most to patients (NHS Wales, 2021). In the context of palliative and end-of-life care, Value-Based Health Care requires careful balancing of population-level and person-centred goals. Health systems must address equity of access and service efficiency, whilst also ensuring that care is aligned with the preferences and values of individuals. These priorities are reflected in both national guidance and international frameworks, for example, the National Institute for Health and Care Excellence's (NICE, 2019) recommendations on coordinated and person-centred end-of-life care and the Organisation for Economic Co-operation and Development's (OECD, 2023a) call for an integrated systems approach to care.

Despite these aspirations, evidence suggests that the use of unscheduled care remains highly prevalent among people in the last year of life. The Time to Care Wales report, part of the Better End of Life Programme, showed that 90% of people with a palliative condition contact 999 in their final year, with nearly one-third doing so in their last week of life (Better End of Life Programme, 2024). Almost half of these patients visit emergency departments in their final three months and around 70% of these attendances result in hospital admission, with a mean length of stay of 23.4 days. At any one time, between 20–25% of hospital beds in Wales are occupied by people at the end of life and one in nine people who die in hospital do so within 24 hours of admission. These findings suggest that emergency admissions to manage the dying phase are a common occurrence. Such encounters are often distressing for patients and their families, highlighting a persistent misalignment between the care delivered and the outcomes and experiences that matter most to patients at the end of life.

Meeting this challenge requires a purposeful, systems-level analysis of end-of-life care at a population scale, with an emphasis on generating insights that can be translated into practical improvements for frontline clinical teams. By defining clear boundaries around both the population of interest (those in the last year of life) and the system of care (unscheduled and emergency care services), it becomes possible to generate learning that is both strategically relevant and clinically actionable.

Routine health data, such as that collated in the All-Wales Last Year of Life Dashboard, provide a powerful means of describing patterns of service interaction and identifying areas of potentially avoidable care. However, data on service utilisation alone cannot capture the full complexity of care quality. Increasingly, patient-reported outcome measures (PROMs) and patient-reported experience measures (PREMs) are recognised as essential for understanding care from the perspective of those receiving it (Hurley et al., 2025). The OECD's Patient-Reported Indicator Surveys (PaRIS) programme has developed standardised tools to collect these perspectives internationally. Early findings from its end-of-life care module highlight persistent gaps in symptom management, care coordination and emotional and practical support for families (OECD, 2023b). In Wales specifically, data from the PaRIS chronic conditions survey reveal striking challenges, with fewer than a quarter of patients reporting good experiences of care coordination and less than half of respondents reporting trust in the healthcare system, compared with around 60% across OECD countries (OECD, 2023b).

Integrating PROMs/PREMs with objective routine data offers a more nuanced and multi-perspective understanding of end-of-life care. This approach enables researchers and clinicians to explore not only what happens in terms of system exposure and outcomes, but also how patients and their families experience care. Such integration is central to both advancing the strategic aims of Value-Based Health Care at a population level and upholding the ethical imperative of person-centredness at the level of individual care.

For this study, we focus on unscheduled care use among patients with lung cancer, dementia, heart failure and liver disease, as identified in the UK-wide Planning for the End report (National Confidential Enquiry into Patient Outcome and Death [NCEPOD], 2024). These conditions represent diverse disease trajectories and patient demographics and correspond to some of the most common causes of death in Wales (ONS, 2023). By exploring how PROMs/PREMs data can be meaningfully combined with routine service data in this defined population, this work aims to generate learning that can inform national policy and be implemented at the local clinical level to improve the quality of care at the end of life.

## 4.5 AIMS AND OBJECTIVES

The central research question guiding this study is:

*"What can integrated data from a national digital dashboard and a national patient-reported outcome and experience survey tell us about*

*unscheduled care use in people with dementia, heart failure, liver disease and lung cancer during their last year of life in Wales?"*

The overall aim of this work is to generate new insights into the quality and patterns of end-of-life care by combining routinely collected health service data with patient reported perspectives. In doing so, the study adopts a purposeful, systems-level lens that recognises both the population burden of unscheduled care and the lived experiences of patients and families.

The specific objectives are:

- To describe and compare unscheduled care use in the last year of life among people with dementia, heart failure, liver disease and lung cancer in Wales, drawing on data from the All-Wales Last Year of Life Dashboard.
- To explore variation in service utilisation within and across these groups, with a focus on identifying where patterns of care may reflect inequities, inefficiencies or potentially avoidable hospital use.
- To integrate findings from routine service data with PROMs/PREMs data collected through the OECD PaRIS programme, to generate a more nuanced understanding of the quality of end-of-life care from both system and patient perspectives.
- To identify gaps in current data linkage and evidence that would be required to build a complete and more robust picture of the last year of life, including opportunities for enhancing national datasets and digital dashboards.
- To contextualise exploratory findings in relation to policy and service priorities, informing recommendations for upstream interventions and systems redesign aimed at improving equity, efficiency and person-centredness in end-of-life care across Wales.

Addressing these objectives will establish an integrated, multi-perspective framework for assessing end-of-life care quality at the population level. This approach aims to fill a critical knowledge gap and support the development of actionable strategies that can be implemented at both national and local clinical levels to improve outcomes, experiences and quality of life for individuals in their final year of life.

## 4.6 METHODS Study Design

This study employed a retrospective, observational design, utilising multiple routinely collected health service datasets combined with PROMs/PREMs from an international survey. The work is reported in line with the RECORD guidelines (Reporting of studies Conducted using Observational Routinely collected health Data) (Benchimol et al., 2015).

## 4.7 Study Population

The study population included all adults who died in Wales between 2018 and 2024 with a primary cause of death recorded as dementia (ICD-10 codes F00–F03, G30), heart failure (I50), liver disease (K70–K77) or lung cancer (C33–C34). These conditions were selected in accordance with the NCEPOD Planning for the End report (2024) to represent diverse disease trajectories and common causes of death in Wales. Deaths due to external causes (for example, accidents or injuries) were excluded as these would not usually be considered within the remit of palliative or end-of-life care.

For each individual, unscheduled care use was examined for the twelve months preceding death. Linkage across datasets was achieved using anonymised NHS numbers, with aggregation at the population level to ensure confidentiality.

## 4.8 Data Sources

Routinely collected data were accessed via the All-Wales Last Year of Life Dashboard, a digital platform maintained by Digital Health and Care Wales. The following datasets were utilised:

- NHS 111 calls (advice, triage and onward referral)
- General Practice out-of-hours contacts
- Welsh Ambulance Service activity (999 calls, dispatches and patient clinical records)

- Emergency Department attendances (including minor injuries units)
- Admitted Patient Care (consultant-led inpatient episodes)
- Office for National Statistics (death registration data)
- Welsh Demographic Service (demographic and registration data)
- Cancer Network Information System Cymru (clinical and palliative care records for cancer patients)

To complement these service-use data, patient-reported insights were drawn from the OECD PaRIS programme. The PaRIS survey is a 121-item questionnaire designed to capture the outcomes and experiences of patients with chronic conditions receiving primary care. It covers several holistic domains including symptom scores, physical functioning, psychosocial well-being, coordination of care, access and trust in the healthcare system. A shorter, matched version was also administered to healthcare providers, allowing for a comparison between patient and provider perspectives. Although not limited to people in their last year of life, the Welsh PaRIS sample offers insights into how people with life-limiting illness experience the healthcare system, which can be conceptually aligned with patterns of unscheduled care use observed in this study.

## 4.9 Permissions and Governance

Digital Health and Care Wales granted access to the All-Wales Last Year of Life Dashboard in April 2024. All data were anonymised at source, and a small number suppression method was applied, with any values of five or fewer not reported for confidentiality purposes. As the study constituted a service evaluation using anonymised secondary data, formal NHS research ethics committee approval was not required. All work was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013) and in line with NHS Wales' commitments to Value Based Health Care.

## 4.10 Analysis

Analysis proceeded in three stages. First, descriptive analyses summarised demographic characteristics (age at death, sex and deprivation quintile) and patterns of unscheduled care, including NHS 111 use, GP out-of-hours contacts, ambulance attendances, emergency department visits, hospital admissions, hospital bed days and length of stay.

Second, variation in care use was explored within and between the four diagnostic groups, including comparisons by comorbidity burden using the Charlson Comorbidity Index. Outcomes were further examined in relation to place of death (home, care home, hospice, hospital or other) and the provision and timing of specialist palliative care.

Third, service-use data were conceptually integrated with PROMs/PREMs evidence from the PaRIS survey. Although linkage was not performed at the level of individual patients, population-level findings from both sources were synthesised to provide a multi-perspective account of end-of-life care quality. Illustrative patient journeys generated through the "patient on a page" function of the last year of life Dashboard were used to demonstrate how unscheduled care use might be shaped by contributory or mitigatory factors, informed by insights from patient-reported data.

This analytic approach aims to demonstrate the feasibility of integrating routine utilisation data with PROMs and PREMs evidence to generate a more nuanced and actionable understanding of care quality in the last year of life.

# 5 RESULTS

Figure 1 presents descriptive characteristics of the whole cohort of deaths in Wales and the subgroups of people who died with dementia, heart failure, liver disease or lung cancer. Data are presented as absolute numbers (n) and percentages (%). Categories include age group, sex, receipt of specialist palliative care (SPC) and 5-year Charlson comorbidity index. Percentages for each disease subgroup represent the proportion of the total cohort with that condition, unless otherwise indicated. Suppressed values are marked with * to protect confidentiality.

| **FIGURE 1** | **General Population** | | **Dementia** | | **Heart Failure** | | **Liver Disease** | | **Lung Cancer** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % | n | % |
| Deaths | 238,885 | 100 | 19,368 | 8.1 | 2,970 | 1.2 | 4,531 | 1.9 | 12,813 | 5.4 |
| Age Group | | | | | | | | | | |
| < 18 | 599 | 100 | * | * | * | * | * | * | * | * |
| 18–69 | 48,570 | 100 | 278 | 0.6 | 164 | 0.3 | 3,160 | 6.5 | 3,796 | 7.8 |
| 70+ | 185,353 | 100 | 18,997 | 10.2 | 2,776 | 1.5 | 1,248 | 0.7 | 8,593 | 4.6 |
| Sex | | | | | | | | | | |
| Male | 119,318 | 100 | 7,074 | 5.9 | 1,392 | 1.2 | 2,759 | 2.3 | 6,731 | 5.6 |
| Female | 119,567 | 100 | 12,294 | 10.3 | 1,578 | 1.3 | 1,772 | 1.5 | 6,082 | 5.1 |
| Specialist Palliative Care | | | | | | | | | | |
| SPC Input | 80,976 | 33.8 | 3,291 | 17.0 | 761 | 25.6 | 1046 | 23.1 | 10,032 | 78.3 |
| 5-year Charlson Comorbidity | | | | | | | | | | |
| None | 40,417 | 100 | 2,839 | 7.0 | 304 | 0.8 | 753 | 1.9 | 720 | 1.8 |
| Mild | 66,514 | 100 | 7,960 | 12.0 | 804 | 1.2 | 945 | 1.4 | 1,063 | 1.6 |
| Moderate | 54,021 | 100 | 5,265 | 9.7 | 931 | 1.7 | 1,037 | 1.9 | 1,826 | 3.4 |
| Severe | 77,933 | 100 | 3,304 | 4.2 | 931 | 1.2 | 1,796 | 2.3 | 9,204 | 11.8 |
| Unscheduled Care Contacts in last year of life | | | | | | | | | | |
| Emergency Department Attendances | 332,313 | 100 | 22,977 | 6.9 | 4,414 | 1.3 | 8,705 | 2.6 | 18,655 | 5.6 |
| Ambulance Call Outs | 280,438 | 100 | 25,832 | 9.2 | 3,829 | 1.4 | 5,968 | 2.1 | 13,508 | 4.8 |
| Emergency Admissions | 337,370 | 100 | 18,763 | 5.6 | 4,577 | 1.4 | 8,614 | 2.6 | 22,299 | 6.6 |
| *ICD-10 codes: dementia, F00–F03 & G30; heart failure, I50; liver disease, K70–K77; lung cancer, C33–C34. Charlson comorbidity: none, 0; mild, 1–2; moderate, 3–4; severe, 5+.* | | | | | | | | | | |

Figure 2 describes the OECD paired sample of deaths in Wales, including the general population and subgroups with dementia, heart failure, liver disease and lung cancer. Data are presented as absolute numbers (n) and percentages (%). Categories include age group, sex, receipt of specialist palliative care and 5-year Charlson comorbidity index. Percentages for each disease subgroup represent the proportion of the total cohort with that condition, unless otherwise indicated. Suppressed values are marked with * to protect confidentiality.

| **FIGURE 2** | **General Population** | | **Dementia** | | **Heart Failure** | | **Liver Disease** | | **Lung Cancer** | |
|---|---|---|---|---|---|---|---|---|---|---|
| | n | % | n | % | n | % | n | % | n | % |
| Deaths | 45 | 100 | 8 | 17.8 | 5 | 11.1 | 6 | 13.3 | 22 | 48.9 |
| Age Group | | | | | | | | | | |
| < 18 | 0 | 100 | * | * | * | * | * | * | * | * |
| 18–69 | 13 | 100 | 1 | 7.7 | 0 | 0.0 | 4 | 30.8 | 8 | 61.5 |
| 70+ | 31 | 100 | 7 | 22.6 | 5 | 16.1 | 2 | 6.5 | 13 | 41.9 |
| Sex | | | | | | | | | | |
| Male | 27 | 100 | 4 | 14.8 | 3 | 11.1 | 4 | 14.8 | 15 | 55.6 |
| Female | 18 | 100 | 4 | 22.2 | 2 | 11.1 | 2 | 11.1 | 7 | 38.9 |
| Specialist Palliative Care | | | | | | | | | | |
| SPC Input | FIGURE 2 | General Population | Dementia | Heart Failure | Liver Disease | Lung Cancer | | | | |
| 5-year Charlson Comorbidity | | | | | | | | | | |
| None | 7 | 100 | 3 | 42.9 | 1 | 14.3 | 0 | 0.0 | 2 | 28.6 |
| Mild | 3 | 100 | 1 | 33.3 | 1 | 33.3 | 0 | 0.0 | 0 | 0.0 |
| Moderate | 10 | 100 | 2 | 20.0 | 0 | 0.0 | 4 | 40.0 | 3 | 30.0 |
| Severe | 25 | 100 | 2 | 8.0 | 3 | 12.0 | 2 | 8.0 | 17 | 68.0 |
| Unscheduled Care Use in last year of life | | | | | | | | | | |
| Emergency Department | 57 | 100 | 10 | 17.5 | 7 | 12.3 | 5 | 8.8 | 26 | 45.6 |
| Ambulance Call Outs | 22 | 100 | 4 | 18.2 | 3 | 13.6 | 1 | 4.5 | 9 | 40.9 |
| Emergency Admissions | 88 | 100 | 3 | 3.4 | 6 | 6.8 | 29 | 33.0 | 44 | 50.0 |

*ICD-10 codes: dementia, F00–F03 & G30; heart failure, I50; liver disease, K70–K77; lung cancer, C33–C34. Charlson comorbidity: none, 0; mild, 1–2; moderate, 3–4; severe, 5+.*

Figure 3 presents responses from the OECD paired sample to PROMs/PREMs. It includes demographic characteristics (age, gender, comorbidities and medications), health status (emergency admissions, overall health rating and symptom burden) and experiences of care (communication, involvement in decision-making, coordination, care planning and perceptions of care quality. Responses are shown at the individual level for illustrative cases. Percentages are not provided; qualitative categories (e.g., Good, Excellent, To Some Extent) reflect participants' self-reports. Missing or suppressed responses are indicated by '- '.

| LUNG CANCER | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Demographics | Pseudonym | Mary | Matt | Peter | Tom | Lily | Paul | Tracy | James | Chris |
| | Age | 65 – 69 | 80 – 84 | 75 – 79 | 75 – 79 | 65 – 69 | 75 – 79 | 65 – 69 | 60 – 64 | 75 – 79 |
| | Gender | Female | Male | Male | Male | Female | Male | Female | Male | Male |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Co-morbidities | 2 | 5 | 1 | 3 | 2 | 2 | 2 | 2 | 1 |
| | Medications | 5 – 9 | 5 – 9 | 1 – 2 | 1 – 2 | 5 – 9 | 3 – 4 | 1 – 2 | 1 – 2 | 5 – 9 |
| | Emergency admissions | 11 | 4 | 4 | 2 | 2 | 2 | 2 | 2 | 2 |
| | Overall health rating | Poor | Poor | Fair | Good | Fair | Fair | Good | Good | Good |
| | Rating for medical care over last 12 months | Very good | Good | Excellent | Excellent | Fair | Very good | Excellent | Excellent | Excellent |
| Physical | Breathless | Somewhat | Very much | Quite a bit | Not at all | Not at all | A little | Not at all | A little | Quite a bit |
| | Fatigue | Mild | Severe | Moderate | Mild | Mild | Moderate | Moderate | Mild | Severe |
| | Pain (/10) | 6 | 2 | 3 | 0 | 3 | 4 | 7 | 9 | 4 |
| Psychological and emotional | Cheerful and in good spirits | More than half the time | Less than half the time | More than half the time | Most of the time | Most of the time | Most of the time | More than half the time | More than half the time | More than half the time |
| | Emotional care and support needed | No | Yes | No | No | No | No | No | No | No |
| Social | Satisfaction with social activities and relationships | Fair | Poor | Good | Very good | Very good | Poor | Good | Good | Good |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Getting help from family if needed** | Very easy | Easy | Easy | Very easy | Easy | Very easy | Very easy | Neither easy nor difficult | Very easy |
| **Functional and occupational** | **Feels active and vigorous** | More than half the time | None of the time | Less than half the time | Most of the time | Most of the time | Some of the time | Some of the time | Most of the time | Less than half the time |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Able to carry out everyday activities independently** | Mostly | A little | Completely | Completely | Mostly | Mostly | Mostly | Completely | Completely |
| | **Help needed with personal care** | No | Yes | No | No | No | No | Yes | No | No |
| | **Help needed with healthcare related activities** | No | Yes | No | No | No | No | No | No | No |
| **Care planning and coordination** | **Confident managing own health and well being** | Not confident | Not confident | Confident | Somewhat | Confident | Confident | Somewhat | Confident | Not confident |
| | **Confident in knowing when it is necessary to seek medical care** | Confident | Not confident | Confident | Somewhat | Confident | Confident | Confident | Confident | Confident |
| | **Confident in following instructions from health professionals on how to care for themselves at home** | Confident | Somewhat | Confident | Somewhat | - | Confident | Confident | Confident | Confident |
| | **Relies on health professionals to tell them everything they need to** | Agree | Strongly agree | - | Agree | Disagree | Agree | Agree | - | Agree |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | know to manage and make right decisions about care | | | | | | | | | |
| | Important to be kept informed about health issues | Agree | Agree | Agree | Agree | Agree | Agree | Agree | Agree | Agree |
| | Need to know about health issues so can keep themselves and family healthy | Agree | Strongly agree | Agree | Agree | Agree | Neither agree nor disagree | Agree | Agree | Agree |
| | Felt considered as a whole person rather than just a disease/ condition | To some extent | Definitely | Definitely | Definitely | Not really | Definitely | To some extent | Not really | Definitely |
| | Discussed with health care professionals involved in her care what was most important to her in managing her own health and wellbeing | Yes | - | Yes | Yes | To some extent | Yes | To some extent | To some extent | To some extent |
| | Involved as much as they want to be in decisions about their care | Yes | - | Definitely | Yes | Not really | Yes | Not really | To some extent | To some extent |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **HCPs involve family/ friends/ carers as much as they wanted them to be in decisions about their care** | - | To some extent | Definitely | - | Definitely not | Definitely | - | Not really | - |
| | **Single allocated professional who took responsibility for coordinating their care across the services they use** | Yes | No | No | Yes | - | No | - | Yes | Yes |
| | **Health care organised in a way that works for them?** | Yes | To some extent | Definitely | Yes | - | To some extent | - | To some extent | To some extent |
| | **Care plan in place that took into account all their health and wellbeing needs** | No | - | Yes | No | No | No | No | No | No |
| | **Times when they have had to repeat information that should have been in their care records?** | No | Definitely | No | No | Yes | No | No | To some extent | No |
| **Demographics** | **Pseudonym** | Karen | Sarah | Rhys | Ffion | Sian | Luke | Jac | Tobias | Richard |
| | **Age** | 65 – 69 | 55 – 59 | 70 – 74 | 60 – 64 | 60 – 64 | 75 – 79 | 75 – 79 | 75 – 79 | 75 – 79 |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Gender** | Female | Female | Male | Female | Female | Male | Male | Male | Male |
| | **Co-morbidities** | 0 | 4 | 4 | 4 | - | 3 | 6 | 3 | 2 |
| | **Medications** | - | 3 – 4 | 3 – 4 | 3 – 4 | 5 – 9 | - | 10 + | 10 + | 5 – 9 |
| | **Emergency admissions** | 2 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 |
| | **Overall health rating** | Good | Poor | Fair | Fair | Poor | Fair | Poor | Poor | Poor |
| | **Rating for medical care over last 12 months** | Good | Excellent | Good | Fair | Excellent | - | Good | Excellent | Good |
| **Physical** | **Breathless** | Not at all | Somewhat | A little | A little | A little | Quite a bit | Very much | Quite a bit | Somewhat |
| | **Fatigue** | Mild | Moderate | Moderate | Moderate | Very severe | Moderate | Severe | Severe | Very severe |
| | **Pain (/10)** | 7 | 3 | 6 | 5 | 7 | 5 | 8 | 0 | 9 |
| **Psychological and emotional** | **Cheerful and in good spirits** | Most of the time | Less than half the time | Some of the time | Less than half the time | Some of the time | Some of the time | Some of the time | Some of the time | None of the time |
| | **Emotional care and support needed** | No | Yes | No | No | Yes | - | Yes | Yes | No |
| **Social** | **Satisfaction with social activities and relationships** | Very good | Fair | Fair | Fair | Fair | Fair | Poor | Fair | Fair |
| | **Getting help from family if needed** | Very easy | Neither easy nor difficult | Very easy | Difficult | Very easy | - | Very easy | Very easy | Easy |
| **Functional and occupational** | **Feels active and vigorous** | More than half the time | Less than half the time | None of the time | None of the time | Less than half the time | None of the time | None of the time | None of the time | None of the time |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Able to carry out everyday activities independently** | Mostly | Somewhat | Completely | Completely | A little | Moderately | A little | A little | Not at all |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Help needed with personal care** | No | No | No | No | Yes | - | Yes | Yes | No |
| | **Help needed with healthcare related activities** | No | No | No | No | No | - | Yes | Yes | No |
| **Care planning and coordination** | **Confident managing own health and well being** | Confident | Somewhat | Not confident | Not confident | Somewhat | Confident | Not confident | Somewhat | Not confident |
| | **Confident in knowing when it is necessary to seek medical care** | Very confident | Somewhat | Somewhat | Somewhat | Confident | Confident | Not confident | Somewhat | Confident |
| | **Confident in following instructions from health professionals on how to care for themselves at home** | Very confident | Somewhat | Somewhat | Confident | Somewhat | Confident | Somewhat | Somewhat | Somewhat |

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|---|---|---|---|---|---|---|---|---|---|---|
| | **Relies on health professionals to tell them everything they need to know to manage and make right decisions about care** | - | - | Neither agree nor disagree | Agree | Strongly agree | - | Strongly agree | - | Agree |
| | **Important to be kept informed about health issues** | Agree | Agree | Agree | Agree | Neither agree nor disagree | Agree | Strongly agree | Strongly agree | Agree |
| | **Need to know about health issues so can keep themselves and family healthy** | Agree | Agree | Neither agree nor disagree | Agree | Neither agree nor disagree | Agree | Strongly agree | Strongly agree | Agree |
| | **Felt considered as a whole person rather than just a disease/ condition** | - | Definitely | To some extent | - | - | Definitely | To some extent | To some extent | To some extent |
| | **Discussed with health care professionals involved in her care what was most important to her in managing her own health** | - | Yes | No | To some extent | - | Yes | Yes | To some extent | Yes |

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|---|---|---|---|---|---|---|---|---|---|---|
| | **and wellbeing** | | | | | | | | | |
| | **Involved as much as they want to be in decisions about their care** | - | Yes | Yes | Not really | - | To some extent | To some extent | Not really | To some extent |
| | **HCPs involve family/ friends/ carers as much as they wanted them to be in decisions** | - | - | Definitely | - | - | - | Definitely | Definitely | To some extent |
| | **about their care** | | | | | | | | | |
| | **Single allocated professional who took responsibility for coordinating their care across the services they use** | - | Not sure | No | - | - | Yes | No | No | Yes |
| | **Health care organised in a way that works for them?** | - | Yes | To some extent | - | - | Definitely | To some extent | Not really | To some extent |
| | **Care plan in place that took into account all their health** | - | Not sure | No | No | - | No | No | Yes | No |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **and wellbeing needs** | | | | | | | | | |
| | **Times when they have had to repeat information that should have been in their care records?** | No | No | No | Yes | No | - | Definitely | No | |

| DEMENTIA | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| Demographics | Pseudonym | Lucy | Simon | Oliver | Megan | Tara | Linda | Georgia | Gwen | Louis |
| | Age | 65 – 69 | 70 – 74 | 85 + | 85 + | 85 + | 65 – 69 | 85 + | 65 – 69 | 85 + |
| | Gender | Female | Male | Male | Female | Female | Female | Female | Female | Male |
| | Co-morbidities | 2 | 6 | 4 | 2 | - | 4 | - | 1 | 3 |
| | Medications | 1 – 2 | 10 + | 10 + | 3 – 4 | - | 1 – 2 | - | - | 10 + |
| | Emergency admissions | 2 | 1 | 1 | 1 | 0 | 0 | 0 | 0 | 0 |
| | Overall health rating | Good | Poor | Fair | Poor | Poor | Poor | Good | Very good | Fair |
| | Rating for medical care over last 12 months | Excellent | Excellent | Excellent | Excellent | - | Fair | - | - | Good |
| Physical | Breathless | Not at all | A little | A little | Somewhat | Quite a bit | Not at all | Somewhat | Not at all | Very much |
| | Fatigue | Moderate | Moderate | Moderate | Very severe | Severe | None | Mild | Mild | Severe |
| | Pain (/10) | 4 | 1 | 5 | 10 | 6 | 3 | 6 | 0 | 6 |
| Psychological and emotional | Cheerful and in good spirits | More than half the time | Less than half the time | More than half the time | None of the time | Some of the time | None of the time | Less than half the time | Less than half the time | Less than half the time |

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|---|---|---|---|---|---|---|---|---|---|---|
| | Emotional care and support needed | Yes | No | Yes | No | - | No | - | - | No |
| Social | Satisfaction with social activities and relationships | Good | Fair | Good | Poor | Fair | Fair | Fair | Good | Fair |
| | Getting help from family if needed | Very easy | Very easy | Very easy | Easy | - | Very easy | - | - | Very easy |
| Functional and occupational | Feels active and vigorous | Some of the time | None of the time | None of the time | None of the time | None of the time | None of the time | Some of the time | More than half the time | None of the time |
| | Able to carry out everyday activities independently | Moderately | Not at all | A little | Not at all | A little | Not at all | Not at all | Completely | Not at all |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Help needed with personal care** | Yes | Yes | Yes | Yes | - | Yes | - | - | Yes |
| | **Help needed with healthcare related activities** | No | Yes | Yes | Yes | - | Yes | - | - | Yes |
| **Care planning and coordination** | **Confident managing own health and well being** | Somewhat | Somewhat | Somewhat | Confident | Somewhat | Not confident | - | Confident | Not confident |
| | **Confident in knowing when it is necessary to seek medical care** | Somewhat | Somewhat | Somewhat | Very confident | Somewhat | Not confident | - | Somewhat | Not confident |

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|---|---|---|---|---|---|---|---|---|---|---|
| | **Confident in following instructions from health professionals on how to care for themselves at home** | - | Somewhat | Somewhat | Very confident | Not confident | Not confident | - | Very confident | Not confident |
| | **Relies on health professionals to tell them everything they need to know to manage and make right decisions about care** | Agree | - | Agree | - | Agree | Agree | - | Strongly disagree | Agree |
| | **Important to be kept informed about health issues** | Agree | - | Agree | Strongly agree | Strongly agree | Neither agree nor disagree | - | Agree | - |
| | **Need to know about health issues so can keep themselves and family healthy** | Strongly agree | - | Agree | Agree | Neither agree nor disagree | Neither agree nor disagree | - | Agree | - |
| | **Felt considered as a whole person rather than just a disease/ condition** | To some extent | To some extent | Definitely | To some extent | - | To some extent | - | - | To some extent |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Discussed with health care professionals involved in her care what was most important to her in managing her own health and wellbeing** | To some extent | To some extent | - | Yes | - | - | - | Yes | No |
| | **Involved as much as they want to be in decisions about their care** | Not really | To some extent | Definitely | To some extent | - | - | - | - | - |
| | **HCPs involve family/ friends/ carers as much as they wanted them to be in decisions about their care** | Definitely | Definitely | Definitely | Definitely | - | Definitely | - | - | Definitely |
| | **Single allocated professional who took responsibility for coordinating their care across the services they use** | - | No | No | Yes | - | No | - | No | No |
| | **Health care organised in a way that works for them?** | - | Not really | Definitely | To some extent | - | Not really | - | Not sure | Not sure |

| | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | **Care plan in place that took into account all their health and wellbeing needs** | No | No | No | Yes | - | No | - | - | Yes |
| | **Times when they have had to repeat information that should have been in their care records?** | No | No | - | Yes | - | No | - | - | Yes |

| HEART FAILURE | | | LIVER DISEASE | | | | | |
|---|---|---|---|---|---|---|---|---|
| Demographics | Pseudonym | Stu | Gary | Sue | | Dennis | Ian | Karl |
| | Age | 85 + | 70 – 74 | 85 + | | 55 – 59 | 60 – 64 | 70 – 74 |
| | Gender | Male | Male | Female | | Male | Male | Male |
| | Co-morbidities | 1 | 3 | 3 | | 1 | - | 1 |
| | Medications | 3 – 4 | 5 – 9 | 5 – 9 | | 3 – 4 | - | 1 – 2 |
| | Emergency admissions | 2 | 1 | 0 | | 1 | 1 | 1 |
| | Overall health rating | Good | Fair | Fair | | Fair | - | Fair |
| | Rating for medical care over last 12 months | Very good | Poor | Very good | | Fair | - | Very good |
| Physical | Breathless | Somewhat | A little | A little | | A little | - | Not at all |
| | Fatigue | Moderate | Moderate | Moderate | | Moderate | - | Moderate |
| | Pain (/10) | 0 | 2 | 2 | | 4 | - | 5 |
| Psychological and emotional | Cheerful and in good spirits | More than half the time | Most of the time | Most of the time | | More than half the time | - | Most of the time |
| | Emotional care and support needed | No | No | No | | | - | No |
| Social | Satisfaction with social activities and relationships | Excellent | Very good | Very good | | Good | - | Good |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Getting help from family if needed | Very easy | Easy | Very easy | [redacted] | Easy | - | Very easy |
| Functional and occupational | Feels active and vigorous | Less than half the time | Less than half the time | Some of the time | [redacted] | Less than half the time | - | More than half the time |
| | Able to carry out everyday activities independently | Somewhat | Moderately | A little | [redacted] | Completely | - | Somewhat |
| | Help needed with personal care | No | No | Yes | [redacted] | No | - | No |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **Help needed with healthcare related activities** | No | No | No | [redacted] | No | - | No |
| **Care planning and coordination** | **Confident managing own health and well being** | Confident | Somewhat | Confident | [redacted] | Somewhat | - | Somewhat |
| | **Confident in knowing when it is necessary to seek medical care** | Confident | Somewhat | Confident | [redacted] | Somewhat | - | Somewhat |
| | **Confident in following instructions from health professionals on how to care for themselves at home** | Confident | Somewhat | Confident | [redacted] | Somewhat | - | Confident |
| | **Relies on health professionals to tell them everything they need to know to manage and make right** | Agree | Agree | Agree | [redacted] | Agree | - | Agree |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **decisions about care** | | | | [redacted] | | | |
| | **Important to be kept informed about health issues** | Neither agree nor disagree | Agree | Agree | [redacted] | Agree | - | Agree |
| | **Need to know about health issues so can keep themselves and family healthy** | Neither agree nor disagree | Agree | Agree | [redacted] | Agree | - | Agree |
| | **Felt considered as a whole person rather than just a disease/ condition** | Definitely | Definitely | Definitely | [redacted] | Not really | - | Definitely |
| | **Discussed with health care professionals involved in her care what was most important to her in managing her own health and wellbeing** | To some extent | Yes | To some extent | [redacted] | To some extent | - | Yes |
| | **Involved as much as they want to be in decisions** | Definitely | Definitely | Definitely | [redacted] | To some extent | - | Some |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **about their care** | | | | [redacted] | | | |
| | **HCPs involve family/ friends/ carers as much as they wanted them to be in decisions about their care** | Definitely not | Definitely not | Definitely | [redacted] | To some extent | - | Definitely |
| | **Single allocated professional who took responsibility for coordinating their care** | No | No | No | [redacted] | Yes | - | Yes |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **across the services they use** | | | | [redacted] | | | |
| | **Health care organised in a way that works for them?** | Definitely | Definitely | To some extent | [redacted] | To some extent | - | Definitely |
| | **Care plan in place that took into account all their health and wellbeing needs** | No | Yes | No | [redacted] | Yes | - | No |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | **Times when they have had to repeat information that should have been in their care records?** | No | No | No | [redacted] | No | - | Sometimes |

## 5.1 Dementia

Among people who died with dementia between 2018 and 2024, ambulance contacts and emergency department attendances were frequent, with a median of around two emergency department visits per person in the last year of life. This mirrors national data showing that people with dementia have high rates of emergency department use, particularly in the months preceding death (Williamson et al., 2023; Williamson et al., 2021). Many of these encounters did not result in prolonged hospital stays and the median length of stay was shorter than in other conditions. Previous research has highlighted similar patterns of short, repeated admissions, reflecting fragmented pathways and crisis-driven care (Sleeman et al., 2014). Most patients in our study died in hospitals or care homes, consistent with population-level data indicating that these are the most common places of death for dementia in the UK, with relatively few people dying at home (Sleeman et al., 2014). Access to specialist palliative care was lower than for other cohorts, with referrals often occurring only in the final days of life. This echoes wider evidence that people with dementia are less likely to receive timely palliative input despite high symptom burden and carer needs (NICE, 2018; Low et al., 2017). Patient perspectives and routine data in our study highlighted repeated transfers between care homes, emergency departments and acute wards, poor communication and limited involvement in care planning, findings that align closely with the wider literature on care fragmentation and the failure to deliver person-centred, coordinated support (NICE, 2018; Hudson et al., 2019).

## 5.2 Heart Failure

Patients who died of heart failure experienced high levels of unscheduled care. The median number of emergency department attendances was three per person and frequent hospital admissions often accumulated to more than two weeks of inpatient care in the last year of life. This aligns with previous studies demonstrating recurrent hospitalisations and high hospital death rates among patients with advanced heart failure (Singh et al., 2023; Abel et al., 2024). Although bed days were substantial, the median length of each stay was shorter than in cancer or liver disease, reflecting the “revolving door” admissions seen in other research (Singh et al., 2023). Most patients in this cohort died in hospital, though some died at home or in care homes, again reflecting national data (Office for Health Improvement and Disparities, 2022). Specialist palliative care involvement was inconsistent and often occurred late in the trajectory, a gap widely recognised in the literature, despite evidence of a significant symptom burden (Strachan et al., 2024). Routine data and PROMs/PREMs describing repeated admissions without holistic review or anticipatory planning are consistent with prior findings that end-of-life care in heart failure is poorly coordinated and rarely involves proactive planning (NICE, 2018; Tammes et al., 2017). PROMs highlighted the significant burden of fatigue and breathlessness, consistent with prior studies. At the same time, PREMs indicated gaps in coordination and self-management support, issues also emphasised in reviews of continuity and quality of care (Hudson et al., 2019).

## 5.3 Liver Disease

Patients who died of liver disease had the highest levels of emergency service use across all four conditions, with median emergency department attendances exceeding three per person in the last year of life. This is in line with earlier studies demonstrating very high acute care utilisation and crisis-driven patterns among patients with cirrhosis and end stage liver disease (Low et al., 2017; Peng et al., 2019). The hospital was the most common place of death, with relatively few patients dying at home or in hospice. This is consistent with population data showing that patients with liver disease are disproportionately likely to die in acute hospitals (Peng et al., 2019). Specialist palliative care access was lowest among the groups studied and usually limited to the final days of life, a pattern repeatedly identified as a significant inequity in the literature (Low et al., 2017; Low et al., 2015). Our dataset illustrated the unpredictable nature of liver disease with frequent crisis-driven attendances and admissions, likely for complications such as ascites, bleeding or encephalopathy. This unpredictable course has been described as a key barrier to anticipatory planning, contributing to reliance on emergency services (Low et al., 2017). PROMs data revealed very high levels of pain and fatigue, while PREMs captured low levels of trust in the healthcare system and dissatisfaction with coordination. These findings align with qualitative research highlighting poor communication, lack of prognostic clarity and missed opportunities for advance care planning in liver disease (Low et al., 2017).

### 5.4 Lung Cancer

People with lung cancer also had high levels of emergency service use, including multiple emergency department attendances and hospital admissions, but their care patterns differed from those of other groups. Median bed days were the longest of any cohort, yet specialist palliative care involvement was far more common and typically initiated weeks before death. This is consistent with robust evidence demonstrating earlier and wider use of palliative care in lung cancer compared with non-malignant conditions (Temel et al., 2010; Kochovska et al., 2020). As a result, a higher proportion of patients with lung cancer in our study died at home or in hospice, reflecting both policy targets and prior research findings (Office for Health Improvement and Disparities, 2022). Data highlighted the central importance of early specialist palliative care involvement, with patients reporting support aligned with their values, avoidance of repeated emergency transfers and improved decision-making. These effects have also been demonstrated in randomised trials of early palliative care (Temel et al., 2010; Temel et al., 2024). PROMs confirmed an ongoing symptom burden, particularly pain and breathlessness; however, patients were more likely to report coordinated care and involvement in decisions compared with those with other conditions. These findings align with the broader literature that positions early specialist palliative care as a key determinant of improved quality of end-of-life care in cancer (Kochovska et al., 2020).

## 6 DISCUSSION

This study demonstrates that unscheduled care use in the last year of life is extensive across all four conditions examined. However, the patterns differ in ways that reflect both underlying disease trajectories and systemic inequities in access to palliative care. Our findings add to a substantial body of literature documenting high rates of emergency and hospital use near the end of life, particularly in non-malignant conditions (Singh et al., 2023; Williamson et al., 2023; Low et al., 2017).

Patients with dementia and liver disease were especially disadvantaged, experiencing frequent crisis-driven contacts with services and minimal access to specialist palliative care. These results echo previous research showing that people with dementia or cirrhosis are less likely to receive timely specialist palliative care despite high levels of symptom burden and carer need (Low et al., 2017; Sleeman et al., 2014; NICE, 2018). Both groups experienced repeated transitions between care settings, poor communication and limited involvement in planning, consistent with qualitative studies that highlight fragmented pathways and a lack of coordinated anticipatory care (Hudson et al., 2019; Williamson et al., 2021).

Heart failure patients in our study also experienced repeated hospitalisations and substantial inpatient stays, reflecting a “revolving door” pattern described widely in the literature (Singh et al., 2023; Abel et al., 2024). Despite symptom burdens comparable to those of cancer patients, specialist palliative care referrals for heart failure remain inconsistent and typically occur very late in the disease trajectory (Strachan et al., 2024). This gap persists despite NICE guidance (NG106) explicitly recommending proactive planning and access to palliative care in advanced heart failure (NICE, 2018). Our patient perspectives reinforced these system-level gaps, describing a lack of holistic review, poor self-management support and missed opportunities for anticipatory care.

By contrast, lung cancer patients were more likely to receive earlier specialist palliative care and to die at home or in hospice, reflecting both the longer-standing integration of palliative care within oncology and robust trial evidence that early specialist palliative care improves quality of life, decision-making and alignment of care with patient preferences (Temel et al., 2010; Kochovska et al., 2020). Our findings closely align with the existing literature: patients who accessed early specialist palliative care reported more consistent support, coordinated care, and respect for their wishes, while also avoiding some of the distress associated with repeated emergency transfers (Temel et al., 2024).

The integration of PROMs/PREMs into this analysis adds important nuance. Across conditions, patients consistently identified poor care coordination, lack of involvement in decisions and limited trust in the system as potential drivers of repeated emergency care. These perceptions align with evidence linking relational continuity, such as sustained GP or community team involvement, to reduced hospitalisations and improved end-of-life experiences (Barker et al., 2017; Tammes et al., 2017). Conversely, patients who described strong communication, family support and proactive planning often reported fewer admissions and more goal-concordant care. This confirms earlier observations that continuity and coordination are protective, even when disease burden is high (Hudson et al., 2019).

Taken together, our findings highlight persistent inequities in access to palliative care across various conditions. Lung cancer patients continue to benefit from earlier specialist palliative care. At the same time, those with dementia, liver disease and heart failure face delayed recognition of palliative needs, poor coordination and crisis-driven care journeys. These results reinforce calls for systematic early identification of palliative needs in non-malignant disease, in line with NICE guidance (NG31, NG97, NG106, NG50) and for commissioning continuity-enhancing models of care that reduce avoidable emergency use and improve patient and family experience (NICE, 2015, 2018; Barker et al., 2017).

## 6.1 Strengths and Limitations

This study has several important strengths. It is the first attempt in Wales to integrate routinely collected, population-level data on unscheduled care with individual perspectives using PROMs/PREMs in the context of end-of-life care. By drawing on the All-Wales Last Year of Life Dashboard (Digital Health and Care Wales, 2024), we were able to capture service use for every person who died with dementia, heart failure, liver disease or lung cancer between 2018 and 2024, providing a uniquely comprehensive and population-wide perspective. This approach reduces selection bias and allows for the identification of variation both within and between diagnostic groups. Significantly, the study extends beyond cancer to include non-malignant conditions, a group for whom inequities in access to palliative care remain most pronounced (NCEPOD, 2024). The use of linked PROMs/PREMs data, drawn from the OECD PaRIS programme (OECD, 2023b), adds further strength, offering a multi-perspective view that complements traditional service utilisation metrics.

At the same time, some limitations must be acknowledged. Many of these reflect broader challenges associated with the use of digital dashboards and routine datasets. Coding completeness, although high (currently 89.3%), is not absolute, which introduces some uncertainty. Primary care and social care data were not fully available within the dashboard at the time of analysis. However, linkage with primary care data via the SAIL Databank commenced in April 2025 (SAIL Databank, 2025), representing an essential future opportunity. Similarly, key demographic and social variables, such as ethnicity and living situation, were not captured, which limits our ability to fully assess how social determinants shape patterns of care (Marmot, 2020).

There are also specific limitations to the measurement of “unscheduled care use.” In practice, this metric largely reflects emergency department attendances and hospital admissions, as these are the most consistently coded and comparable across time and datasets (NHS Digital, 2023). Other forms of unscheduled contact (such as ambulance events not resulting in conveyance, NHS 111 calls or GP out-of-hours encounters) were incompletely captured. For example, patient clinical records from the Welsh Ambulance Service are missing between 2021 and 2023, resulting in an underrepresentation of non-conveyance events. NHS 111 data were only consistently available for the 2018–2019 period and GP out-of-hours coding remains incomplete. Specialist palliative care data also records only initial contacts, meaning ongoing input is not visible (Marie Curie, 2024). These limitations mean that our estimates of unscheduled care may understate the full scale of system exposure, particularly outside hospital settings.

## 6.2 Next Steps

This study demonstrates the feasibility and value of employing a national digital dashboard, supplemented with PROMs/ PREMs data, to assess the quality of end-of-life care at the population level. However, the analysis provides primarily descriptive insights and does not yet elucidate the mechanisms underlying high levels of unscheduled care or specify where and how targeted interventions should be implemented.

Future work should therefore focus on addressing this explanatory gap. Mixed-methods approaches are likely to be essential, combining routine data linkage with primary care, social care, nursing and specialist palliative care records, as well as incorporating qualitative enquiry (NICE NG142, 2019). Case note reviews, incident report analyses and in-depth interviews with patients, families and clinicians can provide the contextual understanding that dashboards alone cannot capture (Allsop et al., 2022). Such work would enable a more comprehensive analysis of the human and system-level factors that drive crisis-driven care, including communication breakdowns, gaps in anticipatory planning and inequities in service access.

Building on the foundations of this exploratory study, these next steps can contribute to the creation of a fully integrated, multi-perspective framework for evaluating and improving end-of-life care in Wales. This would not only help to identify points where unplanned hospital use could be safely reduced but also highlight opportunities to enhance dignity, person-centredness and equity in the last year of life (OECD, 2023a; NHS Wales, 2021).

### 6.3 CONCLUSIONS

Unscheduled and emergency care dominate the last year of life for people with dementia, heart failure, liver disease and lung cancer in Wales. While high levels of service use were observed across all groups, stark inequities remain, particularly for those with non-malignant conditions who receive less timely access to specialist palliative care. By combining routine health service data with PROMs/PREMs, this study demonstrates the value of a multi-perspective approach to assessing the quality of end-of-life care. The findings show not only what happens in terms of system exposure but also how patients and families experience this care.

Policy and practice implications are clear. To deliver on the ambitions of Value-Based Health Care in Wales, future work should focus on expanding the systematic collection and linkage of PROMs/PREMs data, addressing inequities in specialist palliative care access across conditions and embedding multi-perspective dashboards into clinical practice. Doing so would help reduce avoidable unscheduled care, improve the alignment of services with patient values and support more equitable, efficient and dignified end-of-life care.

## 7 Report Conclusion

This project has demonstrated that unscheduled and emergency care dominates the last year of life for people with dementia, heart failure, liver disease and lung cancer in Wales, but with striking inequities in access to specialist palliative care between malignant and non-malignant conditions. By integrating routine utilisation data from the All-Wales Last Year of Life Dashboard with patient-reported outcome and experience measures, the analysis revealed not only what services are used but how care is experienced, highlighting persistent gaps in coordination, communication and trust.

The findings make clear that high-intensity, crisis-driven hospital care is neither inevitable nor aligned with person-centred priorities. Earlier access to palliative care, proactive anticipatory planning and embedding PROMs and PREMs into digital dashboards represent feasible, value-based interventions that can reduce avoidable hospital use while improving dignity, equity and person-centredness at the end of life.

For the client, Digital Health and Care Wales and wider NHS Wales stakeholders, this work demonstrates both the feasibility and the value of adopting a multi-perspective digital framework for evaluating end-of-life care. Implementing the recommendations outlined, which span anticipatory care triggers, specialist palliative care referral criteria, PROM/PREM integration and strengthened community capacity, would deliver measurable improvements in outcomes for patients and families, support a more efficient use of NHS resources and advance the national Value-Based Health Care agenda.

In conclusion, the project provides actionable, evidence-based insights that can inform policy, guide service redesign and enable NHS Wales to shift from a reactive, hospital centred model of end-of-life care towards one that is equitable, coordinated and truly person-centred.

## 8 Key Recommendations

Improving end-of-life care in Wales requires more than merely describing patterns of unscheduled service use; it necessitates systematic, actionable change that is meaningful for Digital Health and Care Wales, the NHS Wales Executive, Health Boards and frontline clinical teams. The findings of this project highlight clear opportunities to reduce avoidable crisis-driven admissions, address inequities in specialist palliative care access and strengthen person-centred outcomes by embedding patient-reported outcomes and experiences into routine practice.

The following recommendations are designed to be practical, cost-sensitive and transformational. Each link directly addresses identified system gaps, is aligned with *NICE NG142* on end-of-life care service delivery and supports the national ambition for Value-Based Health Care in Wales. They are presented in a tabular form to outline stakeholders, resources, timelines, measurable success indicators and associated potential risks, along with corresponding mitigations.

## 8.1 Recommendations Table

| **Recommendation** | **Stakeholder(s)** | **Resources Required** | **Approx. Timelines** | **Example Success Measures** | **Example Risks/ Mitigation** |
|---|---|---|---|---|---|
| Embed anticipatory **Last Year of Life Dashboard (e.g., flag patients with ≥2 ED attendances in 90 days for proactive** care triggers in the review) | DHCW, Health Board clinical leads | Data analysts, IT development, clinical governance oversight | 6 months to prototype;<br>12 months for rollout | Reduction in repeat ED attendance; increase in documented advance care plans (ACPs) | *Risk:* Alert fatigue.<br>*Mitigation:* Limit triggers to top risk groups; test thresholds with clinicians. |
| Standardise early SPC referral criteria across malignant and nonmalignant conditions | NHS Wales Executive, Health Boards, SPC services | National clinical guideline update; training for heart failure, dementia, liver disease teams | 9–12 months for consensus and adoption | Median time from SPC referral to death 3 months; reduction in hospital deaths | *Risk:* Resistance to change.<br>*Mitigation:* Align with NICE NG142 and professional bodies; pilot in one Health Board. |
| Integrate routine PROMs/PREMs collection into community and acute contacts | Health Boards, GP clusters, SPC teams, DHCW | Digital survey tools, staQ training, patient engagement materials | Pilot in 6 months; scale in 18 months | PROM/PREM response rate; percentage points in PREM “care coordinated” | *Risk:* Low uptake.<br>*Mitigation:* Keep surveys short; embed in existing workflows. |
| Expand community rapid response and non-conveyance protocols (WAST + SPC joint model) | Welsh Ambulance Services Trust (WAST), SPC providers | Paramedic training, access to Just-in-Case meds, telehealth SPC support | Pilot in 1–2 Health Boards within 12 months | Increase in nonconveyance rates for palliative calls; reduction in ED conveyance at end of life | *Risk:* Clinical safety concerns.<br>*Mitigation:* Governance framework; virtual SPC oversight. |
| Improve data completeness and linkage (close gaps in | DHCW, SAIL Databank, NHS Wales Executive | Data engineering staQ, governance | 12–24 months phased | Improved data completeness for core feeds | *Risk:* Technical delays.<br>*Mitigation:* |

| | | | | | |
|---|---|---|---|---|---|
| WAST, NHS 111, OOH, | | | | | Phased rollout; |
| add primary care & social care) | | agreements,<br>funding for linkage expansion | | and social<br>determinants | prioritise high-<br>impact datasets<br>first. |
| Establish ongoing<br>PPIE (Public and<br>Patient Involvement and Engagement)<br>panel to co-design metrics and dashboard outputs | DHCW, NHS<br>Wales Executive, patient/carer representatives | Funding for<br>PPIE, facilitation staQ, digital feedback platform | Launch within 6<br>months; report annually | Co-designed metrics<br>adopted; annual<br>PPIE report published | *Risk:* Tokenistic engagement. *Mitigation:*<br>Provide clear influence<br>pathways;<br>feedback loop to participants. |

## 8.2 Summary

Collectively, these recommendations provide a structured roadmap for transformation. Embedding anticipatory triggers, standardising specialist palliative care referrals, integrating PROMs and PREMs, and strengthening community capacity will enable NHS Wales to transition from a reactive, emergency care-focused model to a proactive, person-centred system. Enhancements in data completeness and patient involvement will support sustainability, equity and accountability, ensuring that the digital dashboard functions as a tool for continuous improvement.

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# 10 AUTHOR DECLARATIONS

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## 10.2 Competing interests

Digital Health and Care Wales developed the dashboard used in this study in collaboration with the Welsh Value in Health Centre and NHS Wales palliative care clinicians. Some authors are affiliated with Digital Health and Care Wales. The authors declare that they have no other competing interests.

## 10.3 Data availability statement

Data were accessed through the All-Wales Last Year of Life Dashboard, developed by Digital Health and Care Wales with the Welsh Value in Health Centre and NHS Wales palliative care clinicians. Access is available to all NHS Wales stab and selected Welsh Government professionals. Queries and requests for further information should be directed to the Information Services team at: dhcw.info@wales.nhs.uk.

## 10.4 Contributors

IJJ, AB, AS and JA conceived the study. All contributors designed the study and secured access to the data. IJJ, AS and JA conducted the analyses with support from AB. IJJ drafted the initial manuscript. All authors contributed to the interpretation of the findings, critically revised the manuscript for important intellectual content and approved the final version.

## 10.5 Ethics

This study was reviewed by the Digital Health and Care Wales Innovation Board, which classified it as a service evaluation. As such, formal NHS Research Ethics Committee approval was not required. All work was conducted in accordance with the principles of the Declaration of Helsinki (World Medical Association, 2013).

No identifiable patient, participant or sample data were used in this study. All data were anonymised at source and small number suppression was applied in line with NHS Wales information governance requirements.

The study was not a clinical trial and therefore did not require registration with an ICMJE approved registry. Reporting followed the RECORD (Reporting of studies Conducted using Observational Routinely collected health Data) guidelines (Benchimol et al., 2015).

# Information sharing in a hospital discharge context: could we do better?

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## Abstract:

Hospital discharge has long been an issue for the NHS and Local Authorities to contend with, as much in Wales as in the rest of the world.

Despite efforts toward improvements, it is still a part of the health and care system that puzzles.

One element of the process identified as incomplete is information sharing, both as a primary tool of work for operational staff and for secondary, strategic, purposes.

This paper considers information sharing in the context of hospital discharge and whether we could be doing better. It explores why this question matters by delving into the literature and talking to staff involved in the work; it identifies obstacles to good information sharing, and what could help mitigate against them.

**Keywords:** hospital discharge, data, information, health and social care, automation, primary data use, secondary use of data, delay, governance, routine data.

## Table of Contents

# 1 Introduction

Personal experience in supporting front line colleagues, and the difficulties they encounter in obtaining relevant and timely information for the purpose of safely and expeditiously discharging individuals from hospital, was the reason for asking the question: ‘could we be better at information sharing in a hospital discharge context?’

The question felt was equally useful in considering secondary use of data, if not more so. Similarly, the underused functions of linking and automating data were also valid and relevant avenues of research.

# 2 Background

There have been several drives to improve this aspect of service provision over the years with such models as Home First and, currently, D2RA. They link up with concepts found in the Social Services and Well-being (Wales) Act 2014 that support the establishment of very local Community Resource Teams which aim to improve collaboration between services that traditionally operated very independently of each other, and to address such ideas as ‘single care coordinator’ and ‘single referral to the community resource team’.

There have been failed attempts at creating a single record for health and social care e.g., WCCIS in recent years, which have led to the pursuit of alternative means (i.e., ‘workarounds’) of sharing information – formally, but mainly informally.

One (implicit) aspect of collaboration as suggested in the above model, therefore, is the seamless flow of information between relevant individuals, professions, and organisations. There are clearly many factors that influence the good and expeditious discharge of individuals from hospital, and, understanding whether information sharing has a direct or indirect bearing on an individual’s progress from hospital to home is beyond the scope of this research. For the purpose of this work, it will be assumed that information sharing is a key part of the puzzle and worthy of in-depth consideration.

We have the legislation at our disposal in Wales, IT has advanced to the point where it ought no longer to be a barrier in a practical sense, in the way it once would have been. However, there is a general feeling that in information sharing, we could indeed do better within and across organisations.

Thus, there are still calls for improvements in information sharing, within and across organisations, including to support hospital discharge. This perhaps comes predominantly from Local Authority colleagues, who see their health board counterparts sitting on vast arrays of data relating to their clients and only being able to acquire information in a piece-meal manner and on a need-to-know basis. (You don’t know what you don’t know so you don’t know what to ask).

In Wales, the Welsh Accord on the Sharing of Personal Information (WASPI), created in 2005, has led the way for safe and intelligent information sharing, with many organisations, including the health boards and Local Authorities signing up as partners.

In 2017, Welsh Government published a Statement of Intent regarding the “Better use of health and care data for safe, effective care and efficient services”. Here, the Government outlines its key priority areas and principles for information sharing. It states: “Our intention is to ensure that the health and care system in Wales is able to take full advantage of the value that data offers.”

“...we want health and care workers to have the digital tools and access to information they need to coordinate and deliver care, and for individuals to be empowered to play an active role in decisions about their own health and wellbeing through access to their own health and care information.”

It related to the sharing of routine data for primary purposes as well as making secondary use of the data to plan and strategize.

Much of the sharing that is done is to assuage the information generating demands of Welsh Government in its desire to meet targets. StatsWales’ once monthly Census which provides a single day snapshot of Delayed Transfers of Care (DToC) and reasons (instigated and coded by the Health Boards, corroborated or otherwise, by Local Authorities) is a prime example of where data may highlight certain trends. However, missed in this is any purposeful effort to generate data sets that are actionable and applicable to the day-to-day work of organisations in executing their statutory duties.

Thus, this paper aims to understand some of the barriers that exist to effective information sharing, with a focus on hospital discharge. It considers the literature as well as evidence from personal experience – both reflexive and via interviews and questionnaires and also examines the legislation and WG directives that relate to information sharing to see how they help or hinder.

# 3 Literature Review

## 3.1 Introduction

Coming from a perspective that information sharing in a hospital discharge context can be improved, and that this is a worthy endeavour, a literature review was undertaken to gain a greater understanding of the matter. It would also serve to identify knowledge gaps and either counter personal and anecdotal findings and assumptions or lend credibility to them.

All types of studies/papers were included, as the purpose of the exercise was to gain a wide perspective and be open to other relatable sources not necessarily covered by the search terms. Discussions about all types of data and information were considered to be in scope, as were the reasons for using the data, as long as they could be related in some way to hospital discharge.

Although the academic integrity of the reviews was important, of greater value was their relevance to the main topic.

The review explored whether literature existed that discussed hospital discharge as the responsibility of health *and* social care organisations, not just as a function of health. If discussed only in terms of health settings, then identifying the perspective mattered. Also, the perceived status of data and information, and the perceived value of data sharing; was it seen as worthy endeavour? If so, why?

The purpose was also to understand whether there were any obstacles to sharing information (within and across organisations) beyond one's own experience, especially in a hospital discharge context. If so, what were they? Were there commonalities? Were there any obvious themes? Were there contradictions?

Initial searches would be focused on such themes as information sharing, hospital discharge, patient flow, data and delayed transfer of care, secondary use of data, health and social care; and also, hospital discharge information sharing, health and social care information sharing, linking health and social care data.

Searches were conducted in Scopus, Cronfa (Swansea University Database), Google Scholar, PubMed and ChatGPT.

## 3.2 Themes

There are different types of data that were prevalent in this context: this review was interested in routine data only (also known as routine information and real world data) i.e. data gathered about clients/patients in the normal course of work, and the way they are used or shared, especially to support hospital discharge. It did not consider papers that related to research-generated information and data.

Data was classed in relation to its use for primary or secondary purposes. For primary purposes, data would be used by staff in executing their daily functions; for secondary purposes, to understand the landscape and to inform planning and strategy.

The definitions hospital data, health data and personal health data seemed to be interchangeable; likewise, care or social care information or data. The terms Transfer of Care (or Delayed Transfer of Care – DToC), hospital discharge, patient flow, handovers – were also related.

Any terms that could be substituted for each other would be interpreted in the same way, in general.

Automation was another aspect of information sharing that would be within scope, as it had already been achieved locally. Understanding whether this had been done elsewhere and how well, would be pertinent.

In undertaking the review, the scope did expand. This was to incorporate unforeseen themes that were clearly relevant i.e. the views of citizens in the sharing of personal data, which had thematic resonance with information governance and ethics; health information systems or (shared) electronic record systems or electronic patient records – the IT component of data; and factors that influenced uptake of new ideas or technologies.

## 3.3 Debates

One paper, a 2024 study by de Bell, S., Zhelev, Z., Bethel, A. et al., delved into the “Factors influencing effective data sharing between health care and social care regarding the care of older people...” This was the paper that most resonated with the theme of this research. Its focus was on the care of older people, which is of practical interest, and it emphasised the necessity of information sharing around this cohort of people due to the complexity of their needs and multi-agency involvement. More importantly, however, was its focus on information sharing between health and social care. It identified four main themes: goals, relationships, interorganisational processes and procedures, and technology.

Within the goals theme, the researchers found five reasons for sharing data and information, including hospital discharge (or the transfer from hospital to home). This is reassuring and confirms the empirical view around information sharing and its value in this context. For the other themes, they reasoned that fostering good relationships between professionals supported information sharing – and that sharing information should be done in ‘multiple ways’; similarly processes and procedures between organisations relating to information governance and formal agreements were important; finally, technology and infrastructure were viewed as vital for data sharing.

Another study proposed that for patients in ED, individuals who present frequently are likely to access other community and health support provisions. Therefore, they advocate that in any interventions, including integrated data systems, partners beyond the ED should be involved (Raven, M.C., Kanzaria, H.K. 2021).

Other papers reiterate that support (or lack thereof) by senior leaders also influences the outcomes of endeavours in this field, as do legislation and funding.

Out of the twenty-eight abstracts read, eight referred to the ethical matters surrounding information sharing, and were concerned with public engagement and collaboration on the matter. Whilst relevant to the broader discussion, these studies were not conducted in Wales, where information governance legislation relating to the sharing of personal information is more comprehensive and somewhat ahead of the curve (see WASPI). Nevertheless, they make salient points and reiterate the need for information sharing across agencies.

There was debate around such topics as consent and the right to withdraw it. And whilst information governance processes were viewed as vital in ensuring public trust in organisations, they were felt to pose barriers to progress. In one study, participants in focus groups tended to regard primary data use over secondary data use more favourably – and this was reiterated in other studies. Furthermore, there was consensus around the need for improved communication with the public about the secondary use of data in particular.

Nevertheless, all papers concerned with information governance and the public view agreed that information sharing in a health context was a useful endeavour – but needed to be done ethically, and with care and consideration. Of these papers, some considered the real time sharing of real-world information for operational purposes; fewer were the studies that considered the secondary use of data other than in its ethical context. None delved deeply into the flow of patients and information between the acute setting and the community, with the involvement of social care.

Pertinently, Heslop PA, Davies K, Sayer A, et al., in their 2020 paper *Making consent for electronic health and social care data research fit for purpose in the 21st century*, offer solutions to some of the issues noted above in obtaining consent. Among suggestions, they advocate that governance “shift to platform level rather than project level” as used by the Dundee Health Informatics Centre, in which a “single umbrella ethics approval covers a wide range of health informatics projects, with per-project approval devolved to a data access committee with external oversight”. Yet, they concede that this advancement in the way data can be used – for operational and strategic purposes in health and social care - in line with supporting technology, does likely clash with people’s views about the use of their personal information to this end without express consent, and that this needs to be managed to mitigate the risk of losing public support.

## 3.4 Gaps

Given the prevalence of consent as a theme of information sharing in the cited literature, it is difficult to ignore the fact that no reference was found to the Wales Accord on the Sharing of Personal Information (WASPI). WASPI presumes in favour of sharing information and supports this by providing broad guidance and supporting forms and documentation. There may be room therefore to further consider this omission in the literature and understand how including it in further studies could inform data sharing developments elsewhere.

Hospital discharge is one aspect of patient flow, but with a critical component, that is, its juncture with community services. In studies concerned with hospital discharge and patient flow, focus tended to be on the health or hospital aspect rather, and reference to community partners was sparse. This included matters of data sharing and information flow, and governance issues.

Although a few of the studies acknowledge a role for Social Care or other partners, the main focus of information sharing was within health. One study, however, did explicitly examine data sharing between health and LA partners (de Bell, S., Zhelev, Z., Bethel, A., et al.), and although it proposed solutions, the focus was general and hospital discharge seen as part of a bigger network of matters that needed attention. This was in keeping with the broad scope of the paper, but its findings do warrant further, individualised attention.

Therefore, there is room for considering information sharing and data linking in a broader Health Board/Local Authority context: in terms of their immediate application for front line/operational staff, and in terms of using linked data sets for secondary (e.g., strategic/planning) purposes.

The underlying purpose of this being facilitating and improving discharge arrangements, prevention of unnecessary admission/readmission, and tapping into the greater role information sharing has in improving systems for staff and, ultimately, supporting the health and well-being of citizens. One study does recognise the need to involve other partners beyond the acute setting and considers integrated data systems (i.e., information sharing) to be part of this solution (Raven, M.C., Kanzaria, H.K., 2021). However, this focused on the matter from the ED perspective only.

Where Transfer of Care and/or Patient Flow were the main areas of study, less emphasis was given on information sharing / data linking (both for operational and secondary / strategic use) than on more obvious “culprits” such as lack of home care and residential placements.

I found no studies that identified the express lack of information sharing in any of its guises (linked data sets, operational information) as a hinderance to good and expeditious hospital discharge. Nor were any studies found, bar one, that critically examined the impact of information sharing on hospital discharge. However, information/data sharing or data linking were cited as elements of collaborative, person centred services. But, in terms of automation of data – for example, to save time – nothing was found in the literature that examined this idea.

There is a need to understand what good looks like for front line staff as they contend with inadequate information when attempting to provide the best service possible. Especially in relation to the flow of persons (and their information) between settings – usually from the acute into the community but also in the other direction.

However, there were no obvious references to the difference in the type of information needed by various practitioners e.g., front-line staff needing real time information to make operational choices, whereas for planning purposes there was a greater need to make secondary use of data. Neither were there any detailed discussions that related to the sharing of information at particular junctures e.g., handovers in hospital settings, handovers between professions, referrals within and across organisations.

# 4 Methodology

## 4.1 Approach

For my research I applied a mixed methodological approach to the question of Information sharing in a hospital discharge context: could we do better?

Although the research, derived from primary sources of information, would tend toward the qualitative, some of these results would be further examined and coded to provide quantitative insights.

The aim of the research was to identify themes and narratives within hospital discharge and associated fields and see whether they converged or diverged. This would be important later on in understanding whether the outcomes of this research resonated with findings from the literature review.

Instigating the conversation would be my personal reflections, having worked and supported LA and health colleagues for over five years with hospital discharge.

## 4.2 Data collection

A combination of personal reflections, semi-structured interviews, a questionnaire, and e-research would be employed to gather the information with as broad a perspective as possible.

### 4.2.1 Personal reflections

Personal reflections would be used as a benchmark from which to understand the output from the other research avenues. It stems from working with social care and health colleagues on this agenda, with experience of obstacles and successes. The value of this line of research is its subjectivity, which also dictates a need for input from other methodologies as a counterbalance.

It provides firsthand insight into what has already been achieved to facilitate information sharing in a hospital discharge context; what barriers have been overcome; and what helped remove or circumvent these barriers.

### 4.2.2 Semi-structured interviews and questionnaire

Semi-structured interviews were conducted with two senior colleagues. Interviews were requested with these individuals due to their proximity to the work around hospital discharge, their leadership roles, and influence. Both have different priorities but work on similar agendas. Although the question of information sharing framed the conversation, participants were free to follow their own train of thought, with follow up questions asked for clarity and to further probe.

A further purpose for the interviews was to get a more in-depth picture from a strategic perspective, as compared to the questionnaires. And, although exploring a personal perspective again, the views would differ from mine, thus ensuring a balanced commentary.

Since the interviews were anonymous, colleagues also felt comfortable to converse openly.

A questionnaire was circulated to twelve other colleagues with a request to circulate further if possible. The respondents were selected due to their association and interest in collaborating to improve hospital discharge. Their roles ranged from front line staff to managers, and roles were diverse, operational, and strategic. Results were anonymous, and there were ten responses.

To be considerate of participants' time and other duties, questions were few (16) and fairly superficial. Respondents were requested to answer as many of the questions as they wanted or were able to, and not to take too long pondering the answer. This was also so that answers would be instinctual rather than contrived.

It was also important that the questionnaire be available in Welsh and English to provide choice for the participants and ensure they felt comfortable and able to respond naturally.

As far as possible, questions were worded openly, to avoid leading the respondents. Some questions were repeated in different contexts for counterbalance. Wherever a negative term was used e.g., obstacle, the respondent was also asked to think about the positive e.g., enabler.

Having open questions also provided the respondents with space to give their own slant on the matter. E.g., the terms primary and secondary uses of data was not mentioned – this would have meant little to some respondents, and could have shut down the conversation, for others who were more familiar with data, it would have perhaps led the participant.

Since the purpose of improving hospital discharge is to support individuals to have better lives and a better experience, it was important to bring this into the recipients' minds. Therefore, a question was included to this end.

As the recipients are expert in their own fields, I was also keen to understand whether there was anything that should have been asked and was not included. So, an additional question addressed this matter as well as a follow up request to state what this question should have been, and the answer.

Understanding to which organisation the respondents worked and their position in the organisation were important to establish the relevance of data and/or type of data to their roles.

The questions also attempted to elicit the respondents' thoughts and views about information sharing as a general topic, but also about the effectiveness of information sharing within and across organisations.

### 4.2.3 Web-based and E-research

The e-research mainly examined the legislative context and the political landscape, the purpose of which was to understand the way and the degree to which information sharing (in a hospital discharge context) was supported.

Within scope was any publication or Government Report or Publication that referenced hospital discharge, patient flow, information sharing/collection, data sharing/collection. Terms were inputted into search engines, and the Welsh Government website was trawled to find any further information under social care sub-topic, for example.

A similar search was undertaken on the NHS website, and the website of Information Controller's Office and that of Digital Health and Care Wales (DHCW).

Of relevance was whether there existed any guidance around information sharing across organisations, and whether government focused on primary or secondary uses of data, and were they seen as discrete concepts or as part of a whole. Any existing or proposed mechanisms or initiatives for improving data sharing would also be within scope.

# 5 Results, findings, discussion

## 5.1 Objective

This mixed methodological approach undertakes to identify whether there exists a body of evidence to support the idea that barriers do exist to information sharing in a hospital discharge context. Further, the hope is to understand what these barriers may be and whether there are suggestions on how to overcome them.

Personal and anecdotal evidence presumes a need to improve information sharing in a hospital discharge context within and between health and social care services, for front line (operational) and planning (strategic) purposes. Due to increasing pressure from the Government and the public to improve this aspect of services, the research is timely.

## 5.2 Results, findings and discussion

### 5.2.1 Reflexive methodology

Below are some of the impressions gained over the past five years from direct and indirect involvement in supporting teams with hospital discharge processes.

Anecdotal and experiential evidence points to various elements of hospital flow or discharge that could probably benefit from better information sharing and, if resolved, could help front line staff with their duties. These obstacles generate additional work for staff and lead to wasted time. Examples include the inability to contact the ward or social services over the phone, emails being blocked or bouncing, information being out of data, referral forms being incorrectly filled and sent back and forth, patients changing ward, no knowledge about other professions involved in a patient's care e.g. home care, a lack of knowledge about home care packages or the name of the provider, whether the patient needs equipment upon returning home, and whether there is family or community social support.

From a planning and strategic point of view, the current inability to use data for secondary purpose is a hinderance. Both LAs and HBs miss out on a great deal of useful data: data that, if shared, could support better planning of services and more intelligent allocation of resources, and facilitate better discharges.

There seems to be little automation in information sharing, particularly across organisations, despite this being supported by various WG directives and statements of intent, and little is known as to the efficacy such an approach could have on improving hospital discharge. However, to this end, some health boards and hospitals have developed patient dashboards that, among the information, show the intended discharge pathway for an individual. As a rule, this kind of dashboard, despite its clear benefits, would rarely be shared with colleagues from other organisations, such as the Local Authority, because of IT restrictions. However, there is work ongoing to break down some of these barriers, and there are examples where two-way information sharing across organisations (Health Boards and Local Authorities) does happen. These dashboards show real-time information about patients in a hospital setting coupled with Local Authority data such as home care provider, package of care, and social worker. But they are not yet commonplace or well promoted.

Lack of easily available or automated and well-presented information creates work for staff on multiple organisational levels. This links back to both primary and secondary data uses. As noted above, much staff time is spent chasing information from various sources for use in direct patient care. Middle and senior management are also required to present information to Government such as the monthly census that feeds StatsWales' statistical reports on DToC. Again, this requires time consuming data gathering and inputting – work that could be automated or at least be facilitated by IT and better information sharing platforms.

Welsh Government created the WASPI information sharing framework in 2005. It is founded on the principles of the Data Protection Act and GDPR and provides ample supporting documentation for good and ethical information sharing. It is in keeping with the Eight Caldicott Principles of information sharing and should make data and information sharing a much easier process. However, there is still fear around the improper use of data and of breaking GDPR. This hinders progress, as does the perception of lengthy form filling related to comprehensive, lawful data sharing.

Given the benefits, however, the paperwork should be of little concern. Nevertheless, this partly relates to data literacy and to a possible lack of understanding of the wealth of knowledge inherent in shared data sets. The possibilities are enormous and could transform our ability to support services to better serve citizens. In which case, the obstacles would seem less unsurmountable. Understanding the tools at our disposal to interpret and present data and to use them appropriately is part of this learning curve, and it seems an aspect we are missing.

Greater collaboration between organisations and individuals within and across organisations instigate and enable a better understanding of how things work on both sides. In terms of information and information sharing, this currently happens on an ad-hoc basis without real structure. Therefore, how good we are ebbs and flows according to the level of interest of those involved. It depends on push from government and additional funding to increase capacity and to drive the work forward, and on the interest and attention of senior leaders to galvanise colleagues within their own organisations and beyond.

### 5.2.2 Interviews and questionnaire

Two semi-structured interviews were conducted to gain a high-level view of information sharing from a front-line service perspective and from the perspective of a support service. They are referred to as Participant A and Participant B.

Several themes emerged from the conversations; and, given the different roles of the participants, this is no surprise. However, there seems to be one prevailing message, other than that we could be doing better, and that is, the influence of information sharing on (staff/personnel) resources and ultimately on time.

Participant A identifies where poor information sharing practices exacerbate already complex situations, whilst Participant B proposes means of overcoming them. And, whilst Participant A discusses the matter more from a front-line perspective, whilst alluding also to reporting purposes, Participant B considers information sharing more in terms of planning and strategy.

Both participants identify the time wasting created by poor information sharing as an issue.

What information is shared, when the information is shared, how the information is shared, and with whom are four questions that are raised – directly or indirectly – as themes in the interviews. All of which influence the use of time as a valuable commodity. The why of information sharing is also touched upon.

Different services need different types of information, one's place in the system really does dictate what is necessary to know to participate successfully.

It is implied that much time is wasted due to the inaccuracy of information shared between organisations. This stems as much from the dynamic nature of hospitals as anything else and both participants are cognisant that information sharing is a two-way street.

Inadequate or incomplete information, according to Participant A, makes it "difficult to take action." This sentiment is reflected by Participant B, who says that "without information we can't deal with things pre-emptively". However, this participant also discusses and considers the information that is needed to instigate and conduct conversations to facilitate good discharges, and the differing type of information that would be useful to take pressure off front line teams as a result of adequate pre-emptive planning capabilities.

Neither participant details the exact information that would be needed in different situations, as the conversation was more general, given that we had only half an hour to discuss this broad subject.

According to Participant A, to initiate discharge to community services e.g., home care, information initially needs to be transferred to from the health board to the local authority. It seems that the quality of the information shared has an impact on the ability of the receiving service to respond. There seems to be a discrepancy between what is provided and what is needed in terms of volume, accuracy, timeliness, specificity.

Participant A discussed the fact that "information may be out of date by the time it reaches the Local Authority and, since things change so rapidly in a hospital setting, needs to be checked time and again to ensure accuracy."

What this describes sub-textually is that much time spent on chasing information. It also suggests, sub-textually, that this is something that occurs frequently and has consequences if not done right and if information is taken at face value.

This also erodes trust which needs rebuilding; and this takes time and dedication.

Participant B alludes to primary and secondary uses of data. The primary data uses being consistent with Participant A's views in that access to the same data is required for the front line. Yet, Participant B talks in greater detail about the potential to generate efficiencies, and consequently better services, through using data properly [as secondary use].

Timeliness of information sharing is also a theme that comes up in the conversation with Participant B. Participant B explains how improving information sharing could help "speed up processes" and expands on this by describing how some services may "find out about things at the last minute" and don't know "for a long time".

Participant B also discusses a different aspect of the idea of time and information sharing. Implicit in this individual's words is the power of information to enable organisations to plan and work pre-emptively – thus helping teams be proactive rather than reactive, as happens when information isn't shared expeditiously – and use the time resource wisely.

For front line staff and management, the methods of information sharing are mostly email (including referral forms or excel sheets), or verbal – over Teams meetings, telephone, or in person.

This modus operandi does not provide the best foundation for good discharge. In fact, given the complexity of the situation in the first place (a person's multiple needs perhaps or home circumstances), the diverse means of communicating and the many variables that staff have to contend with, makes hospital discharge a precarious endeavour.

There is no explicit mention of the automation of data sharing in either interview, although, this is implied as one solution by both Participants – e.g. Participant B refers to "shared data sets" and Participant A mentions "access to dashboards" with the ability to highlight delays or gather accurate information promptly.

Thus, a case is made for a better information sharing system. This is reflected by Participant B who expresses the need for "systems that talk to each other" in the absence of one shared system.

The "whys" and "with whom" of information sharing are closely related themes, since the why dictates the whom.

For the Local Authority, the escalation of DToC cases takes place by various means and for various reasons. This information tends to be reserved initially (in bulk) for senior leaders who then refer to team leaders and then to individual practitioners.

For senior staff, information sharing from the discharging body to the receiving body seems to be driven by escalation of concerns, particularly Delayed Transfers of Care. There is the DToC list created by the health board and shared with LA teams via email. "Escalation emails are also sent." There are also the hour-long DToC meetings that take place three times a week over Teams.

One reason for sharing DToC information, as discussed by Participant A, is the need to report to Welsh Government for the monthly census. It is a “lengthy and time consuming” process.

Health Boards and Local Authorities are also required to submit data on Delayed Transfers of Care to Welsh Government. Delay reasons are coded, and statistics displayed on the StatsWales website and can be filtered to Health Board and/or Local Authority level. “It does show where the obstacles are - residential beds, dementia beds,” but it also feels like a “performance monitoring exercise.”

In the same way that Participant B suggests that better systems, systems that “talk to each other” and “shared data sets,” could pave the way for greater collaboration and understanding between organisations, Participant A proposes ways in which it could directly support time saving endeavours. DToC meetings, for example, are held for an hour, three times a week to escalate and discuss individuals who have been in hospital for 48 hours or longer after being declared medically optimised. With existing systems and correct procedures, the escalation procedure could be conducted electronically and to greater effect.

Both participants allude to the inadequacy of the resource currently available to support hospital discharge – referring to information sharing directly and indirectly in this context. Participant A notes that “without resources, nothing will change” (despite the Government’s wishes); whereas Participant B says that “more resources... could be provided to make it work” and notes the “need” for more “dedicated officers who work full time on data”.

Whereas Participant A is referring to the shortage of e.g., residential home beds and dementia placements, Participant B is referring to investing directly in information sharing infrastructure and personnel. This is noteworthy, as it demonstrates the value placed on information sharing as a tool and where it stands in the pecking order of needs.

Participant B frequently refers to processes, demand and planning, pre-empting demand, and the “proper” use of data. This individual sees data as a means of supporting the front line and create efficiencies. Currently, for Participant A, data and information sharing are problematic, and in many respects are themselves barriers.

Shortcomings in this respect creates blockages and generates additional work for staff – both Health Board and Local Authority. Again, this relates to ‘the use of time’ as a theme of Information Sharing in a Hospital Discharge context.

The questionnaire contained sixteen questions and there were ten responses. Four participants work for the LA, four for the HB, one is a unique post that spans the HB and LA, and another works for Public Health Wales. Of the respondents, six were middle managers and four were front-line staff.

Two questions asked participants about their views on information sharing. One asked about what they thought when hearing the term ‘information sharing.’ the other asked about their feelings.

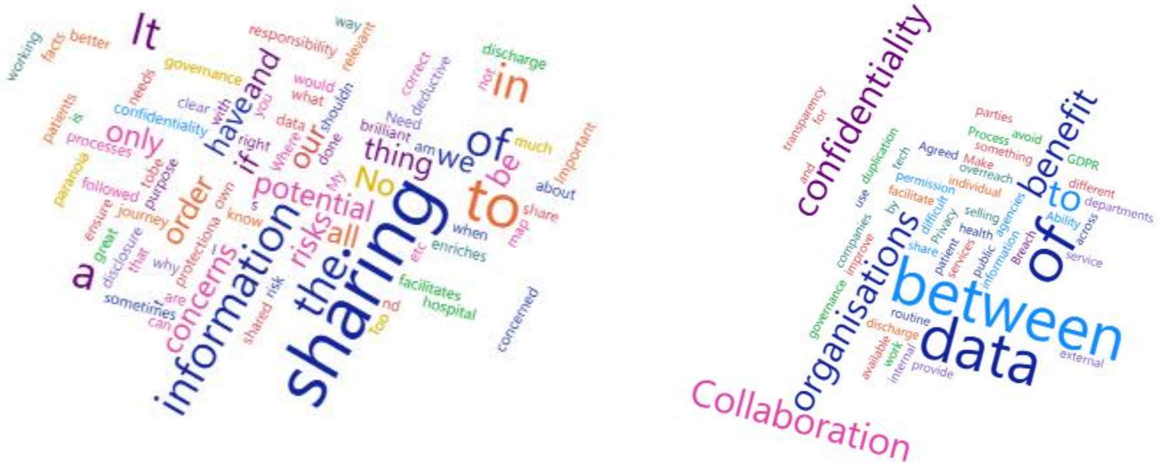

Figure 1. PowerBI generated word cloud showing how respondents to the questionnaire feel about information sharing

Of interest is the positivity of the larger words, which include collaboration, sharing, between, organisations, benefit. Secondary, are words such as: concerns, risks, confidentiality, and potential. These secondary words temper the enthusiasm implied by the former and point to some reservations around the subject.

Coding the responses revealed that both front line staff and middle managers felt equally positively toward ‘information sharing’, and this reflected the sentiments in the word clouds. Fifty percent of terms were positive compared to 17% neutral words and 33% negative words. For front line staff, the split was 50% positive, and 25% neutral and negative, respectively. For middle managers, words that resonated positively were sharing, potential, between; and for front line staff, the stand-out positive words were collaboration, benefit, facilitate, and individual.

However, the percentage of negative words evoked by the term ‘information sharing’ was greater among middle managers than front line staff. For the managers, the downside seemed to be around governance, privacy, and stealing data, whereas for the front-line staff it was ‘breach of confidentiality’ that seemed to carry the greatest burden.

Across the Health Board (including Public Health Wales) and Local Authority, participants felt more positively about information sharing within their respective organisations, with 50% of responses reflecting this compared to 33% positivity when considered across organisations.

For additional nuance, the exuberance with which participants rated the information sharing differed for these two questions. Whereas the positive scale for sharing within organisations ranged from good to very good; across organisations, the pinnacle of excellence was rated ‘fair’.

There is consensus that information flow is better within organisations than across. Within respective organisations, the percentages of negative (33.5%) and positive (66.5%) responses were the same for the HB and LA. However, all front line/operational staff felt positively about internal information sharing, but the figure dropped among middle managers to 20%. Twenty percent of middle managers had neutral feelings, and 60% were not impressed.

Only a third of participants felt optimistic about the current state of sharing information across the LA and HB. Common negative themes that emerged related to IT systems and culture and “hurdles devised by all parties.” Information governance was quoted as a barrier, as was “signing off” [on information sharing] which “can be a lengthy process which could lead to delays and loss of interest.”

One participant highlights the WASPI framework developed 20 years ago that exists to “facilitate the sharing of information between organisations.” However, this participant also cautions that a lack of awareness of its existence “may mean that... organisations feel that Data Protection is a barrier to sharing information.”

On a positive note, however, the good relationship front line staff had with each other helped information sharing across organisations. This observation was reflected negatively by other participants who noted that “we depend on individuals” for effective information sharing i.e., it is individuals despite the system that make things work; similarly, a focus on bureaucracy inhibits “verbal communication” which another participant implied was more effective.

There was ambivalence with regards to progress within the field over the past year, but feelings were more positive than otherwise.

As regards to contributing factors (not necessarily over the past year), collaboration, close multi-agency working, sharing workspace, face to face/virtual communication (rather than electronic [text] comms), were all identified as positive influences. The theme that emerged here was ‘culture/personnel – ways of working’. This theme was most prevalent among front line/operational staff, whereas with middle managers, Information Governance, and IT & data literacy also featured e.g., through the use of PowerBI and such software.

What hindered good information sharing according to the responses, however, was linked to processes and system efficiency, IG, and IT. It was insinuated that much time was wasted because of these types of obstacles: E.g. Insufficient time, resources, and the “requirements for signatures” (which takes time); inability to see calendars when organising meetings and lack of response to correspondence (which takes time); lack of permissions and subsequently emails being blocked (which takes time); and the “many requests for referrals and delayed meetings” (which also take time).

Opinion on the best way to share information differed according to role.

Of note is that two managers who also have operational roles state that the best way of sharing information is verbally. One front line respondent reiterates this.

For others, it is systems - the way they are used and access to them are important, as are security matters.

The type of information that is sought varies between professions.

The most prevalent theme that emerges here is information governance with its close links to IT systems. Participants mention the best way of sharing information being secure files, computer system, integrated systems (e.g., PowerBI), confidential access to systems. IG and IT accounted for 66% of the responses.

However, 33% of respondents stated that matters related to 'Trust and relationships' were the best ways of sharing information. This matters, because – although respondents that rated "trust and relationships" as being of utmost importance predominantly had front line roles – building the necessary IT systems (as described by participants) with the support of sound information governance needs these two vital elements.

For operational staff, knowing who is involved is important. So is obtaining information about the patient from the "other" organisation's perspective. Having access to this information is necessary, but it would help if there was "one record for the patient instead of 10". This knowledge would be best conveyed either verbally or via access to systems, or via integrated systems (with information presented in dashboards, such as with PowerBI).

In the interest of information sharing for strategic purposes, security is again vitally important; so is the ability to bring information together. And, although "...It is important for organisations to understand the legal and ethical grounds for sharing and distinguish between the arbitrary ownership of data... and important separation of data", we must also guard against "too much governance paranoia".

Participants unanimously felt that information sharing benefited individuals, with one participant suggesting that the benefits are indirect. The message here is that more information means an improved service. It supports individuals to achieve what matters to them and avoids having to repeat one's story unnecessarily. There is a note of caution in that information sharing must be "done right and with a purpose", and that there is a need to be clear about "why [we are] sharing and potential risks [from] (deductive disclosure)". This is supported by another participant, who notes the importance of following "correct processes."

Time features yet again: "expedient and smoother discharge," and "less delays" are identified as outcomes of better information sharing.

### 5.2.3 Web-based research and e-research

In 1997, six initial principles of information sharing were identified as part of a review into NHS information sharing, chaired by Dame Fiona Caldicott. Revised in December 2020, the (now) Eight Caldicott Principles provide organisations and services with a firm foundation in the good and ethical sharing of confidential information in supporting citizens. They examine the way the use of confidential information must be "justified", used "only when necessary", kept to a necessary "minimum", shared on a "strict need-to-know basis", ensuring those with access must be "aware of their responsibilities", that it must be lawful, that the "duty to share for information for individual care is as important as the duty to protect patient confidentiality", and that "patients and service users" must be informed about "how their confidential information is used".

The importance of adhering to these principles is indisputable, and for the question of information sharing in a hospital discharge context, Principle 7 stands out as an enabler.

"Health and social care professionals should have the confidence to share confidential information in the best interests of patients and service users within the framework set out by these principles. They should be supported by the policies of their employers, regulators and professional bodies."

In Wales, since 2005, "The WASPI Framework provides a practical approach to sharing personal information, providing common standards and templates for developing Information Sharing Protocols (ISPs) and Data Disclosure Agreements (DDAs). Its overall aim is to help public service providers deliver effective services while complying with their legal obligations – namely the UK General Data Protection Regulation (UK GDPR) and the Data Protection Act 2018."

On the WASPI home page, it explains the benefits it brings to organisations and the public. They include, breaking down of perceived barriers to sharing personal information, improving staff confidence, promotes sharing of good practice and reduces duplication of effort; also, potentially reduces the need for individuals to provide the same information to multiple agencies, and for providers to provide more proactive services.

In 2017, Welsh Government published a Statement of Intent relating to Information sharing, called “Better use of health and care data for safe, effective care and efficient services”.

It discusses the importance of sharing data for primary and secondary purposes and states that “Our intention is to ensure that the health and care system in Wales is able to take full advantage of the value that data offers.”

Within this statement are six principles to effective sharing and use of data:

- Individuals have a right to know how data about them is being used
- Data should be collected once, used many times
- Data is an asset and should be used
- Data should be managed effectively and transparently
- Data should be fit for purpose
- Public Data should be made available.

In keeping with the above Statement of Intent, Digital Health and Care Wales was established in 2021, and aims to transform the way data is used in the provision of health and care in Wales.

One of its main focuses is the National Data Resource – which is a “national data platform that will join up health and social care data services from across Wales.” NDR will make data easier to access and analyse in a safe, secure and ethical manner”.

The NDR function leads on three main areas: Care Data Repository, National Data and Analytics Platform and the Secure Data Environment.

Thus, is information sharing provided with a solid foundation in Wales. However, from the literature review and the interviews and questionnaires, there are shortcomings.

To bring it back to hospital discharge and whether we could do better in this context, these facilitators have paved the way for improvements to take place. So, what is missing?

# 6 Conclusion and recommendations

To improve information sharing in a hospital discharge context, collaboration, trust and relationships matter greatly – at every level.

For information sharing to succeed, Welsh Government needs to drive the agenda and provide resources, and senior leaders need to support their staff and lead the collaboration.

There needs to be a focus on secondary data use, as well as primary data use for operational purposes, in order to better understand the landscape, plan and work pre-emptively. Ideally, there should also be a focus on the automation of data linking and transfer, and input from all levels as to the information needed to carry out relevant duties. Data literacy is an enabler here.

Control over information sharing needs to be a shared responsibility, and the way this is agreed and implemented, such as through SLAs, DPIAs, DDAs, DSAs

is vital. In Wales, we have the mandate from Government and the framework through WASPI, and they need to be used. This is where ownership comes into play in shaping the agenda.

Otherwise, information sharing will continue to happen ad hoc and will be dependent on “individuals” and their relationships to make it happen. Time will be used unwisely, as staff and citizens will miss out on vital elements that could improve services and support better hospital discharge.

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# Navigating Medical Ultrasound Demand in Wales: What are the solutions to create capacity

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## Abstract:

**Background:**
Ultrasound is a key diagnostic tool in Wales, but rising demand, limited training capacity, and persistent workforce shortages have led to long waiting times and increased service pressures. National policy highlights the urgent need for sustainable, evidence-based strategies to expand capacity and strengthen workforce resilience.

**Methods:**
This mixed-methods study combined a national workforce survey, semi-structured interviews with imaging leads across the UK and Ireland, and an All-Wales focus group with ultrasound leaders and policy stakeholders. Quantitative workforce modelling projected future capacity requirements, while thematic analysis explored workforce challenges, training capacity, demand management, and retention barriers.

**Results:**
The survey revealed a significant and growing sonographer workforce deficit, with modelling indicating that, under current training and retention conditions, capacity for planned care waits will fall far short of demand by 2031. Qualitative findings highlighted interconnected challenges, including training bottlenecks, limited career progression, occupational health concerns, and inconsistent demand management practices. Stakeholders identified potential solutions, such as establishing a national ultrasound academy, creating principal sonographer roles, improving workforce analytics, standardising referral pathways, and addressing musculoskeletal injury and burnout risks.

**Conclusions:**
The findings underscore the need for a coordinated, data-driven strategy to ensure safe, timely, and sustainable ultrasound services in Wales. Expanding training pipelines, improving retention through career development and occupational health initiatives, and adopting standardised demand management frameworks are essential for long-term workforce resilience and service sustainability.

**Keywords:** Ultrasound workforce; sonographer shortages; training capacity; demand management; workforce retention; occupational health; diagnostic imaging; health service planning; mixed-methods research; Wales

## Table of Contents

# 1 Introduction

## 1.1 Background and Context

Ultrasound imaging is the most widely utilised imaging modality globally (Dietrich et al., 2019) and represents the second most frequently used modality in the UK for both adults and children, after X-ray (NHS Digital, 2023, 2025). Its widespread adoption is attributed to several advantages: the absence of ionising radiation, portability, relative affordability, and non-invasive nature (Dietrich et al., 2019; Wang et al., 2020). In Wales, escalating diagnostic demand has been driven by an ageing population with a higher prevalence of chronic disease, increasing prioritisation of diagnostics following the COVID-19 pandemic, rising referral rates, evolving patient expectations, the expanded application of established technologies, and the emergence of novel approaches to care (BMA, 2005). These pressures are compounded by a persistent shortage of sonographers, linked to factors such as musculoskeletal injury-related attrition, limited training capacity, professional burnout, and challenges around professional identity (Parker et al., 2015; Harrison et al., 2015; Skelton et al., 2023). Collectively, these dynamics have contributed to ongoing failures to meet national Referral to Treatment (RTT) targets for imaging, a situation projected to intensify in the coming years (Welsh Government, 2025; Venables, 2024).

In response, the Welsh Government introduced the *Diagnostics Recovery and Transformation Strategy* (2023), outlining a national framework to address backlog recovery and support the modernisation of diagnostic services, which underpin approximately 85% of patient care pathways. The strategy emphasises solutions and innovations are needed, such as workforce expansion, the development of regional diagnostic hubs, investment in digital innovation, the standardisation of quality and procurement processes, and the reduction of inequalities in access.

Against the global, national, and local context and policy backdrop, this study makes an original contribution to the evidence base by examining how sustainable and safe ultrasound services can be developed through value-based pathways and innovative workforce models. There is an absence of validated research about ultrasound service development and an evidence gap regarding ultrasound capacity management and its inherent complexities.

By synthesising quantitative, qualitative, and mixed-methods evidence, this study aims to provide a rigorous assessment of the pressures on ultrasound provision in Wales and to identify scalable strategies for service redesign. The goal is to inform workforce development and guide the implementation of the Welsh Government's strategy through the establishment of an evidence-based, benchmarked, and resilient ultrasound service capable of meeting rising demand and supporting long-term system sustainability.

## 1.2 The Current Situation in Wales

In Wales, outpatient ultrasound is requested by a range of healthcare professionals across multiple specialties in high volume with subsequent growing waiting list demand (see figure 1.0). Although waiting lists peaked in the immediate post COVID-19 period, the number of patients awaiting non-obstetric ultrasound has continued to rise steadily, reaching its highest levels by June 2025.

Most ultrasound examinations are performed within radiology departments by radiographers. Radiology services also deliver ultrasound investigations for obstetric patients and inpatients; however, only non-obstetric outpatient examinations are systematically monitored for waiting times, which are subsequently reported to the Welsh Government as part of RTT targets.

**Figure 1. Year-on-year increase in patient waits (June 2019–June 2025). Source: NHS Wales Diagnostic and Therapy Service Waiting Times.**

Patients breaching the recommended Referral to Treatment (RTT) target of eight weeks for ultrasound imaging, Wales, June 2025 remain high (see fig 1)

As of June 2025, a total of 13,784 patients were waiting longer than the eight-week RTT target for an ultrasound scan in Wales.

**Table 1.0**

| **Classification of waits** | **Total patient numbers** |
|---|---|
| Total Patients Waiting | 40382 |
| 0–7-week total | 7867 |
| Over 8-week total | 13784 |
| Over 14 weeks total | 7867 |
| 14–23-week total | 4521 |
| 24+weeks | 3346 |

*(Source: NHS Wales Diagnostic and Therapy Service Waiting Times June 2025)*

The Tier 1 Referral to Treatment target requires patients to receive imaging within eight weeks (Office for National Statistics, 2024).

In 2025, the Welsh Government published the *Ministerial Advisory Group (MAG) Report* (Welsh Government, 2025) written by an expert consensus informed by opinions from multiple clinical specialists gathered from within and outside of Wales. The report identified non-obstetric ultrasound as the imaging modality with the most challenging waiting list position, and the one most urgently requiring redesign to reduce delays. As a short-term measure, the MAG, endorsed by Welsh Government, recommended that NHS services draw on independent sector capacity to reduce waiting times, although no long-term, sustainable solutions were proposed. The use of the independent sector in Welsh healthcare has been viewed as politically sensitive and contentious, often regarded as an unsustainable and costly means of generating capacity (BMA, 2024).

## 1.3 Sonographer workforce challenges

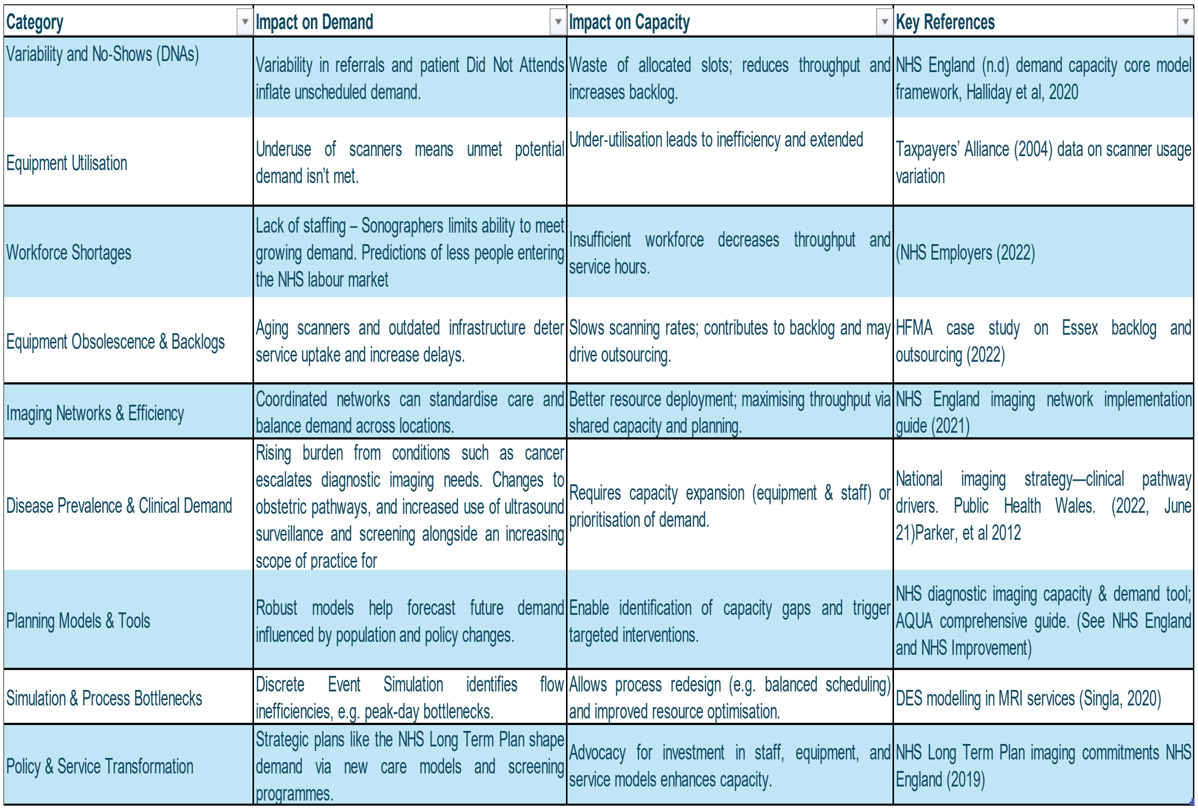
### Factors impacting demand and capacity.

Management of the sonographer workforce presents a complex and multifaceted challenge, characterised by incomplete workforce data, the involvement of multiple stakeholders, and competing organisational priorities. The difficulty is further compounded by the need to effectively allocate a resource that is presumed to be of critical importance and scarce.

Table.2.0 Factors influencing the delivery of timely ultrasound services.

The table outlines a range of factors that affect the capacity to deliver ultrasound services within target timeframes. While some factors act as enablers of efficiency, others present significant barriers to timely service delivery.

**Table 2.0**



| Category | Impact on Demand | Impact on Capacity | Key References |
|---|---|---|---|
| Variability and No-Shows (DNAs) | Variability in referrals and patient Did Not Attends inflate unscheduled demand. | Waste of allocated slots; reduces throughput and increases backlog. | NHS England (n.d) demand capacity core model framework, Halliday et al, 2020 |
| Equipment Utilisation | Underuse of scanners means unmet potential demand isn't met. | Under-utilisation leads to inefficiency and extended | Taxpayers' Alliance (2004) data on scanner usage variation |
| Workforce Shortages | Lack of staffing – Sonographers limits ability to meet growing demand. Predictions of less people entering the NHS labour market | Insufficient workforce decreases throughput and service hours. | (NHS Employers (2022) |
| Equipment Obsolescence & Backlogs | Aging scanners and outdated infrastructure deter service uptake and increase delays. | Slows scanning rates; contributes to backlog and may drive outsourcing. | HFMA case study on Essex backlog and outsourcing (2022) |
| Imaging Networks & Efficiency | Coordinated networks can standardise care and balance demand across locations. | Better resource deployment; maximising throughput via shared capacity and planning. | NHS England imaging network implementation guide (2021) |
| Disease Prevalence & Clinical Demand | Rising burden from conditions such as cancer escalates diagnostic imaging needs. Changes to obstetric pathways, and increased use of ultrasound surveillance and screening alongside an increasing scope of practice for | Requires capacity expansion (equipment & staff) or prioritisation of demand. | National imaging strategy—clinical pathway drivers. Public Health Wales. (2022, June 21)Parker, et al 2012 |
| Planning Models & Tools | Robust models help forecast future demand influenced by population and policy changes. | Enable identification of capacity gaps and trigger targeted interventions. | NHS diagnostic imaging capacity & demand tool; AQUA comprehensive guide. (See NHS England and NHS Improvement) |
| Simulation & Process Bottlenecks | Discrete Event Simulation identifies flow inefficiencies, e.g. peak-day bottlenecks. | Allows process redesign (e.g. balanced scheduling) and improved resource optimisation. | DES modelling in MRI services (Singla, 2020) |
| Policy & Service Transformation | Strategic plans like the NHS Long Term Plan shape demand via new care models and screening programmes. | Advocacy for investment in staff, equipment, and service models enhances capacity. | NHS Long Term Plan imaging commitments NHS England (2019) |

## 1.4 Workforce Data Gaps

Accurate and comprehensive workforce data is essential for effective planning within sonography services. Robust data enables health systems to quantify workforce supply and demand, anticipate future shortages, and align training capacity with service needs (Taylor, 2005; Willis et al., 2017). In the UK, the absence of consistent metrics on sonographer numbers, training throughput, and attrition rates has been identified as a critical barrier to evidence-based workforce planning and policy development (Won et al., 2024).

Workforce planning in ultrasound is hindered by the inconsistent use of the job title "sonographer" within the Welsh Electronic Staff Record (ESR), which prevents accurate assessment of workforce size, demographics, and attrition rates. The absence of a national mandate to standardise job titles, combined with the lack of statutory regulation within the profession, further limits the potential for consistent workforce data collection.

Currently, no national workforce planning data are available specifically for ultrasound. This gap is partly attributable to the diverse professional groups undertaking ultrasound across various areas of practice, including maternity services and physiotherapy. In 2024, Health Education Improvement Wales (HEIW), in collaboration with the NHS Executive, developed a national Diagnostics Workforce Plan. This plan consolidated a series of workforce actions and recommendations across pathology, endoscopy, imaging, and healthcare science programmes. While some of these recommendations acknowledged ultrasound as a fragile service and highlighted persistent gaps in workforce data, a paucity of immediate in-service actions have been implemented to increase ultrasound capacity (HEIW, 2024). Consequently, the most recent diagnostic workforce recommendations for Wales have missed the opportunity to address the longstanding challenges associated within the ultrasound workforce.

## 2 Literature Review

Although the past decade has seen a marked increase in publications addressing critical workforce shortages, as well as registration and educational challenges (Coleman, Skelton, Harrison, and Parker), there remains a scarcity of literature examining the broader management of ultrasound as a service or healthcare system.

Effective workforce planning is critical and may be defined as ensuring that "the right people with the right competencies are in the right jobs at the right time" (Taylor, 2005, p.100). The consequences of inadequate planning are considerable: patient safety may be compromised, employment opportunities for highly trained staff may be lost, and substantial public funding may be misallocated. Willis et al. (2017) describe workforce planning as constrained by three challenges: systematic delays, combinational complexity, and dynamic complexity. Within ultrasound, systematic delays are particularly evident, while combinational complexity arises from the multiplicity of care pathways in which ultrasound functions as a diagnostic tool. Dynamic complexity further complicates planning by requiring anticipation of both predictable and unpredictable uncertainties. Together, these challenges exacerbate persistent workforce shortages in ultrasound services.

Hamlin (2019) identifies a range of factors that have driven the need for continuous organisational change and adaptation, among which technological advancement has been particularly influential. Within healthcare, technology has significantly shaped the utilisation of imaging modalities. More recently, the integration of artificial intelligence (AI) has facilitated improvements in image quality, accelerated data processing, enhanced pattern recognition, and optimised workflow efficiency (Ahuja et al., 2024). Nevertheless, AI is not expected to supplant the role of human professionals (Mollura et al., 2020; Huisman et al., 2021; Hardy et al., 2020). These developments underline the continued importance of workforce planning to ensure sustainable service delivery.

### 2.1 Professional Identity and Regulation

*Sonographer* is an unprotected professional title in the United Kingdom, unlike Dr or Nurse, rendering it an unregulated profession (Society of Radiographers, 2021). The role of Sonographer was developed during the 1980s through an expansion of radiographers' scope of practice, in response to a national shortage of consultant radiologists who had traditionally undertaken ultrasound examinations (Hart & Dixon, 2008). However, this career pathway has been criticised for contributing to a "blurring of professional boundaries" (Stevens, 2017), due to increasingly changing scopes of practice and expansion of professional autonomy.

In Wales, some measures have been established regarding qualifications such as CASE (Consortium for the Accreditation of Sonographic Education) accredited post graduate medical ultrasound qualification and relevant professional registration, particularly in antenatal screening (Public Health Wales, 2022). Internationally, however, the scope of practice varies considerably, with no recognised global standard (Miles et al., 2022). This variability complicates international recruitment, particularly because there is a lack of effective mechanisms currently established to assess equivalence for practitioners trained outside the UK (Society of Radiographers & British Medical Ultrasound Society, 2024)., Recruitment of foreign-trained sonographers may be as resource-intensive in terms of finances and time as training additional NHS staff, and this has raised concerns about the sustainability of the domestic workforce due to lack of supporting business cases to increase existing staffing establishments and concerns regarding shortages in core professions like radiography, nursing and midwifery. Concerns regarding the resilience of the future NHS workforce continue with predictions of less people entering the NHS labour market (The Kings Fund, 2023).

### 2.2 Education and Training Capacity

Training capacity for trainee sonographers is constrained by clinical workload pressures of mentors and supervisors and the absence of higher education institutions offering ultrasound programmes within Wales (Venables, 2024; Edwards et al., 2024). The existing funded postgraduate training model based at the University of the West of England supports only small cohorts (Stevens, 2017; Skelton et al., 2025). Although England has piloted alternative approaches such as direct entry routes and apprenticeships, registration for graduates of these pathways remains problematic due to the complexities around professional registration (Society of Radiographers & British Medical Ultrasound Society, 2024; Venables, 2024). This emphasises that without adequately resourced and work-integrated learning opportunities, meaningful workforce growth is unlikely (Edwards et al,2024). Thus, training challenges compound existing staffing shortages, particularly as capacity constraints intersect service demand. Whilst existing sonography staff are required to train student sonographers, dedicated mentors are becoming increasingly thin on the ground, with very few organisations funding dedicated clinical tutors or practice educators.

## 2.3 Workforce Wellbeing

The COVID-19 pandemic highlighted pressures on the sonography workforce, with staff resignations and elevated sickness rates attributed to moral injury, burnout, and declining job satisfaction (Skelton et al., 2023). These findings align with Clarkson et al (2023), who reported that staff shortages often prevent access to support services. Retention of experienced sonographers, required for service delivery and training others, requires attention to job planning of workload and investment in staff wellbeing. However, efforts to address shortages of staff are within a wider context of sustained austerity within the NHS, limiting the scope of interventions and innovations and growth (Rees & Duffy, 2024).

## 2.4 Managing Ultrasound Demand

The longstanding shortage of sonographers has been exacerbated by increasing demand for ultrasound, particularly in obstetrics (BMUS, 2021). In Wales, most ultrasound examinations, including obstetric scans, are undertaken within radiology departments.

Rising obstetric demand is directly reducing non-obstetric capacity (Welsh Government, 2025). While birth rates continue to decline, the proportion of high-risk pregnancies is rising, further increasing demand for ultrasound surveillance (Dodsworth, 2023). Despite this, accurate estimates of demand remain unavailable. Improvement Cymru (2023) have reported that three health boards were unable to provide serial growth scans for all women at risk of fetal growth restriction, despite this being national guidance since 2014. The reasons given for the constriction in availability were the limited number of trained sonographers. The financial implications of poor maternal outcomes are substantial: in 2023/24, maternity services accounted for 54.5% of the total estimated cost of clinical negligence cases in Wales, amounting to £439 million, despite representing only 15.7% of the case load (NHS Wales Shared Services Partnership, 2024).

Recent studies have also questioned the effectiveness of current approaches to obstetric ultrasound. Butterfield and Skelton (2024) found that implementation of the GAP protocol in one NHS centre reduced rates of small-for-gestational-age births by just 0.3%, while increasing false positives fivefold, with no significant impact on stillbirth rates. Although limited to a single setting, these findings highlight the importance of critically evaluating the clinical value of ultrasound surveillance strategies relative to their costs.

Within non-obstetric imaging services, the *Get It Right First Time* (GIRFT) programme has sought to promote imaging practices that demonstrably improve patient outcomes (Halliday et al., 2020). However, overuse of ultrasound procedures remains a challenge, with clinicians often requesting scans that exceed diagnostic requirements, a pattern observed across radiological modalities. Venables (2023) suggested that managing demand therefore requires strong leadership to direct resources towards evidence-based care pathways and away from poorly justified investigations.

Competing priorities for ultrasound capacity and poor vetting of referrals compound the demand issue. Urgent cases, such as cancer referrals, acute presentations, and obstetric examinations, are given time-sensitive priority, which extends waiting times for routine patients (NHS England, 2025). In Wales, this has particularly affected primary care, where patients often face prolonged waits for ultrasound. Initiatives such as Community Diagnostic Centres (CDCs) in England were designed to address this issue but have delivered mixed results. Sivey et al. (2024) found that CDCs did not significantly reduce waiting times and noted that increasing test availability may drive additional demand or create a ‘demand response’. However, the impact of post-pandemic demand surges was partially considered, and therefore limited conclusions about their long-term effectiveness could only be surmised.

Concerns persist around direct access to imaging from primary care referrers. Merriel et al. (2023) cautioned that such policies are unlikely to succeed without parallel investment in secondary services infrastructure and workforce capacity. Similarly, Mahase (2022) highlights that as imaging becomes more complex, training and updating general practitioners to ensure the right requests are made for the correct scans is vital to avoid costly duplication and delays in treatment or missed pathology. These literature analysis findings underscore the complex and interconnected nature of demand management, training, and workforce capacity within ultrasound services.

# 3 Summary and Research Aims

Managing ultrasound services and capacity is inherently complex, involving multiple stakeholders, competing priorities, and persistent constraints on resources. Findings from this review reveal broad consensus that enduring shortages in the sonography workforce present significant risks to service capacity and the sustainability of the wider healthcare system. Effective workforce planning is widely recognised as essential. However, the absence of robust workforce metrics and long-term strategic planning remains a critical barrier to addressing capacity gaps (Won et al., 2024).

There is clear agreement that rising demand for both obstetric and non-obstetric ultrasound, combined with shortages of trained sonographers, has led to service backlogs, longer waiting times, and potential threats to patient safety (BMUS, 2021; NHS England, 2025). Furthermore, studies consistently highlight the detrimental effects of moral injury, burnout, and stress-related attrition, exacerbated by the COVID-19 pandemic on staff retention and training capacity, underlining the urgent need to address workforce wellbeing for long-term sustainability (Skelton et al., 2023; Clarkson et al., 2023).

Despite these concerns, few studies have examined in depth the consequences of inconsistent workforce metrics for service design, policy development, and implementation (Won et al., 2024). When viewed holistically, the literature demonstrates how challenges related to professional identity, education and training capacity, workforce wellbeing, and demand management converge to intensify workforce shortages within the Welsh ultrasound service.

The review underscores the systemic risks associated with inadequate workforce planning: insufficient staffing threatens service provision, patient outcomes, and the sustainability of the wider healthcare system through rising costs, inefficient resource allocation, training bottlenecks, and declining staff wellbeing. Moreover, while advances in imaging technology and diagnostic pathways present opportunities to improve patient outcomes, these benefits cannot be achieved without a resilient and sustainable sonographer workforce.

Accordingly, this study seeks to address the identified evidence gap by exploring barriers to workforce growth and identifying sustainable strategies to support timely and effective ultrasound provision in Wales. Specifically, the study aims to:

- Quantify the workforce gap within the Welsh sonography service.
- Identify sustainable solutions already implemented across the UK and the Republic of Ireland.
- Recommend strategies that can be adapted and scaled within the Welsh context.

By aligning these aims with the existing evidence base, the study will contribute to a clearer understanding of the sonographer workforce landscape and inform practical, contextually appropriate policy and service solutions.

# 4 Research Methodology and Design

## 4.1 Introduction

This chapter outlines the research methodology adopted to address the study's primary question: *What solutions can create ultrasound capacity in Wales?* Specifically, the study aimed to identify the current sonographer workforce gap in Wales and use this data to contextualise the ongoing failure to meet waiting time targets. The research design was pragmatically selected following careful evaluation of qualitative and quantitative approaches and was influenced by time and resource constraints.

The study also explored solutions to similar workforce and capacity challenges implemented in other healthcare systems across the UK and Ireland. To maximise the depth and breadth of insights, a mixed-methods approach was adopted, combining a literature review, workforce survey, semi-structured interviews, and a focus group. Mixed-methods research enhances both validity and reliability by drawing on established traditions within each paradigm and employing rigorous frameworks for their integration. Quantitative methods allow for hypothesis testing, measurement, and generalization (Campbell & Stanley, 1963; Messick, 1995), while qualitative methods offer depth, contextual insight, and understanding of participants' experiences (Lincoln & Guba, 1985; Maxwell, 2005). As Creswell and Plano Clark (2011) note, mixed methods approach leverages the strengths of both paradigms, mitigating individual weaknesses and yielding more credible and applicable findings.

Ethical approval for the study was secured through Swansea University's Ethics Committee on 24 June 2025 (see Appendix A). Participant information and consent forms were developed in accordance with Swansea University guidance and submitted as part of the ethics application (see Appendix B).

Three primary data collection methods were employed:

- Workforce survey
- Semi-structured interviews
- Focus group.

An adapted grounded theory methodology (Glaser & Strauss, 1967; Charmaz, 2006; Tie et al., 2019) guided the research design, supporting the integration of mixed methods and enabling findings to inform operational rather than purely theoretical outcomes. This alignment between research outputs and practical implementation ensured relevance for policy development, service planning, and workforce transformation.

Figure 1.0 illustrates the position of grounded theory within the research onion, adapted from Saunders et al. (2019).

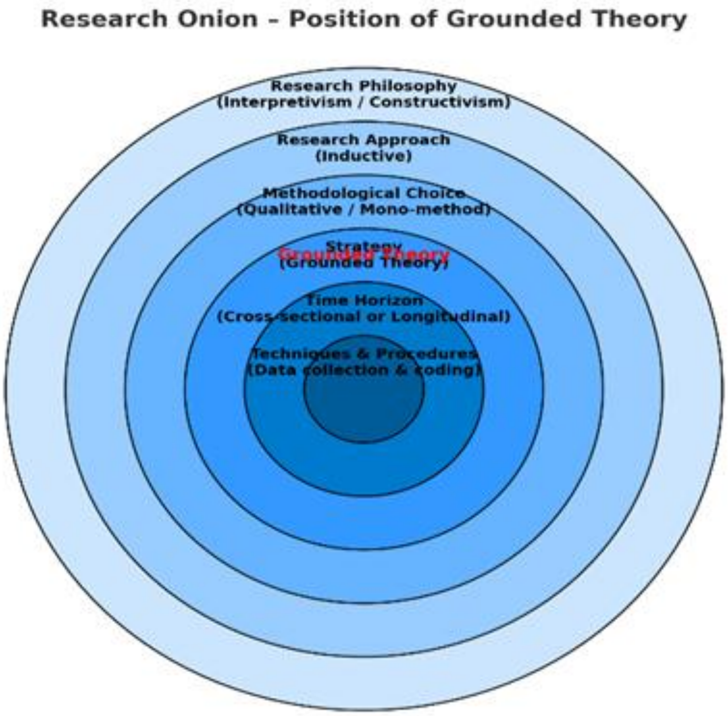


**Figure 1.0**
**Research Onion – position of Grounded Theory. Adapted from Research Methods for Business Students (8th ed., p. 130), by M. Saunders, P. Lewis, & A. Thornhill, 2019, Pearson Education. Copyright 2019 by Pearson Education. Drawn utilising generative AI.**

Thematic analysis was employed to analyse qualitative data from the survey, interviews, and focus group. Themes and sub-themes were identified inductively (Glaser & Strauss, 1967). Interview themes shaped the focus group agenda, ensuring that discussions reflected participants' experiences rather than researcher assumptions (Carter et al., 2014). This iterative process enhanced credibility through triangulation of individual and group perspectives and aligns with best practice in qualitative research (Shiyanbola et al., 2021). A hybrid approach was utilised combining NVivo software with AI-assisted tools to support data management, coding consistency, and theme development, while retaining researcher-led interpretation.

## 4.2 Literature Review Approach

A narrative literature review was undertaken to synthesize existing research on the sonographer workforce. This approach allowed for a broad, descriptive synthesis rather than the rigid structure of a systematic review, enabling interpretation of findings within the specific context of workforce and capacity challenges.

A systematic search strategy was developed across multiple databases (e.g., PubMed, CINAHL) via I-Find and Google Scholar using predefined filters. Studies published in English between 2010 and 2025 were included to ensure contemporary relevance. Inclusion criteria focused on studies addressing medical ultrasound workforce and capacity issues, while studies with insufficient methodological detail or irrelevant scope were excluded. Some grey literature (e.g., policy reports, professional body publications) was also incorporated where peer-reviewed studies were lacking.

In addition to database and keyword searching, this review used *citation chasing* (also called citation tracking) to identify supplementary literature. Backward citation chasing involved examining reference lists of initially included studies to locate earlier relevant research, and forward citation tracking (e.g. via Google Scholar or citation indices) identified more recent studies that cited those works. This iterative approach ensures that studies which might not surface through keyword-based searches alone are included. Hirt et al. (2021) discuss combining electronic database searches with citation tracking as good practice.

Literature predominantly comprised qualitative studies offering in-depth insights into workforce challenges, supplemented by survey-based research providing broader perspectives. Overall, the literature revealed variability in ultrasound education, training, and workforce planning approaches, with notable gaps in operational capacity management evidence.

**Table 3.0 summarises the literature search criteria and scope.**

| Activity | Purpose |
|---|---|
| Literature search criteria | Key terms: sonographer, workforce, ultrasound, demand, capacity, imaging, radiology, obstetric, non-obstetric |
| Repositories used | I-find, Google Scholar |
| Inclusion criteria | English-language papers, published after 2010 (for focused topic), studies on medical ultrasound in healthcare, books, peer-reviewed articles, abstracts, unpublished manuscripts, and full text sources |
| Exclusion criteria | Non-human ultrasound use; non-English papers; studies published prior to 2010 (for focused topic). Insufficient mythological detail |

The literature revealed significant gaps in the availability and consistency of workforce data for sonographers, justifying the need for a multifaceted approach to data collection. To address these limitations and capture a comprehensive understanding of workforce dynamics, this study employed three complementary methods: a workforce survey to generate quantitative insights across departments, semi-structured interviews to explore individual perspectives and contextual factors in greater depth, and a focus group to facilitate collective discussion and validate emerging themes. Together, these approaches were designed to enhance the breadth and depth of the data collected, thereby enabling a more robust and nuanced analysis of workforce capacity and demand.

## 4.3 Workforce Survey Design

### Participant selection

The challenges of defining the professional identity of “sonographer,” have been expounded within the previous sections, and the stance supported by the existing literature around the subject. Creating a survey aimed at harvesting the opinions of this group of health professionals who may work within the role but have an alternative title and a variety of role definitions is challenging. Understanding the targeted group working under, or around the title of “sonographer” within radiology departments is required to ensure consistency and focus to capture as many opinions as is feasible. To this end, departmental ultrasound leads have been identified through the National Imaging Programme database, which helpfully provided names and NHS email addresses.

The design of the survey questions was intentionally aligned with the type of workforce data that could, in principle, be retrieved from the Electronic Staff Record (ESR), had such information been systematically available for the sonographer workforce. To broaden the scope of the inquiry and capture workforce dynamics more comprehensively, additional variables were incorporated, including the number of trainees and the proportion of non-permanent staff, such as agency workers. Data collection efforts were confined to radiology departments, where electronic record-keeping practices for study volumes are generally robust and comprehensive. This methodological decision was based on the premise that, should workforce data be integrated into demand and capacity modelling, the accuracy and reliability of such analyses would be enhanced by drawing on datasets characterised by higher levels of completeness and validity.

To ensure clarity of the survey questions and validity of the methodology, the survey was peer reviewed by senior NHS Radiology colleagues in the NHS Wales Performance and Improvement organisation, and experienced senior sonographers with leadership and service development experience. The survey was designed to be highly pragmatic for users, concise and quick to complete to maximise participation, in acknowledgement of existing service pressures and the limited time available for the research study turnaround and delivery. The survey was available for a 3-week period from 23 June to 19 July 2025.

**Table 4.0 Workforce Survey - Design and Distribution**

| **Survey Tool** | **Microsoft Forms** |
|---|---|
| Data collection | NHS work email addresses |
| Survey focus | Workforce numbers and capacity |
| Questions | - Health board and respondent name<br>- Number of sonographers (headcount and WTE)<br>- Anticipated retirements within 2 years<br>- Use of locum or outsourcing arrangements<br>- Weekly proportion of obstetric scanning<br>- Number of students currently in training |

## 4.4 Interview Methodology

Semi-structured interviews were designed following an initial scoping of key topics, informed by the researcher's prior experience in ultrasound service management, a comprehensive analysis of the academic and grey literature, consultations with service providers and peers, and feedback from practicing sonographers. This method is particularly appropriate for exploring complex workforce issues, as it enables the collection of rich, detailed insights from participants while maintaining a consistent thematic structure to facilitate comparison (Peterson, 2000). The primary aim of employing this approach was to examine how other services have attempted to address sonographer workforce shortages and to identify potential strategies that could be adapted or scaled for implementation within the Welsh context.

Participants were selected via recommendations from professional bodies (e.g., Society of Radiographers, British Medical Ultrasound Society) and Universities. A total of eight participants were recruited out of a possible ten and were contacted via email addresses supplied or via introductory emails.

To ensure a wide perspective was sought and UK comparisons could be gleaned, clinical and service leads, and senior decision makers from all four nations were included in the invitation to participate and nominate appropriate colleagues. England (2 participants), Scotland (2 participants), Wales (2 participants), and Republic Ireland (2 participants).

The inclusion of senior decision-makers within the NHS and Health Service Executive (HSE Ireland) resulted in an accruement of differing strategic perspectives on workforce policy and service delivery. Representation from across nations helped prevent the dominance of the larger English context and gave the opportunity for nuance and outlier opinions to be captured.

As the research concerned professional roles and service development, direct patient involvement was not included within the methodology. The tight timeframes and paucity of funding for the research largely prohibited patient views from being captured.

**Table 5.0: Interview Format**

| **Feature** | **Detail** |
|---|---|
| Length | Maximum of 1 hour |
| Questions | Four open-ended, themed questions:<br>1. Current solutions to manage demand<br>2. Approaches to increasing capacity<br>3. Barriers to employing more sonographers<br>4. Perceptions of sustainable solutions over 5–10 years |
| Recording | Microsoft Teams (video), transcribed with consent, transcripts verified by researcher |

## 4.5 Focus Group Methodology

An All-Wales focus group was convened online following the interviews. The participant selection is offered below in table 6.0. Inclusion of a representative from every Welsh Health Board was paramount to ensure validity and applicability of findings. The format, themes, and questions, were informed by the interview themes, and circulated in advance to participants to support engagement and ensure relevance (see Appendix C) Participants met in one large online group on order to promote rich, collaborative discussion across a range of professional perspectives. Participants included ultrasound service leads, senior workforce planners, national programme representatives, and clinical leaders, capturing both operational and strategic perspectives across Wales. Participant consent was included in the meeting invitation.

A focus group approach was selected to enable the collection of rich, interactive data by encouraging participants to discuss, challenge, and build upon one another’s perspectives (Krueger & Casey, 2015). This method is particularly valuable for exploring complex workforce issues, as it brings together individuals from diverse professional and organisational backgrounds, thereby capturing a wide range of experiences and viewpoints (Morgan, 1997). The dynamic nature of group discussion also allows participants to raise issues of importance to them, providing a more participant-led exploration of workforce needs and potential solutions.

The focus group lasted two hours, which the researcher deemed was enough time for discussion but not too long to lose engagement from participants. The meeting was recorded and transcribed using Microsoft Teams according to the research protocol and consent documentation. *Table 6.0 details participant roles and inclusion rationale.*

**Table 6.0: Focus Group Participants**

| **Participant** | **Reason for Inclusion** |
|---|---|
| Ultrasound/radiology service leads (1 per Health Board) | Ensured representation of all Welsh Health Boards/Trusts, capturing diverse demographic, geographic, and service delivery contexts |
| Senior leader in workforce transformation | Brought expertise in system-level planning, redesign, and sustainability |
| Programme portfolio lead – National Imaging Programme | Provided strategic insights on alignment with national programme priorities |
| Assistant Director of Planned Care (Diagnostics) | Added operational and strategic expertise in elective and scheduled diagnostic services |
| Director of Healthcare Science | Contributed expertise on innovation, workforce development, and service leadership |
| Consultant Radiologist | Offered frontline clinical perspective on service pressures and patient pathways |
| National Imaging Academy representative | Provided insight on training, workforce development, and innovation across Wales |

All interview and focus group transcripts were transcribed and imported into NVivo (version 13) for organization and initial coding. The data was anonymised prior to analysis to ensure confidentiality and compliance with ethical guidelines. AI-assisted transcription and summarisation tools were used at the preliminary stage to enhance efficiency, though all outputs were manually reviewed for accuracy to maintain data integrity. The analysis followed Braun and Clarke's (2006) six-phase framework.

### 4.6 Methodology Chapter Summary

This study employed a mixed methods design to develop a comprehensive understanding of the sonographer workforce challenges in Wales. A workforce survey generated quantitative data on staffing levels, service capacity, and immediate workforce pressures, while semi-structured interviews captured strategic perspectives from senior leaders across the UK and Ireland. Building on these findings, the All-Wales focus group facilitated collective reflection, enabling emergent themes to be refined and contextualised within the Welsh health system.

By integrating these methods, the study combined breadth through survey data offering a system-level overview, with depth provided by qualitative approaches that revealed nuanced experiences, structural barriers, and potential solutions. This methodological triangulation enhanced the rigor, validity, and transferability of the findings, supporting the study's aim to inform sustainable workforce policy and service delivery planning.

Cross-method analysis identified several key themes, including workforce shortages, training and retention challenges, role expansion opportunities, and the impact of service demand on staff well-being. Comparable levels of agreement across all three methods underscored the urgency of addressing recruitment and retention issues and advancing national workforce planning, while interviews and the focus group provided deeper insights into context-specific challenges and solution feasibility. The following section explores these findings in detail, highlighting areas of consensus, divergence, and implications for workforce strategy in Wales.

# 5 Findings

## 5.1 Survey findings

### 5.1.1 Workforce Profile

The survey achieved a 100% response rate, including four additional responses submitted within one week of the deadline following a final reminder from the researcher. This high level of participation strengthens the reliability of the workforce data presented.

Table 7 summarises the sonographer workforce employed within radiology departments across Wales. A total of 191 sonographers were identified, supported by 129.8 WTE through locum and insourcing arrangements. Retirement within the next two years accounted for 14.6 WTE (11.2%), while 20.8 WTE (16%) were trainees. On average, obstetric scanning represented 40.2% of weekly departmental capacity.

**Table 7. Survey responses: Sonographer workforce in radiology departments, Wales.**

| Workforce Indicator | National Total | % of Workforce (WTE) |
|---|---|---|
| n = Sonographer numbers (head count) | 191 | – |
| n = Locum and insourcing activity (WTE) | 129.8 | – |
| n = Due to retire within 2 years (WTE) | 14.6 | 11.2% |
| n = Trainees (WTE) | 20.8 | 16.0% |
| Average obstetric demand (% of weekly capacity) | 40.2 | – |

Note: Percentages reflect proportion of substantive workforce expressed in WTE derived from the survey data.

The results illustrate both the scale and fragility of the workforce. A combined retirement and attrition risk affecting over 11% of the workforce within two years highlights significant vulnerability, particularly when compounded by heavy obstetric commitments that limit capacity for other services.

Demographic information such as age, gender, and length of service was not collected, as this information is not typically available through the Electronic Staff Record. As outlined in the methodology, the survey was intentionally designed to be quick and easy to complete to encourage higher participation. However, the lack of demographic detail limits the ability to analyse workforce characteristics in greater depth.

### 5.1.2 Workforce Requirements and Projected Deficits

Calculations for workforce modelling, provided in Appendix D, adapted metrics from the *Diagnostic Imaging Workforce Plan for NHS Scotland* (Imaging Executive Board & SRTP Workforce Planning Steering Group, 2023). These models assumed annual demand growth of 5%, attrition at 6%, and training expansion at 16%.

Table 8 shows projected workforce requirements compared to current training capacity. Even with optimistic training growth assumptions, the workforce is predicted to reach only 103.1 WTE by 2031, compared to a projected need for 172.8 WTE.

**Table 8. Projected workforce requirements and current workforce trajectory (WTE)**

| Year | Required workforce with 5% demand growth (WTE) | Required workforce with 6% attrition (WTE) | Projected workforce (WTE) under current training capacity (16%) with 6% attrition, 5% demand growth |
|---|---|---|---|
| 2025 | 121.6 | 128.9 | 58.4 |
| 2026 | 127.7 | 135.6 | 64.0 |
| 2027 | 134.1 | 142.1 | 70.4 |
| 2028 | 140.8 | 148.4 | 77.5 |
| 2029 | 147.7 | 156.6 | 85.2 |
| 2030 | 155.2 | 164.5 | 93.8 |
| 2031 | 163.0 | 172.8 | 103.1 |

Note: Figures rounded to one decimal place. Projections exclude locum/agency and outsourcing/insourcing staff.

This persistent shortfall signals that without immediate and substantial interventions, such as scaling training pipelines, improving retention, or international recruitment, future service provision will face serious constraints.

### 5.1.3 Demand and Capacity Projections

Table 9 compares projected monthly demand for ultrasound scan hours in planned care non-obstetric examinations with current workforce capacity.

**Table 9. Projected monthly demand versus current workforce capacity (scan hours)**

| Year | Projected Monthly Demand (hours) | Projected Workforce Capacity (hours) |
|---|---|---|
| 2025 | 11,070.5 | 6,331.3 |
| 2026 | 11,624.0 | 6,940.3 |
| 2027 | 12,205.2 | 7,663.9 |
| 2028 | 12,815.5 | 8,396.9 |
| 2029 | 13,456.2 | 9,236.4 |
| 2030 | 14,129.0 | 10,160.2 |

| Year | Projected Monthly Demand (hours) | Projected Workforce Capacity (hours) |
|---|---|---|
| 2031 | 14,930.0 | 11,175.6 |

Note: Demand projections assume a 5% annual increase; capacity projections reflect substantive sonographer workforce only.

In 2025, demand is estimated at 11,070.5 hours per month against a capacity of only 6,331.3 hours, leaving a deficit of 4,739.2 hours. Even with projected workforce growth, the gap remains at 3,754.4 hours by 2031. This highlights that expanding training capacity alone may be insufficient unless paired with demand management strategies.

As one focus group participant observed:

> *"We're constantly firefighting. Even as more trainees come through, demand grows faster than we can keep up with."*

### 5.1.4 Obstetric Demand Analysis

Although not specified in the original research protocol, an exploratory analysis was undertaken to clarify obstetric demand, given its major impact on non-obstetric capacity. Radiology examination records from four health boards showed an average of 6.8 ultrasound examinations per live birth, ranging between 5 and 8.

**Table 10: Summary of obstetric examination information collected.**

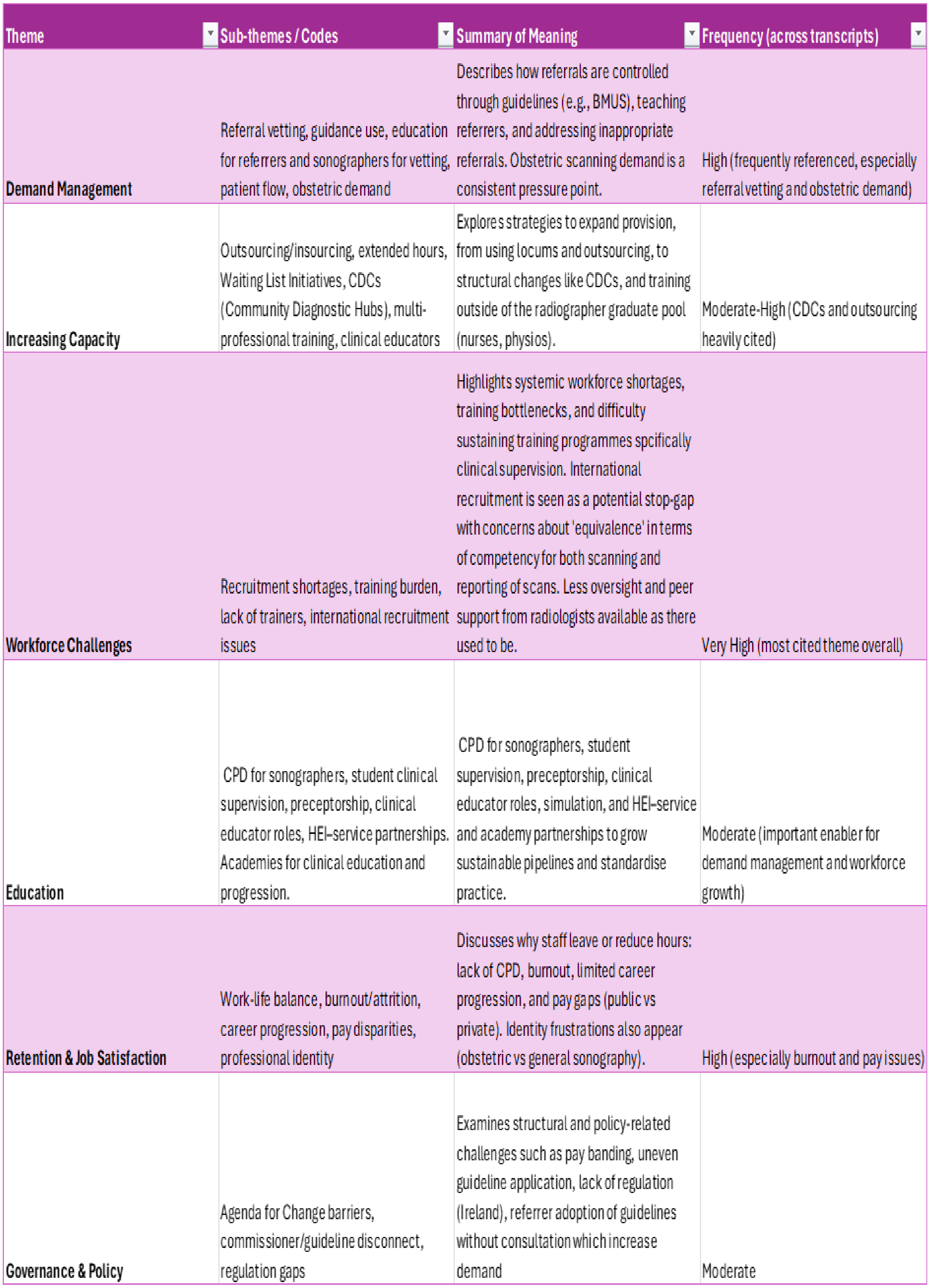
| Category | Details |
|---|---|
| Exclusions | Tertiary fetal medicine providers were excluded due to disproportionate volumes of out-of-area referrals. |
| Approach | Obstetric examination codes (first to third trimester, including Doppler and cervical length) were extracted from PACS/RADIS systems by health board PACS managers. Annual totals were normalised against live birth rates. |
| Assumptions | - Examinations were accurately coded and archived in accordance with governance standards.<br>- A proportion of examinations were performed outside radiology departments (e.g., by midwives, consultants, or nurses).<br>- Regional service arrangements may have inflated demand in specific health boards. |

This analysis highlights both the complexity of measuring obstetric demand and the significant impact it may have on the delivery of other non-obstetric ultrasound examinations as suggested in the literature review. Across all departments there was a variance of obstetric demand, likely due to some ultrasound capacity existing within the midwifery workforce outside of radiology departments. The mean obstetric demand across Wales was calculated at around 40% of radiology ultrasound capacity.

## 5.2 Thematic analysis of interviews.

Eight interviews underwent thematic analysis, producing the overarching themes in Table 11. Frequency counts assessed the relative prominence of each theme. A hybrid approach using NVivo software and AI-assisted tools supported data management, coding consistency, and theme development. Themes and subthemes were stored in Excel to enable visual mapping of relationships, as shown in Diagram 1.0.

Table 11



| Theme | Sub-themes / Codes | Summary of Meaning | Frequency (across transcripts) |
|---|---|---|---|
| **Demand Management** | Referral vetting, guidance use, education for referrers and sonographers for vetting, patient flow, obstetric demand | Describes how referrals are controlled through guidelines (e.g., BMUS), teaching referrers, and addressing inappropriate referrals. Obstetric scanning demand is a consistent pressure point. | High (frequently referenced, especially referral vetting and obstetric demand) |
| **Increasing Capacity** | Outsourcing/insourcing, extended hours, Waiting List Initiatives, CDCs (Community Diagnostic Hubs), multi-professional training, clinical educators | Explores strategies to expand provision, from using locums and outsourcing, to structural changes like CDCs, and training outside of the radiographer graduate pool (nurses, physios). | Moderate-High (CDCs and outsourcing heavily cited) |
| **Workforce Challenges** | Recruitment shortages, training burden, lack of trainers, international recruitment issues | Highlights systemic workforce shortages, training bottlenecks, and difficulty sustaining training programmes spcifically clinical supervision. International recruitment is seen as a potential stop-gap with concerns about 'equivalence' in terms of competency for both scanning and reporting of scans. Less oversight and peer support from radiologists available as there used to be. | Very High (most cited theme overall) |
| **Education** | CPD for sonographers, student clinical supervision, preceptorship, clinical educator roles, HEI–service partnerships. Academies for clinical education and progression. | CPD for sonographers, student supervision, preceptorship, clinical educator roles, simulation, and HEI–service and academy partnerships to grow sustainable pipelines and standardise practice. | Moderate (important enabler for demand management and workforce growth) |
| **Retention & Job Satisfaction** | Work-life balance, burnout/attrition, career progression, pay disparities, professional identity | Discusses why staff leave or reduce hours: lack of CPD, burnout, limited career progression, and pay gaps (public vs private). Identity frustrations also appear (obstetric vs general sonography). | High (especially burnout and pay issues) |
| **Governance & Policy** | Agenda for Change barriers, commissioner/guideline disconnect, regulation gaps | Examines structural and policy-related challenges such as pay banding, uneven guideline application, lack of regulation (Ireland), referrer adoption of guidelines without consultation which increase demand | Moderate |

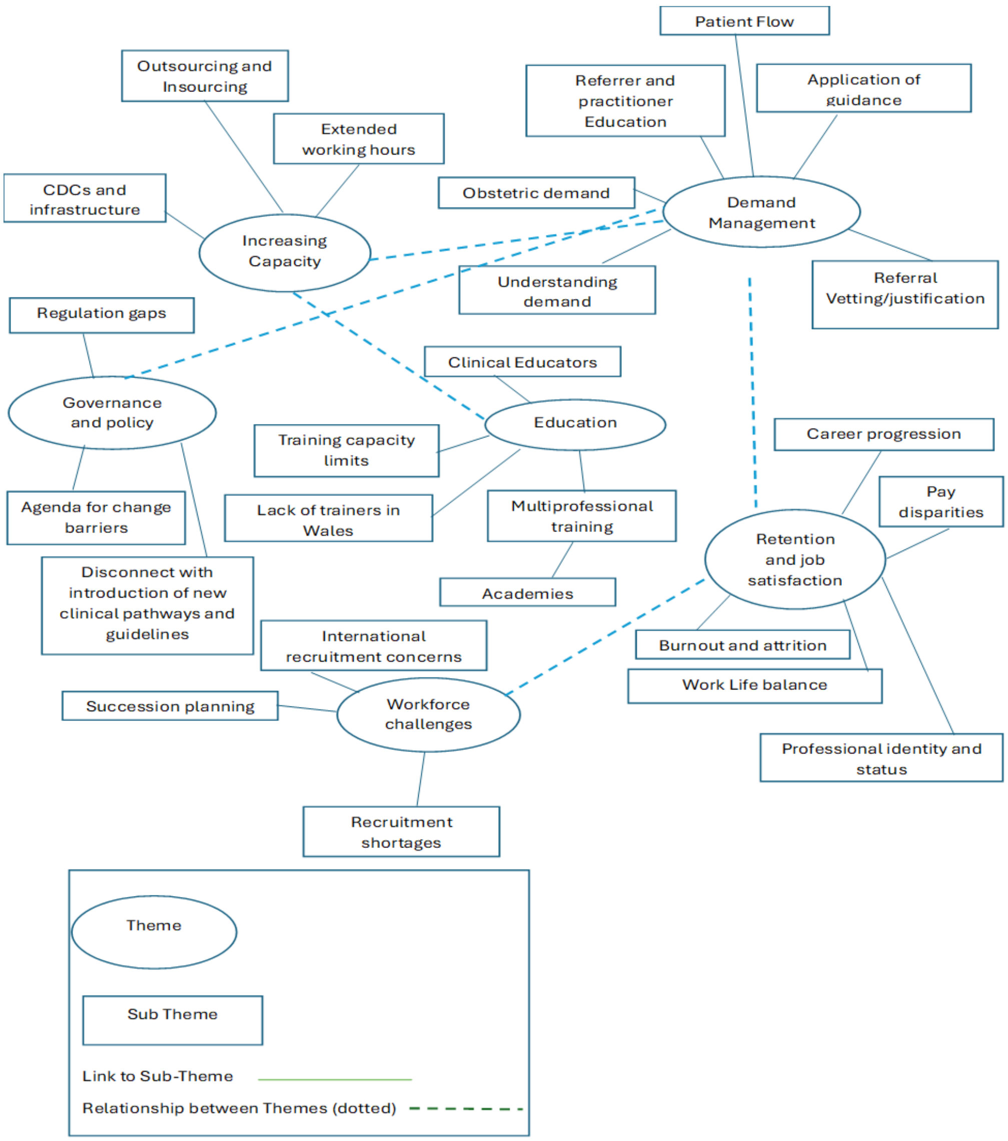


**Diagram 1.0. The diagram below demonstrates the relationships and links between the interview themes and sub themes.**

## 5.3 Interview Themes

The following sections explore each theme in detail, integrating participant comments to illustrate key points. Overall, interviewees engaged strongly with the questions, offering thoughtful insights that enriched understanding of workforce pressures, service challenges, and potential solutions.

## 5.4 Demand Management

Participants consistently described demand regulation as a major challenge. Referral vetting and adherence to criteria were widely implemented but with uncertain impact. Several argued for managing demand at the level of entire patient pathways rather than by expanding capacity alone.

As one participant put it:

> *"It's no good just adding more scans. We need to look at the whole pathway, -why patients are ending up here in the first place."*

Concerns also centred on the growing burden of follow-up imaging for chronic conditions, with limited mechanisms to prioritise or discharge low-risk patients.

## 5.5 Increasing Capacity

### 5.5.1 Community Diagnostic Centres (CDCs) Insourcing and Outsourcing

Experiences from England suggested that CDCs could improve staff wellbeing by offering structured environments outside acute hospitals. Predictable demand also benefited trainees by enabling supervision and learning. However, recruitment challenges limited their direct impact on capacity.

*“CDCs are great for training and staff morale, but they’re not a magic fix for workforce shortages.”*

Strong governance, rather than the professional background of trainees, was viewed as the key determinant of service quality.

## 5.6 Workforce Challenges

Workforce issues emerged as the most consistently reported theme, spanning pay inequities, migration to private practice, job satisfaction, and limited career progression.

Participants frequently cited the public - private pay gap as a key driver of attrition:

> *“People are leaving for private work because the pay is better, and the working conditions better. It’s hard to blame them.”*

Additional challenges included limited peer support from radiologists, many of whom now focus on MRI, CT, or interventional imaging and insufficient recognition and utilisation of advanced or consultant-level sonographer roles.

## 5.7 Education and Training

Interviews consistently highlighted significant challenges in ultrasound education, particularly the difficulty of securing sufficient clinical placement opportunities for students in the context of growing service pressures. Participants also identified a lack of structured educational pathways for the existing qualified workforce, which contributed to limited awareness of progressive career opportunities and reduced motivation for professional development. Although national initiatives, such as the establishment of ultrasound academies in Scotland and England, have sought to enhance training capacity and clinical supervision, local responses have varied. Some departments reported appointing education coordinators and developing advanced and consultant-level roles through targeted business cases, thereby beginning to create a clearer and more sustainable career framework within their organisations.

### 5.7.1 Participant Perspective

> *"We want to train more people, but finding supervisors and placement time is the real challenge."*

## 5.8 Retention

Retention emerged as central to workforce sustainability. Participants stressed that training expansion alone would fail without addressing attrition:

> *“There’s no point training more people if we can’t keep the ones we already have.”*

## 5.9 Governance and policy

Interviews revealed that the absence of national clinical guidelines for ultrasound use in Ireland posed significant challenges for demand management. In contrast, the adoption of clinical guidelines and recommendations in England, Scotland, and Wales helped mitigate some of these issues. Participants also highlighted the lack of structured banding and career frameworks in Ireland, which contributed to inconsistencies in pay across hospital sites and organisations. By comparison, adherence to the *Agenda for Change* pay scales in England, Scotland, and Wales ensured parity across the profession; however, some respondents felt this system limited flexibility when attempting to recruit and retain staff within ultrasound roles.

Regarding demand, participants expressed frustration at the introduction of new clinical pathways without adequate consultation with radiology or ultrasound services. In many cases, these pathways significantly increased ultrasound demand without corresponding financial support to expand workforce capacity. Given the scarcity of ultrasound resources, several participants argued that insufficient consideration was given to the impact of these pathways, particularly when applied to surveillance for specific conditions where the incidence of poor outcomes may be considerably lower than among symptomatic patients already experiencing long delays.

## 5.10 Focus Group Thematic analysis

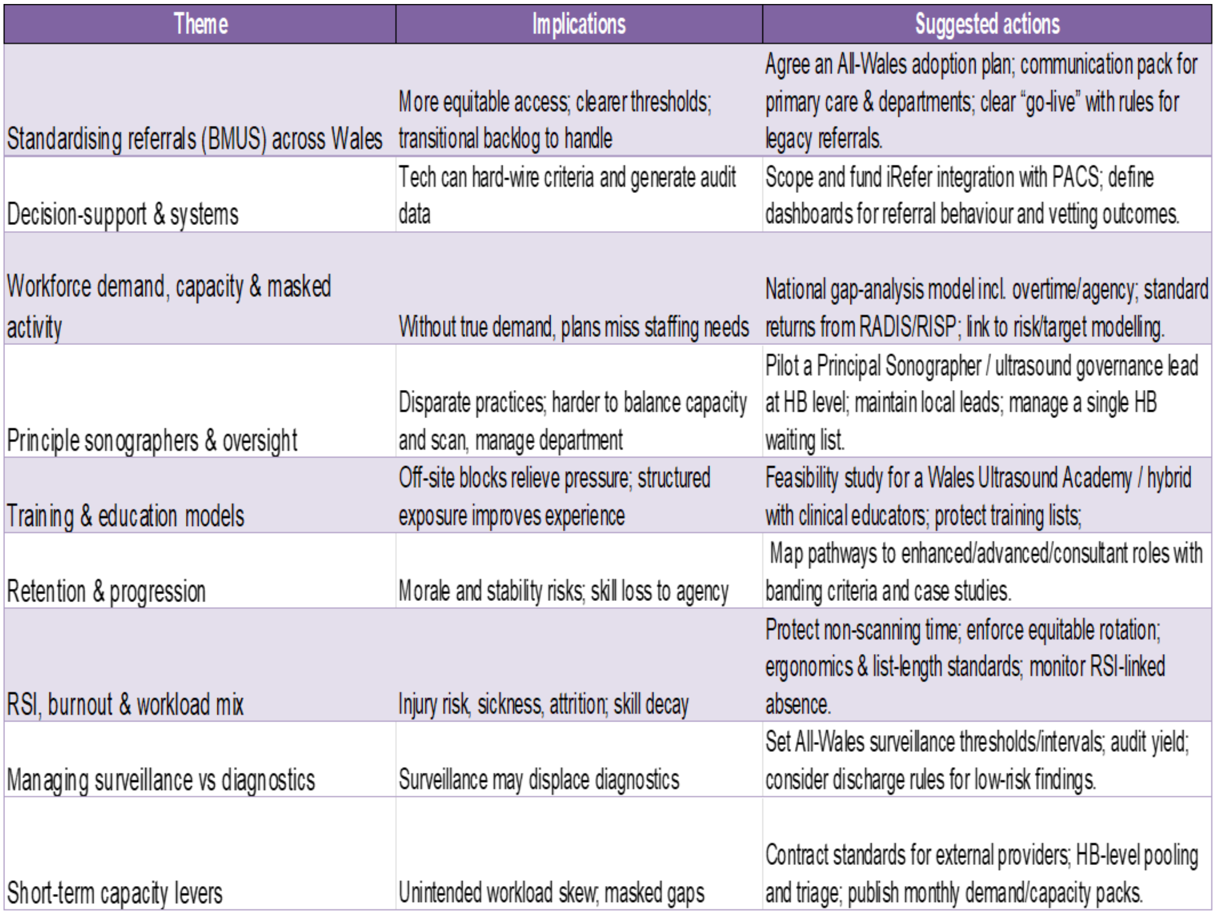
The focus group achieved high attendance and engagement, underscoring the importance of the topic. Although Directors of Healthcare Science were unable to attend, they offered ongoing support for future discussions.

The focus group findings broadly validated the themes from the interviews, reinforcing the critical importance of workforce sustainability, demand regulation, and the potential role of CDC models and application of software to support the GIRFT principles such as *I Refer*. Participants also highlighted the need for stronger national coordination to address training bottlenecks and retention challenges.

Overall, the focus group provided confirmatory evidence that the themes identified through interviews are widely recognised across the wider professional community.

**Table 12** summarises the key themes identified in the focus group transcript with corresponding recommended actions. Some actions emerged directly from the discussions and were informed by interview findings; for example, establishing ultrasound academies and adopting BMUS guidance. Others were proposed by participants, such as integrating *I Refer* software into the electronic requesting module of the new Wales-wide Radiology Information System (RIS) to support referrers in selecting appropriate imaging tests. RIS will streamline radiology workflows, while the Picture Archiving and Communication System (PACS) will enable secure storage, retrieval, and sharing of medical images across healthcare networks.

Table 12



| Theme | Implications | Suggested actions |
|---|---|---|
| Standardising referrals (BMUS) across Wales | More equitable access; clearer thresholds; transitional backlog to handle | Agree an All-Wales adoption plan; communication pack for primary care & departments; clear "go-live" with rules for legacy referrals. |
| Decision-support & systems | Tech can hard-wire criteria and generate audit data | Scope and fund iRefer integration with PACS; define dashboards for referral behaviour and vetting outcomes. |
| Workforce demand, capacity & masked activity | Without true demand, plans miss staffing needs | National gap-analysis model incl. overtime/agency; standard returns from RADIS/RISP; link to risk/target modelling. |
| Principle sonographers & oversight | Disparate practices; harder to balance capacity and scan, manage department | Pilot a Principal Sonographer / ultrasound governance lead at HB level; maintain local leads; manage a single HB waiting list. |
| Training & education models | Off-site blocks relieve pressure; structured exposure improves experience | Feasibility study for a Wales Ultrasound Academy / hybrid with clinical educators; protect training lists; |
| Retention & progression | Morale and stability risks; skill loss to agency | Map pathways to enhanced/advanced/consultant roles with banding criteria and case studies. |
| RSI, burnout & workload mix | Injury risk, sickness, attrition; skill decay | Protect non-scanning time; enforce equitable rotation; ergonomics & list-length standards; monitor RSI-linked absence. |
| Managing surveillance vs diagnostics | Surveillance may displace diagnostics | Set All-Wales surveillance thresholds/intervals; audit yield; consider discharge rules for low-risk findings. |
| Short-term capacity levers | Unintended workload skew, masked gaps | Contract standards for external providers; HB-level pooling and triage; publish monthly demand/capacity packs. |

### 5.11 Summary of findings

Across all methods – survey, interviews, and focus group, four interrelated challenges emerged:

- Workforce shortages and retention difficulties threatening service sustainability.
- Rising demand outpacing workforce growth, particularly for non-obstetric imaging.
- Training capacity constraints limiting the speed of workforce expansion.
- Variable governance frameworks influencing both service delivery and professional development opportunities.

Quantitative survey data revealed the scale of workforce deficits, while qualitative interviews and the focus group provided critical context, illustrating the human and organisational factors shaping workforce challenges. Together, these findings underscore the urgency of coordinated national strategies addressing recruitment, retention, training, and demand management to ensure sustainable ultrasound services in Wales.

## 6 Discussion

Navigating Medical Ultrasound Demand in Wales: What are the solutions to create capacity?

This study reveals a persistent mismatch between sonographer workforce capacity and projected demand in Wales, with survey data showing significant shortfalls even under conservative modelling assumptions. Interviews and focus groups reinforced these findings, highlighting workforce shortages, retention challenges, and the limits of current demand management strategies.

While Community Diagnostic Centres (CDCs) and expanded training routes offer potential solutions, their impact is constrained by recruitment difficulties, limited clinical training capacity, and pay inequities. Several participants also warned against overreliance on private insourcing, citing risks seen elsewhere when prolonged use draws staff away from the public sector.

Education emerged as central to workforce growth, linking directly to professional development, retention, and capacity building. Alongside this, participants stressed the need for improved demand management. Together, these insights provide a clear evidence base for coordinated national strategies integrating workforce planning, service redesign, and retention initiatives.

### 6.1 Managing the workforce as a limited resource

Workforce modelling necessarily involved assumptions; however, the findings were unequivocal: a significant deficit exists in non-obstetric ultrasound capacity compared with substantive staffing levels, reflecting the scarcity of sonographers employed in NHS roles in Wales.

Focus group evidence suggested that many sonographers routinely work beyond the standard 37.5-hour week, despite modelling assumptions to the contrary. This hidden additional workload accelerates attrition and undermines long-term workforce sustainability, a concern echoed by earlier studies (Skelton & Harrison, 2019), which highlight how service delivery often relies on staff goodwill rather than robust capacity planning.

Key challenges identified included:

- Limited opportunities for progression and continuing education
- High levels of burnout
- Widespread musculoskeletal injury

These findings mirror the wider literature, which consistently underscores the fragility of the sonography workforce. As Zhichao et al. (2024) argue, sustainable service delivery requires a multifaceted approach encompassing staff optimisation, targeted recruitment, and enhanced employee engagement.

### 6.2 Training and Education

Despite the risks posed by workforce shortages, there was strong consensus on the need to expand the training pipeline. Both the literature (Edwards et al., 2024; Skelton et al., 2025) and stakeholder consultations emphasised the potential of an ultrasound academy to increase clinical training capacity while also upskilling existing staff. This need is particularly pressing given the imbalance between the high proportion of sonographers approaching retirement and the limited number currently in training.

The National Imaging Academy already provides simulation facilities, experienced faculty, and agreements to scan NHS patients. Although its current remit focuses on radiologist training, expansion to sonography within the non-medical or additional medical backgrounds could:

- Standardise academic and clinical assessment.
- Increase access to simulation-based learning, widely recognised as valuable in sonography training (Skelton et al., 2025)
- Foster collaboration between radiologists, sonographers, and other medical specialists.

Challenges remain, however. The Academy's location in Southeast Wales limits accessibility for trainees in North Wales, although this aligns with current demand patterns, as over two-thirds of patients waiting longest for ultrasound are based in the Southeast (Welsh Government, 2025).

## 6.3 Retention and Recognition

Retention was consistently linked to education, supervision, and career development. An expanded academy model could ease pressures on clinical mentors, offer structured peer support, and provide clearer progression pathways.

However, participants described inconsistent access to clinical educators and education leads, reflecting national variability reported by Coleman et al. (2024). Professional supervision was identified as a potential mechanism to reduce burnout and support retention.

Participants also made a strong case for creating Principal Sonographer roles to provide service-level leadership and coordination. Currently, limited management training and preparation exist for overseeing services across health boards, a gap reflected in the Ministerial Advisory Group Report (Welsh Government, 2025), which recommended accredited training in waiting list management but did not specifically include imaging. This highlights the lack of understanding around the service level managerial structures that exist within imaging services at policy level.

Workforce Analytics

Improved workforce analytics and data availability were identified as essential for effective planning. Robust datasets would enable:

- Forecasting retirements, attrition, and training needs
- Identifying inefficiencies in deployment
- Accurately modelling service demand and capacity

Emerging evidence suggests that Big Data approaches, including electronic staff records and real-time utilisation data, could enhance workforce modelling and planning (Sharma et al., 2025). In contexts of workforce shortages and rising burnout, predictive analytics for recruitment and retention represent increasingly critical tools (Zhichao et al., 2024).

## 6.4 Occupational Health, Burnout, and Workload pressures

Musculoskeletal injury was repeatedly raised as a serious concern. However, reliable Welsh data was difficult to obtain due to inconsistent reporting practices. This finding aligns with previous studies showing that 80–95% of sonographers scan in pain (Harrison et al., 2015; Morton et al., 2008). Participants also highlighted negative cultural consequences of reliance on private-sector outsourcing/insourcing, including reduced morale among NHS staff, and increased reliance on NHS staff to undertake obstetric scans. This resonates with wider concerns about fragmentation of service provision.

## 6.5 Surveillance versus Diagnostics

Several participants questioned whether the current balance between surveillance and diagnostic scanning represented the most effective use of limited resources. Long waiting times for diagnostic ultrasound raise concerns about the risk–benefit balance of surveillance activity.

The European Society of Radiology (2017) emphasises value-based healthcare (VBH), prioritising patient outcomes relative to cost. Current radiology metrics inadequately capture contributions to outcomes or cost savings (Sawar et al., 2015). Overall, surveillance remains important, but refinement and clearer evaluation are required to ensure that scarce resources are allocated efficiently.

### 6.6 Demand Management and Standardisation

Demand management approaches varied across Wales, but participants expressed strong support for an all-Wales approach. A unified system could:

- Improve consistency in referral and access.
- Reduce variation in practice across health boards.
- Enable more efficient use of workforce capacity.

The iterative development of BMUS (British Medical Ultrasound Society) guidelines was identified as a promising mechanism for creating pathway-specific referral criteria. Root cause analyses at pathway level were also recommended to support both demand understanding and workforce planning.

### 6.7 Limitations

The interconnected nature of key themes, particularly education and workforce retention, indicates that a comprehensive workforce plan would require more granular analysis of service demand, incorporating patient pathways and demographic variables. Such work may be better suited to public health research methodologies. Accordingly, the recommendations in this report target national, strategic implementation, while future studies could explore local demand analyses with potential scalability to wider populations.

The study also did not consider the impact of public health interventions such as reducing BMI among women of childbearing age which could decrease the incidence of high-risk pregnancies and associated ultrasound demand. In addition, analysis focused solely on sonographer workforce numbers, excluding supporting roles such as radiology healthcare assistants, consultant radiologists, and administrative staff, all essential to service delivery.

The most significant limitation was the restricted timeframe, which prevented full application of grounded theory methodology and limited thematic saturation across interviews. Finally, researcher bias may have played a minor role due to professional links with two interview participants, though overall impact on validity is considered minimal.

### 6.8 Future Research

Future studies should evaluate the impact of proposed interventions, including standardised ultrasound referral systems, on service efficiency, patient outcomes, and potential unintended consequences. Further research into the management of repetitive strain injury (RSI) among sonographers is also warranted, particularly through the analysis of national datasets. Investigations into equipment procurement and collaborations with manufacturers could identify opportunities for ergonomic innovation, AI integration, reduced injury risk, and enhanced workforce wellbeing informing long-term service planning across Wales.

## 7 Key Recommendations

### 7.1 Expand Training Capacity through an Ultrasound Academy

There is a pressing need to expand the training pipeline for sonographers in Wales. The National Imaging Academy is well placed to take on this role, with existing faculty, simulation facilities, and agreements to scan NHS patients. Extending its remit to include ultrasound within the non-medical workforce would:

- Support structured training of new entrants while reducing pressure on already overstretched clinical staff.
- Facilitate upskilling of the existing workforce, improving flexibility and resilience.
- Enable greater standardisation of training and assessment, which has been highlighted as a current challenge.
- Develop additional diagnostic capacity by outsourcing NHS patients from existing waiting lists for training purposes, following the model currently used in Scotland.

However, accessibility issues must be addressed, as the Academy's Southeast location limits opportunities for trainees in North Wales. Options include developing satellite hubs, peripatetic delivery models/shared faculty arrangements to ensure equity of access.

## 7.2 Strengthen Workforce Retention and Career Progression

Retention is inseparable from education, support, and recognition. Evidence from interviews highlighted that many sonographers feel career progression opportunities are limited, and that advanced practice roles are not always matched with appropriate pay banding. To address this, it is recommended that:

- Principal Sonographer roles could be scoped or piloted to assess its effectiveness in providing improved professional leadership, service coordination, and strategic workforce planning across organisations.
- Professional supervision and mentorship structures are introduced to support wellbeing, reduce burnout, and improve job satisfaction.
- Clear, accredited pathways for advanced and consultant-level sonography are aligned with appropriate banding, recognising the complexity and responsibility of these roles.

This would support retention by demonstrating a visible, valued career framework and ensuring professional recognition.

## 7.3 Improve Workforce Data and Analytics

Current data on workforce capacity, demand, and attrition is fragmented and insufficient to support strategic planning. Strengthening data collection and analytics would:

- Enable accurate forecasting of retirements, attrition, and regional gaps.
- Allow modelling of different training pipeline scenarios and their impact on service delivery.
- Support evidence-based resource allocation, ensuring that investments in training align with projected need.

Integration of Big Data approaches, drawing on electronic health records, service utilisation, and workforce metrics, would allow more accurate demand modelling and improve decision-making at a national level (Sharma et al., 2025).

## 7.4 Address Workload Pressures, Burnout, and Musculoskeletal Injury

Sonographer wellbeing is a critical issue to address this:

- A national policy on managing RSI and musculoskeletal injury risk should be developed, including regular assessments, ergonomic training, and shared responsibility between staff and managers.
- Workload distribution, particularly in obstetric ultrasound, should be reviewed to ensure capacity is matched to demand and medico-legal risks are not disproportionately shouldered by sonographers.
- The reliance on private-sector outsourcing should be reviewed, with recognition of its cultural and morale impact on NHS staff.

These measures would help reduce attrition caused by injury and exhaustion, while supporting safer, more sustainable practice.

## 7.5 Adopt a Standardised All-Wales Demand Management Approach

Demand management was repeatedly raised as a critical issue. While local practices varied, stakeholders expressed strong support for an all-Wales approach to referral and vetting criteria. This would:

- Ensure consistency of patient access across regions.
- Reduce inappropriate referrals and create more predictable demand.
- Free up capacity for high-value diagnostic work, rather than low-yield surveillance.

Building on BMUS guidelines, pathway-specific referral criteria could be developed, alongside root cause analyses to identify drivers of demand. This would also support workforce planning, by linking demand data directly to workforce capacity and training needs.

# 8 Conclusion

This study demonstrates that the sustainability of ultrasound services in Wales is under serious threat from workforce shortages, rising demand, and structural weaknesses in training and retention. For the National Imaging Programme, the findings highlight the need for a coordinated national strategy integrating expanded training pipelines, stronger retention through improved career pathways and leadership roles, and consistent demand management via an all-Wales referral framework underpinned by BMUS guidelines. Interventions require coordinated, system-wide action rather than short-term measures such as outsourcing, which fail to address the underlying drivers of capacity gaps. Investment in workforce analytics and Big Data approaches will be essential for strategic planning, while addressing wellbeing, workload, and occupational health will be critical to reducing attrition. Future project work should ensure these interventions are rigorously evaluated to understand their impact on both patient outcomes and staff experience, guiding the development of a sustainable ultrasound service for Wales.

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# 10 Appendices

Appendices can be found in the following page:

https://cronfa.swan.ac.uk/Record/cronfa71902

# Seeking help now: How may mental health help-seeking be effectively promoted in Wales?

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**Abstract:**

Improving the accessibility of mental health services is a key element of agenda to ensure that people receive timely support, and for improving population mental health. However, the acceptability of mental health support and services is also recognised as important. Indeed, this can be considered equally or even more greatly important, particularly in relation to people who may experience barriers in seeking support. Such barriers can result from numerous factors, even relating to the effects of a person's mental health issue or illness—which can affect recognition of the need to seek support, a lack of understanding about what support exists, perceptions that services may not understand need or be able to help, and perceived barriers in thinking forwards about the journey through support and towards recovery. This poses a question—how effective is improvement within mental health services for populations who may not connect with seeking support or accessing services? Help-seeking is considered an important concept in relation to understanding delays and the timely provision support, and this research report explores help-seeking as a "problem-focused, planned behaviour" (Cornally & McCarthy, 2011, p. 280), and how it may be effectively elicited, in a mental health context. The report examines two key models in particular: the COM-B Model and Behaviour Change Wheel (Michie et al., 2011) (as set out by West & Gould, 2022), and the Integrated Behavioural Model of Mental Health Help-Seeking (Hammer et al., 2024); considering their applicability, through the lens of current strategic improvement plans for mental health support in Wales. This research reflects that, while there are generalised universal or targeted strategies for improving the conditions in which help-seeking can occur (such as combatting stigma), a facilitative approach to help-seeking may require models that take into account the complexity of barriers to and enablers of help-seeking, specific to the needs of a target population, and integrative approach to developing interventions to achieve this.

**Keywords:** Mental health help-seeking, Behaviour change models, Service accessibility, Barriers and stigma, Intervention design Wales.

## Table of Contents

## 1 Introduction

Improving the accessibility and acceptability of mental health services is recognised as important in reducing mental health inequalities (Senedd Commission, 2022). Welsh Government have published that mental health is a fundamental human right that belongs to everyone, without exception (2024). They also recognise that mental health is shaped by the social, economic, and physical environments in which people live; that social conditions contribute to mental health inequalities; and that the mental health system can both mitigate and exacerbate these inequalities (Welsh Government, 2025).

New plans are now in place in Wales for the transformation and improvement of mental health services—with the recent launch of the new ten-year national Mental Health and Wellbeing Strategy 2025-2023 ('the Strategy') and the earlier establishment of the Strategic Programme for Mental Health / NHS Wales Performance and Improvement (NHSPI), and a key focus on ensuring open access to services. However, this report considers whether these plans are alone sufficient to enable actual early mental health support.

Effective help-seeking is known to be important in managing health—catalysing timely access to appropriate support and the process of recovery from illness (Liu et al., 2025; Cornally & McCarthy, 2011), but this can be challenging. Numerous perceived and material barriers have been identified that can preclude help-seeking (Tunks et al., 2023; Barrow & Thomas, 2022; Ali et al., 2017), and it is also known that some people will experience cognitive, affective, and/or physical effects relating to mental health issues or illness, which can influence decision-making and help-seeking behaviour (Treasure et al., 2024). Indeed, it has been suggested that there may be a significant gap between those who may require mental health care, support, and treatment, and those who seek support (Liu et al., 2025; Hammer et al., 2024; Radunz & Wade, 2023).

Existing studies have identified barriers to and facilitators of help-seeking in mental health; and the need for further research to develop and evaluate strategies to address such barriers has been recently recommended from within clinical academia (Mills et al, 2024). However, it has also be identified that limited holistic understanding of how people seek help for mental health problems has impeded the development of evidence-based strategies to facilitate help-seeking (Liu et al., 2025).

At a unique time of transformation in Wales for mental health services, this report seeks to understand the importance of help-seeking towards closing potential gaps in care, support, and treatment, and ensuring early and appropriate mental health care; and considers how this can be approached—utilising new national resource.

## 2 Identification of Project Requirements

This research has been inspired by an innovation project, undertaken by the Eating Disorders Network team—part of the national Strategic Programme for Mental Health. It's thought that eating disorders could affect around 60,000 people in Wales (Beat, 2022), however studies suggest only a minority of people with eating disorders (~23%) seek treatment; with approximately 50% of those who do seek and complete treatment making a full recovery (Mills et al., 2023). It seems that this may not only be relevant in the context of eating disorders. Hammer et al. (2024) mentions:

> *Despite the severe toll of untreated mental illness (World Health Organisation, 2022) and the documented effectiveness of professional mental health care services (Huhn et al., 2014; Wampold & Imel, 2025; Ziguras & Stuart, 2000), there exists a significant treatment gap between those who have a mental health condition and those who receive professional support for that condition (p. 316).*

They suggest that in order to address this gap, it is necessary to understand constructs that influence access to mental health care, which includes research on "help seeking" (2024, p. 316).

The Strategic Programme for Mental Health was established in 2023, as the revised national mental health programme, within NHS Wales Performance and Improvement—a new national support function: to work on behalf of Welsh Government; acting as a "central guiding hand" to the NHS in Wales, and driving improvements in the quality and safety of care (Welsh Government, 2023, p. 6). They key purpose of the Strategic Programme is to: "Provide system leadership, reduce unwarranted service variation, and improve safety and outcomes, whilst working towards equity and parity between physical and mental health services" (Welsh Government, 2023, p. 12). Hosted organisationally by Public Health Wales NHS Trust, this affords new national oversight and coordination for the improvement of healthcare and population health in Wales.

The Strategic Programme also has a key role in supporting the delivery of the new national Mental Health and Wellbeing Strategy (Welsh Government, 2025). Most closely aligned with the following key vision statements of the Strategy, the Strategic Programme currently works to guide transformation, with a current key focus on ensuring universal open access to mental health services—through a stepped, recovery-focused model of care:

- Vision Statement 3: “There is a connected system where all people receive the appropriate level of support wherever they reach out for help” (p. 32).
- Vision Statement 4: “There are seamless mental health services – person-centred, needs led and guided to the right support first time, without delay” (p. 47).

The ambition of this is to enable rapid access to mental health support for everyone who may need it; with data predicting an increase in prevalence in mental health needs, and a need for a system that can better respond to this (Welsh Government, 2025). Wales’ leading health and care think tank, the Bevan Commission, project that this rise in prevalence could be by as much as a third over the next 20 years (Prince, 2025) and have published that one in five of Wales’ adult population report receiving treatment for a mental health problem (Bevan Commission, 2024).

While improving the accessibility of mental health services has been recognised as an importance part of reducing mental health inequalities (Senedd Commission, 2022), Welsh Government also recognise a need to promote equity in people’s experiences and outcomes, rather than solely a focus on reducing inequity in service access. It is this need/focus that this research seeks to support, by exploring the nature of help-seeking in mental health within the current context in Wales, and its role in people’s pathways from issue/illness to resolve/recovery. It is hoped that this will enable greater equity, by exploring how help-seeking can best be promoted within current transformation—particularly for groups who may experience greater barriers thereof; to ensure that underserved groups can be better reached and engaged in appropriate support, as opposed to merely improving access and assuming that all people who require support will reach services.

In addressing this, this research aligns to details in the following key milestone of Phase 2 (“Preparing for Success”), in the current transformation roadmap (Stepped Care Solution, 2025): “explore opportunities for expanding services and identify barriers to accessing care as well as potential solutions” (p. 43).

Therefore, in summarising the key requirements for this research project, it will consider the following questions:

**What are the key barriers and factors that could preclude early access to mental health support?**

**Can the current national plans to improve mental health services in Wales address these factors?**

**What is the nature and role of help-seeking in ensuring early, recovery-focused action and support for mental health? What are the key barriers to this?**

**What are some promising approaches through which help-seeking may be enabled and facilitated; and what are the implications of this at a system-level perspective, currently?**

# 3 Main Analysis

## 3.1 Understanding barriers to mental health care, support and treatment

A report by the Welsh Parliament’s Health and Social Care Committee (Senedd Commission, 2022), referenced in the Mental Health and Wellbeing Strategy, acknowledges a “triple barrier” of mental health inequality (p. 18). This suggests that:

- Some groups are at a disproportionately higher risk of poor mental health; often linked with social inequalities.
- Groups with particularly high levels of poor mental health can experience the most difficulty in accessing services.
- When people do access support, their experiences and outcomes are often poorer.

More specifically, the report details the following barriers, from engagement with those most likely to experience mental health inequalities:

- Stigma, including fear of being judged, of losing existing support, or of being penalised.
- Discrimination, including on the basis of age, ethnicity or sexuality.
- Cultural barriers and language issues.
- Lack of trust in services, including as a result of previous negative experiences or concerns about being dismissed or not feeling listened to.
- Lack of knowledge about what help may be available or how to access it.
- Lack of capacity within existing services, long waiting times, high thresholds for access, and gaps or variability in services provision, including a lack of specialist services.
- Lack of clarity about referral processes, restrictive referral processes, and exclusion from services as a result of diagnostic overshadowing.
- Geographical issues, for example due to rurality.
- Digital exclusion.

The report recommends that improving not only the accessibility but also the acceptability of mental health services is key to reducing mental health inequalities:

> *We will not see mental health inequalities reduce unless [services] feel accessible and welcoming to everyone who may need them. We agree with [Platfform] that it is not that people are hard to reach, rather services are too often structured and managed in ways that make it hard for them to reach (p. 48-49).*

A rapid evidence summary (Csontos, 2024) from Health and Care Research Wales suggests the following areas in which improvements may better enable access to mental health services:

- Language and cultural adaptations.
- Better information provision.
- Sector/cross-sectoral collaboration.
- Improving and facilitating referral routes and pathways.
- Involving communities.

It can be seen that factors influencing access to mental health services are varied but could also be considered to relate to two key domains—perceived and material. There are systemic, practical, and relational barriers (e.g., discriminatory, cultural and language-based, and those that related to service capacity and protocols, geography, and/or digitalisation), and barriers that may be considered more subjective or perceived in nature (e.g., stigma, knowledge about support available, and/or negative perceptions about services). All of these barriers can be considered systemic from a system-leadership perspective and with a view to driving national improvements in mental health. For example, while stigma may have acute impact as experienced on an individual-level—such as in influencing a person’s perceptions about mental health issues or accessing support, this is also recognised as something that is targeted at scale (Salaheddin & Mason, 2016). It may also be reasonable to suggest that perceived and material barriers interrelate; for example, negative experiences of mental health services could in turn exacerbate negative perceptions about services, more widely. However, an important distinction can also be drawn here, between: (1) the accessibility of services themselves, and (2) individuals experiences that can predict or preclude access. It seems that while the two sit in close proximity, they should perhaps not be conflated into a singular concept, as they relate to different parts of a person’s process, towards support and recovery. One related to people’s experience of services, while the other precedes this. Again, both can perhaps be considered systemic, in the context of improving outcomes for population mental health.

## 3.2 Improving access and offer: the Stepped Care 2.0 Model

The Strategic Programme for Mental Health current explores the Stepped Care 2.0 (SC2.0) (Cornish, 2020), with the aim of ensuring universal, same-day open access to mental health care—at the point of need and stage of readiness; set to include online, phone, and walk-in care options (Welsh Government, 2025).

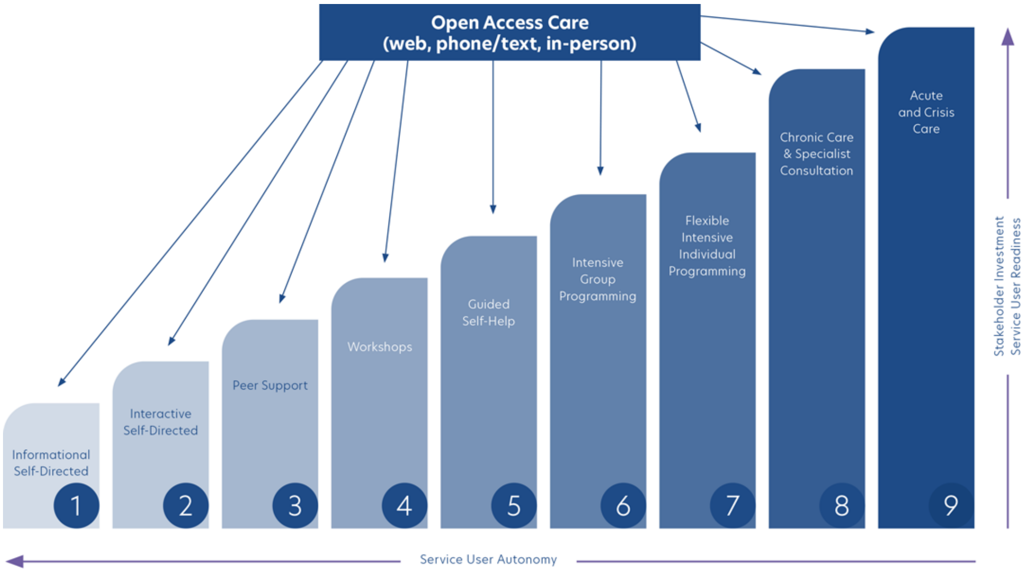


**Figure 1: The nine-step framework of the Stepped Care 2.0 Model.**

*Note:* The framework presents interventions across a continuum of care. Implementation of this involves selecting services that align with the structure and number of steps required for each community (Stepped Care Solutions, n.d.)

This model presents a framework wherein potential support options, meeting varying levels of need, are mapped across nine intervention types—ranging from self-directed to acute and crisis care, across a continuum of need. Service user autonomy is a key factor that guides the type of support offered and delivery, within an open access “one-at-a-time” approach (Stepped Care Solutions, 2025).

The transformative potential of this framework is clear, with it being described as offering a fundamental shift in how services are conceptualised and delivered: from system-centred, to person-centred; designing pathways around people’s needs, rather than organisational convenience; prioritising choice, control, and autonomy for service users; and measuring success through meaningful outcomes for individuals and communities. The accessibility and convenience of open access and OAAT services are highlighted as features that can encourage individuals to seek help sooner, thereby preventing potential crises from developing (Stepped Care Solutions, 2025); as Hammer (n.d.) considers, “How much easier would it be to seek help if you had immediate walk-in access to mental health professionals?”

This appears promising, particularly inclusive of people who may experience greater complexity or severity in their mental health need(s). As has been identified, people with particularly higher levels of poor mental health can experience the most difficulty in accessing services (Senedd Commission, 2022). It is also known that often, longer durations of untreated illness (DUI) are associated with poorer treatment outcomes (Mills et al, 2024; Kisely et al., 2018)—making early interventions important for recovery. In addition, the integration of the values of autonomy, choice, and control, within the SC2.0 Model—considered to be core human needs (Human Givens Institute, n.d.)—can easily be seen as of great benefit to person-centred care with service user agency; also enabling the co-production of care, as outlined as a core tenet of prudent healthcare philosophy (Bevan Commission, n.d.). However, it could also be argued that these values are experiential in nature, and still dependent on an individual first engaging with such a model of support. Although access may be improved with this, and with a greater range of entry routes to services (i.e., in-person, telephone, and online), does this necessarily ensure that early help-seeking and engagement with services will be enabled? It may be better enabled, but this question prompts relevance of the distinction between the accessibility, and/or even acceptability of services, and the propensity of individuals to seek help for their mental health needs, particularly where there may be significant subjective barriers in doing so—distinct from service-related factors. It is clear that service accessibility can better support early help and support but appears that a truly people-centred approach requires and earlier focus into people's experiences and pathways from issues/illness to recovery; and a deeper and more holistic understanding of what enables or prevents help-seeking.

This seems to be in the spirit of the SC2.0 model, in designing services (or the system) around people's needs, rather than from an organisational view—a population-based perspective, rather than a services-based one; but perhaps requires a closer examination of help-seeking, particularly in relation to mental health.

## 3.3 Defining help-seeking

Cornally and McCarthy (2011) consider that help-seeking has gained popularity as an important vehicle for exploring and understanding patient delay and prompt action, across a variety of health conditions; and suggest that concept clarification can aid professionals' understanding, and guide theory, development, and practice. They describe that help-seeking can be considered as "a problem-focused, planned behaviour, involving interpersonal interaction with a selected healthcare provider" (p. 280). This recognises the nature of help-seeking as a precursor to service access—that is: part of the journey to, rather than experience on arrival.

In relation to mental health help-seeking particularly, several other definitions are offered, as follows:

- "[T]he proactive pursuit of external support to address psychological issues" (Liu et al., 2025, p. 1).
- "[E]ither observed or self-reported readiness to seek help for psychological distress from any source of help" (Szucs et al., 2025, p. 3).
- "[A]n adaptive coping processes that attempts to obtain external assistance to deal with mental health problems, including not only formal (e.g. psychiatrists) but also from informal sources of help" (Doll et al., 2021, p. 2).

Key themes in these definitions are preparedness, pursuance, or action towards external sources of support, though this may not necessarily be from formal services. Cornally and McCarthy describe help-seeking as being characterised by intentional action, planned behaviour, and interpersonal interaction (2022, p. 280). These definitions are particularly relevant in the current context of mental health transformation in Wales, as the Strategy (Vision Statement 3: "There is a connected system where all people receive the appropriate level of support wherever they reach out") acknowledges:

> *"[a] range of services create a connected system where all people receive the support they need. This support should range from informal wellbeing support systems in local communities, through to help within wider services, advice and signposting opportunities for support and self-management." (p. 32)*

Additionally, in relation to digital development, the Strategy discusses action to ensure "high quality digital services designed around the needs of the citizen" and "Digital inclusion – [equipping] users with the access, skills and confidence to engage with digital health and social care services based on their specific needs or preferences" (Welsh Government, 2025, p. 51).

These actions correspond with Liu et al. (2025), who capture that people seek support for their mental health needs from a variety of sources, including social networks and increasingly digital platforms, as well as professional services.

Therefore, in the current context in Wales, it can be considered that help-seeking in relation to mental health need not only be defined as the access of professional services, but by an individual's readiness to obtain, or pursuit of obtaining, any form of support that may be relevant or acceptable to them. It may include access of self-directed resources and may not be interpersonal in the first instance. While interpersonal support or formal treatment may be necessary for people with urgent needs, the stage of readiness tenet of the Strategy and SC2.0 model seek to enable a "no wrong door" approach (Welsh Government, 2025, p. 7): "This full spectrum of support can range from providing information and advice, signposting and/or referral to other services, social prescribing, or an NHS or social care service" (Welsh Government, 2025, p. 28).

Having defined this, consideration next leads to what enables or prevents help-seeking.

## 3.4 Barriers to and facilitators of help-seeking

Existing studies identify numerous barriers and facilitators in relation to mental health help-seeking.

Several studies identify that a person's accurate perception, understanding and/or recognition of their mental health and the need to seek help are key enabling factors (Varma & Batterham, 2025; Tunks et al., 2022; Ali et al., 2016). Mental health literacy is another facilitator commonly cited, which is understood to enhance a person's recognition of their mental health and perception of the need for support (Liu et al., 2025; Varma & Batterham, 2025; Barrow & Thomas, 2022).

Stigma is identified as a significant barrier to help-seeking (Tunks et al., 2022; Ali et al., 2016); Salaheddin & Mason, 2016), with stigma-reduction initiatives multiply recommended (Tunks et al., 2022; Salaheddin & Mason, 2016). Doll et al. (2021, p. 2) explore that stigma can be divided into various categories, as below:

- Structural stigma: Defined on a macro-social level, as institutional policies and practices, societal-level conditions, cultural norms, and institutional practices that constrain opportunities, resources, and wellbeing for stigmatised population.
- Perceived stigma: This can be considered a part of structural stigma; expressed on a macro-social level through community prejudices and negative perceptions of people with mental illness.
- Self-stigma: Prejudices and negative stereotypes internalised by affected people, before the development of a mental illness and themselves identifying with a stigmatised group.
- Personal stigma: Similar to self-stigma, but relating to unaffected individuals' prejudice and negative stereotypes—often manifest as a "wish for social distance"; to avoid persons with a mental illness.
- Anticipated stigma: Relating to discrimination by others, with a misconception that they could develop mental illness by being in proximity to people with mental illness.

In slight contrast to this, Mobayed (2025) considers that—while stigma, shame, or embarrassment are factors validly identified to prevent people from seeking help—self-reliance is the most commonly identified barrier in literature. It is highlighted that the difference in instruments to measure this can mean variation in how this is framed, but that thematically, this has ranked as the strongest barrier, in different populations and across cultures. Proximate ideas, such as the belief that mental health problems will resolve themselves, or feelings that such problems are not severe enough or do not warrant treatment, appear to rank second. Self-reporting is acknowledged as a methodological consideration that may temper these findings; Mobayed considers the possibility that people may prefer to not mention fears of stigma or perhaps may not realise the extend of the influence of stigma. He states that while the role of stigma in preventing help-seeking should not be discounted, literature presents a clear cause to attribute reluctance to seek help to self-reliance. He writes, "there is a common current of not recognizing the importance of help-seeking […], or at least not acting on this idea" (2025, para. 4).

The above presents a range of considerations as to what barriers may prevent a person from seeking help, and it is possible that targeting such barriers could be an approach to better enable help-seeking. However, as Salaheddin and Mason (2016) highlight, despite a conscious effort to improve public awareness and reduce stigma surrounding mental health in recent time, evidence still suggested that some groups were unlikely to seek help, particularly from professionals' sources.

In addition to widening support offers across a more connected system, the current Delivery Plan (2025-2028) (Welsh Government, 2025) for the Mental Health and Wellbeing Strategy features the following actions that could target barriers to help-seeking, such as those identified above:

- VS 2.6: "Tackle any form of stigma which stops people taking action to protect and promote mental health and wellbeing and seeking help for mental health conditions." (p. 9).
- VS 3.1. "Provide joined-up information, advice and self-care resources to help individuals support their mental health." (p.10).
- VS 4.6. "Ensure there is a plan to provide information about mental health services and support, and how to access them." (p.19).

In relation to communications, the wider Strategy commits to the following: "ensure that the public know how they can access support and services and what people can expect from this support.'" (p.54).

However, the robustness of this to elicit actual help-seeking and recovery-focused action within populations—particularly in relation to those who may experience considerably potent subjective barriers, isolation, or illness-related factors that could influence help-seeking—could be questioned. In relation to eating disorders, for example, Treasure (2024) writes:

> *'Starvation and food refusal can produce a mixture of emotions, such as anxiety and/or frustration, which in turn leads to overprotection and accommodation to the eating disorder or criticism or withdrawal. [...] The social reaction to binge spectrum disorder can also include anxiety, but also disgust, anger, and shame. These, and the secretive nature of these behaviours, can also serve to isolate the individual, which in turn leads to anxiety and low mood...' (p.16-17).*

Could the targeting of specific barriers (e.g., via stigma-reduction initiatives), or the promoting of enabling factors (e.g., mental health literacy or self-help resources), be sufficient in isolation to increase help-seeking, reduce care/support/treatment gaps, and have a material impact on population mental health?

It could be considered that such initiatives would require tailoring to particular population groups. For example, the influence of stigma on young people affected by eating disorders may be different from the way in which it influences another sociodemographic experiencing other types of mental health condition.

Considering this, part of the function of NHS Wales Performance and Improvement (NHSPI) includes the facilitation of national networks and communities of practice—enabling the bringing together of clinical communities and stakeholders, to focus on national pathways and practice for particular services and/or conditions (Welsh Government, 2021). This supports efforts to reduce variation and improve population health. These allow structures through which developments relating to particular mental health pathways, conditions, or populations, can be achieved at scale.

However, what is insofar absent is an understanding of how help-seeking can be facilitated holistically, distinct from targeting barriers or facilitators to help-seeking, in isolation. Liu et al. (2025) consider that, while existing reviews identify numerous barriers to help-seeking, limited holistic understanding of how people seek help for mental health issues and neglect of the theoretical foundations therein, has impeded the development of evidence-based interventions to facilitate help-seeking behaviour. Here, a crucial identification can be made—that is, help-seeking as behaviour. In principle and from a high-level system perspective, help-seeking is a construct that relates to the timely pursuit and access of support; but in practice, in individuals' experience, help-seeking is a behaviour that determines action—from mental health issues or illness, to support and recovery; problem-focused and intentional (Cornally & McCarthy, 2011). This opens consideration of a promising approach through which help-seeking may be facilitated.

Public Health Wales define behaviours as "observable, measurable actions" (Knowles, 2024, p. 4). Knowles (2024) also explores:

> *Activity to improve and protect health and reduce inequity happens continuously across the public health system and almost always relies on individuals doing something differently [...]. Similarly, most interventions aiming for better health – be they legislation, policy, services or communications – require changes in behaviour. Behavioural science is the centred with understanding the determinants of those observable measurable actions, and then deploying approaches or techniques most likely to change or sustain them, depending on the objective. By deploying behavioural science we can 'get what we aim for, more often' – we can realise a behavioural dividend and optimise our impact (p. 4).*

Could a behavioural science approach be effective to facilitate help-seeking?

## 3.5 A behavioural science approach to help-seeking

Wittchen et al. (2014) advocate a need for behavioural science in relation to research for mental health and mental disorders—posting a fragmentation in research strategies, lying in narrower cognitive or neurobiological perspectives. They pose questions as to why some people are able to cope with traumatic stress and anxiety, while others develop avoidance behaviours; and what may be critical trajectories in the development of maladaptive behaviours to diagnoseable mental disorders. They write:

> *The well known translational barriers can only be overcome when segregated research approaches are combined in a concerted, interdisciplinary action, linking biological, psychological and social sciences within a developmental framework (p. 37).*

While Wittchen et al. discuss this in relation to the study of mental health and mental disorders broadly, it could be said that they recognise and are inclusive of the broad bio-psycho-social domains in which mental health issues can be predetermined, precipitated, and perpetuated (Treasure, 2024), and the need for trans-disciplinary efforts—including behavioural, as well as clinical and neuroscientific perspectives. They present and discuss the benefits of integrative translational research models to conceptualise how individual vulnerabilities interact with the environment over time and promote critical which can act as proximal risk factors to ill health and/or mental disorders. In relation to symptom progression models from an integrative translational public health perspective, Wittchen et al. suggest these to be of great heuristic value. This shows relevance to people who may experience symptom- or illness-related effects that might act as barriers to help-seeking, as similarly explored by Treasure (2024) (see 3.3).

### 3.5.1 Public Health Wales guidance on behavioural science

Public Health Wales (PHW) describe behavioural science as “the scientific study of behaviour – what enables it, what prevents it, and how best to elicit and maintain it” (West & Gould, 2022, p. 4). This is provided in guidance that their Behavioural Science Unit has published in partnership with colleagues from University College London, on the use of behavioural science in policy and practice. This states that behavioural science has become a widely applied approach in the public and commercial sectors—with growing examples of how it has optimised policymaking, service development, and communications. It considers that most decisions on such developments are made by people who do not hold expertise in behavioural science, and that this is not necessary. However, they advocate the importance of recognising when behavioural science can add value—noting that costly failures are known to have been made where there has been reliance on “common sense” to predict how people will react to developments.

An important practical use of behavioural science is to develop effective behaviour change interventions. In doing so it is crucial to not jump into such interventions prematurely, but to adopt a systematic method to arrive at ones that stand a good chance of meeting their objectives (West & Gould, 2022, p.4).

This Guidance centres around the COM-B Model and Behaviour Change Wheel (BCW) (Michie *et al.*, 2011), which posits that in order for a person to enact a particular behaviour at a given time, they must have the capability to do so (e.g., the knowledge and skills), the opportunity to do so (e.g., time, resources, and a conducive social environment), and must be motivated to do so, more than anything else they may be doing at the time. It is shown that each of these components can be further refined, in the following subcategories:

- Capability: physical capability; psychological capability.
- Opportunity: physical opportunity; social opportunity.
- Motivation: reflective motivation; automatic motivation.

This is described as providing a “unifying, transdisciplinary framework for other models and theories in behavioural science” (West & Gould, 2022, p. 4). First developed by Michie et al. (2011), this acknowledged a range of existing frameworks for behaviour change interventions but questioning their efficacy and identifying the need for a method of characterising interventions and linking them to targeted behaviours. Michie et al. explore that, from a systematic search of electronic databases and consultation with behaviour change experts, 19 frameworks of behaviour change interventions were identified, which covered nine intervention functions (types) and seven policy categories through which such interventions could be implemented. These were evaluated against three criteria: comprehensiveness, coherence, and a clear link to the overarching model of behaviour. It was considered that none of these frameworks covered the full range of intervention functions and policies, and only a minority met the evaluation criteria. From this, a new framework was developed to meet these criteria and its reliability tested in the following two domains: the English Department of Health’s 2010 tobacco control strategy; and the National Institute of Health and Clinical Excellence’s guidance on obesity control. Michie et al. describe that the results of these tests indicated that the framework was used reliably in both, to characterise interventions.

It seems that the framework has since been widely applied for behaviour change interventions in health (Willmott *et al*., 2021; Boyd *et al*., 2020; Li & Li., 2025; Whittal *et al*., 2021; McDonagh *et al*., 2018). While its use in relation to mental health behaviour change interventions appears limited (Wilde *et al*., 2023), several studies do indicate positive outcomes.

#### 3.5.1.1 Previous application of the COM-B model/BCW for mental health help-seeking

A study by Wilde et al. (2023) aimed to provide insight on student help-seeking behaviour by applying the COM-B model, particularly in relation to mental health literacy. A cross-sectional survey was conducted, collecting qualitative data. The authors found the model to be reliable in understanding help-seeking behaviours—identifying a positive relationship between mental health literacy and help-seeking when mapped to the COM-B components.

Ma *et al.* (2023) explore the use of the COM-B model to analyse barriers and facilitators of help-seeking behaviour in people with diagnoses of schizophrenia. It is outlined that in-depth semi-structured interviews were conducted with 13 participants. Findings were summarised under three categories: capability, opportunity, and motivation, and 12 subthemes corresponding with these categories. Results indicated that the help-seeking behaviour of people with schizophrenia results from the interaction of many barriers and facilitators, and the authors recommend that trials involving multiple COM-B components be implemented and evaluated.

An earlier study (Sagar-Ouriaghli et al., 2019), on mental health help-seeking behaviours in male students, explored the following: previous help-seeking interventions and their evaluation methods; a theoretical framework for understanding factors important to male students when accessing support; and how these factors could be mapped to a model of behaviour change, to inform development of evidence-based interventions. It is discussed that the COM-B model was selected due to its predictive validity; "Mapping help-seeking factors to the COM-B model provides greater guidance and clarity as to how to improve help-seeking in male students via the intervention and function as indicated by the BCW" (p. 13).

#### 3.5.1.2 Applying the COM-B Model and Behaviour Change Wheel

This section provides an overview of the COM-B and Behaviour Change Wheel (BCW) framework, for the development of behaviour change interventions, as set out in Public Health Wales' behavioural science guide (West & Gould, 2022).

The Guidance provides the following staged process for the development of behaviour changes interventions.

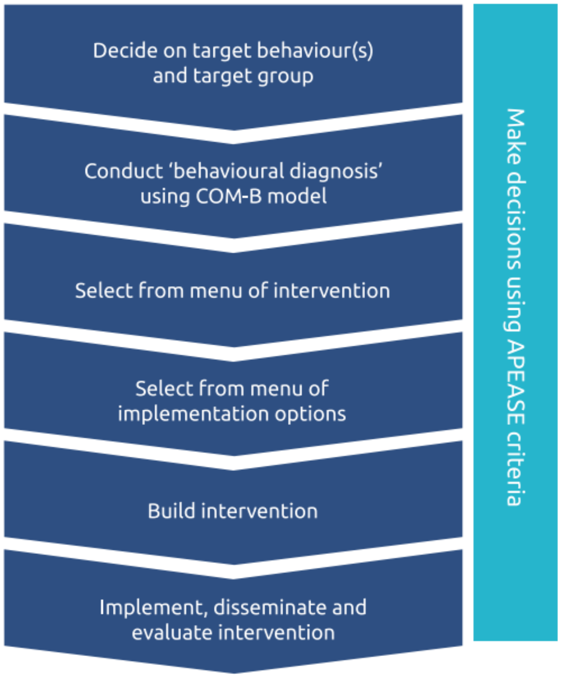


**Figure 2: Development stages behavioural change intervention.**

*Note:* As published by Public Health Wales (West & Gould, 2022, p. 20).

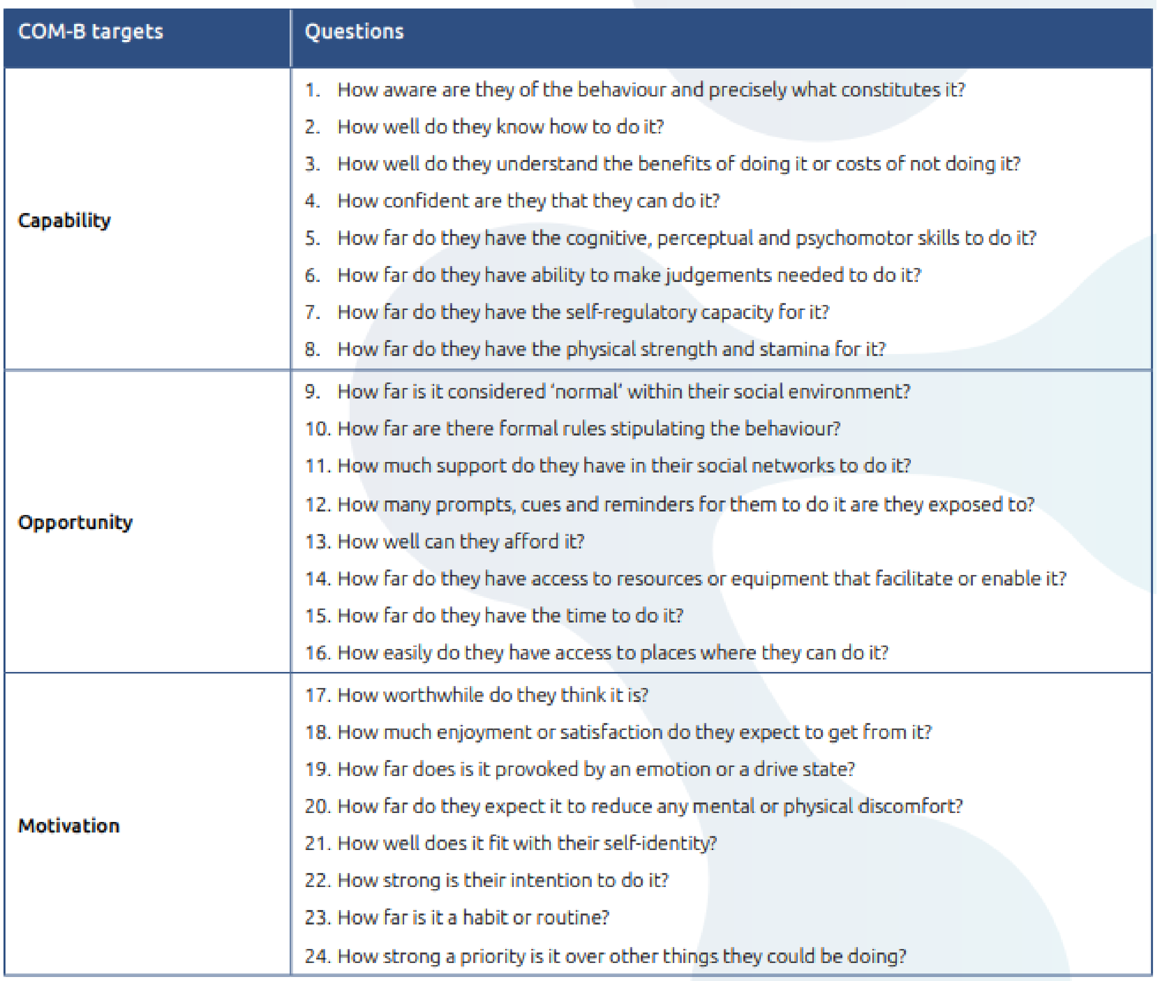
As shown, the first step given for the development of a behaviour change intervention is to determine a target population and target behaviour: i.e. who needs to do what, when, and for how long—to achieve an objective. System maps are noted as a tool that can support this initial process.

From here, an assessment is made on the following, to determine whether:

a. a target group has the necessary abilities to perform the target behaviour(s);
b. a target group's physical and social environments support the target behaviour(s);
c. a target group are more motivated to enact the target behaviour than anything else.

This process is described as a behavioural diagnosis, which the authors say can be achieved by drawing on—as far as time and resources permit—literature reviews, primary research, evaluations of previous interventions, and stakeholder engagement. Questions are provided that can prompt developers during this process, as in Table 1.

**Table 1: Questions to inform behavioural diagnosis.**

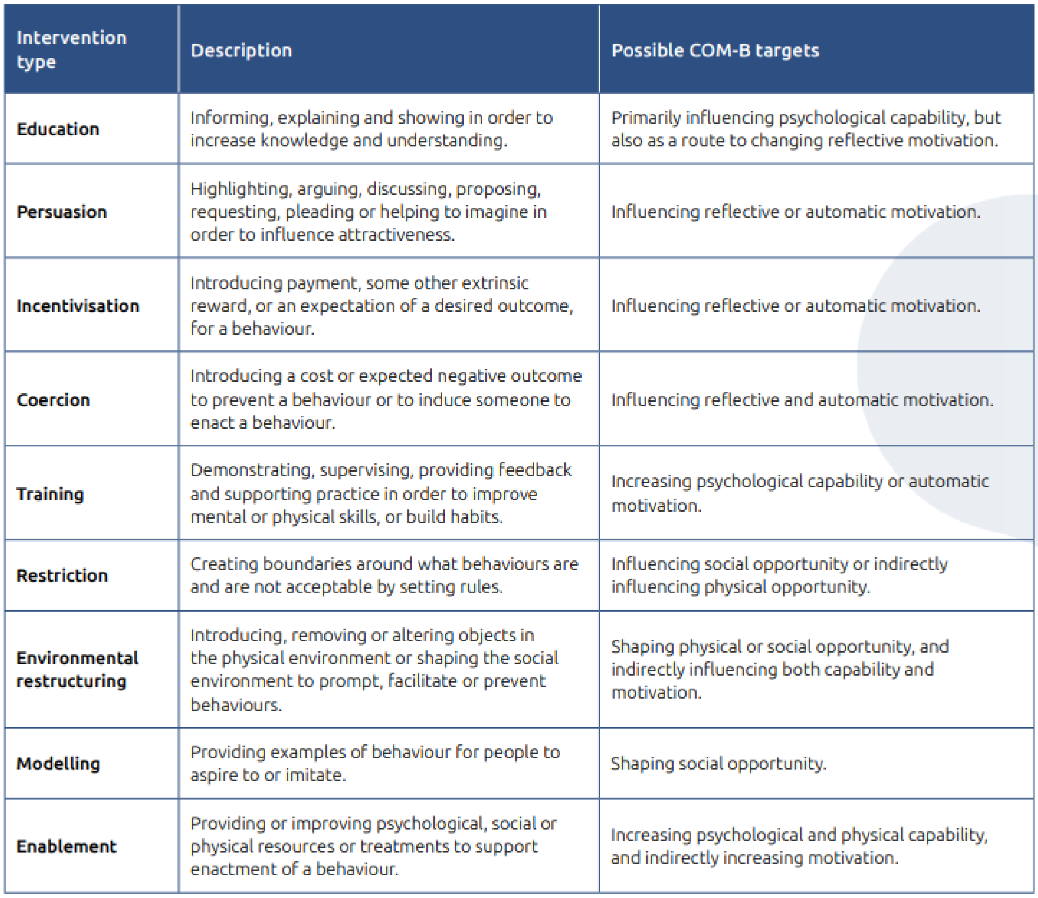


| COM-B targets | Questions |
|---|---|
| **Capability** | 1. How aware are they of the behaviour and precisely what constitutes it?<br>2. How well do they know how to do it?<br>3. How well do they understand the benefits of doing it or costs of not doing it?<br>4. How confident are they that they can do it?<br>5. How far do they have the cognitive, perceptual and psychomotor skills to do it?<br>6. How far do they have ability to make judgements needed to do it?<br>7. How far do they have the self-regulatory capacity for it?<br>8. How far do they have the physical strength and stamina for it? |
| **Opportunity** | 9. How far is it considered 'normal' within their social environment?<br>10. How far are there formal rules stipulating the behaviour?<br>11. How much support do they have in their social networks to do it?<br>12. How many prompts, cues and reminders for them to do it are they exposed to?<br>13. How well can they afford it?<br>14. How far do they have access to resources or equipment that facilitate or enable it?<br>15. How far do they have the time to do it?<br>16. How easily do they have access to places where they can do it? |
| **Motivation** | 17. How worthwhile do they think it is?<br>18. How much enjoyment or satisfaction do they expect to get from it?<br>19. How far does is it provoked by an emotion or a drive state?<br>20. How far do they expect it to reduce any mental or physical discomfort?<br>21. How well does it fit with their self-identity?<br>22. How strong is their intention to do it?<br>23. How far is it a habit or routine?<br>24. How strong a priority is it over other things they could be doing? |

*Note:* As presented by West & Gould (2022).

Following this, the Guidance directs to deciding on the most appropriate approach to achieve the target behaviour and objective—selecting one or more options from a menu of evidence-based intervention types ("intervention functions", as described by Michie et al., 2011). These can be seen overleaf.

**Table 2: Behavioural intervention types.**



| Intervention type | Description | Possible COM-B targets |
|---|---|---|
| **Education** | Informing, explaining and showing in order to increase knowledge and understanding. | Primarily influencing psychological capability, but also as a route to changing reflective motivation. |
| **Persuasion** | Highlighting, arguing, discussing, proposing, requesting, pleading or helping to imagine in order to influence attractiveness. | Influencing reflective or automatic motivation. |
| **Incentivisation** | Introducing payment, some other extrinsic reward, or an expectation of a desired outcome, for a behaviour. | Influencing reflective or automatic motivation. |
| **Coercion** | Introducing a cost or expected negative outcome to prevent a behaviour or to induce someone to enact a behaviour. | Influencing reflective and automatic motivation. |
| **Training** | Demonstrating, supervising, providing feedback and supporting practice in order to improve mental or physical skills, or build habits. | Increasing psychological capability or automatic motivation. |
| **Restriction** | Creating boundaries around what behaviours are and are not acceptable by setting rules. | Influencing social opportunity or indirectly influencing physical opportunity. |
| **Environmental restructuring** | Introducing, removing or altering objects in the physical environment or shaping the social environment to prompt, facilitate or prevent behaviours. | Shaping physical or social opportunity, and indirectly influencing both capability and motivation. |
| **Modelling** | Providing examples of behaviour for people to aspire to or imitate. | Shaping social opportunity. |
| **Enablement** | Providing or improving psychological, social or physical resources or treatments to support enactment of a behaviour. | Increasing psychological and physical capability, and indirectly increasing motivation. |

*Note:* Intervention types with descriptions and possible COM-B-targets that could relate.

Next leads to consideration of how best to implement the appropriate intervention type(s), by selecting from a range of policy/implementation options, including: by providing a service or developing a product; mounting a communications or marketing campaign; legislating; producing regulations; developing guidelines; using fiscal measures; using environmental or social planning mechanisms. In relation to both the intervention types and implementation options, the Guidance stipulates that one or more options may be applicable, and that some options will be more relevant to others, towards achieving particular objectives.

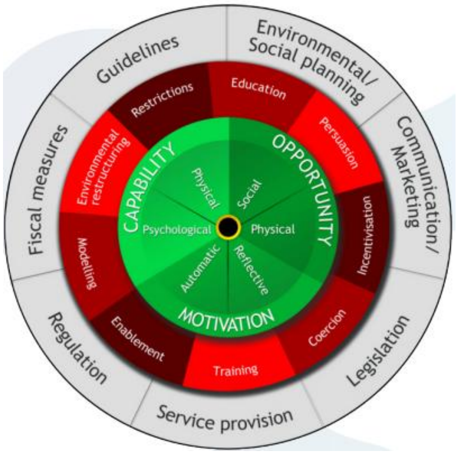


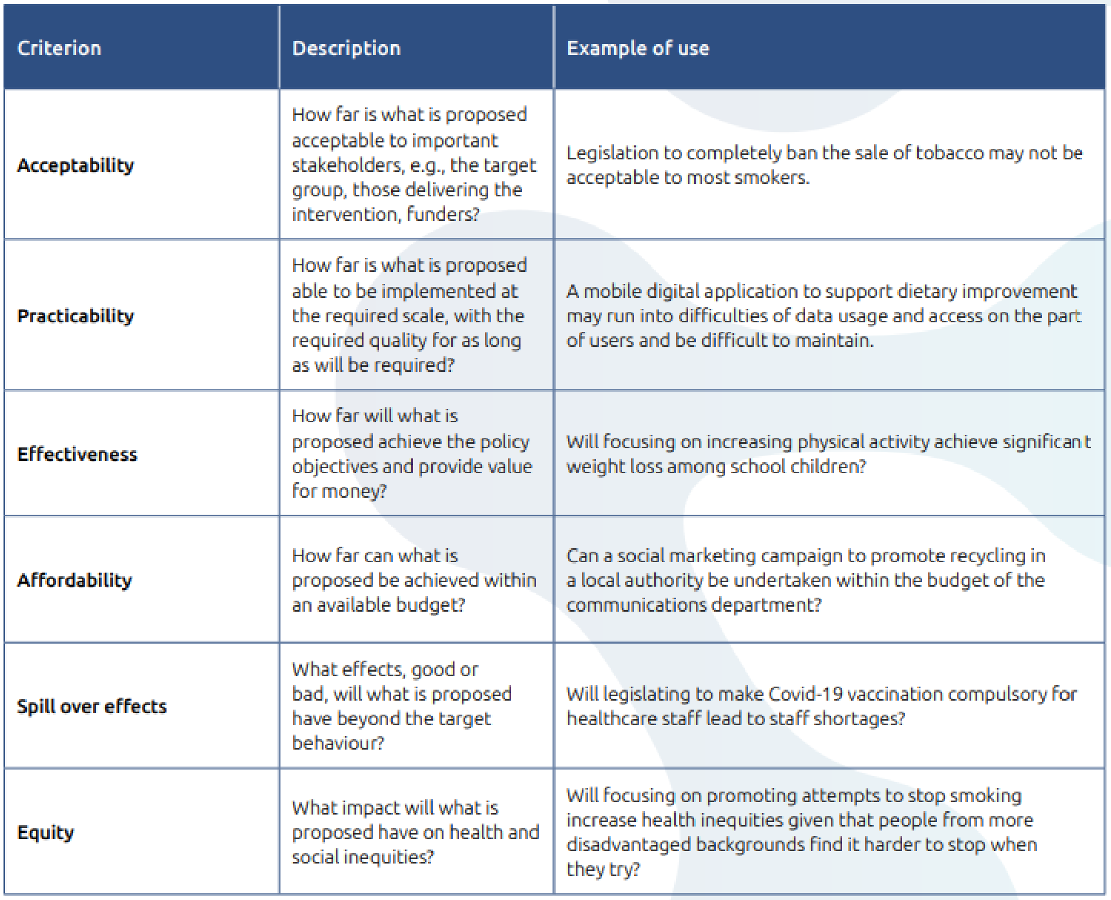
**Figure 3: The Behaviour Change Wheel (Michie et al., 2011).**

*Note:* Demonstrating the links between all components of the model, as a developer works from the "hub" in (green), to the "rim" (grey), through a combination of factors, intervention types, and implementation options. As presented by West & Gould (2022, p. 27).

Finally, but not least importantly in the process, the Guidance outlines that the intervention is to be actioned: implemented, disseminated, and evaluated. It is described as not sufficient simply to consider whether an intervention will have the desired impact in principle, but that throughout the process—from initial conception to finished intervention, and particularly where a decision is to be made that will shape the intervention—it is important to consider a range of factors, from the perspective of the target population.

To this end, the Guidance provides a set of criteria, 'APEASE'—representing the following areas of consideration: acceptability, practicality, effectiveness, affordability, spill-over effects, and equity.

**Table 3: The APEASE Criteria**



| Criterion | Description | Example of use |
|---|---|---|
| **Acceptability** | How far is what is proposed acceptable to important stakeholders, e.g., the target group, those delivering the intervention, funders? | Legislation to completely ban the sale of tobacco may not be acceptable to most smokers. |
| **Practicability** | How far is what is proposed able to be implemented at the required scale, with the required quality for as long as will be required? | A mobile digital application to support dietary improvement may run into difficulties of data usage and access on the part of users and be difficult to maintain. |
| **Effectiveness** | How far will what is proposed achieve the policy objectives and provide value for money? | Will focusing on increasing physical activity achieve significant weight loss among school children? |
| **Affordability** | How far can what is proposed be achieved within an available budget? | Can a social marketing campaign to promote recycling in a local authority be undertaken within the budget of the communications department? |
| **Spill over effects** | What effects, good or bad, will what is proposed have beyond the target behaviour? | Will legislating to make Covid-19 vaccination compulsory for healthcare staff lead to staff shortages? |
| **Equity** | What impact will what is proposed have on health and social inequities? | Will focusing on promoting attempts to stop smoking increase health inequities given that people from more disadvantaged backgrounds find it harder to stop when they try? |

*Note:* Descriptions and examples of the APEASE criteria (West & Gould, 2022, p. 21).

Another framework provided in the Guidance is 'NEAR-AFAR'. This acknowledges that there can be difficulty in understanding the large number of behaviours change techniques available, and provides a simple framework for noting that:

> *[B]ehaviours are more likely to occur when they are: normal, easy, attractive and routine (NEAR). Conversely, behaviours are less likely to occur when they are: abnormal, fraught (in the sense of being difficult to do), averse, and involving reflection (having to stop and think) (AFAR) (West & Gould, p. 32).*

### 3.5.1.3 Application of the COM-B/BCW: a test example

While this research project has not conducted a pilot application of this model in relation to mental health help-seeking, Public Health Wales host a digital Behavioural Discovery Tool, which has been used to explore how this model may work in practice, and what some of its results may suggest. This tool enables the inputting of information to questions, similar to those provided in Table 1. This has been completed in relation to common barriers identified as impact on the help-seeking of people experiencing eating disorders, as an example. The results of this are as below:

*Based on your answers, we suggest you consider:*

- Gathering more evidence about the current behaviour and systems.
- Providing/improving information or education on what you want people to do and how to do it.
- Changing systems, making the process easier, and/or providing support or training.
- Reducing the costs or highlighting/bringing forward the benefits of the behaviour.
- Framing your communication to draw what influences your audience (e.g. think about who delivers the message).

As can be seen, these recommendations aim at better enabling behaviour by offering actions that could enhance capability, opportunity, or motivation, in relation to potential intervention types—here including information/education, restructuring, and communication. These are interventions which can be targeted to particular population groups but disseminated as scale.

### 3.5.2 Integrated Behavioural Model of Mental Health Help-Seeking (IBM-HS)

Hammer et al. (2024) posit another theory of help-seeking behaviour, more specifically in relation to mental health—that it is driven by help-seeking intention, which is itself influenced by several mechanisms: (1) help-seeking determinants (e.g., structural forces; cultural influences; past help-seeking experience; evaluated need; mental health perceptions, knowledge, and skills; social support) which influence (2) help-seeking beliefs (i.e., outcomes beliefs, experiential beliefs, beliefs about others' expectations and behaviour, logistical beliefs), which in turn determine respective help-seeking mechanisms (i.e., attitude, perceived norm, personal agency). This is drawn together in the Integrated Behavioural Model of Mental Health Help Seeking (IBM-HS). As a more recently published model, research and evaluation on its application appears limited currently, however, the authors describe it as "a help-seeking-specific adaptation of the empirically supported integrated behavioural model and integrative model, which are themselves evolutions of the theory of planned behaviour and theory of reasoned action" (p. 315).

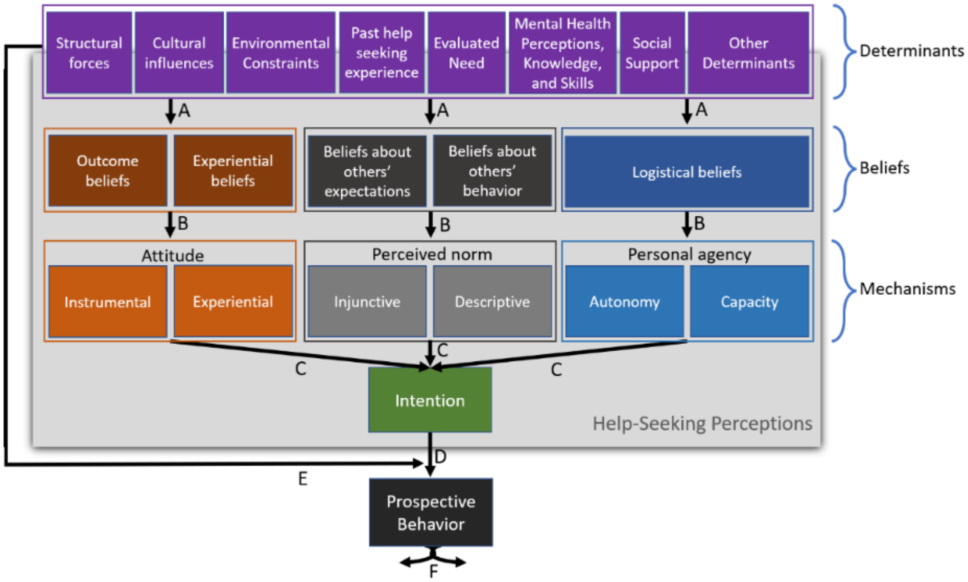


**Figure 4: The Integrated Behavioural Model of Mental Health Help Seeking.**

*Note:* Model presented by Hammer et al. (2024), displaying determinants, beliefs, and mechanisms for help-seeking in mental health (p. 317).

It is explored that the reasoned action tradition was first formalised in the theory of reasoned action (Azjen & Fishbein, 1980); then enhanced by Ajzen (1985), in the creation of the theory of planned behaviour. Hammer et al. acknowledge that later extensions refined existing theory and incorporated constructs from other behavioural theories, notably moderating variables that influence whether a person who intends to perform a given behaviour will actually perform this behaviour. However, it considered that these extensions are generalised theories of behavioural prediction and are not tailored to mental health help-seeking behaviour.

In relation to this foundational theory (theory of planned behaviour/TPB), a scoping review by Adams et al. (2022) aimed to map literature on TPB as applied to mental health help-seeking in adults, which the authors suggest presented a considerable evidence base on the TPB for predicting mental health help-seeking intentions, although knowledge on its predictability for mental health help-seeking behaviour and on TPB-based interventions was described as limited. They conclude, “Thus, the role of the TPB in developing help-seeking interventions remains unclear” (p. 1). Therefore, although research on the TPB in relation to help-seeking behaviour in mental health appears inconclusive, as an adapted mental health-specific model, it is possible that the IBM-HS may offer greater predictability for mental health help-seeking behaviour.

#### 3.5.2.1 Applying the IBM-HS

Similar to that of West and Gould (2022), Hammer (n.d.) outlines the following stepped process for applying the IBM-HS model, in targeting help-seeking behaviour for mental health specifically.

- Step 1: Identify a population of interest and sociodemographic groups therein
- Step 2: Define the help-seeking behaviour
- Step 3: Conduct a mixed-method study
- Step 4: Develop help-seeking belief measures
- Step 5: Refine help-seeking belief measures
- Step 6: Administer baseline survey containing help-seeking belief measures and direct measures
- Step 7: Administer follow-up survey to determine the help-seeking moderators of the relationships between intention and prospective help-seeking

Like the COM-B Model and BCW, this also provides a structured and methodical framework for exploring help-seeking behaviour, within population of interest; also enabling an extended focus into particular sociodemographic segments with given populations. This takes a close focus on specific components of help-seeking behaviour in mental health—including determinants, beliefs, mechanisms, perceptions/intentions, and behaviour. It could be suggested that this more detailed focus may enable the tailoring of interventions in a way that could better optimise outcomes.

However, while offering a more detailed and richer framework for exploring mental health help-seeking behaviour and the components therein, it can be recognised that this comes with more complexity—requiring context-specific adaptation and multiple feedback loops, as presents by Steps 5 and 7. This could enable more effective interventions for specific groups (e.g., younger men from particular sociocultural backgrounds experiencing eating disorders; or mature university students experiencing common mental problem). Although, new information and/or dynamics that may arise during the generation of data about a population group, or in the development process, could influence longitudinal validity and necessitate more continuous, iterative development, to deliver an outcome that has an effective impact on the population group of interest. Therefore, this model’s value can be recognised in potential it offers towards developing more targeted, individual and group-level help-seeking behaviour.

#### 3.5.2.2 Discussion

It appears that behavioural science presents value in research and strategies to address mental health and related issues/disorders (Wittchen et al., 2014), that can enable understanding of proximal risk factors that can negatively impact upon individuals, and a broader understanding in how these can be countered. Further, Liu et al. (2025) advocate holistic approaches to developing culturally sensitive, multi-level interventions for help-seeking behaviour, which take into account the broad range of factors and components that may be required to enable help-seeking in given groups and populations, including individual-, interpersonal-, and community-related factors. Both the COM-B/BCW and IBM-HS seem to present as frameworks that can enable the development of such interventions, with theoretical foundations that take into account the complex factors that can inhibit or enable behaviour, or help-seeking behaviour more specifically. The COM-B/BCW framework explores this in relation to capability, opportunity, and motivation towards behaviour more broadly, and appears widely applicable—with a range of policy-based intervention types that can be tailored towards specific objectives for a population or group. This seems valuable as part of public health initiatives, to ensure behaviourally informed policy, service developments, and/or communications. Meanwhile, the IBM-HS offers a framework wherein strategies can be developed in greater details for mental health help-seeking, specifically. This could enable the development of more focused interventions that may better target the needs of particular population groups and segments therein.

As suggested by West and Gould (2022), the COM-B model allows for integration with other models and theories, and so there could be potential for elements of these two models to be used in conjunction with each other.

These models bear resemblance to action research (or action science), wherein research seeks to find an effective way of bringing about conscious change in a partly controlled environment; "the main aim [...] is to enter into a situation, attempt to bring about change, and monitor the results" (Collis & Hussey, 2013).

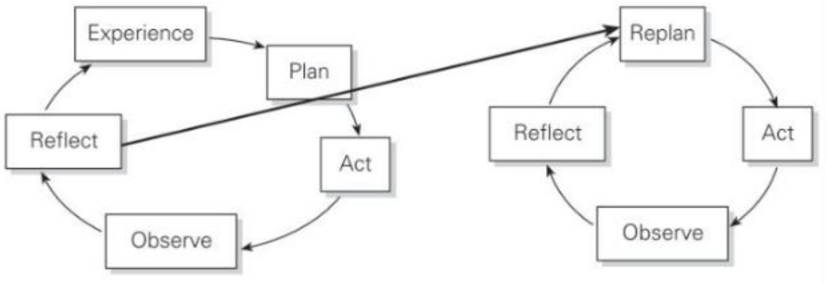


**Figure: Spirals of action and research**

*Note:* The iterative nature of action research (Wisker, 2007, p. 234).

The reciprocal cycles of data/evidence informing action and iterative development is also reflected in the development of behaviour change interventions, where there is a close focus on learning about and influencing a target population, through tailored intervention design.

### 3.5.2.3 A keynote on ethics

Public Health Wales feature "Involve key stakeholders" as a core principle in their Guidance (West & Gould, 2022, p. 37-38), for the development of behaviour change interventions, and this draws key consideration the role of co-production in this area of research and practice. Two reasons are provided for this: firstly, that as behaviour change interventions involve shaping choices and habits, it is ethical to respect the rights of people in relation to decision-making; and secondly, non-engagement in co-productive working increases risk of errors, stemming from false assumptions about a target population and factors influencing their behaviour. It is highlighted that this also denies developers opportunities to gain richer insights from populations of interest, which could otherwise valuably shape interventions. Similarly, of action research, Bradbury writes: "[it] is a democratic and participative orientation to knowledge creation [, bringing] together action and reflection, theory and practice", and is "a pragmatic co-creation of knowing *with*, and not *on about* people" (2023, p. 3). These are principles and perspectives, it should be said, may be considered essential, particularly in encouraging help-seeking, prudently but sensitively. It could be suggested that engaging with populations who may experience difficulty in relation to mental health help-seeking could be a challenge, as people with such experience may not readily recognise their mental health needs or the need to engage with topics relating to help-seeking, or have the means to actively engage in co-production with services or systems. However, this practice enables opportunities for dialogue, improved reciprocal understanding, and greater innovation to meet need; wherein innovators within the mental health system can act "not as [solvers] of predefined problems, nor as an [optimisers] of systems or jobs, but [with] perceptual and ethical practice of staying with the unfolding of lived experience" (Lawer & Sutton, 2025).

## 4 Conclusion

While improving the accessibility of mental health services is an important part of reducing mental health inequalities, reducing gaps between those who do/do not receive care, support, and/or treatment, and improving population mental health, this research has explored how improving the acceptability of mental health support—beyond just formal access of services, is key as part of a more robust approach to ensure early support. This requires an extended focus—early into people's experiences of mental health issues/illness, to better understand factors that can inhibit or enable this, within pathways towards support and recovery. Help-seeking is an important activity that can enable people to move along this pathway, to early support, as required. This can be considered as behaviour, and a greater understanding of this by those within the mental health system, can better enable help-seeking to be encouraged—with strategies that can prompt people earlier towards support and recovery. Promoting help-seeking behaviour appears to require more than merely the targeting or removing of specific help-seeking barriers, in isolation; but rather a facilitative approach that considers enablement more holistically. That can be achieved at a broader population-level and can be tailored into more targeted strategies. The COM-B Model and Behaviour Change Wheel present a framework through which help-seeking behaviour has been soundly predictable in existing studies, and this provides a means for developing behaviourally informed, policy-based interventions. Meanwhile, the Integrated Behavioural Model of Mental Health Help-Seeking seems to provide a framework where strategies can be tailored with a closer focus on the components that can enable help-seeking within mental health, for particular populations and sub-segments. Further research will enable application and testing of this framework.

## 4.1 Key Recommendations

- Exploring help-seeking as part of plans to improve access to mental health services and ensure early support can enable greater understanding of factors that may influence people's journey towards support and recovery, including the access of services. This considers experiences early in people's pathways, and not merely from the point of access or assuming that everyone in need with reach services, even with improved accessibility.
- The absence of a core data set for mental health in Wales may present difficulty with gaging the scale of the mental health treatment gap at present, however raising awareness and engaging with populations can generate valuable understanding and development to better meet population need. Co-productive approaches can enable richer design and development of interventions and strategies to facilitate help-seeking and help-seeking behaviour, beyond purely data-based approaches.
- The COM-B/Behaviour Change Wheel model presents a framework through which such developments to promote help-seeking and ensure early access of mental health support and services can be behaviourally informed, to better achieve desired impact.
- The Integrated Behavioural Model of Mental Health Help-Seeking (IBM-HS) also presents as another promising framework, to understand the components of help-seeking, with more specific tailoring to particular populations, groups, and segments. Further application and research will enable the study and evaluation of its benefits.

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