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The potential of PROMs: An opportunity for digitally-enabled patient-reported outcome measures to revolutionise person-centred healthcare at Velindre Cancer Centre, Wales

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

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Abstract

xxx

Acknowledgements

XXX UPDATE ME XXX

I owe many thanks to my academic supervisors Stephen, Matt, Alan; Hayley and Tom for your expertise and support.

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Special thanks to my mum Denise, to Fergus, and to all of my friends in the CDT.

Contents

Acronyms

ANP Advanced Nurse Practitioner. 25

CANISC Cancer Network Information System Cymru. 32, 35

EHR Electronic Health Record. 37

ePROM Electronic Patient Reported Outcome Measure. 32

nVCC New Velindre Cancer Centre. 35

PCH Patient-Centred Healthcare. 20, 34

PPEP PROMs, PREMs, & Effectiveness Programme. 22, 36

PRO Patient Reported Outcome. 26

PROM Patient Reported Outcome Measure. 20

QoL Quality of Life. 49

VBHC Value-Based Health Care. 22

VCC Velindre Cancer Centre. 38

ViH Value in Health Programme. 31

VUNHST Velindre University NHS Trust. 21

WCP Welsh Clinical Portal. 43

Chapter 1

Introduction

NHS Wales is currently experiencing the darkest period in its 23 year history, with rapidly deteriorating wait times, inequalities, staffing shortages [1], and public dissatisfaction driven by unforgiving UK Government budget cuts and a total lack of agility in the service's organisation and planning [2–5]. The last decade has brought several iterations of ineffective Welsh Government policy and a misguided myriad of national improvement programmes — all of which failed to gain more than micro-scale success in practice. Change is afoot for the service, however, with a raft of recent policies from the latest Government finally putting technological improvement and innovation at the front-and-centre whilst shifting the service's prime directive from ruthless frugality to improving the quality of patient care.

At the core of this redesigned approach is the need to redevelop the service to one that is more preventive than it is reactive, with a large emphasis on enabling home-based and self-managed care and hospital referral only "when it is essential" [6, 7]. To achieve this, NHS Wales is to adopt a PCH model of practice[1] whereby practice "focus[es] on meeting the goals and preferences of our patients through involving them in decision making" [9] (see Figure 1.1). The primary strategic foci of this redesigned approach is the total integration of PROMs into the service; PROMs are subjective

[1] NHS Wales call this 'value-based healthcare (VBHC)', however their interpretation is not congruent with either of the two main interpretations of VBHC in the literature. Therefore, we more appropriately refer to NHS Wales' redesigned approach as PCH. Recently, the service has in fact used VBHC and PCH interchangeably to describe this their approach [8]

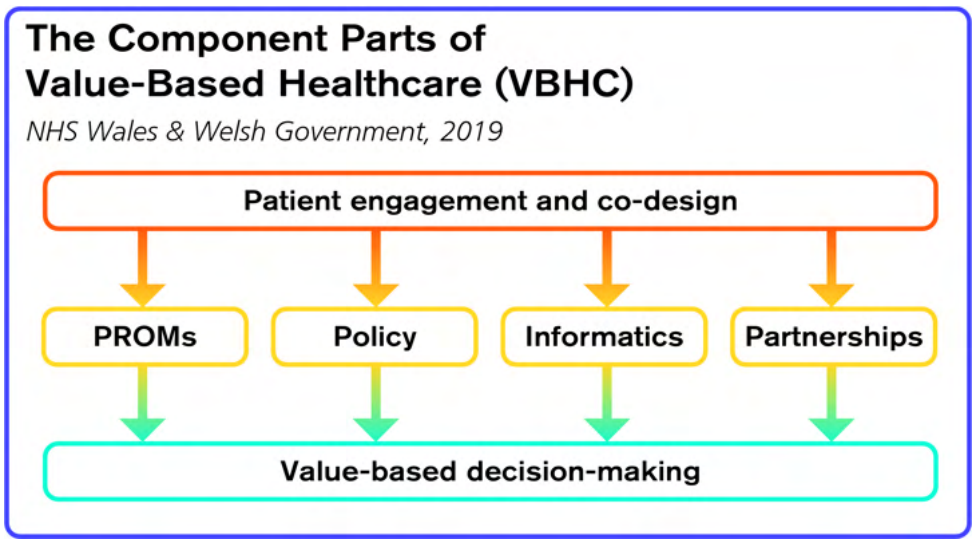

Figure 1.1: Diagram of the 'component parts' of NHS Wales' VBHC programme. The aim is to achieve value by engaging and co-designing new systems with patients, with the intent to use a combination of policy, PROMs, informatics, and strategic research and industrial partnerships to achieve this [9].

measures of patient HRQoL — usually in the form of a questionnaire — which patients complete themselves without clinician input [10]. This revitalised plan bodes well for NHS Wales, as PROMs have been shown in trials to improve XXX and, if executed successfully, have the potential to completely transform NHS Wales into an efficient, equitable, person-centred powerhouse. Indeed, the service is banking heavily on PROMs to ameliorate their current crisis — with the Welsh Value in Health Centre setup recently to orchestrate PROMs Wales-wide [8] alongside national programmes for PROMs standardisation and ensuring PROMs readiness at the health-board level [11, 12].

However, when it comes to PROMs' employment in the healthcare domain, we find the current function and form of PROMs is decidedly flawed; divergence between design and need means clinicians and patients do not want to use them, a lack of innovation over PROMs' long history means they are contextually and technologically outdated (some of the most common PROMs are nearly three decades old!), and numerous attempts at standardisation over the years have made understanding and implementing them even more painful.

We find the core issues holding back a successful system-wide PROMs deployment

are three-fold:

- Public healthcare systems breed an atmosphere of tremendous change-aversion and rigidity,
- An insistence on PROMs standardisation completely detracts from their usage as an enabler of PCH, congruent with a greater loss-of-focus of PROMs' primary function: empowering patients,
- PROMs research and development is a vacuum devoid of any real technological innovation.

For NHS Wales' redesigned, PROMs-focussed approach to be successful, the service must address the three aforementioned issues suitably or face another decade of deterioration.

Despite these challenges, we believe that PROMs are the instruments with the greatest potential for the successful practical implementation of PCH, with the literature indicating that their successful employment can bring great improvements in patient outcomes, HRQoL, and system efficiency. NHS Wales appears to finally be displaying some ambition to achieve this; the COVID-19 pandemic — for all of the devastating effects and loss it has inflicted upon the service — has resulted in the service operating with unprecedented dynamism, strength of leadership, and a doubling-down on technology. This response to the pandemic's rude awakening shows that the service is possible of rapid change, and this period of great tragedy could prove the catalyst that kick-starts NHS Wales' new era of innovation, technology, and PCH.

1.1 Our contributions

We are working with VCC — a tertiary cancer treatment hospital providing an all-Wales cancer referral service — under their TCS improvement programme, in which the Centre is to be overhauled both physically in the form of a bigger, brand-new hospital and organisationally, with an ambitious integrated and "digital first" philosophy [13, 14]. We seek to bring agile, computational, and person-centred attitudes to VCC as we work with patients and clinicians to re-energise the PROMs research space whilst benefitting NHS Wales as a whole in overcoming core issues with their redesigned, PROMs-

first approach. We are enthusiastic to be able to work with VCC and VUNHST as they undergo their pioneering digital evolution, and we highly value the organisation's willingness and ability to implement our research into meaningful clinical practice.

In this dissertation, we demonstrate that fresh digital innovation in the PROMs space can lead to more useful and better integrated PROMs implementations, which are received more highly by healthcare professionals and better uphold the principles of PCH. We provide an exploratory analysis of the state of digital PROMs, finding that X. providing insight into how PROMs are currently received in the context of VUNHST. We look at the necessary considerations for how to evolve PROMs in an innovative, digital manner through a prototype system, and collect valuable feedback from expert users. Specifically:

- XXX Talk about the state of (digital) PROMs (innovation) XXX - We explore the intricacy of interconnected systems and organisations within an integrated public healthcare system - We assess the attitudes of healthcare professionals on PCH, PROMs, and technology to understand XXX - We provide a novel design provocation for an innovative digital PROMs pathway, with evaluation from practicing PROMs experts

This work is just the beginning of our involvement with NHS Wales as this has huge potential for both work and the ability to change NHSW i.e. the integration of VUNHST as part of a public healthcare systems affords the potential for our work to be highly transferable across NHS Wales, further increasing its impact.

Chapter 2

Literature review

2.1 The public healthcare crisis

The past decade has been brutal to public healthcare across the UK, with ever-lengthening backlogs and a perpetual staff shortage being met year-on-year with marginal budget increases and unclear strategy [1]. The prevailing model of cost-driven, technology-averse, disjointed healthcare is crumbling under its own inefficiency as budgets tighten and patient outcomes worsen [2]. The COVID-19 pandemic has worsened an already dire situation, with NHS Wales facing record waiting times for emergency, hospital, and cancer treatments [15].

The existing NHS Wales policies and systems are clearly unsuitable, and there is urgent need for total redevelopment. In order to deliver the necessary improvements at a time when budgets grow ever-smaller, we urge that Wales implements a new national system that is above all else integrated, effective, and person-centred. The concerning fact is that the Welsh Government has been considering this since 2013 — well before major problems began — and yet the situation continues to worsen. Why is this?

2.1.1 NHS Wales' attempts to adapt

After the announcement of the UK Government's austerity programme and the prospect of severe funding cuts to Wales, the Welsh Government established the Bevan Com-

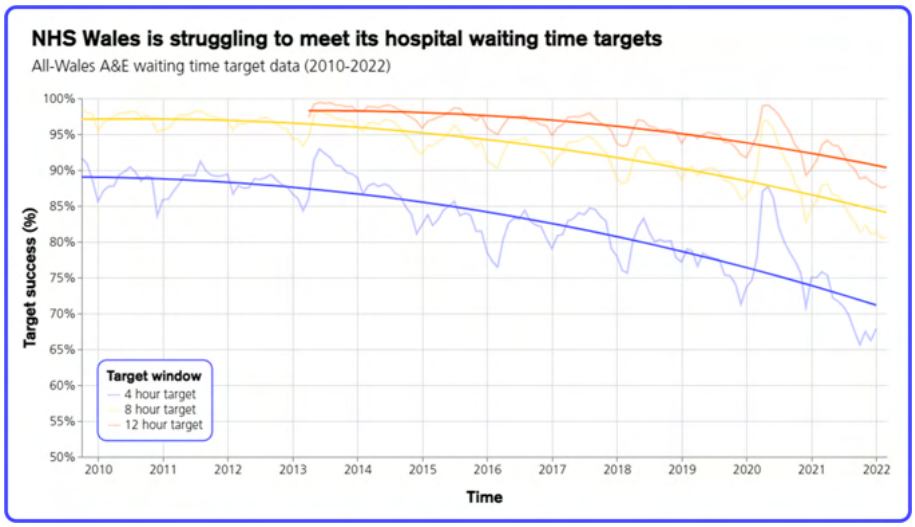

Figure 2.1: Longitudinal data showing an increasing decline of met emergency treatment performance targets across NHS Wales over the past 14 years [16]. The time window represents the amount of time a given patient waits in an emergency department from arrival to admission, referral, or discharge.
The target for emergency departments is that 95% of patients should wait for less than four hours, and no patient should wait more than 12 hours [17]. We can see from the graph that more than 25% of patients will be waiting more than four hours, and 1 in 10 will be waiting more than 12 hours. Trends (represented on this graph as a smoothed, bolder line) indicate that the rate of decline is increasing, and we can see that this decline began well before the COVID-19 pandemic.

mission to create an independent national healthcare think-tank with the aim of "maintain[ing] and enhanc[ing] a values-based service in NHS Wales during a time of social and economic challenges" [18]. They were tasked by the Welsh Government to consider a plan to drastically and urgently reorganise NHS Wales, and so they — along with Public Health Wales — produced a lengthy series of recommendations and actions to be taken under a new "prudent healthcare" programme [18]. They stressed the need for the term 'prudent healthcare' to be consistently understood by all parties, and so framed the programme on the following three central themes to be respected:

- Minimise avoidable harm
- Carry out the minimum appropriate intervention
- Promote equity between the people who provide and use services [19]

In essence, this meant enacting person-centred healthcare with consideration of pa-

tient safety and financial prudence. It was a watershed moment for NHS Wales, whom finally had a refined and comprehensive improvement plan akin to the US' seminal *To Err Is Human* [20].

Despite this, the years since have shown little progress in regards to an effective overhaul of the system, due to what we consider a chronic misinterpretation of the Bevan Commission's report. The much needed top-down oversight of the redevelopment by the Welsh Government was lacking and uncertain, with multiple fairly rapid revisions of policy creating confusion [6], XXX, XXX. The need for person-centred healthcare was never emphasised, despite NHS Wales' own guidance indicating its immense value. Indeed, a 2019 study [21] looked at the state of the 'prudent healthcare' programme, and found the majority of the system was still disjointed and riddled with inefficiencies. Staff were highly receptive of the concepts of the programme, and some services in secondary care had managed to reorganise prudently, however major issues regarding information-sharing, patient outcome reporting, and inadequate staffing stifled the overall system's capability.

This could be accounted for, in part, by NHS Wales' apparent aversion to technological improvement for most of the past decade. We consider the absence of any technological recommendations in the report as a grave oversight, with NHS Wales now notorious for its poor and outdated technology provision (see: [22,23]). A damning 2018 report by the Welsh Government's Public Accounts Committee described "deep concerns" for just about all aspects of NWIS (NHS Wales' centralised SHA for digital services) — culture, management, competence, understanding, governance, scrutiny, infrastructure, and resilience [24]. Whilst changes have been made and improvements are finally being delivered, NHS Wales lags far behind NHS England and private health organisations in technological aptitude.

However, NHS Wales is changing. The Welsh Government's latest plan — A Healthier Wales [6] — prioritises patient quality-of-life as the true measure of healthcare improvement, with core system values of integration, person-centred care, equality, and innovation. Across the organisation, the newly-created Welsh Value in Health Centre spearheads value-based healthcare implementation across NHS Wales with technology and person-centred healthcare at its core, and a wholly restructured Digital Health

and Care Wales (née NWIS) is fervent at total technological improvement.

Our work seeks to support NHS Wales in implementing its person-centred healthcare across Wales as we develop innovative, technological solutions to empower patients and improve patient outcomes. It is therefore important that we first of all ensure our understanding of the concept of PCH — what it represents, how we may define it, and why we should use it — so that we can best design solutions that truly support patients and avoid the danger of irrelevance of similar attempted implementations.

2.2 Person-centred healthcare

Person-centred healthcare (PCH) is a term that describes an egalitarian ethos of clinical practice, in which the patient and clinician are equal collaborators in the planning, development, and delivery of healthcare services and treatments [25, 26]. The patient is known as a unique individual that is listened to, informed, respected, and involved in their care, with their beliefs, values, and behaviours put at the centre of the decision-making [26–28]. It is often contrasted to prior 'beneficent' models of care in which the clinician exercised an authority over the decision-making for the patient [29]; instead, PCH requires clinicians to address patients as people beyond just the medical perspective [30]. This concept of patient autonomy — whereby patients are entrusted to make informed decisions about their care of their own accord — is essential to PCH. Patients are freed from controlling interference and abide by their own principles in their decision-making, and crucially this is afforded even when the clinician may disagree, or if it means the patient refuses treatment, or if the resulting outcome is patient death [29].

Whilst we recognise the general philosophy that encourages PCH, clinicians worldwide have failed to come to a consensus on exactly what the practical implications of PCH are. It is unclear why the term remains so ambiguous, especially since the US' highly influential Institute of Medicine (IoM) recognised the importance of PCH and called for its implementation over two decades ago in its seminal report *Crossing the Quality Chasm* [31]. This lack of definition has slowed the implementation of PCH into practice [25, 27, 32, 33], and so over the concept's lifespan many groups have attempted to formalise PCH into a set of more practical guidelines to which the health professionals

should adhere [25, 28, 31, 34–39].

There exists a myriad of such guidelines, with a confusing mix of recommendations derived from lived experience, reviews, and meta-reviews of other guidelines. Langberg et al. [33] provide the most up-to-date review of the PCH literature, in which they present an updated version of Mead Bower's seminal 'five conceptual dimensions of patient-centredness' [37][1] based on their findings. Despite this, they recognise that there is still much variance in the interpretation of PCH, and so offer a further distilled set of 'three elements of PCH' synthesised from commonalities found in the literature. We use these three elements to identify similar themes across different guidelines to aid comparison and interpretation.

McCormack et al. have developed and refined an immensely popular person-centred practice framework that has become the de facto standard for practice in the field of nursing, and represents nurses' embrace of and transition to PCH [28, 40]. Recently, the same authors produced *The Person-Centred Practice Framework* (see Figure 2.2), which generalised their prerequisites, requirements, processes, and recommendations for the nursing field into broader concepts applicable to all healthcare domains [28]. This is what would be considered a 'systems model' by Pelzang, as it outlines the end-to-end requirements for the creation a patient-centred environment — as opposed to the 'process model' of the other PCH guidelines we discuss, which describe notions of PCH practice as a sort of ethos for healthcare professionals to adopt [27]. Whilst typically presented as discrete solutions, we believe that systems and process models are actually complementary and will need to both be implemented to properly enact PCH in healthcare; it follows that the healthcare environment will need to be structured to support PCH-abiding healthcare professionals.

In the UK, The Health Foundation is the organisation leading the country's charge toward PCH, conducting extensive research on its potential for the NHS and patient outcomes and advocating for its adoption. They recognise that giving an absolute definition of PCH would be 'limiting' due to its 'emerging and evolving' nature, and so offer a broader framework of *Four Principles of Person-Centred Care* (see Figure 2.3). This is

[1] Which itself was based on Stewart et al.'s six 'interactive components of the patient-centered clinical method', from 1995 [34].

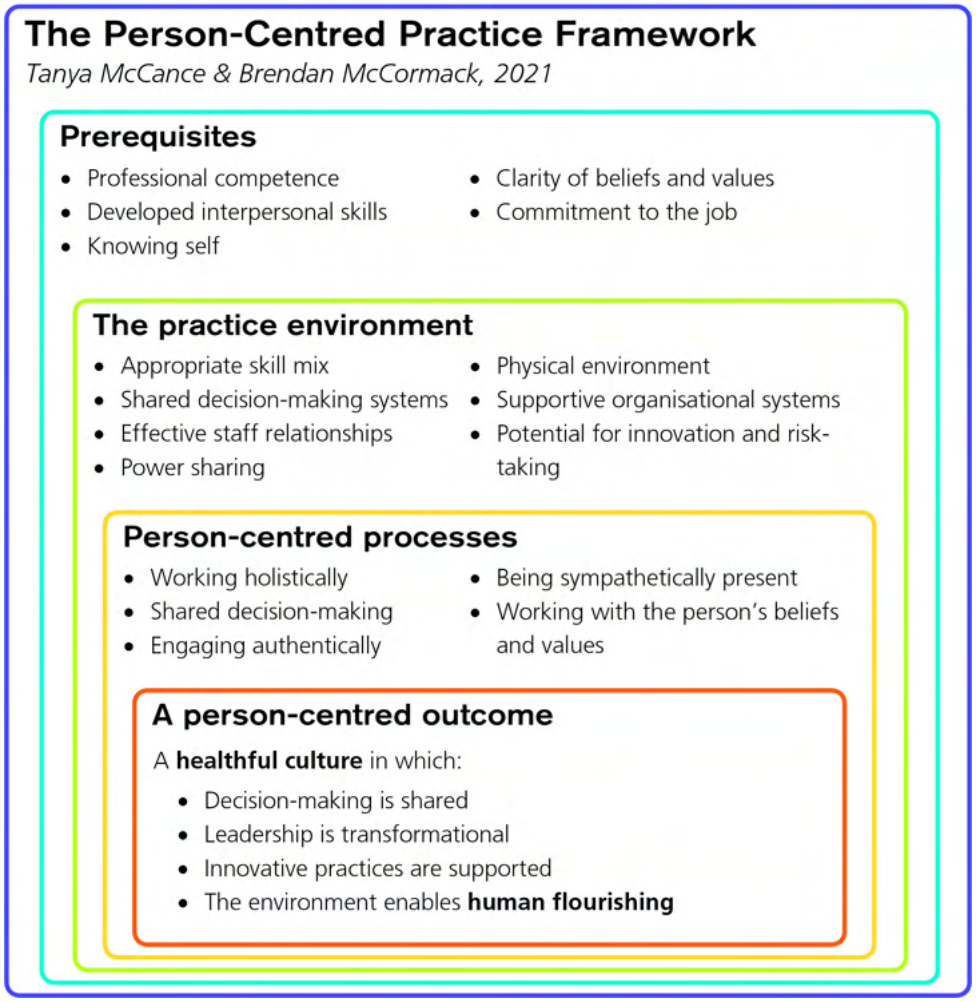

Figure 2.2: McCormack et al.'s recent *Person-Centred Practice Framework*, adapted from their established nursing framework.

prepended with an emphasis on how the operational needs, circumstances, and preferences will change from patient to patient, and that the ultimate goal of PCH is to enable the patient. As they put it:

> *"For care to be enabling, the relationship between health care professionals and patients needs to be a partnership rather than the professional being the expert while the patient simply follows their instructions." [25]*

We find the framework, whilst not comprehensive, captures the core recognised

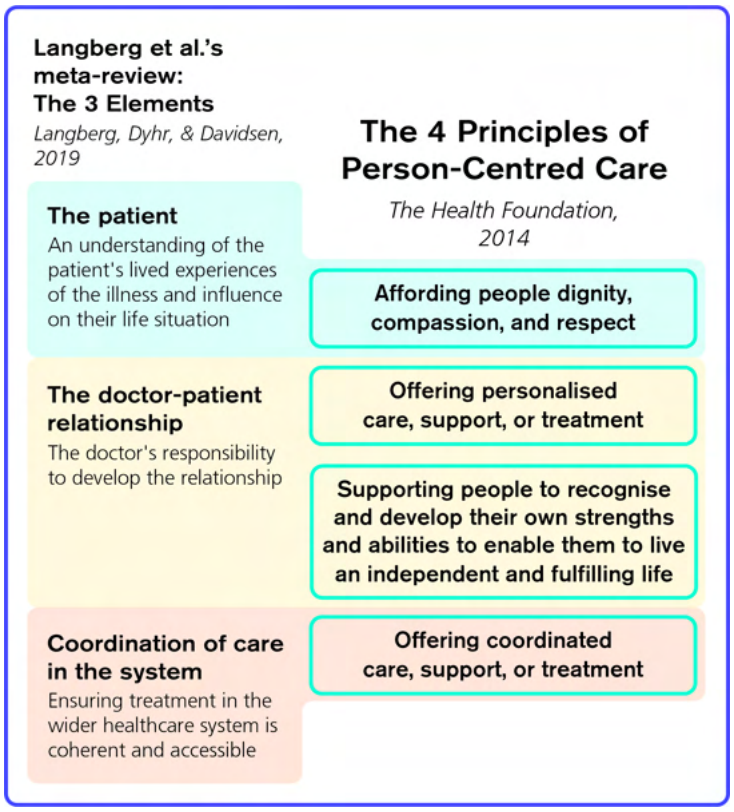

Figure 2.3: The Health Foundation's *Four Principles of Person-Centred Care* [25], overlaid with what we see is the categorisation of the principles according to Langberg et al.'s 'three common elements' of PCH frameworks to aid comparison. [33]

aspects of PCH and will be useful in our future work to succinctly convey PCH principles.

The Picker Institute (now simply *Picker*) provides the longest-standing and most adopted set of guidelines in the health literature [32], and now acts as the de facto global organisation for person-centred care advocacy. The outcome of a landmark five year research programme, Picker's eight dimensions of person-centred care defined for the first time a set of actionable goals for PCH in practice [36, 41]. In 2001, the IoM published the aforementioned *Crossing the Quality Chasm* report on healthcare quality in the US, listing patient-centred care as one of their six specific aims for improvement and effectively endorsing Picker's dimensions as the gold standard of achieving this [31]. Curiously, the IoM reduced Picker's eight dimensions to six — combining the three relating to coordination of the system. Perhaps this was due to what they saw

as repetition, or perhaps it was because, contextually, the PCH section of the report places much more emphasis on the need to improve the doctor-patient relationship rather than on the efficiency of the healthcare system. What it does spell, however, is that confusion is introduced to the literature whereby authors consider Picker's and the IoM's principles synonymous despite actually being similar but different. Since the IoM's report, Picker have continued to refine their principles [38] and today provide essentially the same principles as their original eight, albeit reworded to be more descriptive [42]. We produced Figure 2.4 to better illustrate the differences between Picker's original eight and current eight principles, plus the IoM's six derived principles.

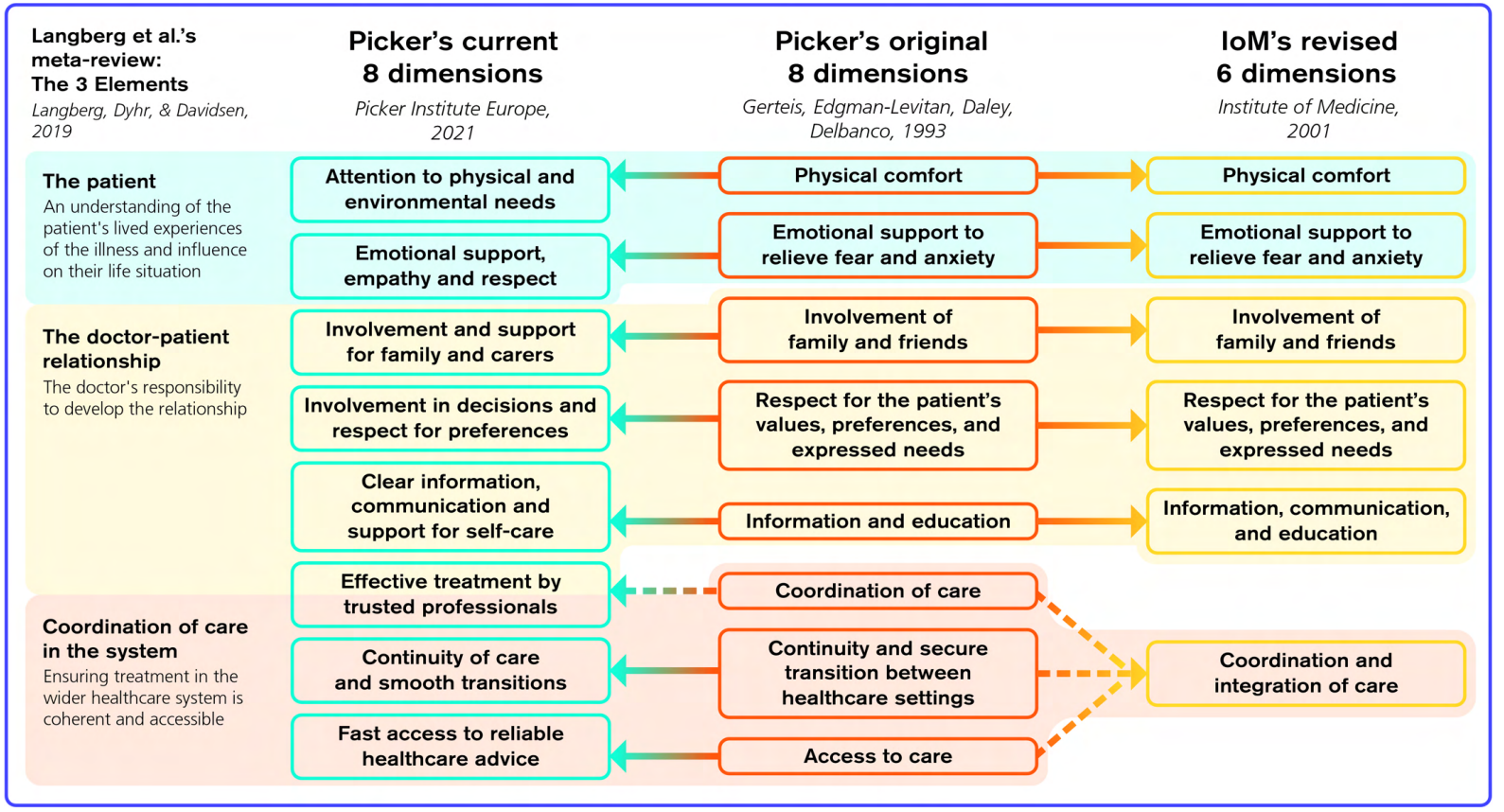

Figure 2.4: A comparison of three conceptual frameworks for PCH: Picker's original eight dimensions [36], their current evolution of the eight dimensions [42], and those adopted by the US Institute of Medicine in *Crossing the Quality Chasm* [31]. The continuity of the original eight dimensions into newer guidance is indicated by the arrows. With this, we can see the IoM adopted five of Picker's dimensions unchanged, however merged three into one (shown with dashed arrows). Picker's current eight dimensions are essentially the same as their original eight, although they have been re-worded to be more descriptive (slight changes shown with dashed arrows).
We have also overlaid what we see is the categorisation of the dimensions according to Langberg et al.'s 'three common elements' of PCH frameworks [33] to aid comparison.

We consider Picker's current eight dimensions the preferred set of process model guidelines for ensuring PCH practice, and McCormack et al.'s *Person-Centred Practice Framework* as the preferred systems model for ensuring a PCH-enabled environment. We will be using both to guide our work.

2.2.1 Nomenclature

There are many similar terms that describe what we refer to as 'person-centred healthcare'; patient-centred care, personalisation, family-centred care, mutuality, and occasionally client- and relationship-centred care [25, 30]. Generally, these terms are seen as interchangeable, with the different terms simply stemming from different contexts in healthcare yet carrying the same underlying meaning [43]. However, recent literature indicates less agnosticism in terminology, with a divergence forming in particular between patient-centred versus person-centred (health)care [25, 30, 33]. In their meta-review of the terms, Håkansson Eklund et al. found "considerable overlap between the two concepts", but were able to identify distinct differences between the two;

- in empathy, where person-centred care meant recognising and accommodating the person's emotional state — "entering their world" — as opposed to feelings solely towards extending and structuring the person's life,
- in communication, where person-centred care meant multifaceted information sharing with an emphasis on dialogue, keeping the person fully informed to enable a common ground of understanding and cooperation — as opposed to maintaining (even if unintentionally) a knowledge or power imbalance with the person,
- in focus, where person-centred care meant considering decision-making from a truly holistic perspective, valuing the psychosocial aspect of treatment as much as the biological — as opposed to decision-making led by statistical analyses and/or convention [30].

More succinctly, they contrasted patient-centred care as care with the goal of obtaining a "functional" life versus person-centred care, where the goal was to obtain a "meaningful" life. We believe it to be crucial to discern the difference in ethos behind these two terms, and understand delivering the best possible care involves eliminating this lingering 'sick role' treatment of persons undergoing treatment. With this in mind,

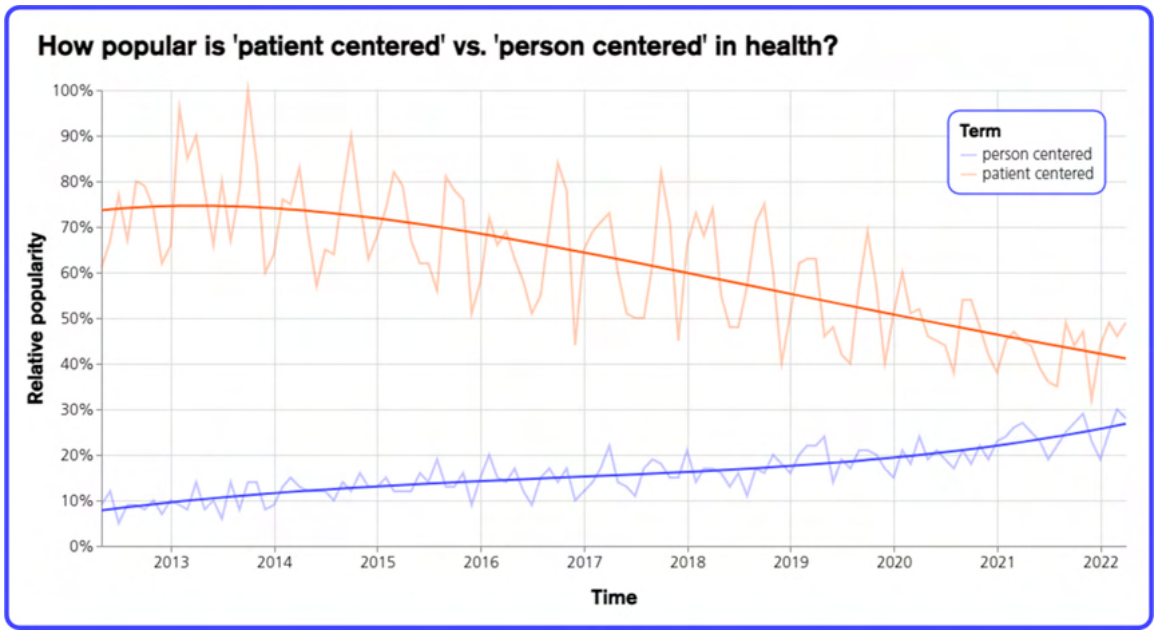

Figure 2.5: An illustration of the shift in conversation from patient- to person-centred healthcare over the past decade, based on (anecdotal) global Google Trends health data. [44]

we have deliberately chosen to use the term person-centred healthcare (PCH) for our interpretation of this model of practice:

- person reflecting the fact that the individual undergoing treatment is a human being, with wants, needs, and preferences that must be respected,
- centred relating to the need for the person themselves to be actively involved in the decision-making of their treatment and not considered simply as a sufferer of disease (i.e. a patient),
- healthcare relating to the requirement for PCH to be enacted totally by all parties in the health system, third sector, and adjacent communities in order to ensure improved patient outcomes.

2.2.2 Importance

2.2.2.1 Evidence

The benefits of enacting PCH in clinical practice are overwhelming. Not only is PCH universally recommended to provide better emotional outcomes and wellbeing for indi-

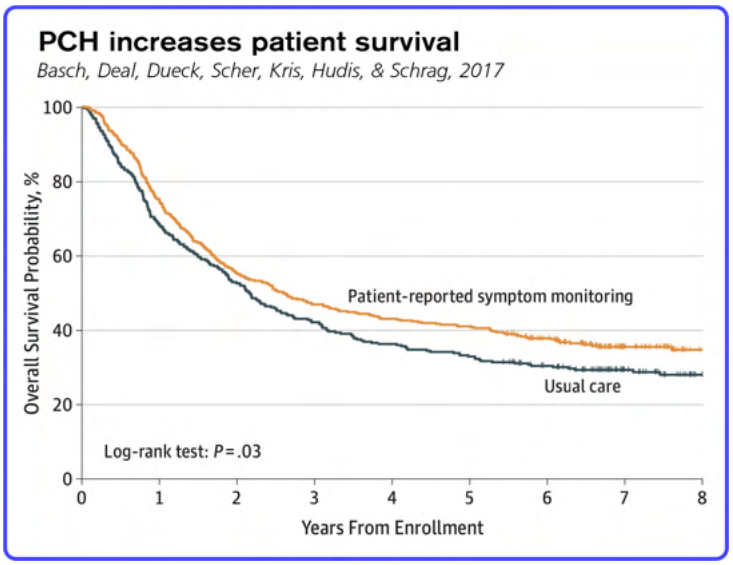

Figure 2.6: In their seminal longitudinal study at the highly regarded MSKCC, Basch et al. found decisive evidence that the use of PCH in routine cancer care directly attributes to increased survival [54]. They suggest that early responsiveness to patient symptoms helped to prevent more serious issues later on, and that patients experiencing PCH were more tolerant of difficult treatments such as chemotherapy.

viduals [45–49], but it has been found to also improve HRQoL [50, 51], reduce discomfort and improve function [45, 48, 49, 52] and critically it improves clinical outcomes — especially for patients with long-term conditions such as cancer [25, 47, 48, 50, 51, 53] (see Figure 2.6).

Patients — again almost unanimously — report a better care experience and greater satisfaction with their services received [46, 47, 52, 55, 56]. One trial of PCH in chemotherapy involved training of patients (n=20) and family to enable independent administration of drugs at home as opposed to in-hospital. All patients preferred the in-home method, with 90% considering it less distressing than hospital admission whilst reporting reduced symptom distress and fewer negative perceptions of their own health [57]. This satisfaction with care unlocks a more active and engaged role for patients, whom are more likely to choose treatments based on their values and preferences (perhaps because of reduced internal decisional conflict), engage in positive health behaviours, and may even be more willing to endure more difficult treatments [25, 46, 58]. Patients want to be more informed about their condition to improve

better their decision-making, and feel more confident working in a 'common ground' with their care team [46, 49, 58].

Truly excellent PCH has the potential to go one further and offer the individual a sense of empowerment [59, 60]. Of course, some individuals can feel empowered in their condition without PCH, so we interpret PCH's ability to empower as a 'levelling of the playing field' — where all individuals in care have the opportunity to be as active in the decision-making as they would like. In this way, we may consider PCH as a mechanism for enabling social justice and equal rights in healthcare that is greater than the 'doctor-patient' relationship [61]; the deconstruction of the 'sick role' and the subsequent enforced social dependence [57, 62]. As Alharbi et al. found of their patients in a study of PCH in nursing practice:

> *"To have the opportunity to express one's thoughts and feelings and be listened to was, in many cases, considered to be the most important aspect." [63]*

Providers and healthcare organisations seek to benefit from PCH too, with less expensive treatments and lower overall costs associated with PCH-based interventions, plus further cost savings through a reduction of referrals, re-admissions, emergency department visits, and increase in self-care [25, 49–51, 53, 55]. Furthermore, PCH has been identified as a conduit of improving efficiency of treatments and specifically reducing 'unwarranted variation' [58] — that is, variation of practice between patients which leads to harmful financial or clinical consequences [64].

PCH trials have also shown an increase in patients' perceived confidence in their care teams, resulting in a greater trust of, and concordance with, providers in relation to decision-making [46, 59, 60, 63]. There have also been reported notable increases in staff self-confidence, morale, performance, and adherence to practice guidelines due to PCH [25, 51, 60].

Chapter 3

Studies

3.1 Preamble

Healthcare is a uniquely complex domain.

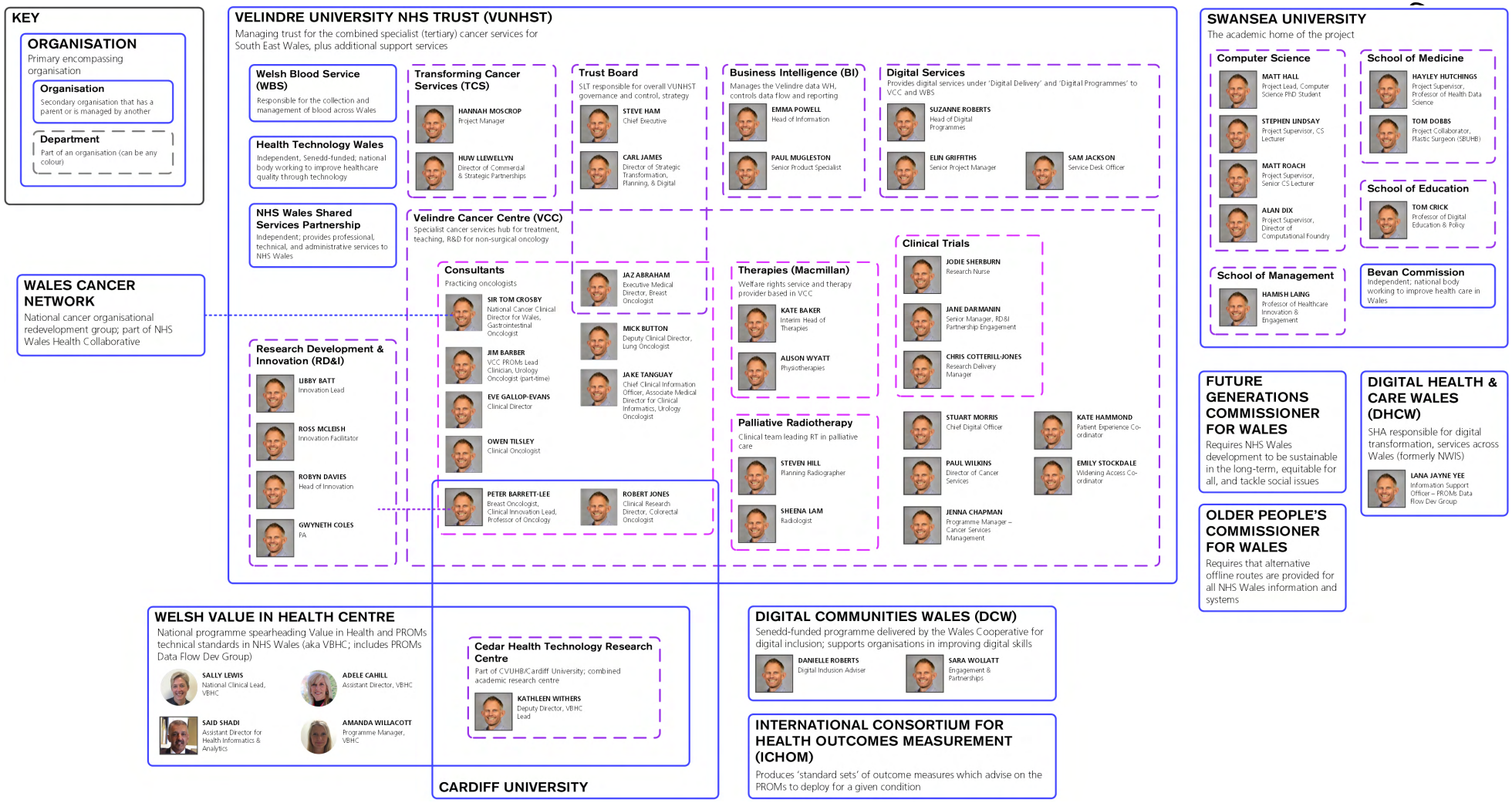

Figure 3.1: A networking diagram of staff who are relevant to our project; illustrating the complex tapestry of our domain.

3.2 Introduction

We wanted to analyse how our findings from the literature were reflected within Velindre, and so we undertook three empirical evidence gathering techniques to gain a comprehensive understanding of PROMs' use in Velindre and of general clinician attitudes towards PROMs and related concepts. It was important for us to build relationships with clinicians during our work, and so an additional benefit to these studies would be in engaging staff in conversation regarding PROMs and digital innovation, and to gather interest in our work to facilitate future collaborations.

Altogether, we conducted a staff survey to assess the state of PROMs within Velindre, followed up with informal interviews of certain staff members, and then finally we produced a design prototype for a PROMs administration and management system, which acted as a 'first step' demonstration of how we wanted to change PROMs for the better.

3.3 Staff survey

Our first study was to 'set the scene' of how PROMs were used in practice at Velindre, how staff felt about using them, and of the general culture of innovation and relationships between clinical and administrative staff. Our intent was to build a picture of all the relevant aspects of Velindre's circumstances on which we would need to build for our subsequent studies. Velindre themselves were unaware of the full extent of PROMs usage within the organisation, so it would inform ourselves and the hospital administrators as to development priorities going forward.

The survey mirrored existing scoping work from the literature, and provide all the staff at Velindre with the opportunity to share their understanding and enthusiasm with PROMs and PCH.

3.3.1 Purpose

We set out to investigate the interpretation of and attitudes towards PROMs, PCH, healthcare technology, and administration by patient-facing Velindre staff in order to

build an understanding of the current circumstances at Velindre. This baseline understanding was important to construct for several reasons; chiefly, it would provide context for our other studies and allow us to compare the scene at Velindre with the general consensus of the literature. It was also to inform our future work, where we could identify early on potential challenges, opportunities, and gaps in knowledge as well as the staff within Velindre who were ready, willing, and able. The latter was especially valuable as to establish relationships with relevant and engaged staff with which we could collaborate in the future.

We wanted the survey to accurately portray the situation at Velindre, and so we intended from the outset to quiz staff on a subjective view of personal experiences and understanding rather than for them to speak for Velindre in general. It was important to make evident the distinction between our survey and the typical reporting and analysis methods of Velindre's administrators to ensure that staff would respond in earnest, and equally that the feedback we would provide to the administrators was an accurate representation of their staff's beliefs.

We formalised our information gathering requirements for the survey as follows:

- Understanding of PROMs
- Current staff use of PROMs and the associated clinical workflow
- Departments within Velindre using PROMs
- Barriers to PROMs usage
- Opinion of PROMs
- Attitudes towards healthcare practice
- Attitudes towards technology in healthcare
- Attitudes towards the administration of Velindre

Due to the incredible clinical burden placed on staff dealing with the ongoing COVID-19 pandemic, we were aware that our survey response rate would be negatively impacted and subsequently our findings would not be representative of all staff. However, as mentioned, the purpose of the survey was manifold and so we knew that we were still able to begin the conversation of PROMs improvement with staff and start to introduce ourselves and engage with relevant clinicians.

It must be noted that, as of writing, VUNHST – being an NHS Wales trust rather

than a health board – has been largely overlooked in the national PPEP and now VBHC programmes, part of which has included a national PROMs patient pathway standardisation effort [65]. Therefore, there has been no formal review of the PROMs used at Velindre, and so our efforts with this survey signify the beginning of a new focus on PROMs and VBHC for the staff of Velindre to ensure that PCH is delivered equally and effectively.

3.3.2 Methodology

3.3.2.1 Design considerations

It was important to respect the needs of our population of interest – staff with direct patient contact within Velindre – to ensure that our survey would be universally received and efficient at data collection. The first and most obvious concern was to ensure the questions were department-agnostic so that oncologists, haematologists, radiologists, nurses, and therapists alike could each provide us with their unique insights. We would also need to consider the general demographics of staff, whom could vary in age, gender, experience, work type, or specialty; for this reason, we predicted that we would have much variance in responses for healthcare technology-related questions, for example.

A critical factor in the design of the survey was the severe time constraint imposed by the extremely demanding everyday workloads of staff. Subsequently, we set a reasonable limit of ten minutes [1] within which the survey should be able to be completed. Questions were written following best practice guidelines in wording [66, 67] – ensuring clarity and simplicity of understanding, and avoiding repetition – to produce a highly efficient set of questions, which could derive much useful insight whilst remaining quick to complete. Additionally, we used closed-type questions with multiple choice answering to speed up the data gathering [67], and broke up questions into different sections to reduce repetition-based fatigue in answering [66]. We had to be mindful, however, that questions with many responses are more susceptible to various forms of recall bias, and so randomisation of question ordering would be needed to mitigate this somewhat [66].

[1] Based on personal communications with executive and managerial staff.

We also had to be mindful of the potential inherent issues with our survey approach, such as with 'faking good' in which respondents respond with socially desirable outcomes rather than the truth [66]. We believed that this could be partially negated through the maintenance of anonymity throughout the survey: in facilitating truthful responses without fear of follow-up or involvement from management, we did not collect any protected characteristics from staff. Also in response management, we were aware that the use of scales (out of 10/100, Likert scales) would require additional design consideration to ensure fairness in reporting, including avoiding 'end aversion', biased scales, and being able to account for unsure or unknown responses [66].

Finally, we were aware of our relative lack of clinical knowledge and experience in communicating with clinicians, and so we ensured that our survey's questions were backed-up by the literature either in format or in the contents of the multiple-choice answers.

3.3.2.2 Construction

We were required to ensure data collection was compliant with VUNHST standards, and so our survey was built using Microsoft Forms as part of the organisation's integrated enterprise technology solution. Responses were collected without authorisation to ensure the anonymity of staff, and the individual response-level data collected was viewed and analysed by ourselves only (MH). English and Cymraeg versions of the survey were offered. See appendix A for the full list of the questions asked in our survey.

The first question on the survey (Q1) was an open question simply prompting for the staff member's role within Velindre as to give context to some of the responses and allow us to determine the most active and willing departments within Velindre for PROMs. In line with our anonymity requirement, this was the only personal information gathered from staff and furthermore it was made the optional, in case staff members felt that they could be identified by their answer alone.

As for the main body of questions, Turner et al.'s recent survey of PROMs in primary care [68] provided an excellent basis for our survey design and we were able to extract a subset of their questions to cover a large number of our requirements. This core subset (Q2B-H) consisted of closed, multiple-choice questions that would capture clinicians'

use of, understanding of, and attitudes towards PROMs; however we found that a lot of the multiple-choice options were obstructively brief and perhaps somewhat poorly considered. Because of this, we decided to investigate the options presented in various other PROMs surveys [69–72] to produce a more well-rounded set of options, which we hoped would be more representative of staff's experiences and would minimise the use of the miscellaneous 'Other' open-question options. We compounded these questions with a simple open-question (Q2A) which asked staff for their description of PROs so that we might observe the different interpretations of the term within Velindre, and also to give context to their other answers.

We designed the subsequent section of the survey (Q3) to expand its scope from a simple PROMs review to a more in-depth evaluation of several relevant concepts. We considered a large number of questions to include from many facets of the literature, before settling on four key areas in which to analyse:

- Q3A: PROMs sought to build a picture of staff members' understanding and competence of PROMs, plus how PROMs were prescribed
- Q3B: Patient-centred healthcare was designed to measure staff members' engagement with Gerteis et al.'s widely accepted eight dimensions of patient-centred care [73]
- Q3C: Technology in healthcare was designed to measure staff members' overall technological capability and readiness, as well as general opinions on its integration
- Q3D: Healthcare administration sought to build a picture of the culture within Velindre

Each of the four key areas had between five and six questions each, and were presented to staff as statements to which they were required to select a suitable rating on a typical 5-point Likert scale. All of the statements were presented positively (i.e. there was no mix of positive and negative statements, which is typical of Likert-scaled questions) as we decided to reduce answering time and compromise on combating 'yea-saying' [66].

3.3.2.3 Dissemination

We initially planned for the survey to be disseminated by email in a top-down approach from management to all relevant patient-facing staff within Velindre by means of a mailing list or similar within a couple of days of its construction, giving us several weeks to collect responses and ensure a large proportion of staff respond. However, this quickly became evident that such a timeline was naïve, and in fact it would be four weeks before the survey was disseminated. Given that the timeline for this entire project was three months, this was obviously an enormous setback and we believe severely impacted the response rate for the survey. Additionally, recipients of our survey were sampled by convenience and snowballing rather than our preferred *en masse* mailing list approach, with it sent to senior managers within three staff groups: consultant oncologists, advanced nurse practitioners, and occupational therapists. Whilst the staff groups were highly relevant to our survey, it was not inclusive of the entire patient-facing staff population within Velindre and so this irregular method further slowed the dissemination of the survey and impeded our efforts.

Informed consent was obtained by providing detailed information about the survey's intent and content before staff answered any questions. We outlined the uses of data collected, who was behind the survey, and advised staff that consent was revocable once granted, then presented a confirmation of consent to staff. The survey could then be completed digitally by staff and would be submitted automatically upon completion.

3.3.3 Results

We collected 14 responses to our survey over a two week period, where we imported and subsequently analysed the raw data in Python 3.8 using various data visualisation libraries to illustrate our findings and identify trends. All respondents agreed to the consent statement, as as of writing there has been no withdrawal of said consent. The response rate was 100% for all questions. Of the 14 staff who responded, the staff group break-down was as follows:

- 6 consultant oncologists (from various tumour sites),
- 3 specialist nurses or ANPs,

- 3 physiotherapists, and
- 2 from other clinical departments.

This was as expected, given the staff areas targeted in our dissemination.

We were pleased to find that the majority of staff (n=8) provided an accurate description of PROs, indicating their subjectivity and use in PCH. We did find some staff (n=3) perceived PROs as a quality-of-service evaluation tool – conflating the idea of collecting PROMs and collecting s somewhat. The rest of the respondents (n=3) provided a description of PROs indicating either a misunderstanding of the term, or one that omitted any mention of patient-centred principles.

We found the majority of our respondents used PROMs in their practice (n=9), with the most common uses including aiding clinical management, improving treatment outcomes, and providing a more holistic view of patient conditions. They were also used as screening tools, and to facilitate conversation with patients during consultations. Those staff who did not use PROMs indicated this being due to a lack of formal PROMs pathways Velindre.

All staff provided what they perceived to be the most important benefits of using PROMs, with the vast majority (71.4%) indicating that improving treatment outcomes and providing a more holistic view of patient conditions was important to them. Also important to most (>50%) was aiding clinical management, monitoring patient performance or safety, empowering patients to direct their own care, improving consultation/administration efficiency, and facilitating conversation with patients during consultations. Two respondents also indicated the importance of PROMs being used to demonstrate a clinical intervention's effectiveness (see figure 3.2).

The staff who used PROMs indicated completing typical survey-based instruments chiefly ad-hoc both during treatment and in follow-up, and often before and after consultations. Several indicated following pre-prescribed structured timelines for completion. PROMs were overwhelmingly paper-based, with most respondents indicating PROMs completion either by patients directly or by staff whilst on the phone with patients. A minority of respondents (n=3) used digital clinical systems, and subsequently patients completed PROMs using an online portal or email. There was also an indication that app-based completion of PROMs was under testing for future usage (see figures 3.4,

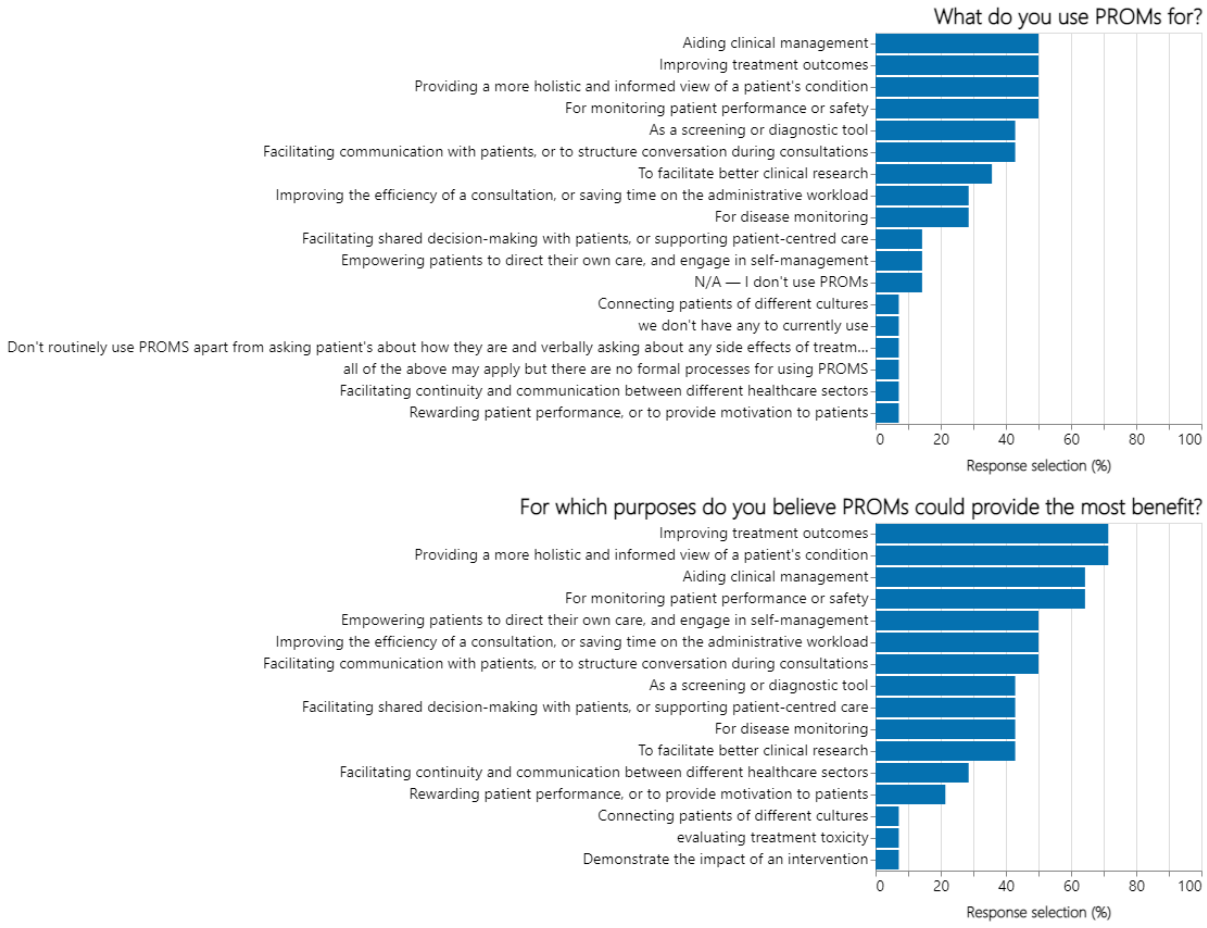

Figure 3.2: Responses to Q2B and Q2H on our staff survey.

3.3).

In their evaluation of the key barriers to PROMs usage, the majority of staff indicated that poor PROMs instrument design and their inability to adapt to the patient's status were the most important issues, as well as poor integration of PROMs with existing systems and practice and the burden of additional work or time demands on staff. It was also indicated that lack of patient understanding and the overburdening of ill patients were important issues. Multiple staff indicated that a lack of robust IT infrastructure for PROMs was stifling their use (see figure 3.5).

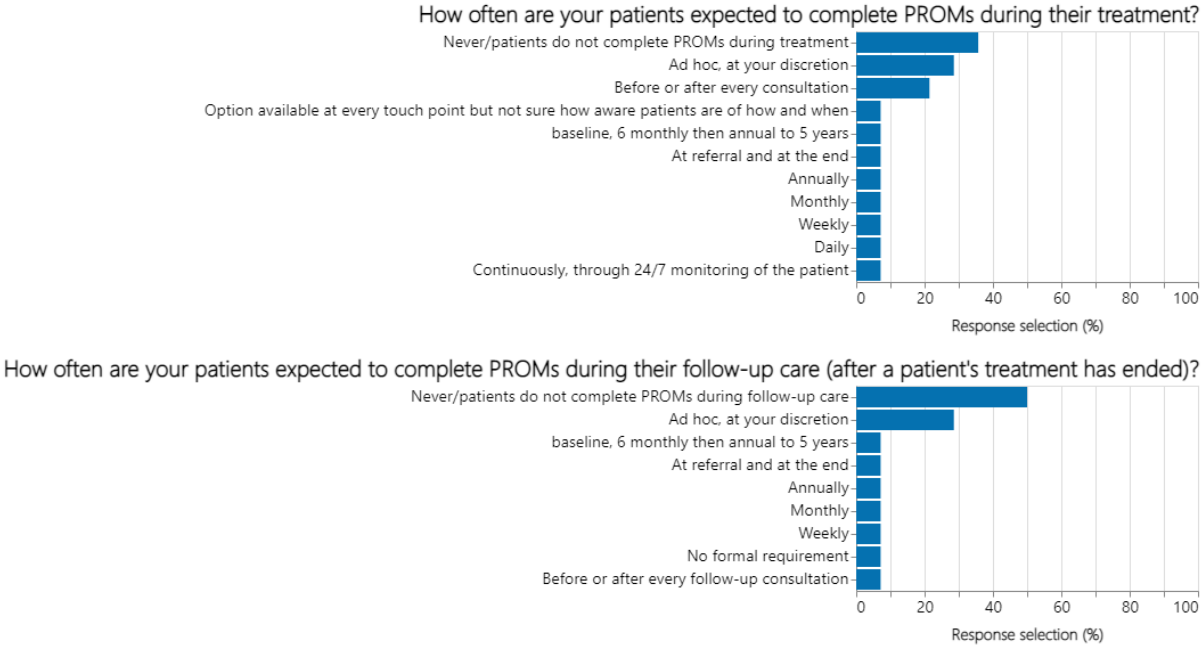

Figure 3.3: Responses to Q2E and Q2F on our staff survey.

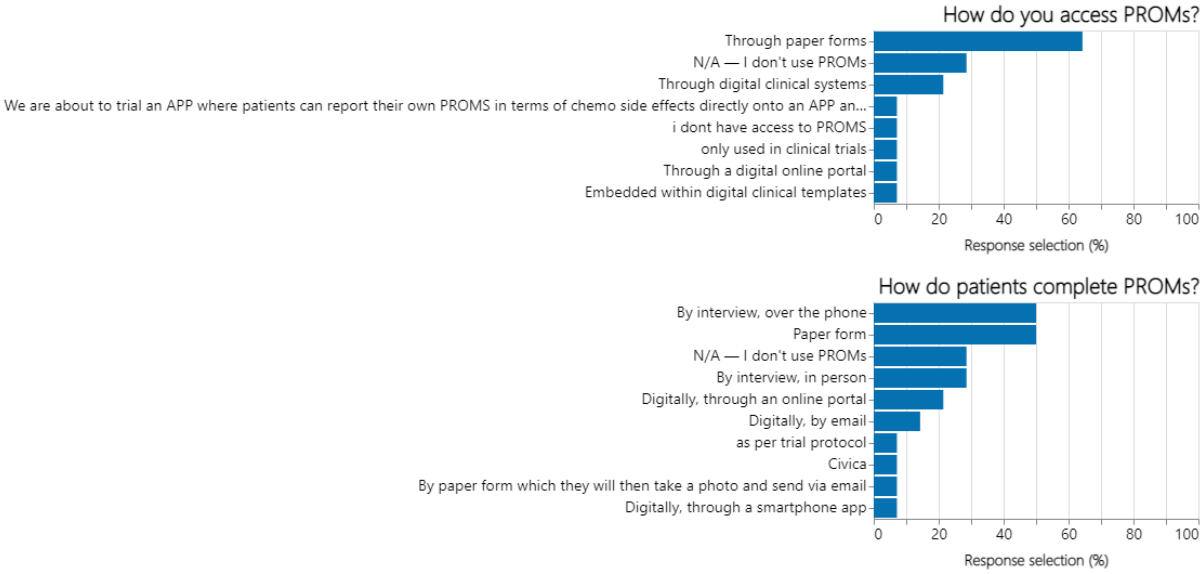

Figure 3.4: Responses to Q2C and Q2D on our staff survey.

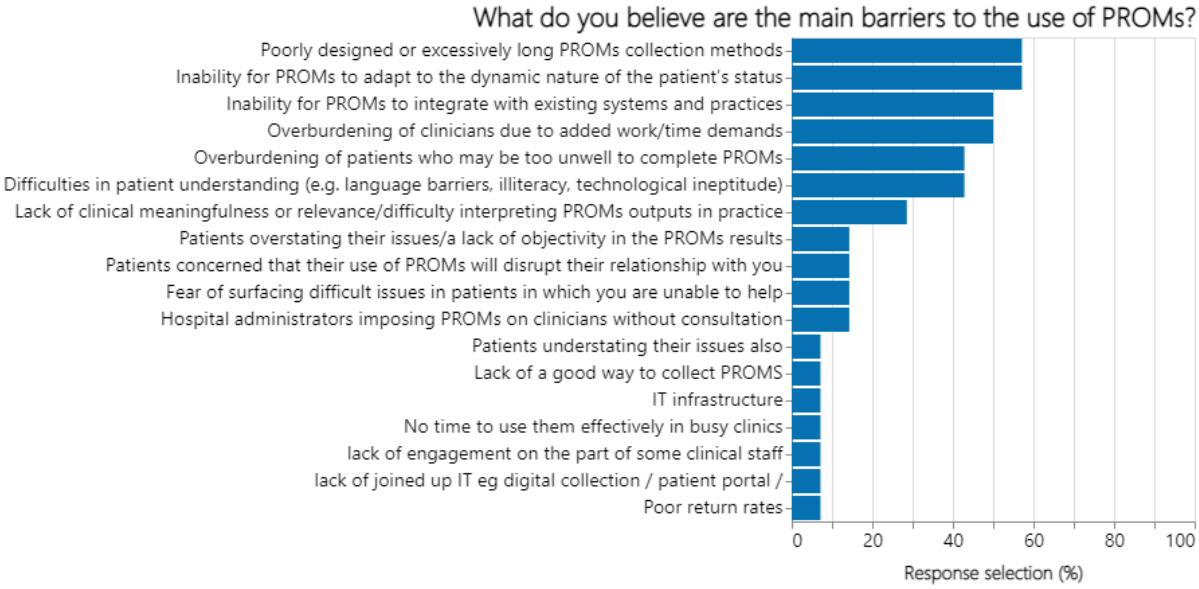

Figure 3.5: Responses to Q2G on our staff survey.

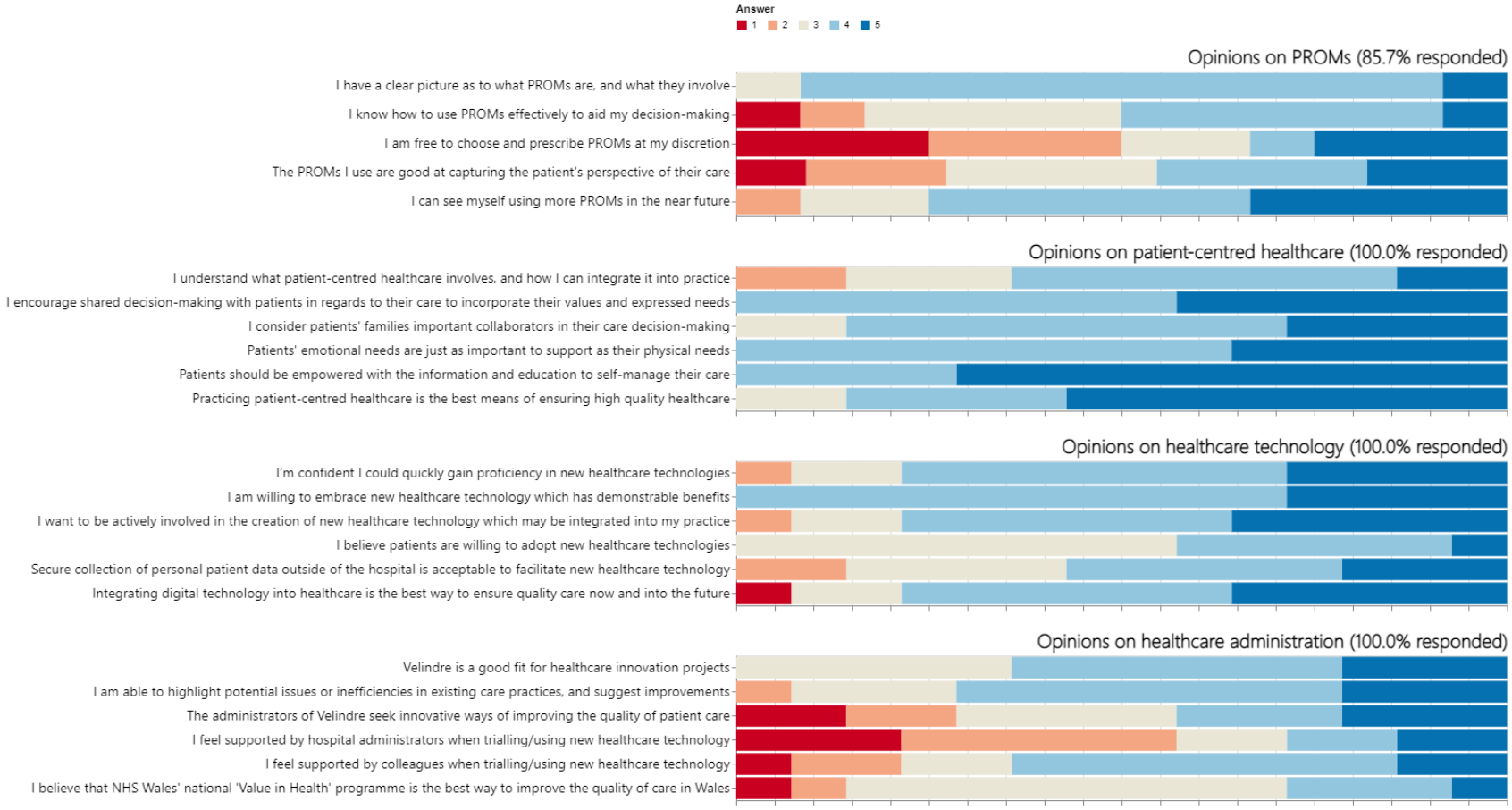

Figure 3.6: Responses to all parts of Q3 on our staff survey.

The following relates to Q3 (see figure 3.6).

Staff opinions on PROMs were typically favourable, however it is important to note that pragmatically staff were sometimes unsure how to use PROMs effectively and perceived issues in particular PROMs instruments' effectiveness. Whilst anticipated future use of PROMs was likely, the majority of staff indicated a lack of freedom in being able to choose and prescribe PROMs. Two staff members whom reported not using PROMs answered 'N/A' to these questions, and so n=12 for the five PROMs questions.

Respondents showed excellent engagement with PCH, with all staff reporting integration of most PCH principles in their practice – even if a minority of staff did not understand what it entailed. There was no evidence of any anachronistic, beneficent 'doctor knows best' [74] attitudes.

Similarly, staff attitudes towards healthcare technology were largely positive, with a unanimous willingness to embrace new technology and enthusiasm in the potential involvement of developing new relevant healthcare technology and in future technological integration. There was, however, a minority of staff showing apprehension towards data collection outside of the hospital and towards potential patient reception of new technologies.

Finally, we encountered the greatest levels of unsure or unopinionated responses in the staff's opinions towards healthcare administration. Whilst generally the culture of innovation and improvement was regarded as positive, there was a majority negative response to feeling supported by administrators when trialling such innovation projects, and in their decision-making. The staff's perceived support from colleagues was substantially more positively rated. The opinions on the national NHS Wales ViH programme were largely neutral or unknown.

Overall, the results of the survey were largely unsurprising, with Velindre staff sharing many of the attitudes found in the literature. Namely, that existing PROMs management is extremely burdensome and remains poorly managed at technological and administrative levels. We found that staff were extremely well engaged with the principles of PCH and demonstrated it in their care, however they were unable to effectively facilitate this through PROMs due to systematic limitations within Velindre. Respondents believed they were not being supported by administrative practices – some to

the extent where they believed that Velindre was against innovation altogether in the improvement space. We believe this is due to a lack of internal administrative responsibility for PROMs support and deployment; staff are currently required to individually learn about the benefits of PROMs, choose PROMs themselves, and finally administer and manage the PROMs individually, without any resources or guidance.

It was made evident the size of the technological gap at Velindre in regards to PROMs, where the vast majority of staff who endeavour with PROMs rely on paper forms due to the aforementioned lack of digital infrastructure. Staff responded positively to healthcare technology and indeed were beginning to employ their own digital solutions to the PROMs problem ad-hoc; however, this need to use non-EHR-integrated systems increases staff workloads and negates entirely the potential time-saving benefits of PROMs usage in practice. We believe this lack of infrastructure for even simple ePROMs collection stemmed from the severely outdated cancer EHR system – CANISC – which we estimated was developed in the mid-1990s, and had been in the 'phasing out' stage for at least the previous 11 years [75] at the time of writing. Staff simply cannot incorporate the technical solutions they would like to due to systemic deficiencies in existing technological infrastructure.

We found notable differences between how PROMs are being used in practice versus their perceived most beneficial purposes. Comparing Q2B and Q2H – which share the same set of multiple-choice options – shows us that PROMs were used for more administrative purposes currently as opposed to what staff believed they would be most useful for, which was more oriented around enabling PCH. Indeed, the top five responses for each indicate a wanted change of direction in how PROMs are used, especially in saving time in the administrative workload and empowering patients in directing their own care. Whilst these differences could be due to the circumstances of Velindre, we are more convinced that the underlying cause is that of poor PROM instrument design.

Staff indicated that poor PROMs design and PROM instruments' inability to adapt to patients' dynamic status were the chief barriers to the use of PROMs. This indicates a wider concern with the current international PROMs strategy and the state of PROMs development and standardisation – 'PROM' seemed to be synonymous with

'questionnaire', with little innovation in collection methods outside of digitising the questionnaire gathering mechanism. The standard pathway to which most PROM instruments prescribe is a structured timeline of intermittent questionnaire issuance to which staff must adhere regardless of any changes in patient status. Additionally, the most popular PROMs instruments typically stretch over more than 30 questions over various domains, and so place great burdens on staff who wish to offer them more frequently than specified.

As for an evaluation of the survey's design, we believed it succeeded in its designed purpose of gathering enough information to portray the internal circumstances of Velindre in regards to PROMs, whilst respecting severe time constraints. In this regard, we recorded the average time taken to complete the survey at just over 11 minutes – within reasonable distance of our 10 minute target. Additionally, our 100% completion rate for respondents indicated that staff were willing to give time to the survey. Reflecting on the results of particular questions, we found that we should have obtained more in terms of opinions of current PROMs usage, rather than just an overview. Additionally, it might have been useful to record changes which staff would like to have made to existing systems and practices in order to better understand their criticisms and preferred future direction for PROMs.

We note that our survey is limited in its implicit assumption that staff had only used one type of PROM, with an inability for staff to indicate their opinions on different PROMs systems. Finally, we found that section Q3D in particular could have been revised with much more focus on the culture within Velindre.

In summary, we found that there was much interest engagement with PCH and a want to use PROMs in Velindre, however organisation-wide administrative and technological issues were stifling their adoption and use. We identified clear issues with the design of PROMs instruments, and how they were being used at Velindre. More work is needed to assess how PROMs administration and management systems can be improved, as well as an exploration of PROMs from the patients' perspective.

3.4 Informal clinician interviews

Having built our baseline understanding of PROMs within Velindre, we wanted to delve deeper into staff experiences with PROMs, PCH, technology, and administration. We also wanted to verify the generalisability of our findings from the staff survey across Velindre, and so we spoke to various members of staff from disparate areas in order to understand how they perceived PROMs.

3.4.1 Purpose

The staff survey informed us on the general use of PROMs within Velindre, and how staff perceived its use. We probed for opinions on four key areas surrounding PROMs and their implementation and subsequently got a good general understanding of staff attitudes on a swathe of relevant issues. As a follow-up to this, we wanted to understand the personal contexts of various staff within the organisation so that our findings could be understood from different perspectives on a deeper, more holistic level. Additionally, we had begun the conversation of PROMs improvement within Velindre and this is something we wanted to continue to develop and to build relationships with members of staff in all areas of Velindre.

We wanted to know the priorities of the different staff, and how they were integrating PROMs and PCH into their workflows. It was important to find out how the individual moving parts worked within Velindre and to understand how the different staff groups were developing PROMs from various aspects.

3.4.2 Methodology

We knew that an informal interview approach was a 'necessary evil' for conducting study, as we wanted to understand a very large and complex topic from the perspective of various different types of staff member, and the severe time constraints afforded by this short project at a time of great pressure for staff all across Velindre meant that interviews would occur fortuitously.

With each interview, we sought to build a profile of how they interacted with PROMs, what their priorities for PROMs are, and what their perspective could tell us about PROM deployment, development, usage, and administration.

3.4.3 Results

Consultant developing ePROMs Our first interview was with a consultant oncologist with experience in developing ePROMs systems for various patient pathways. Frustrated with the paper-based systems in use at the hospital, the consultant took it upon themselves to develop a solution – evaluating the off-the-shelf patient management system *Patients Know Best* [76] before going on to pioneer the first in-house ePROMs system at Velindre in partnership with the business intelligence team. This ePROMs system was used to validate the effectiveness of experimental patient pathways and to facilitate comparison with the literature, with an expressed need to be able to perform such comparisons in order to better patient outcomes. They indicated that nationalised programmes – whilst well-intentioned – are rarely sustainable, and that requiring all changes and improvements to be coordinated by DHCW is obstructive to innovation.

Innovation team member We interviewed a member of the research and innovation team, who informed us on Velindre's research priorities and a conceited effort to improve the digital infrastructure at the hospital. It was evident that they recognised a disconnect between research findings and clinical practice, and that projects to ameliorate this were underway; namely the retirement of CANISC and development of its successor. PCH was a focus for Velindre, and preparations for nVCC were catalysing a shift towards pervasive digital technology in clinical workflows and the opening-up of experimental findings into practice.

Difficulties between administrators and clinicians were mentioned, and that Velindre had evolved into a very PCH-focussed mindset, however it was warned that 'political tension' was an unavoidable part of the NHS Wales healthcare landscape.

Consultant and PROMs expert The final interviewee was a consultant with an extensive history of PROMs use, development, and administration whom had previously

spearheaded PROMs development efforts within Velindre. They expressed many reservations about current PROM instrument designs and uses, rooted in the appropriation of PROMs for PCH – having originally being designed by statisticians as measurement tools for clinical trials. Particular issues with instrument design included excessive length and question duplication, potentially discriminatory differences in measures for gendered diseases, licensing issues and the ethical concerns with the commercialisation of PROMs, the fallacy of PROMs instrument validation, and an unjustified insistence in ensuring PROMs for all diseases.

There was an expressed concern for the “huge black hole” of Velindre’s lacking digital infrastructure, and that there was an immense opportunity for novel digital PROMs that was not being realised. Suggested was a PROMs mechanism that would avoid the “route to failure” of presenting questions to patients altogether, where it would instead digitally infer patient QoL to report back problems to the patient’s care team. It was even suggested that the connotations of PROMs are so dire that abandoning the term might be an option into the future.

Additionally, the attempts of national governance of PROMs through PPEP were said to have generated more issues than it solved, and in their experience the need to adhere to national data gathering and architecture rules severely limited the benefits of using PROMs data within Velindre.

3.5 Prototype PROMs clinical workflow

The final of our three studies was to take our first step towards ameliorating the issues we perceived in existing PROMs clinical workflows by co-developing a design prototype for a ’PROMs-first’ clinical workflow. Working with clinicians, we wanted to use the criticism of existing PROMs systems to shape the clinician-facing design of a new system and allow clinicians’ needs to be realised. The overall aim was not to produce a highly-polished and ready-to-deploy prototype system, but instead a rudimentary concept that could be looked at by ourselves and clinicians to begin to comprehend the real changes that need to be made to the real-world systems, and how we can go about this.

We undertook a three-phase process of requirements gathering, prototype design,

and evaluation with clinicians to facilitate our idea, which we outline in this chapter.

3.5.1 Purpose

We set out to co-develop a low-fidelity design prototype for a PROMs management and monitoring system from the clinicians' perspective in order to demonstrate how the clinical workflow could be adapted to better facilitate a PROMs-first approach in an oncological setting. Co-development of the system with multiple PROMs experts was to ensure that clinicians were actively involved in the design decision-making of a system that, if implemented fully, would affect their clinical workflows. The prototype was to be a digital augmentation of an existing EHR-PROMs system, given our previous findings that creating auxiliary clinical systems that fail to integrate with EHRs is a key barrier to clinician adoption. Similarly, we did not seek to reinvent PROM collection or structure for the purposes of this prototype, as we wanted to implement our proposed improvements from a basis that was familiar to clinicians.

Due to project time constraints, we knew that we would be unable to iterate on our initial design prototype and so this study sought to develop a 'conversation piece' prototype that would facilitate dialogue between the clinical and technological collaborators. Building such close working relationships early in the partnership allows not just for more meaningful and robust solutions in the long-term [77], but it also facilitates a two-way knowledge transfer of clinical expertise to the technological researchers and radically digital ideas to the clinicians. This was important, because whilst our other studies indicated that clinicians were willing to rethink practices and integrate sophisticated technology into the clinical domain – this was, in fact, only half the battle and we will need to overcome the "organisational resistance" to technology [78] which was evidently substantial in the healthcare domain.

Additionally, this study was to give us the first experience of the real clinical systems in use by clinicians in VCC, and so would provide a valuable investigation of clinicians' attitudes to current PROMs clinical workflows and EHR-PROMs integrations. Given that we would be working with the EHR in the future, this study would be extremely useful in giving us a better understanding of the systems that are used by clinicians, how they use them, and what aspects they valued or felt needed improvement.

3.5.2 Methodology

3.5.2.1 Phase 1: Requirements gathering and pre-existing system evaluation

In the first phase, we worked with several PROMs experts to identify the key issues faced by clinicians using PROMs administration and management systems, analysing the shortcomings and methodological issues of current systems. This was followed by a requirements gathering exercise to capture what the PROMs experts wanted from a redeveloped system – in design and deployment strategy – in order to better accommodate clinicians in using and understanding PROMs.

This began with recruitment of the clinical PROMs experts. Whilst it was infeasible to recruit clinicians from VCC due to project time constraints and an overburdened NHS Wales, we were fortunate enough to engage with two local (Swansea, UK) PROMs experts; a professor of health service research specialising in PROMs methodologies, and a plastic surgeon with extensive experience in PROMs usage and research.

From there, one-to-one meetings were held between collaborators to establish the purpose of the study and begin requirements gathering. A semi-structured interview was conducted, following a pre-determined set of topics and sections (see table 3.1) but allowing the PROMs experts' responses to shape the questioning and structure of feedback received [79]. Cognisant of our lack of clinical expertise, a less structured interview format was chosen to allow for freedom of conversation and to enable the experts to highlight what they felt were the most important aspects to consider. We decided against in-depth interviews with our experts as we knew the intended purpose of the prototype and subsequently the topics we wanted to cover.

The interviews consisted of three main topics, starting with a look into the backgrounds of our PROMs experts and for particular experiences with PROMs to give some clinical context to their further responses. We continued with an evaluation of pre-existing PROMs systems, investigating how the systems work, their intended purpose, the patient and clinician interfaces, the expected clinical workflow, and a general qualitative assessment of the systems' usability. Such pre-existing systems were heavily criticised, both in design – where they were described as "haphazard" auxiliary paper or rudimentary digital tools with extremely poor integration with other clinical systems –

Table 3.1: The topics and sections used to guide the semi-structured interview component of phase one

Topic	Section
Background	Occupation and role
	Experience with PROMs
	Current use of PROMs
Pre-existing system evaluation	Purpose and intended use
	Clinician interface
	Patient interface
	Expected clinical workflow
	Prescription of PROMs
	Usability assessment
Prototype requirements gathering	Data sources and granularity
	Extent of data collection
	Information presentation
	Target platform and format
	Customisability
	Affordances
	Prescription of PROMs
	Abstraction and analogues

and in usage, where they were regarded as isolated tools for individual clinical studies, with little to no use of data in practice. There was also a sense that national programmes for value-based healthcare had given most clinicians an awareness of PROMs, however little understanding of what they actually were and how clinicians could benefit from them. PROMs are seen as a time-consuming, administrative burden on clinicians, with little clinical relevance and whose benefits are unknown or unclear.

Building on this feedback, we proposed the creation of a 'best-case, idealistic' new PROMs system concept that would focus on bringing PROMs and PCH to the centre of their practice. We asked the experts to contribute their requirements for such a system, given unlimited resources and creativity, with the ability to collect data and display information from any source in any format as often as would be helpful. It was clear that the experts wanted consideration of a patient's quality of life to be at the heart of their decision-making, and were very motivated to bring PROMs into their care. The apparent need to integrate the new PROMs system into the EHR system was funda-

mental, with great emphasis that the new system should not be standalone nor should it be accessible on personal devices outside of the EHR. There was much resentment at the structured timeline of current PROMs instruments and subsequent inflexibility to adapt to the changing needs of the patient, with the experts wanting more timely notification of poor PROs. They noted, however, that notifications should be reserved for issues of clinical importance only, with a suggested severity level system differentiating urgent and less important information. Additionally, there was noted an inherent balance to be struck between the extent of constant patient data collection and the value to the clinician and patient, which would need to be changeable and established early in the patient pathway. The experts indicated that clinicians would need much support in interpreting PROMs information, as clinicians are rarely familiar with PROMs scoring methods or the clinical value of particular PROs. Simple statements of PROMs status that were related to population-standard averages and backed up by clinical measures were suggested to achieve this.

After the meetings, we performed a basic thematic analysis of the experts' feedback and system requirements to produce the following set of guiding principles for PROMs system design from clinicians' perspective:

- Tight integration into clinical systems and practice
  The system should be wholly integrated within the existing EHR system, supporting clinical decision-making without introducing new services, dashboards, or platforms. As part of this, the new system should not allow practice to creep into clinicians' off-duty hours and therefore should not be accessible from outside of the EHR system (i.e. not accessible on the clinicians' personal mobile devices).
- Versatility to support clinician preferences
  Clinicians should be provided with an easy way to prescribe and manage any PROMs instruments they wish to, and the results of said monitoring should be provided in varying levels of complexity to support their various needs. Additionally, the recorded data should be portable, and support knowledge sharing between systems and clinicians.
- Relativity and concision of information
  Special attention should be paid in ensuring PROMs information is easy to in-

terpret, using visual aids and the ability to view information at different levels of abstraction so that the clinician can decide how much detail they wish to go into. The system should provide a way to inform clinicians on the clinical importance of the information displayed, and be able to display this as simply as possible.

- PROMs should shape the patient pathway
  Rather than follow pre-prescribed, structured timelines for PROMs delivery, it would be more valuable to have critical patient-reported information delivered as soon as it becomes a problem. Valuable clinician time should not be spent on unnecessary PROMs analysis or interventions.
- Adjustability of patient data collection consent
  Patients are unlikely to consent to all of the aspects of constant monitoring that a more digitally sophisticated system may necessitate, therefore there should be levels of monitoring the patient can consent to – rather than an unequivocal 'yes' or 'no' to PROMs.

3.5.2.2 Phase 2: Design prototype development

This phase of the project focussed on realising the PROMs experts' vision of a redeveloped PROMs administration and management system, and involved an assessment of various design considerations in order to produce a low-fidelity digital prototype of the system. A redeveloped patient pathway was developed and 'minimal set' of mock-up interface designs were produced in order to demonstrate the system's functionality to the PROMs experts.

Redeveloping the patient pathway It was evident that in order to accommodate a more patient centred, PROMs-first clinical workflow that we would have to depart from the typical structured timeline for periodical review of PROMs. We instead needed a way to relieve the clinician of their PROMs duties up until the point where there is a problem needing clinical intervention.

A literature review of similar systems found only one study with a similar concept; Schougaard et al. [80] demonstrated the concept of automated PROMs management with *AmbuFlex*, whereby clinicians could 'refer' patients belonging to one of nine di-

agnostic groups to the system at the point of follow-up care in order to have their PROMs automatically monitored instead of requiring the typical timeline of follow-up appointments. *AmbuFlex* would handle the dissemination of PROMs questionnaires automatically, and indicate patient status back to clinicians in one of three severities: red – 'requires clinician intervention', yellow – 'potential intervention required, deferring decision-making to the clinician', and green – 'no intervention required'. Whilst the study was successful in reducing patients' contact with clinicians in treatment follow-up, the overwhelming number of patient statuses reported requiring clinician attention (on average, 87% of system statuses were 'red' or 'yellow') leads us to believe that there must have been an increased burden of dealing with frequent PROMs alerts. Additionally, the lack of adjustability in the system's definitions of 'red' and 'yellow' statuses meant that clinicians would be forever plagued with this burden unless the system underwent another revision. The system is also detached from the rest of the clinical systems, which, based on our expert interviews, is an obvious burden we wish to avoid in our system.

With these considerations, we proposed the following three-stage expected clinical workflow to be used in our design prototype:

1. Pre-intervention baseline assessment
   At the consultation at which a patient is diagnosed or a treatment regimen is planned, the clinician must collaborate with the patient to determine the outcome measures that are important to the patient and the clinician and subsequently require monitoring. There must also be a negotiation between patient and clinician regarding the level of monitoring of personal information to which the patient consents for the purposes of getting the most out of the PROMs monitoring. Once these factors have been established, the clinician administers the relevant PROMs to the patient via the EHR and the system can begin to build a baseline assessment of the patient's outcomes for later comparison.

2. Post-intervention consultation
   At the first point of contact after the treatment has been administered or is complete, alongside informing the patient of the treatment's outcome and relaying all

other needed information, there should be a review of the PROs to be monitored to ensure the measures are still suitable and consent is still given. The patient is then to be informed that further consultations are to be arranged ad-hoc either by the PROMs system when outcomes are poor or by the patient upon request.

3. Automatic monitoring of PROMs
   From this point, until patient or clinician needs require it, the automatic monitoring of PROMs is handled by the system – alerting the clinician only if a clinically important change in PROMs is observed. Clinicians are enabled with *ad libitum* access to patient PROMs, analyses, and data-inferred insights at an individual and departmental level.

Interface design Given our need to integrate the PROMs system into the EHR, we based our prototype on the design and layout of the Welsh Clinical Portal – the national EHR system for Wales, used by all health boards and trusts [81]. On this basis, we implemented the design of our functionality with consideration to several design principles to ensure best practice and good usability for the prototype. The chief principle that shaped the design was that of Shneiderman: "Overview first, zoom and filter, then details-on-demand" [82] – a good fit for our requirement of versatility which involved the ability to display information at varying levels of granularity. We ensure that the clinician is presented with only an appropriate 'minimal set' of information at any one given moment to ensure the clinician is never overwhelmed, given the data complexity of our prototype. Filtering of information displayed is afforded wherever relevant, and similarly there is a link to view more details on almost every element of the system.

The use of subheadings and descriptions wherever possible was to aid clinician understanding of presented information, and similarly the automatically inferred insights presented to the clinician were written in full sentences with context related to patient and population norms. Insights were derived from known data only and no predictions were made as to ameliorate potential clinician mistrust in the information provided; clinicians could also rate insights in order to inform the system as to which information is truly useful. We structured the interface with a consistent style to aid navigation, and ensured the most relevant information for the clinician was made apparent by its place-

ment and appearance. Similarly, the use of iconography for buttons and for important metrics was to provide more context to the actions they may perform and to increase the speed at which clinicians can gather useful information from the interface.

A screen from the prototype is shown in figure 3.7 and the full design prototype that was used in this study is shown in appendix B.

PROMs used Given that this study focussed on adapting the clinical workflow of PROMs administration rather than PROMs instruments themselves, we decided to simply integrate pre-existing and widely used PROMs instruments in our prototype. In oncology, there are a plethora of PROMs instruments used to capture patient quality of life, disease symptoms, and treatment side-effects – with little guidance on how to select particular instruments [83]. In the case of the prototype, the actual PROMs instruments used are of least concern and so we chose them arbitrarily; the modularity afforded by the EORTC's *Quality of Life Questionnaires (QLQ)* system for assessing the quality of life of cancer patients allows for the sharing of a large number of generic PROs between all cancer sites with the addition of specialised 'modules' for particular diseases [84].

In the prototype, we provided the context of an oncologist monitoring a breast cancer patient and subsequently employed the widely used [85] combination of generic PROM *QLQ-C30* plus the breast-cancer specific *QLQ-BR23* [84]. Together, these PROMs cover 11 separate aspects of the everyday life of the patient, plus reporting of various disease symptoms [86]. We amalgamated these aspects into four broader domains for the purpose of maintaining ease of clinician comprehensibility in our prototype, with further details available on-demand (akin to Gensheimer et al.'s recommendations [87]). The prototype designs assumes both full patient data availability and data use consent, with a background system that is able to extract this information from the user in real-time; the mechanics of the PROM collection are outside the scope of the prototype and so such assumptions are made.

Notifications Clinician alerts are a core mechanism of the prototype system, with all post-intervention communication between patient and clinician driven by automated inference and notification. However, there are longstanding and well-reported negative

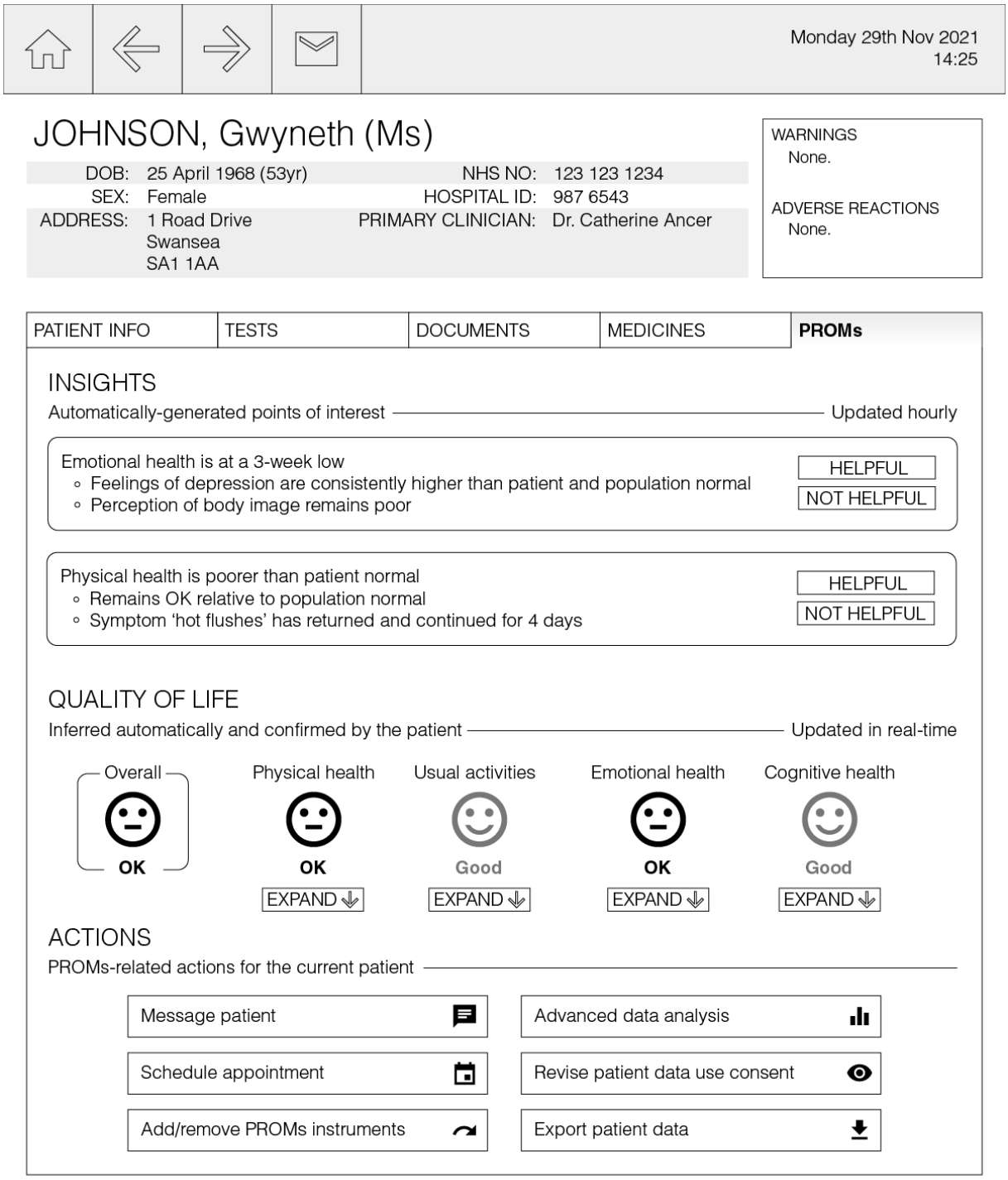

Figure 3.7: A screen from the low-fidelity prototype system, demonstrating the individual patient-level management of PROMs in the EHR. The clinician is able to quickly see automatically-inferred insights into the patient's status plus an overview of their quality of life across four domains.

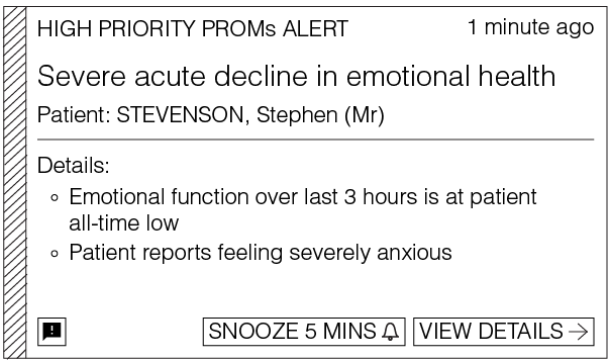

Figure 3.8: An example of the enlarged PROMs dialogue box, giving detailed information about the triggered 'alert' and providing quick actions to the clinician to hasten management.

connotations associated with alert mechanisms in EHR systems by clinicians; poor usability, poor integration with clinical workflow, tedious data entry requirements, and a perception of "excessive and burdensome" alerting [88]. We believed that such issues would arise in the prototype if we were to naïvely integrate it with the EHR's existing notifications system, and so we devised a separate alerting system following notification design best practice to improve clinician recognition of and adherence to notifications – our key concerns for clinician acceptance of the notification system and subsequently our prototype [89].

In their comprehensive review [88], McGreevey et al. outline a set of recommendations for better alert management in EHR systems, with seven key rules in their design. Whilst some rules were irrelevant to the scope of the prototype, the properties of relevance, actionability, transperency, overridability, and reference guided the notification system design. Relevance is reflected in the way that our notifications appear, whereby automated inference of clinically significant events ensures that notifications are triggered if and only if they are deemed important. The details of what triggered the notification are transparent and are made evident within the notification body with reference to supporting PROs, and the clinician is always presented with a set of key actions to enable swift management of notifications. Additionally, the overridability of the system means that the clinician can tailor notification preferences to inform the system on what is considered important from within notifications and on a system-wide level. Figure 3.8 demonstrates the information contained in an enlarged alert notification in our design.

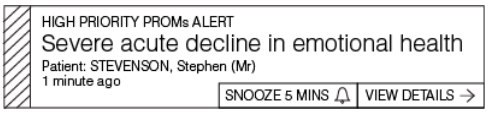

Figure 3.9: An example of the high-priority PROMs 'alert' notification which appears on the navigation bar of the prototype system upon trigger.

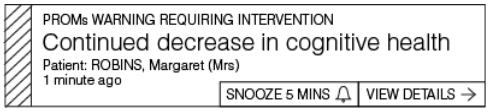

Figure 3.10: An example of the concerned PROMs 'warning' notification which appears on the navigation bar of the prototype system upon trigger.

Murphy et al. [90] observed clinicians' EHR usage in primary care, and gathered a set of five recommendations from the clinicians as to how notification-related burden could be managed. The call for optimisation in the delivery of notifications presented a challenge as to how we could efficiently convey the expected action required by differing PROMs notifications whilst maintaining infrequency and a sense of importance. We decided that the automated inference of clinical significance should be categorised into two levels of notification severity based on the types of anomalies expected to be found with the PROMs:

- Alerts indicate acute anomalies requiring immediate clinical attention. In figure 3.9, we show an example alert of 'severe acute decline in emotional health' caused by significant decline in reported mental health and emotional function compared to the patient normal.
- Warnings indicate anomalies which are developing on a longer-term basis and which may require preventative clinical attention. In figure 3.10, we show an example warning of 'continued decrease in cognitive health' caused by steady decline in cognitive function and significantly lower health compared to the population normal.

We also considered clinicians' needs for team support in notification management, and so notifications are delivered to all on-call staff of a particular patient's care team, and clinicians are able to shortly snooze notifications before acting on them to facilitate more flexible time management. Finally, clinicians can access a log of recent and his-

torical notifications on a per-patient and population level to ensure past notifications are not lost.

3.5.2.3 Phase 3: Prototype evaluation

The final phase of the study involved demonstrating the newly developed design prototype to the PROMs experts for their evaluation. The prototype consisted of a set of low-fidelity design mock-ups, which were shown to the experts in a hypothetical context in order to provoke meaningful qualitative feedback. This feedback evaluated our proposal for a PROMs-first clinical workflow both in methodology and interface design, through our mock-ups.

Our experts were contacted by email two weeks after their initial interviews and given a document containing the screens from our design prototype with guidance interspersed throughout to explain the intended navigation through the system. This guidance demonstrates the design prototype through the completion of three common tasks;

- Monitoring PROMs for all patients: the EHR-integrated all-patients PROMs overview screen is presented
- Monitoring PROMs for individual patients: a patient record is presented with the PROMs tab of the casenote opened
- The event of a PROMs notification: with a patient record opened, a PROMs 'alert' notification appears and the experts are shown the subsequent notification dialogue box

We prompted the experts for qualitative feedback in answer to two main criteria: the effectiveness of the redeveloped clinical workflow in function and in form against their initial system requirements, and the effectiveness of the initial system requirements given the design prototype. In this way, we are able to capture the experts' opinions of our proposed system and additionally give the experts an opportunity to review their system requirements having seen them reflected in the prototype.

3.5.3 Results

The primary goal of this study was to produce a design prototype for a co-developed, PROMs-first clinical workflow to be a 'conversation piece' between clinical and technological collaborators for how PROMs could be better integrated into their care. This began with a discussion of pre-existing PROMs workflows, where we quickly gathered that they were seen as irrelevant, time-consuming burdens by clinicians; typically paper-based, very poorly integrated, with benefits unclear and any findings isolated to clinical studies only. We asked our PROMs experts what they wanted out of a new PROMs management workflow and five key points were highlighted: tight integration into existing clinical systems, versatility, relativity and concision in information displayed, adjustability of patient data collection consent, and a need for PROMs to shape the patient pathway.

As part of the design of our prototype we found very little in the way of PROMs-first clinical workflows in the literature, with Schougaard et al. [80] being the only group to demonstrate the concept, albeit with various flaws in their implementation. Our re-developed workflow was outlined, putting PROMs at the heart of the patient pathway in a three-stage process of pre- and post- intervention consultations with subsequent interventions informed by PROMs reporting only. We illustrated the concept through various low-fidelity prototype screens based on a proposed integration with a real EHR, and demonstrated its intended use to the PROMs experts.

We had a mixed response to our design from the experts, with one indicating that the implementation of our prototype would be a notable improvement to existing systems and the other indicating substantial doubt into the effectiveness of our design. In regards to the general critique of the design of the prototype system, the automatically-generated insights across the prototype were perceived as unnecessary information with little relevance which were likely to be ignored – even with a 'helpful/not helpful' feedback loop system. There was understandable concern behind the notification system and how it would be ensured that notifications shown are of utmost importance, given most clinicians' first-hand of alert fatigue in EHR systems. The expanded QoL section (see figure **??**) was found to be too complex, and the information would need to be further abstracted to produce more digestible "key messages" derived from the

data that would indicate what clinicians could interpret as of 'minimum clinical importance': a finding from the PROMs data that indicated a significant enough change to warrant clinician intervention. There was also a need to marry the PROMs information with clinical measures in order to ease interpretation.

As for our revised clinical pathway – it was noted that whilst improvements had been made, it would only form part of an implementable ready system and that equal change in the patient interface would be necessary to ensure its success. Specifically, there should be a focus on the reliability of patient responses and subsequently better management of this from the clinicians' interface, including a consideration for patients who were not adhering to PROMs programmes or did not consent to very much data collection. Otherwise, our redeveloped system was considered well-integrated into the clinical workflow and much more approachable than pre-existing systems in terms of clinician understanding of PROMs information.

The scope of our project involved the redevelopment of the clinical workflow whilst assuming patient adherence and abundant data collection so that we could showcase the potential of our new concept in putting PROMs at the heart of clinician decision-making. Based on our feedback, we believe that an exploration of how the varying levels of data collection afforded by the system could be managed by clinicians would be salient. Upon reflection, we agreed with the criticism of our automatically-generated insights mechanism, and that more emphasis should have been placed on investigating how we could get information across to clinicians in the most efficient manner. This would have involved consideration of conversation theory, data visualisation methods, system usability principles, and how clinicians routinely used EHR systems. Finally, more work is needed on the verification of our notification system in a real clinical setting, and we anticipated that alert optimisation within Velindre's EHR systems would be an area of interest in our future work.

3.6 Summary

Chapter 4

Conclusion

XXX

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Appendix A

Survey Questions

Qn.	Text	Type	Options
1	What is your role in Velindre?	Short freeform text	N/A
2A	How would you describe ‘patient reported outcomes’?	Long freeform text	N/A

Qn.	Text	Type	Options
2B	What do you use PROMs for?	Multiple choice	• Aiding clinical management • Improving treatment outcomes • As a screening or diagnostic tool • Facilitating shared decision-making with patients, or supporting patient-centred care • Connecting patients of different cultures • Empowering patients to direct their own care, and engage in self-management • Providing a more holistic and informed view of a patient's condition • Improving the efficiency of a consultation, or saving time on the administrative workload • Facilitating communication with patients, or to structure conversation during consultations • For disease monitoring • For monitoring patient performance or safety • Facilitating continuity and communication between different healthcare sectors • Rewarding patient performance, or to provide motivation to patients • To facilitate better clinical research • N/A — I don't use PROMs • Other, please specify all other purposes (short freeform text)

Qn.	Text	Type	Options
2C	How do you access PROMs?	Multiple choice	• Through digital clinical systems • Embedded within digital clinical templates • Through paper forms • Through a digital online portal • N/A — I don't use PROMs • Other, please specify (short freeform text)
2D	How do patients complete PROMs?	Multiple choice	• Paper form • By interview, in person • By interview, over the phone • By interview, via video call (e.g., Skype, Zoom, AttendAnywhere, DrDoctor) • Digitally, by email • Digitally, through an online portal • Digitally, through a smartphone app • N/A — I don't use PROMs • Other, please specify (short freeform text)

Qn.	Text	Type	Options
2E	How often are your patients expected to complete PROMs during their treatment?	Multiple choice	• Ad hoc, at your discretion • Before or after every consultation • Annually • Monthly • Weekly • Daily • Continuously, through 24/7 monitoring of patient • Never; patients do not complete PROMs during follow-up care • Other, please specify (short freeform text)
2F	How often are your patients expected to complete PROMs during their follow-up care (after a patient's treatment has ended)?	Multiple choice	• Ad hoc, at your discretion • Before or after every consultation • Annually • Monthly • Weekly • Daily • Continuously, through 24/7 monitoring of patient • Never; patients do not complete PROMs during follow-up care • Other, please specify (short freeform text)

Qn.	Text	Type	Options
2G	What do you believe are the main barriers to the use of PROMs?	Multiple choice	• Patients overstating their issues; a lack of objectivity in the PROMs results • Patients concerned that their use of PROMs will disrupt their relationship with you • Difficulties in patient understanding (e.g. language barriers, illiteracy, technological ineptitude) • Inability for PROMs to adapt to the dynamic nature of the patient's status • Inability for PROMs to integrate with existing systems and practices • Lack of clinical meaningfulness or relevance; difficulty interpreting PROMs outputs in practice • Poorly designed or excessively long PROMs collection methods • Fear of surfacing difficult issues in patients in which you are unable to help • Overburdening of clinicians due to added work/-time demands • Overburdening of patients who may be too unwell to complete PROMs • Hospital administrators imposing PROMs on clinicians without consultation • Other, please specify (short freeform text)

Qn.	Text	Type	Options
2H	For which purposes do you believe PROMs could provide the most benefit?	Multiple choice	• Aiding clinical management • Improving treatment outcomes • As a screening or diagnostic tool • Facilitating shared decision-making with patients, or supporting patient-centred care • Connecting patients of different cultures • Empowering patients to direct their own care, and engage in self-management • Providing a more holistic and informed view of a patient's condition • Improving the efficiency of a consultation, or saving time on the administrative workload • Facilitating communication with patients, or to structure conversation during consultations • For disease monitoring • For monitoring patient performance or safety • Facilitating continuity and communication between different healthcare sectors • Rewarding patient performance, or to provide motivation to patients • To facilitate better clinical research • Other, please specify all other purposes (short freeform text)

Qn.	Text	Type	Options
3A(i)	I have a clear picture as to what PROMs are, and what they involve	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree • N/A
3A(ii)	I know how to use PROMs effectively to aid my decision-making	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree • N/A
3A(iii)	I am free to choose and prescribe PROMs at my discretion	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree • N/A
3A(iv)	The PROMs I use are good at capturing the patient's perspective of their care	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree • N/A

Qn.	Text	Type	Options
3A(v)	I can see myself using more PROMs in the near future	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree • N/A
3B(i)	I understand what patient-centred healthcare involves, and how I can integrate it into my practice	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3B(ii)	I encourage shared decision-making with my patients in regards to their care to incorporate their values and expressed needs	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3B(iii)	I consider patients' families important collaborators in their care decision-making	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree

Qn.	Text	Type	Options
3B(iv)	My patients' emotional needs are just as important to support as their physical needs	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3B(v)	Patients should be empowered with the information and education to self-manage their care	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3B(vi)	Practicing patient-centred healthcare is the best means of ensuring high quality healthcare	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3C(i)	I am able to quickly gain proficiency in new healthcare technologies	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree

Qn.	Text	Type	Options
3C(ii)	I am willing to embrace new healthcare technology, as long as it has demonstrable benefits	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3C(iii)	I want to be actively involved in the creation of new healthcare technology which may be integrated into my practice	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3C(iv)	Generally, I believe patients are willing to adopt new healthcare technologies	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3C(v)	Secure collection of personal patient data outside of the hospital is acceptable to facilitate new healthcare technology	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree

Qn.	Text	Type	Options
3C(vi)	Integrating digital technology into healthcare is the best way to ensure quality care now and into the future	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3D(i)	Velindre is a good fit for healthcare innovation projects	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3D(ii)	I feel able to highlight potential issues or inefficiencies in existing care practices, and suggest improvements	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3D(iii)	The administrators of Velindre seek innovative ways of improving the quality of patient care	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree

Qn.	Text	Type	Options
3D(iv)	I feel supported by hospital administrators when trialling/using new healthcare technology	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3D(v)	I feel supported by colleagues when trialling/using new healthcare technology	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree
3D(vi)	I believe that NHS Wales' national *Value in Health* programme will improve the quality of care received in Wales	5-point Likert scale	• Strongly Agree • Agree • Unsure/No opinion • Disagree • Strongly Disagree

Appendix B

Design Prototype

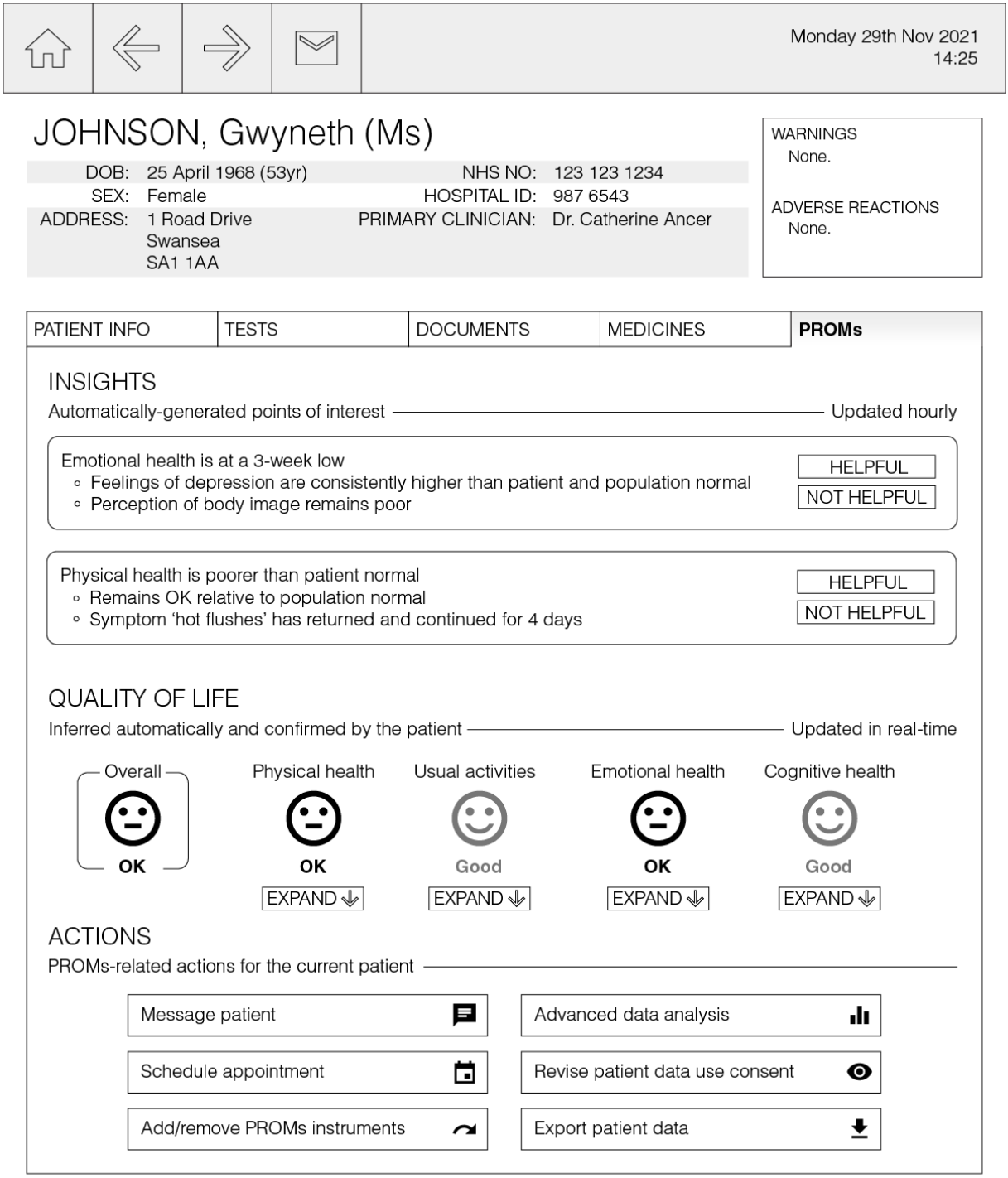

Figure B.1: The patient record displayed in our EHR mock-up. The PROMs tab is open on the casenote.

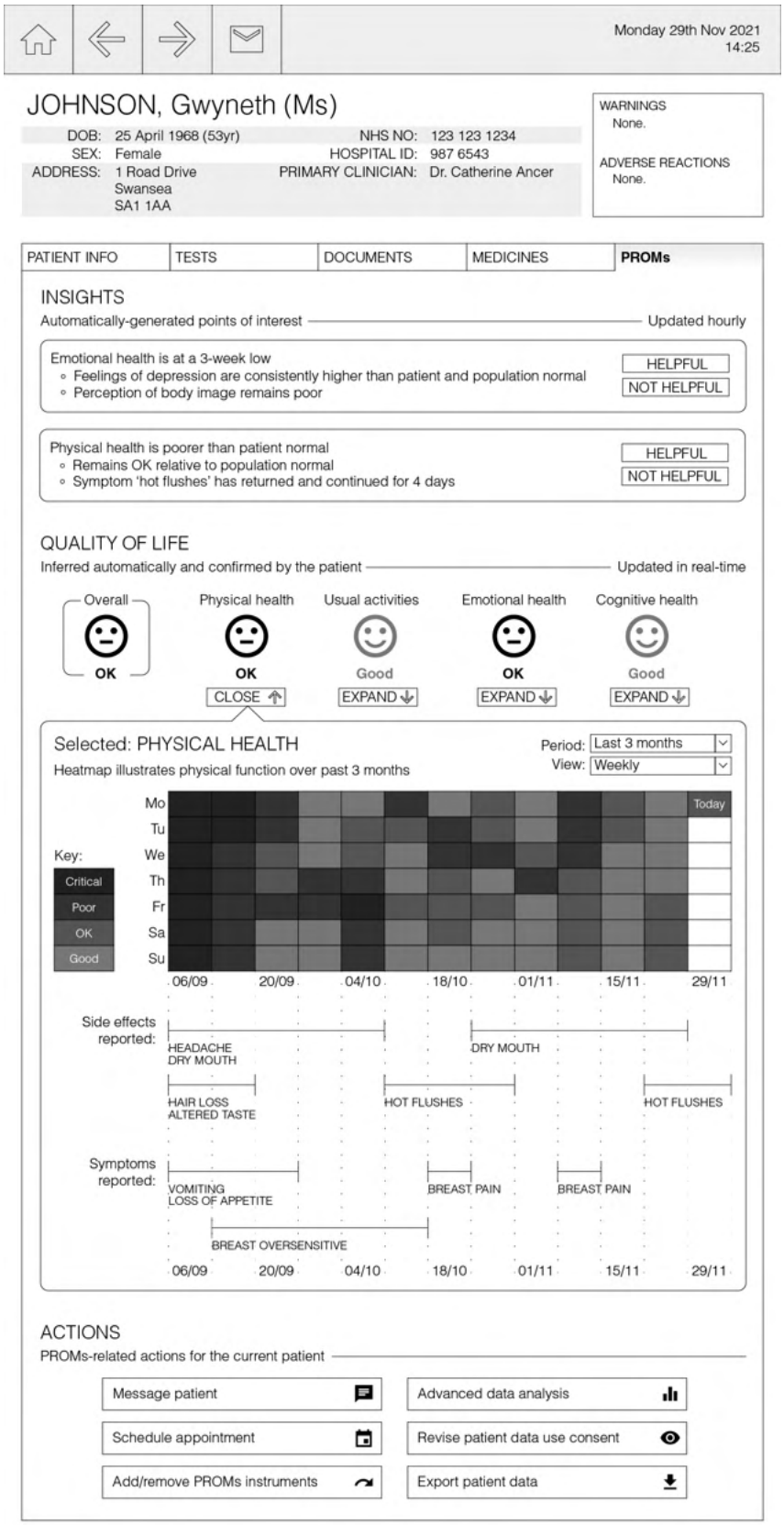

Figure B.2: The patient record displayed in our EHR mock-up. The PROMs tab is open on the casenote and the QoL section has been expanded.

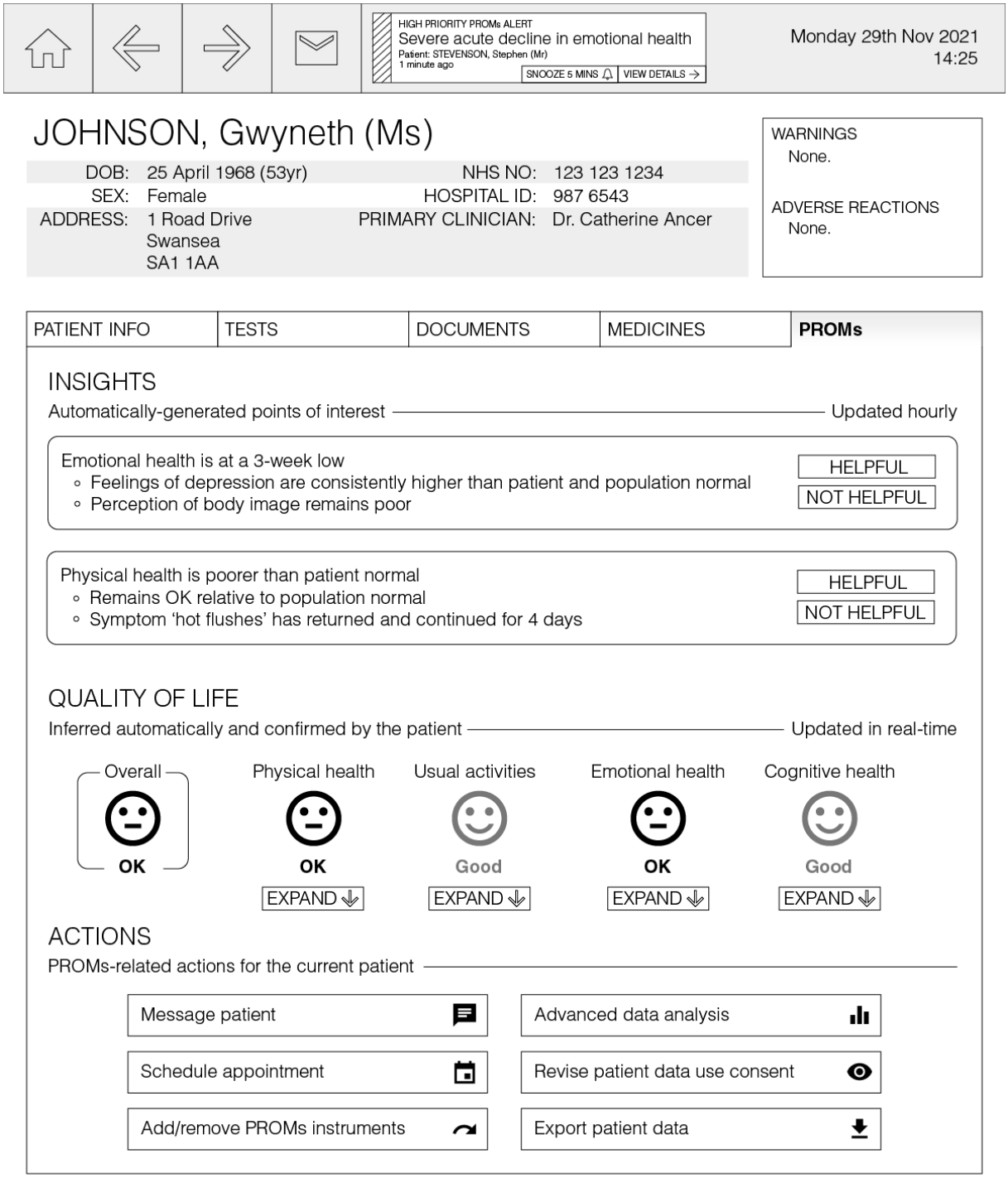

Figure B.3: The patient record displayed in our EHR mock-up, whereby an alert has triggered and is displayed in the navigation bar.

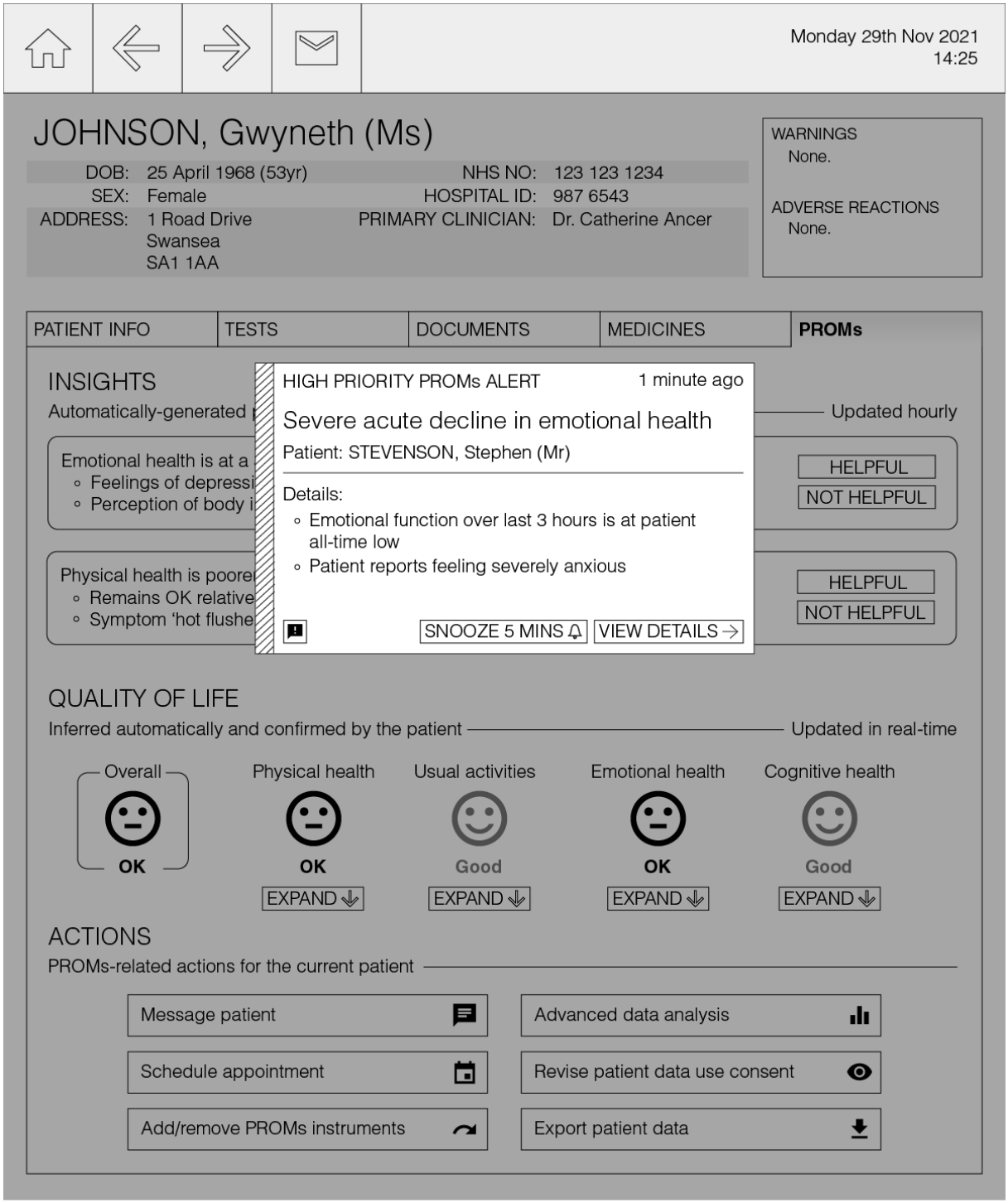

Figure B.4: The alert dialogue box displayed over the EHR, which appears on user interrogation of the alert.