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Healthcare Technology Research Centre

Patient-level PROMs visualisation: a narrative review

A narrative review to inform the PROm VISualisatION (PROVISION) research study

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Date: 23rd May 2023

Version: FINAL

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Cardiff and Vale University Health Board

Canolfan Gwerth mewn Iechyd Cymru
Welsh Value in Health Centre

Abbreviations

CEP	Calgary Comprehensive Epilepsy Program
CKD	Chronic Kidney Disease
CPC	Canadian Problem Checklist
DHCW	Digital Health and Care Wales
EHR	Electronic Health Records
ESASr	Revised Edmonton Symptom Assessment System
HRQoL	Health-related quality of life
ISOQOL	International Society for Quality of Life
NDDI-E	Neurological Disorders Depression Inventory for Epilepsy
PGHD	Patient-generated health data
PREM	Patient Reported Experience Measure
PRO	Patient Reported Outcome
PROVis	Patient Reported Outcome Visualisation
PPEP	PROMS and PREMS Effectiveness Programme
PROM	Patient Reported Outcome Measures
QOLIE-10	Quality of Life in Epilepsy
VAP	Visualisation and analysis platform
WPAI	Work, Productivity and Activity Index
WViHC	Welsh Value in Health Care

Executive summary

Introduction

Patient reported outcome measures (PROMs) are a form of patient-generated health data which measure health from the patient's perspective. PROMs have largely been used at the organisation (meso) and system (macro) level to evaluate treatments and care providers. Extending PROMs to include the patient (micro) level can aid shared decision-making between patients and care-givers and enhance patient care.

Purpose and methods of review

This is a narrative review which focuses on visualisation formats for PROMs. The purpose was to explore the current landscape (with a focus on Wales and the UK) on graphic visualisation formats for PROMs scores for interpretation by patients and clinicians, to help in the design of a research protocol for the PROVISION qualitative study being conducted in Wales.

Narrative review

The available published and unpublished evidence shows that the use of PROMs to guide patient care is not currently routinely embedded within clinical practice in the UK, although examples of good practice exist. Strategies to communicate patient's own PROM data (at the patient-level) have not been widely tested or established.

Current research on PROMs visualisation is limited. Broadly, studies have found that incorporating PROMs into direct clinical practice with patients has many benefits such as promoting patient activation, enhancing patient-clinician relationship, and improved quality of care. Across many clinical specialties there are examples of raw or summarised PROMs data being given as feedback to patients and/or clinicians by using different graphic visualisation formats, but it is not known how interpretable and meaningful these PROMs are by both patients and clinicians. As a result, there is a growing interest from scientists and clinicians to develop patient-facing dashboards to provide a quick, easy and useful method of summarising a patients PROM data.

Studies on PROM data visualisation reveal that bar graphs and line graphs are the preferred approach but with clear axis/bar chart labelling to indicate if the value is of concern. Elements such as score directionality, axis labelling and clinical interpretation for distinguishing symptom severity are important considerations. Evidence suggests that there is not a 'one size fits all' format for visualising PROM data as it is dependent on many factors such as the demographic of patients, clinical condition, and quality of data collected. There remain several challenges with visualising PROMs including interpretation accuracy and both patient and clinician opposition to the use of PROMs.

A focus on Wales

In Wales, PROMs collection has been adopted by all health boards for specific conditions such as cardiac and orthopaedic conditions. PROMs that align to the 38 nationally agreed PROMs sets are collated to enable visualisation for a range of conditions at both patient level within the electronic patient record and at cohort level within dashboards (such as orthopaedics and Lymphoedema).

Work is undergoing to enable PROM visualisation in direct care for patients across a range of clinical specialties. The PROVISION study is likely to help build on this through exploration of patient views on access to and visualisation of patient-level PROMs in three example conditions: heart failure, epilepsy and hip arthroplasty. Results from the study will establish effective ways of presenting PROM data to patients. It is hoped that the results will inform the development and testing of a prototype of PROM visualisation across many more specialties in the near future to improve patient-centred care in Wales and beyond, and to better understand how to support patients to use PROMs as a self-management aid, as well as an effective tool to improve communication between care givers and receivers.

Contents

1 Introduction to PROMs

The collection of patient-generated health data (PGHD) is not new. People have long kept paper logs of data about measures of their health, such as weight, symptoms, blood sugar readings, and medication effects. Patients often bring these paper logs to clinical consultations to assist them in discussing their health status, treatments, and overall care. Technological advances have led to the expansion of PGHD, including wearable technology, giving clinicians and researchers the opportunity to gain a real-life insight into patient health outside of clinical settings.

One form of PGHD are those collected using Patient Reported Outcome Measure (PROMs). These are instruments that measure health from the patient's perspective, including symptoms, functional status, health perceptions and health-related quality of life (HRQoL).

The introduction of PROMs into healthcare settings is not intended to replace the use of existing outcome measures but rather to enhance health outcome measurement by making it more comprehensive, personalised and patient-centred. As such, PROMs data should be viewed as complimentary to conventional clinical measures collected in healthcare systems (e.g. blood tests, functional tests, imaging), and they are increasingly viewed as a key component of patient-centred care (Campbell et al., 2022).

Starting in 2009, NHS England mandated the routine collection of PROMs from all NHS-funded patients undergoing planned hip or knee replacement, varicose vein surgery or groin hernia repair. However, PROMs collection ceased for varicose vein and hernia surgery in 2017 and subsequent progress rolling this out beyond these elective surgical procedures, which were its initial focus, has been limited. The collection of PROMs in some areas of Wales started in 2015 and in 2016 Welsh Government funding helped develop an electronic data collection platform for use in health boards and trusts across multiple pathways of care (Withers et al, 2020).

1.1 How PROMs are used

PROMs were originally developed for use in clinical effectiveness research as a means to incorporate the patient's voice in the assessment of clinical interventions. Gradually, their use has become more common in population health assessments, and there is now increasing momentum internationally for using PROMs in routine clinical practice to support the management of individual patients, as well as informing decisions on an organisational level.

Al Sayah et al (2021) have presented the use of PROMs at 3 levels: micro, meso, macro (Figure 1).

1. **Micro (patient/clinician-level)**
   At this level, PROMs data can inform clinical practice and enhance patient management. Here PROMs data could be used for:

- Screening
- Risk stratification or expectation management
- Prioritisation
- Goal setting
- Monitoring patients' health status over time
- Facilitating communication between patients and health care provider

- Giving patients a voice
- Directly identifying health concerns

An example of micro level PROM use is a patient with type 2 diabetes presenting to a primary care clinic completing the EQ-5D-5L instrument (generic PROM), and indicating that they have moderate levels of pain/discomfort. This response would in turn prompt the healthcare provider to ask the patient about pain/discomfort, and try to uncover the potential causes for it and subsequently provide the necessary clinical management.

2. Meso (organisation-level)

Aggregated PROMs data obtained from a cohort of patients within an organisation, such as a clinic, hospital, or treatment site, can serve as a valuable tool for monitoring health outcomes over time, evaluating the efficacy of health programs, and assessing the effectiveness of healthcare services. At this level, PROMs data can help to identify care gaps and prioritise patients based on their self-reported health status or symptoms, which can subsequently inform service delivery and programming.

One notable example of using PROMs to inform procurement within an NHS Trust was presented by Partridge et al. (2016). The study revealed significant differences in patient outcomes depending on the type of implant utilised for total knee replacement surgery. Consequently, the hospital trust shifted to using a single type of implant, leading to a substantial improvement in patient outcomes.

3. Macro (system-level)

At the macro level, PROMs are aggregated to evaluate the performance of healthcare providers by comparing outcomes across regions. This information supports policymakers in the allocation of resources and emphasises patient-centered, value-based care. An example of this is the NHS England PROMs, where data on hip and knee replacements are widely accessible to both patients and decision-makers. This includes the availability of data on the National Joint Registry website and the NHS Digital website (https://digital.nhs.uk/data-and-information/publications/statistical/patient-reported-outcome-measures-proms), which allow patients to access hospital and surgeon activity and view collated patient outcomes (NHS Digital, 2022). Additionally, since 2014/15, NHS England has utilised a best practice tariff based on PROMs, which provides financial incentives to healthcare providers where their patient outcome scores exceed a specified threshold.

An ongoing initiative in this area is the OECD's Patient-Reported Indicator Surveys (PaRIS) survey which has developed an international PROMs and PREMs survey for use in primary care with people with chronic conditions. Involving 20 countries world wide (including Wales), the study aims to improve the value of healthcare investment (Kendir et al., 2023) and will improve opportunities for national and international comparison.

Despite the multifaceted utility of PROMs, often only collated data are available at a meso and macro level. Consequently, the resources and effort invested in collecting PROM data do not always help inform the individual patient or clinician, and as a result, the full potential of micro-level PROM data are underutilised (Monitor, 2013).

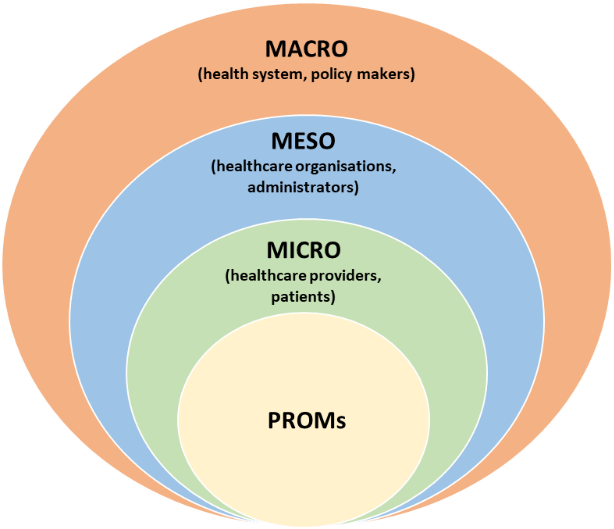

Fig. 1: A multi-level approach for the use of PROMs data (reproduced from Al Sayah et al., 2021).

1.2 PROMs in clinical practice

In the UK, PROMs are one of the cornerstones of NHS reform for the transition towards a patient outcomes-orientated performance model (Gibbons et al., 2021). PROM data can be used to promote patient-centred care and to facilitate patient and clinician understanding of how different treatments affect patient functioning and wellbeing over time. This increased understanding can better inform treatment decision making and, importantly, improve expectation management.

Feeding back patient reported outcome (PRO) data at the level of the individual patient during the consultation provides an opportunity to involve patients in decisions about their care. Understanding a patient's own opinion of their health and their expectations of care can help us provide personalised care, particularly when patient reported outcomes and clinical measures are used in combination (Figure 2).

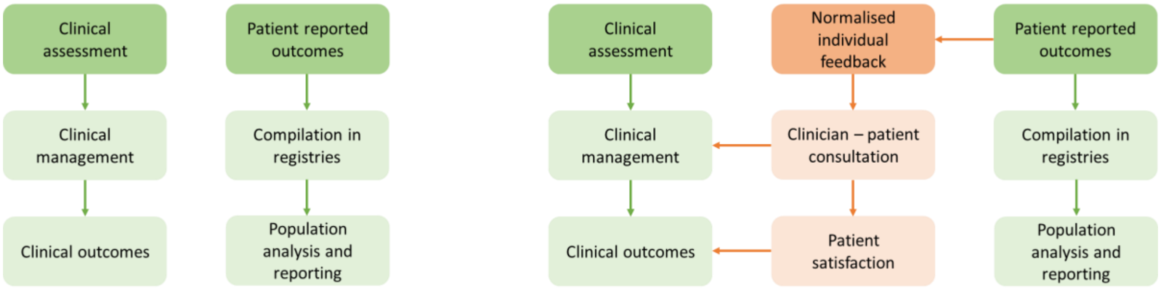

Fig. 2: a) Current usage of patient information data flows; b) Potential usage of patient information data (reproduced from Hamilton et al., 2020)

There are multiple applications of PROM data, including:

1. Using an individual patient's data to inform their care.

2. Providing PROM results from comparative research studies (e.g. clinical trials) in patient educational materials and decision aids to inform patients understanding of the patient-centred outcomes associated with different treatment options.
3. Reporting PROM results from comparative research studies in peer-reviewed publications to inform clinicians of the treatment impacts, both for their own knowledge and for counselling patients.

Evidence is available on the use of PROMs in improving direct patient care, including a recent Cochrane review by Gibbons and colleagues in 2021. This review identified 116 randomised trials up to October 2020, which assessed the effectiveness of PROMs feedback in improving processes or outcomes of care, or both, in a broad range of disciplines including psychiatry, primary care and oncology. A total of 49,785 patients were included across the studies, all of which were from high-income countries. The review found that feeding back PROMs responses to healthcare professionals probably slightly improves quality of life, diagnosis, disease control and communication between patients and their doctors, but probably does not make a lot of difference to social functioning.

A recent systematic review by Campbell and colleagues reported on patient and clinician experiences of using PROMs in clinical practice to inform the management of individual patients. The review identified 52 articles and synthesised evidence indicated that both patients and clinicians reported many advantages of using PROMs in clinic. The review found five key benefits of using PROMs in clinics (Campbell et al., 2022):

1. Promoting active patient involvement in their care by facilitating goal setting, and discussion of sensitive topics
2. Enhancing the focus of consultations by prioritising care around patient needs
3. Improving quality of care by enabling tailored, holistic care and prompting appropriate action
4. Enabling standardised monitoring of outcomes over time to monitor PROM changes and track progress
5. Enhancing the patient-clinician relationship by reassuring patients that clinicians care about them.

A number of limitations were also identified such as the capacity for PROMs to negatively shift the focus of consultations and reduce quality of care by inaccurately estimating symptoms and raising expectations for care that exceed clinicians' resources. In some studies, PROMs were reported to inhibit the patient-clinician relationship, lack clinically meaningful information, and were not considered suitable for all patients.

Regular collection of health data has demonstrated a positive impact on symptom control, overall quality of life and emotional well-being without burdening clinical management. Physicians report that over time the clinical use of PROM information improved their ability to recognise symptoms and health issues and enabled crucial conversation with the patient (Hamilton et al., 2020).

Despite proven benefits for patient-clinician communication and patient satisfaction, there is mixed evidence regarding whether routine assessment of PROMs in clinical practice improves patients' health outcomes (Chen et al., 2013). However, in a study of patients with advanced solid tumours, Basch et al. (2015) found that patients completing regular PROMs reported improvements in health related quality of life, reduced emergency admissions, and improved survival.

1.3 Using PROMs in direct patient care

Al Sayah and colleagues in 2021 set out a roadmap for implementing a PROMs programme (Al Sayah et al., 2021). The International Society for Quality of Life Research (ISOQOL) have also produced guidance on implementing PROMs in clinical practice (Aaronson et al., 2015) together with a 'companion guide' (Chan et al., 2019).

Several limitations have been highlighted in relation to the use of PROMs in clinical practice. Some healthcare professionals have expressed doubts about the clinical utility of PROM feedback, as they consider that little value is added to their clinical judgement (Campbell et al., 2022). Barriers to their use can include patient barriers such as burden / time required, and inability to complete PROMs due to challenges using electronic devices or lack of physical or mental ability. Health professional barriers to their use include lack of time / skill in accessing, interpreting and actioning the PROM data. There can also be service level barriers to PROM use such as lack of integration into existing clinical systems, and insufficient resources to implement PROM collection (Nguyen et al., 2021).

When used in clinical practice at the level of the individual patient level (micro-level), PROM feedback forms part of a complex intervention which can include a number of different components. The fundamental components of a PROM intervention is that patients complete one or more questionnaires and the results are fed back to the clinician, the patient, or both. The ISOQOL research (Aaronson et al., 2015) defined a number of considerations which should be followed when implementing PROMs in clinical practice:

- Establishing the goals
- Identifying patients and settings
- Selecting questionnaires
- Defining the administration and scoring procedures
- Reporting results
- Facilitating score interpretation
- Establishing protocols to address issues raised by the questionnaires
- Assessing the eventual impact of the questionnaire in clinical practice

The success of using PROMs data at the micro level depends on many factors including clinicians' training in using PROMs and their buy-in to support PROMs use, the clinical usefulness of the PROM and the ease and timeliness of collecting and reporting PROMs data. Other factors include integrating PROMs into clinical workflows and electronic health records (EHR), ease of interpreting PROMS data, and guidance to support clinical actions based on PROMs data. Clinicians may also need to be incentivised to draw on data generated by patients and this can only be achieved by developing tools that integrate effectively with existing workflows and that produce data that can be translated into meaningful information that is helpful at the point of care.

2 Aim of review

The purpose of this narrative review is to explore the current research landscape of graphic visualisation formats for PROMs scores for interpretation by patients and clinicians. The review will then help identify the evidence gaps to be addressed in the design of a research protocol for the PROVISION study – a qualitative study into PROMs visualisation for three clinical specialities in Wales.

3 Methods

A literature search was undertaken using a scoping review methodology which is intended to map the literature and provide an overview of evidence, concepts, or studies in a particular field (Pollock et al, 2021). The purpose of the review was to identify all relevant published and potentially unpublished evidence around the visualisation of PROMs in direct patient care. We included a broad scope of evidence including peer-reviewed articles, opinions pieces, editorial letters. In November 2021, a search of published literature was carried out by one researcher by searching both EMBASE and MEDLINE databases using wildcard variations of terms such as ‘PROMs’ OR ‘Patient-reported outcome measure’ combined with (AND) ‘data visualisation’. A thorough analysis of the cited references (“snowballing”) and “cited by” articles. A limited number of peer-reviewed articles were retrieved and therefore we supplemented these using a grey literature search of websites using Google search engine.

4 Review

4.1 PROMs visualisation

Data visualisation refers to a set of tools and approaches to explore, synthesise, display and communicate large amounts of data. Research suggests that the meaning of data is easier to understand when presented visually, which is far more effective than language or numbers alone (Szabo et al., 2019).

4.1.1 Visualisation of PROM data in direct care

The clinician-patient relationship has been an enduring focus of research across many disciplines and has received considerable attention from policy makers internationally. Efforts to increase patient involvement in decision making about their care are proven to improve patient satisfaction, supportive care measures and symptom control (Kontronoulas et al., 2014). Changing the ways in which clinicians and patients communicate with each other, in particular, the practice of patient centred communication is cast as one of the mechanisms through which these outcomes will be realised. The completion of PROMs by patients and the feedback of these data to clinicians is one intervention that has been argued to support communication and, in turn, improve care processes and outcomes (Greenhalgh et al., 2018).

Data visualisation of PROMs is a complex intervention. Components include:

- What PROM instruments will be used?
- How and when will the PROM instrument be administered?

- How will data collection occur?
- What type of data is collected and what level of detail is required?
- What will the data look like and can it be easily summarised?
- Who will see the data once it is collected/collated?
- How can scores be interpreted easily and made clinically relevant?

For the information presented in an online tool or data dashboard to be useful to patients and clinicians, it needs to be easy to interpret, meaningful, and not overburden either the patient or clinician with detail. Pictographic presentation of data is generally well understood and advocated as an effective means of communicating risk (Gutacker et al., 2017). However there remains a paucity of evidence on data visualisation of PROMs for direct patient care. Largely, work on data visualisation focuses on making clinical data more accessible than patient generated data such as PROMs.

There are various ways to present PROM score results as described below:

Numeric presentation

Resources needed:
- Resources to collect and reliably score the PROMs

Advantages:
- Does not require data manipulation
- Relatively easy to integrate into standard workflow
- Can often be presented in the context of normative data ranges

Disadvantages:
- Difficult to interpret as there may be no context for an individual without sophisticated knowledge of the instrument

Graphical presentation

Resources needed:
- Requires manipulation of the data to place them in a graphical context

Advantages:
- Likely easier to interpret than strict numerical presentation
- Allows visual presentation in the context of normative data
- May improve usability by patients and clinicians

Disadvantages:
- More complex presentation requires data manipulation
- Graphical presentation may be more difficult to integrate into standard workflow

A data dashboard of each individual's data would enable a clinician to rapidly understand what is happening with the patient, when it happened, and how long it continued. Visually displaying PROMs data from a panel of patients for whom a clinician is responsible in a manner that integrates and displays several parameters that assess a patient's progress and performance may provide clinicians with an efficient way to identify individuals who need attention. It also allows clinician to identify changes in an individual patients' outcomes over time. A list of potential perceived benefits and barriers and limitations of PROMs for patients/caregivers and clinicians has been collated from the evidence and can be found in table 1.

User	Benefit/barrier	Benefits and barriers to PROMs visualisation
Patients and caregivers	Potential benefits	• Adherence to prescribed treatment • Improve patient satisfaction with their care • Provides reassurance that clinicians care • Higher likelihood of meeting patients' individual needs • Facilitates goal setting • May enable greater patient awareness and help them engage in a process of self-reflection to help identify what is important to them • Facilitates discussion of sensitive topics • Agreement of priorities and expectations of treatment and illness • Facilitate patient-clinician communication, and enhance shared decision making • Allow rapid referral to appropriate specialist care where necessary
	Perceived barriers	• Burdensome for patients to complete • Patients may not understand the advantages of capturing and sharing their data with clinicians • Patients have varying levels of health and technology literacy and so it may not be suitable for all patients • Patients may have concerns about data privacy and security • Provides one piece of the clinical picture • Highlights negative areas to patients which may cause harm
Clinicians	Potential benefits	• Strategy for measuring quality improvement • Impact of prescribed treatment • Standardises measures to monitor disease progression • Helps determine effectiveness and side-effects of treatment • Detection of physical or psychological problems that may otherwise be overlooked • Measuring and benchmarking the performance of health care providers • Assists diagnosis and enables holistic, tailored care • Structures consultations and improves efficiency • Helpful as a screening tool • Allows integration of PROM data with other clinical data
	Perceived barriers	• Requires technical infrastructure, functional workflows and workforce capacity to support PGHD/Data visualisation intake • May be difficult to integrate PROM assessment into a provider's electronic health record • Data may not be specific enough to be clinically meaningful • Requires resources and training to interpret and discuss results with patients • Clinician scepticism about the clinical meaning and relevance of PROMs • Provides one piece of the clinical picture • Clinicians may worry about how PGHD and data visualisation could add to their workloads and disrupt their workflows • Hinders clinician-patient discussion and may inhibit interaction and rapport • The availability of meaningful cut-off points to inform interpretation of results • Clinician preferences for specific measures, including short and easy measures that are most appropriate to clinical practice

Table 1: Summary of potential benefits and perceived barriers of enabling data visualisation of PROM data (adapted from Campbell et al., 2022)

A review by Bantug et al., 2016 reported that the majority of patients and clinicians were able to interpret plain or straightforward graphs and suggested that future research should focus on optimising graphic visualisation strategies (Bantug et al., 2016). After the publication of this review, considerable new evidence has become available. Moreover, the focus of recent studies has shifted towards the effect of aspects such as score directionality (Damman et al., 2019) and axis labelling (Fischer et al., 2020) for correct interpretation by patients and clinicians (Snyder et al., 2019). Furthermore, there is increased attention for guiding the clinical interpretation of PROMs data, e.g. to distinguish severe or clinically relevant symptoms (Albers et al., 2022).

Snyder and colleagues in 2019 conducted a stakeholder-driven, evidence-based, modified-Delphi process to develop recommendations for displaying PRO data in three different applications; one of which was individual patient data for monitoring/management. They found that when presenting individual patient PRO scores there is value in using consistent representation and line graphs are the preferred approach. Their work suggested there should also be reference values for comparison populations if they are available. It was also important to show results that are possibly a concern (i.e. outside normal parameters) in absolute terms, assuming the data to support this are available (Figure 3) (Snyder et al., 2019).

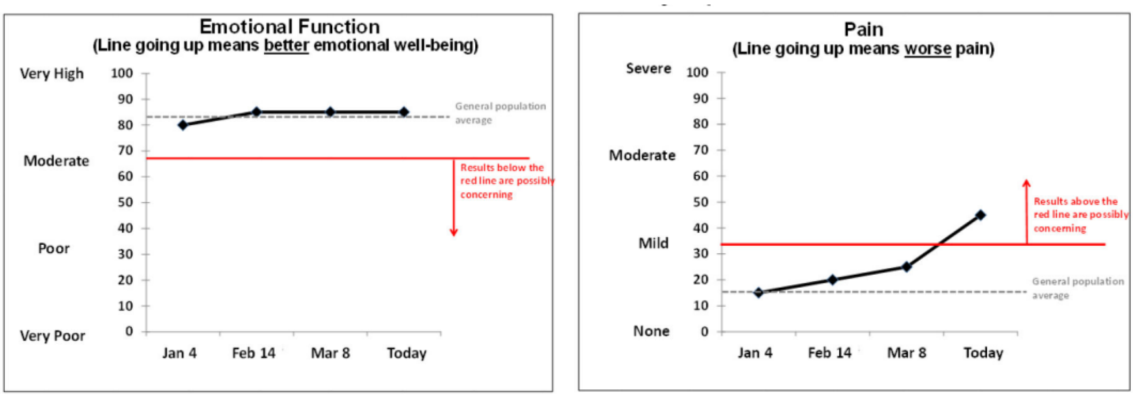

Fig. 3: Graphical illustration of the recommendations for individual patient data line graphs (image credit to Snyder et al., 2019 under the [Creative Commons 4.0 license]() – no changes were made).

In 2020, Stonbraker and colleagues conducted a study looking at longitudinal PROM data visualisation for patients and found that participants preferred bar graphs that incorporated emojis which was also found to be the easiest format for participants to interpret (figures 4). Participants commented that there is not a ‘one size fits all’ format for visualising longitudinal PROM data. These findings are consistent with much of the literature regarding preferred visualisations. Additional design considerations recommended by participants, consistent with the literature, are to use simple images that incorporate large fonts and bright meaningful colours (Stonbraker et al., 2020).

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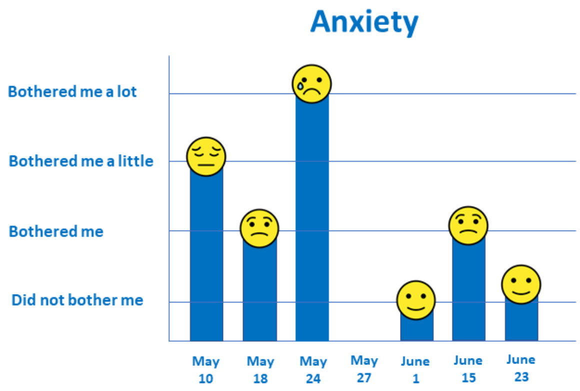


Fig. 4: Bar graph incorporating emojis to help patient data interpretation (adapted from Stonbraker et al., 2020). All emojis designed by OpenMoji – the open-source emoji and icon project. License: CC BY-SA 4.0.

Albers et al., 2022 conducted a systematic review of the latest evidence for graphic visualisation formats of PROMs in clinical practice, and to investigate how clinically relevant PROMs scores are distinguished. The review included 25 studies in different healthcare settings throughout Europe, the US, and Canada, that reported on preferences and interpretation accuracy of patients and clinicians for the visualisation of PROMs scores. Very few graphical visualisation formats for presenting PROMs data could be identified with a limited amount of literature (25 included studies) found.

For individual level PROMs data, patients and clinicians preferred line graphs and bar charts, since they were considered visually clear. Bar charts were most often interpreted correctly by patients, while clinicians had high interpretation accuracy across all graph formats. For presenting group level PROMs data, pie charts and line graphs were preferred: patients most often interpreted line graphs correctly; for proportional data, clinicians most often accurately interpreted pie charts. To guide clinical interpretation by distinguishing clinically relevant scores, PROMs scores were most often compared to patients' previous scores, followed by comparison to mean norm population scores. Here, correct interpretation can be supported by highlighting patients' clinically alarming scores with colours, and by using threshold lines across score bars or lines, or circles around alarming scores. Throughout many of the studies included in Albers et al., 2022, challenges were described that may affect correctly interpreting visualising PROMs data. The challenges and proposed solutions for each are summarised in table 2.

Challenges that may hinder graphic visualisation format interpretation	Possible factors to improve graphic visualisation format interpretation
Patients and clinicians	
Directional inconsistency in longitudinal data (i.e., sometimes higher scores can mean better or worse)	• Make use of standard descriptive labels (consider using ‘better’ instead of ‘normed’ or ‘more’ for describing directionality of scores) • Consistent use of clear ratings: higher scores are always better results (i.e. in some frequently used PROMs, higher score are better when scores describe functioning, but lower score are better when symptom burden is described. This causes interpretation challenges • Indicate with an arrow on the y-axis which direction means the score is better • Describe directionality by plain text that is understandable despite literacy or education level • Provide detailed information on the meaning of high and low score
Interpretation accuracy of what exact PROMs information is represented in the graphic visualisation format	• Provide an instructive aid for patients and clinicians • Use simple iconography for demonstrating single PROMs values • Use brief definitions of different PROMs domains/values • Limit the number of presented symptoms per graphic visualisation format
No ‘one-size-fits-all’ solution	• Make use of a dynamic dashboard, which can display multiple types of visualisation strategies. Thereby, you provide users the ability to select a preferred format instead, including the ability to add or remove dashboard elements such as error bars and shading • Developing a clinic-based video tutorial for the dashboard to explain what is shown on the dashboard and how the patient and clinician can customise the dashboard to their needs
Patients	
Interpretation accuracy of what exact PROMs information is represented in the graphic visualisation format	• Ask patients to prioritise their symptoms, to avoid an overload of information
Timing of providing feedback on PROMs visualisation	• Provide feedback immediately after assessment, and before consultation to significantly improve assessment experience when providing combined graphical and tailored text-based feedback
Patients’ opposition to PROMs use in clinical practice	• Ask permission from the patient to receive their own results and/or the results of the general population

	- Provide information so patients know what PROMs data might show and how their practice might change - Reassure patients that data are trustworthy and are handled confidentially - Visualise as transparently as possible what type of care is delivered
Clinicians Interpretation accuracy of what exact PROMs information is represented in the graphic visualisation format	- Eliminate comparison groups or inform comparison group scores with confidence intervals or error bars, to better counsel the patients about their score (makes it easier to understand) - Link the PROMs outcome scores (scale in the graphic visualisation format) to the meaning of the narrative (i.e.; tell the patient that a higher score on the scale means better functioning)

Table 2: Challenges and factors for improvement to consider when implementing visual individual PROMs feedback in clinical practice (reproduced from Albers et al., 2022. License: CC BY 4.0)

4.2 Real world use of PROMs

The transition of PROMs use from clinical effectiveness research into real-world healthcare setting, with all its variants, imposes numerous practical and methodological challenges on users. For instance, in clinical studies, there are defined time points for data collection and a specified mode of administering PROMs that is often managed by research staff; however, the timing, frequency and completion of PROMs measurements may be challenging to maintain in real-world healthcare settings given various clinical workflows and other contextual factors that vary across settings. Further, in research applications, PROMs data are used at the aggregate level for the whole study sample with a very clear analytical purpose; however, in clinical settings, PROMs data are used both at the individual patient level and at the aggregate level. Perhaps the most important confounder is the patients themselves, many of whom in a real world setting will have multiple co-morbidities and complex medical histories and confounders. While many of the challenges are difficult to address, the practical difficulties could at least partly be managed by standardisation of PROMs measurement, and incorporating the collection of existing measurement frameworks and electronic medical records.

4.3 Case studies: using PROMs visualisation in direct care

Presented below are a few case studies demonstrating the use of PROMs in direct care.

4.3.1 Case study: Bart's digital cardiac pathway

Bart's Heart Centre is the largest cardiac centre in the UK with 3,500 weekly outpatient appointments and diagnostics. Following delays in patient follow-up and a growing post-pandemic cardiac surgery waiting list of 1,400, the centre set up a virtual system which captures biometric data including blood pressure, heart rate and collects PROMs. The system helps facilitate remote monitoring and those showing deterioration can be identified, prioritised, and offered support by message, video consultation, or at an in-clinic consultation. This helped to increase appropriate medication dosage levels from 11% to 88% of patients, follow up times were reduced, and attendance rates increased (NHS England – Transformation Directorate, ND). It has also facilitated earlier discharge from 3-5 days to 1-2 days into a safer and more-responsive aftercare setting. This is the first remote monitoring programme run on this scale in the UK.

4.3.2 Case study: HowsYourHealth

Developed in the USA in 1994 and disseminated on the internet since 1999, ‘HowsYourHealth’ provides an immediate and standard source of information about patient’s function, diagnosis, symptoms, health habits, preventative needs, capacity to self-manage chronic conditions, and their experiences of care. Patients can enter data directly, including generic patient reported outcomes, and it is used by hundreds of practices in the United States and Canada. Patients access their HowsYourHealth data from home or within the doctor’s office. They then have the opportunity to share data with clinical staff, receive information tailored to their needs, and create a personal health plan for tracking and sharing their health status and behaviours (HowsYourHealth.org, 2022). There has recently been a dashboard developed by HowsYourHealth called ‘How’s My Health’ which enable patients to view their health trends over time as shown in figure 5 (Audet et al., 2021).

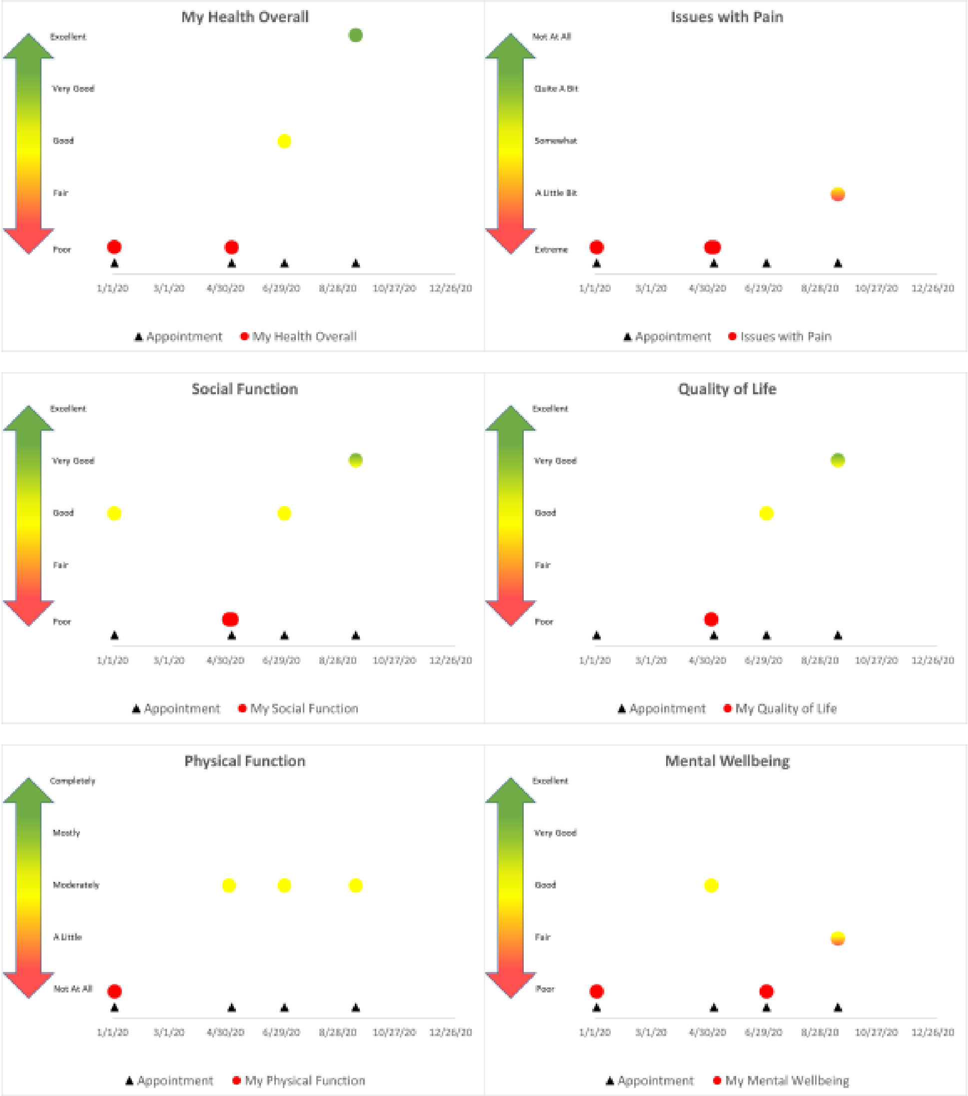


Fig. 5: ‘How’s My Health’ dashboard (taken from Audet et al., 2021)

The dashboard in figure 6 is taken from Audet et al., 2021 which provides a snapshot of the patients most recent health score, goals and a 'health circle'. The health circle shows the patient and their doctor how the patient evaluates their health priorities and what is currently most important to them.

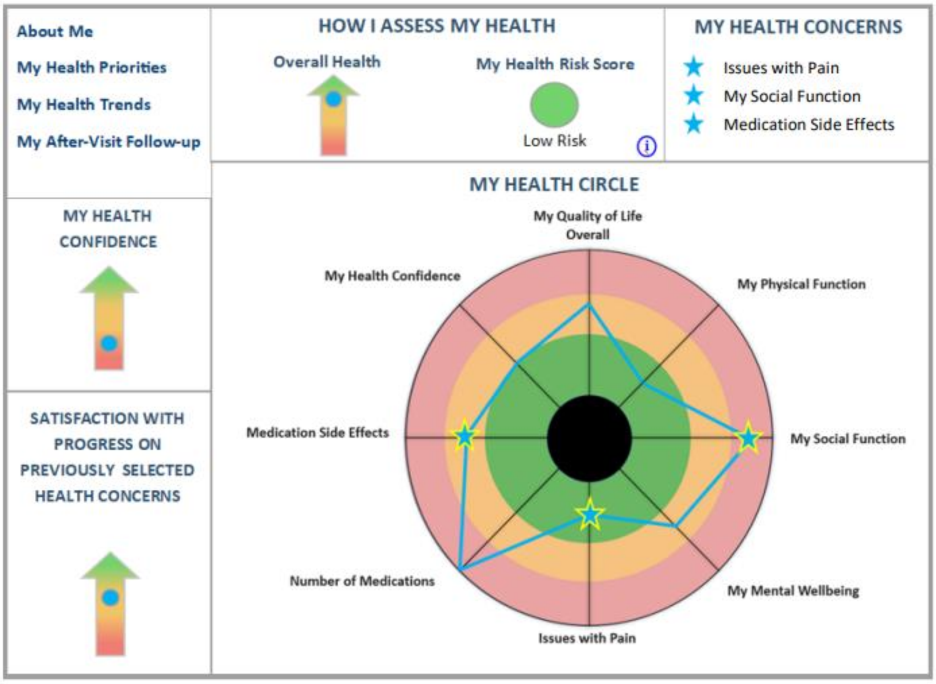
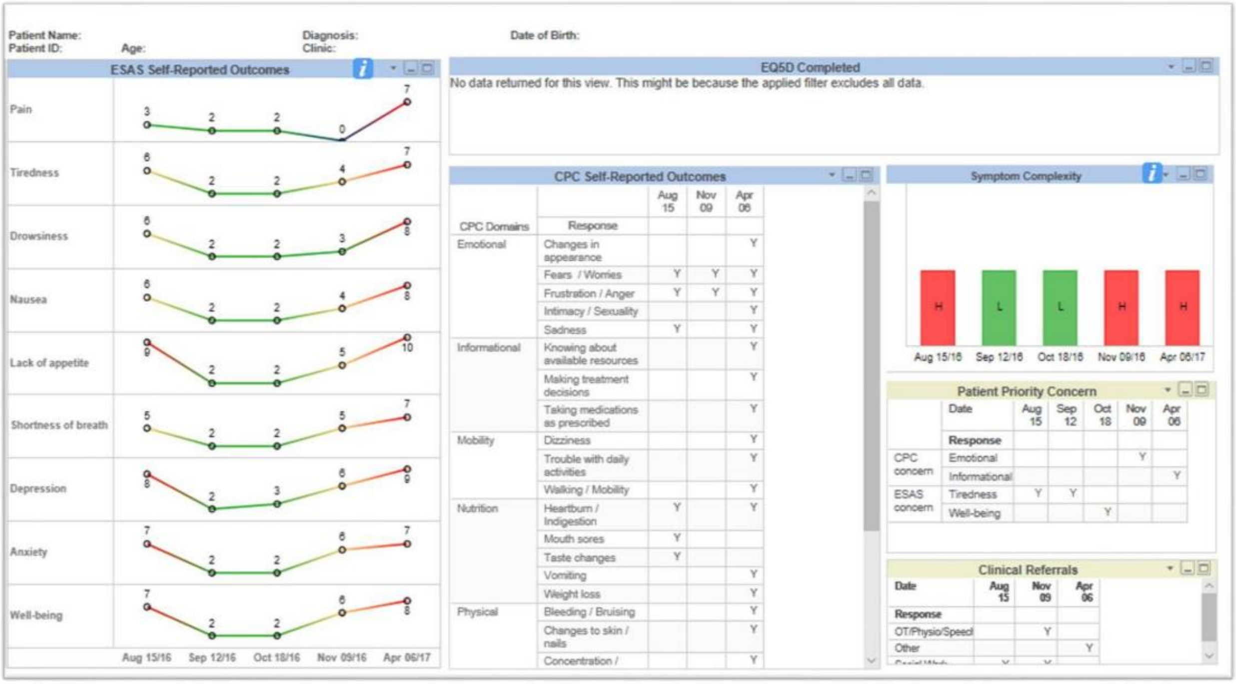


Fig. 6: 'How's My Health' health circle (Audet et al., 2021)

4.3.3 Case study: Cancer Care Alberta

Cancer Care Alberta comprises of 17 cancer facilities across Alberta which support 182,000 people with cancer and over 19,000 newly diagnosed patients every year (Alberta Health Services, 2021). Their patients complete a PROM at each visit which the clinician can access during the clinical encounter and use to evaluate change in PROMs score of a given patient over time. Currently data are collected on paper and then added to the electronic patient record for use on data dashboards, however work is underway to allow direct patient entry prior to their appointment (Watson et al., 2021). This micro level use of PROMs data has been facilitated by extensive training of clinicians, and integrating PROMs collection and reporting into the clinical workflow of oncology clinics.

Cancer Care Alberta started the integration of PROMs in 2012 using the Revised Edmonton Symptom Assessment System (ESASr) and Canadian Problem Checklist (CPC) to assess symptom burden and quality of life. Patients complete PROMs on paper, and the data are entered into the provincial cancer system along with documentation regarding PROM review and clinical response. Once entered, PROMs data flows into a data warehouse where a viewing platform is used to produce several PROM visualisation dashboards and reports. PROMs data are used at the individual patient level, whereby patients scores are displayed on the dashboard trended over time, and the clinician can review and monitor patient's progress and changes in symptoms or overall health from the six most recent PROMs completed and use this in discussion with the patient during the clinical encounter (Figure 7). Clinicians requested visual cues to easily differentiate mild symptoms from moderate or severe, together with a complexity score. In addition to their use in an individual consultation, these cues highlight those patients with greatest need, allowing clinicians to tailor their care. The system also supports high level decision makers in identifying the service needs so that appropriate resources such as dieticians and psychologists can be provided. To date, what has been learnt from the Alberta experience is that once proper training of healthcare providers is done, the use of PROMs data at the micro level is often straightforward (Al Sayah et al., 2020). Further, if PROMs data are collected and reported/presented electronically, the use of PROMs data can be maximised, and more easily applied at multiple levels.



Patient Name:
Patient ID:
Age:
Diagnosis:
Clinic:
Date of Birth:

EQ5D Completed

No data returned for this view. This might be because the applied filter excludes all data.

CPC Self-Reported Outcomes

CPC Domains	Response	Aug 15	Nov 09	Apr 06
Emotional	Changes in appearance			Y
	Fears / Worries	Y	Y	Y
	Frustration / Anger	Y	Y	Y
	Intimacy / Sexuality			Y
	Sadness	Y		Y
Informational	Knowing about available resources			Y
	Making treatment decisions			Y
	Taking medications as prescribed			Y
Mobility	Dizziness			Y
	Trouble with daily activities			Y
	Walking / Mobility			Y
Nutrition	Heartburn / Indigestion	Y		Y
	Mouth sores	Y		
	Taste changes	Y		
	Vomiting			Y
	Weight loss			Y
Physical	Bleeding / Bruising			Y
	Changes to skin / nails			Y
	Concentration /			Y

Patient Priority Concern

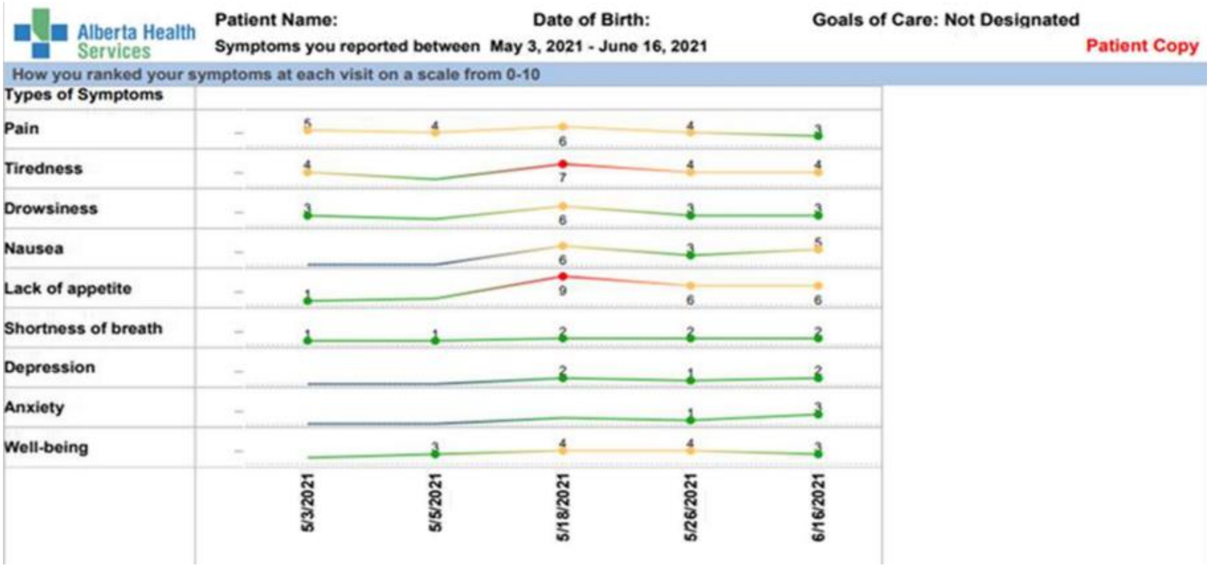
	Date	Aug 15	Sep 12	Oct 18	Nov 09	Apr 06
	Response					
CPC concern	Emotional				Y	
	Informational					Y
ESAS concern	Tiredness	Y	Y			
	Well-being			Y		

Clinical Referrals

Date	**Aug 15**	**Nov 09**	**Apr 06**
Response			
OT/Physio/Speech		Y	
Other			Y

Fig. 7: Trends of individual PROMs dashboard used in Cancer Care Alberta (taken from Watson et al., 2021. License: CC BY 4.0)

A patient-facing version of the dashboard was also created, called the 'Symptom Tracking Report. This version includes only the elements reported by the patient. It is printed out and given to patients upon check in, giving them time to review it independently and bring to their appointment to discuss with their care team (Figures 8a). This routine use of PROMs data has demonstrated benefits including enhancing patient-provider communication, improved self-management and symptom monitoring, an increase in the detection of escalating symptoms and concerns, and improved symptom management opportunities (Al Sayah et al., 2020).



Alberta Health Services

Patient Name: **Date of Birth:** **Goals of Care: Not Designated**

Symptoms you reported between May 3, 2021 - June 16, 2021

Patient Copy

How you ranked your symptoms at each visit on a scale from 0-10

Fig. 8a: Patient-facing Symptom Tracking Report (taken from Watson et al., 2021. License: CC BY 4.0)

4.3.4 Case study: Calgary Epilepsy Program

The Calgary Comprehensive Epilepsy Program (CEP) began the routine collection of EQ-5D-5L in 2016 for clinical and research purposes to supplement existing PROMs collected including both the NDDI-E and QOLIE-10 tools. Patients complete each instrument in advance of their clinic online or in-person at the clinic. Upon completion, data are uploaded to the CEP registry that is stored on a REDCap database on a secure University of Calgary server. The EQ-5D-5L data are then used at the individual patient level, whereby patient's responses at each visit are displayed, and clinicians can assess and monitor changes in these scores alongside all other measurements on a 'one pager' that is appended to the patients' chart at each clinic visit. At the time of publication, 800 patients had completed the EQ-5D-5L at a baseline clinic visit and have found patient engagement with their PROMs enables development of individualised treatment plans to treat the disease beyond just seizures themselves (Al Sayah et al., 2020).

4.3.5 Case study: MySurgery HRQoL

All NHS-funded patients in England aged 15 or over who underwent planned unilateral hip or knee replacement, or groin hernia repair between April 2009 - March 2016 were invited to completed a PROM as part of the NHS PROMs Programme (NHS Digital, 2022). Patients were invited to report their HRQoL using paper-based questionnaires at two time points: at the time of admission or in the preceding outpatient appointment, and then again three months after surgery. Gutacker and colleagues designed an online patient information tool (http://www.aftermysurgery.org.uk/) and an algorithm to utilise the individual level EQ-5D-3L data collected from these returns. The tool was designed to be used by patients in consultation with their primary care physicians in discussions about the likely benefits of surgery. It allows patients to see how 100 patients with the same case mix as themselves felt after their planned surgery to provide an evidence base to support their own decision making.

4.3.6 Case study: Swedish Rheumatology Quality Registry

Established in 1995 and containing data on over 75,000 patients and 500,000 registered visits, the Swedish Rheumatology Quality Registry contains data generated by patients which is fed into a user friendly 'dashboard' and used to support care. It is one of the largest registers collecting data on rheumatoid arthritis and other rheumatic diseases in the world (Guiseppe et al., 2016). A visualisation and analysis platform (VAP) was developed and linked to the registry and visualises data using tabular presentations, cross-sectional and longitudinal comparisons.

Patients have a personal identifier to access the registry, and the system is easy for patients to use and input information. PROMs and clinical data including blood test results can be tracked over time in relation to ongoing treatment. The dashboard displays trends and is used to guide treatment, shared decision making, and self-management (Nelson et al., 2015). Results show the dashboard has helped improve patient engagement and empowerment, increasing their confidence in managing their condition (Hvitfeldt et al., 2009).

4.3.7 Case study: Chronic Kidney Disease (CKD) Dashboard

A collaboration of seven independent Dutch teaching hospitals led to the development of a data dashboard for use in patients with chronic kidney disease (van der Horst et al., 2022). The dashboard was developed to illustrate PROMs, make clinical feedback and treatment goals explicit, and use data visualisation techniques to increase clarity of information during consultations. Professionals and patients agreed on a set of relevant variables (PROMs, clinical measurements and laboratory results) and conditions for data visualisation. Patients reported the potential of the dashboard in increasing condition understanding and motivating treatment goals. Professionals reported that it can support the consultation conversation and decision making, especially by discussing PROMs and changes over time. However, both parties agreed that the dashboard should not overtake the patient-clinician conversation (van der horst et al., 2022).

Overall, the study showed that dashboarding has the potential to enhance the two-way flow of information during consultations, setting the basis for patient activation and shared decision making.

4.3.8 Welsh case study: Using PROMs in cardiology clinics

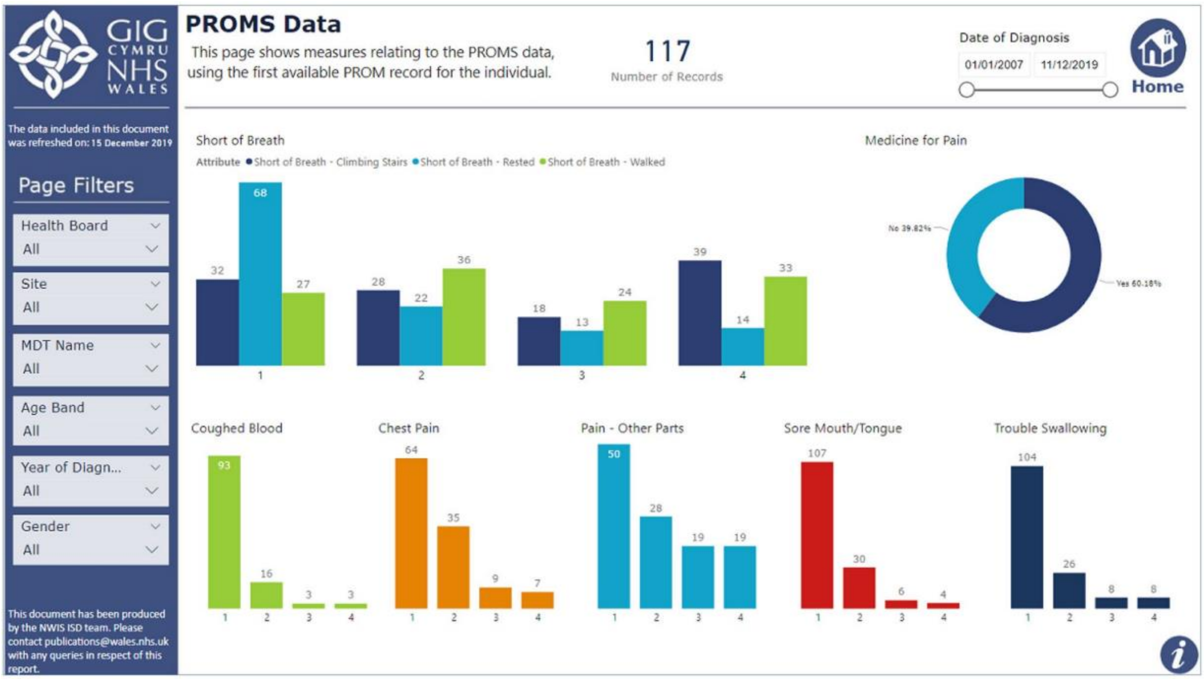
Heart failure clinics in Wales are embracing PROMs questionnaires to collect information prior to in-person consultations. The service introduced PROMs by asking patients to complete a questionnaire before their clinic appointment, either at home before their hospital visit, or using an iPad in clinic waiting rooms before seeing a nurse. In some services, a text reminder message is sent three days before their appointment. The survey consists of approximately 20 questions covering general wellbeing and issues specific to heart failure. This results in an overall score which gives the clinical team an overview of how the patient is doing, as well as details about the areas of concern. This saves time and allows consultations to target what matters most to patients.

4.4 PROMs assessment in Wales

As reported by Withers et al. (2020), PROMs collection has been ongoing at a National level in Wales for a 5-10 years, although the concept for this started much earlier. In order to facilitate standardised collection across Wales, the PROMs, (Patient Reported Outcome Measures) PREMs (Patient Reported Experience Measures) and Effectiveness Programme (PPEP) was initiated, funded by the Efficiency through Technology Programme at Welsh Government to support electronic PROMs capture. The programme aimed to develop an online platform to collect PROMs from all secondary care patients across Wales using a co-ordinated, top-down approach. The 'National Platform' started to collect data in June 2016. Working with all local health boards and trusts in

Wales, and supported by Welsh Government it was decided that the system would collect a generic set of questions, supported, where agreed, by condition-specific tools. The EQ-5D-5L was chosen as an appropriate generic PROM to support between-group/condition comparisons. The work, productivity and activity index (WPAI) was also selected to identify health-related reduction in work productivity. Other 'about you' questions were also chosen to provide information on aspects of life, covering weight, height, exercise levels, alcohol intake and medical comorbidities as shown in figure 9 below.

As this work has been absorbed into the national Welsh Value in Health Centre (WViHC), it has continued to promote the use of PROMs data for shared decision making. PROMs continue to be collected on the National Platform, although no further development of this platform is anticipated, due to a move towards the use of a number of commercial PROMs platforms. The programme has now produced a number of products for visualising information (data dashboards) developed by Digital Health and Care Wales (DHCW) in collaboration with clinical teams. The visuals can be interpreted intuitively to help understand patient reported changes in health in specific clinical areas, in order to improve outcomes for patients. Patient-identifiable PROMs are collected locally, with most data stored in the DHCW data warehouse. There are examples where individual patient responses are also available in the electronic patient record, however not all of the PROMs collected in Wales are stored in the data warehouse, and so not all are available in the dashboards. The current data dashboard similar to that illustrated in figure 9 enables clinical teams to visualise the collated data available for patients (in this case those with Lung Cancer) so that they can easily assess groups of patients at different stages of care and compare variables such as gender, stage of disease, health board and age:



PROMS Data

This page shows measures relating to the PROMS data, using the first available PROM record for the individual.

117 Number of Records

Date of Diagnosis: 01/01/2007 – 11/12/2019

The data included in this document was refreshed on: 15 December 2019

Page Filters

Health Board: All
Site: All
MDT Name: All
Age Band: All
Year of Diagn...: All
Gender: All

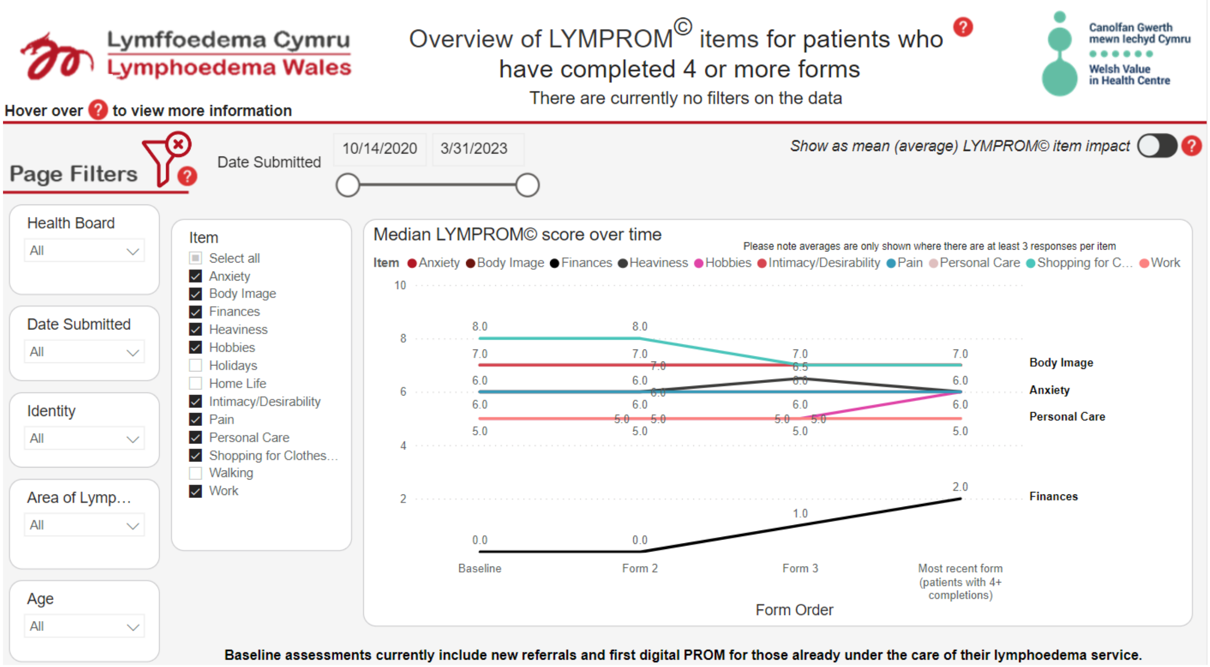
This document has been produced by the NWIS ISD team. Please contact publications@wales.nhs.uk with any queries in respect of this report.

Fig. 9: Screenshot of the NHS Wales PROMs data dashboard (taken from Withers et al., 2021 with permission granted by Digital Health and Care Wales)

LYMPROM is a lymphoedema-specific patient reported outcome measure designed for patients with Lymphoedema (or lipoedema/lipalgia) aged 18 and over in Wales. Initially, Lymphoedema services in

Wales were using a paper-based version of LYMPROM. However, since late 2020, a digitised version of LYMPROM was developed and accessed online using a digital patient platform. This enabled automated sharing of LYMPROM with patients before a planned appointment when a new patient is referred to the Lymphoedema service.

The dashboard provides timely visualisations of LYMPROM data collected digitally as part of the Value-Based Healthcare Initiative. The service is being rolled out across Wales and is not yet available in all seven health boards, but of the four health boards currently collecting LYMPROM data, PROMs can be viewed at the meso and macro level and filtered by health board, gender, area of lymphoedema (arm/hand, breast/chest, genitals, leg/foot etc.), and age. Additionally, LYMPROM asks patients to indicate the level of impact lymphoedema has had on aspects of their life, or 'items', of which there are 13 of. These include home life, finances, body image, and work life – all of which can be filtered for when generating visualisations of the PROM data and provides a population level summary of each item over time (figure 10).



Lymffoedema Cymru
Lymphoedema Wales

Overview of LYMPROM© items for patients who have completed 4 or more forms

There are currently no filters on the data

Canolfan Gwerth mewn Iechyd Cymru
Welsh Value in Health Centre

Hover over ? to view more information

Page Filters

Date Submitted: 10/14/2020 – 3/31/2023

Show as mean (average) LYMPROM© item impact ○

Health Board: All

Date Submitted: All

Identity: All

Area of Lymp…: All

Age: All

Item
- ☐ Select all
- ☑ Anxiety
- ☑ Body Image
- ☑ Finances
- ☑ Heaviness
- ☑ Hobbies
- ☐ Holidays
- ☐ Home Life
- ☑ Intimacy/Desirability
- ☑ Pain
- ☑ Personal Care
- ☑ Shopping for Clothes…
- ☐ Walking
- ☑ Work

Median LYMPROM© score over time

Please note averages are only shown where there are at least 3 responses per item

Baseline assessments currently include new referrals and first digital PROM for those already under the care of their lymphoedema service.

Fig. 10: Median LYMPROM score over time for items of the LYMPROM tool (with permission from the Welsh Value in Health Centre).

Welsh Health Boards have been mandated by Welsh Government to collect PROMs data and the WViHC team aim support this and improve the flexibility of the system so that the Health Boards can use a range of different PROMs suppliers to provide functionality such as text reminders. Data collected on the National Platform, plus other local systems feed into the National Data Warehouse and some data dashboards and other analytical products are available to individual clinicians to help maximise use on a patient-level and population basis. Work is ongoing to develop a National Data Resource which will host all PROMs data collected in Wales. Additionally a Framework is being agreed which will host a number of PROMs platform suppliers who meet a minimum set of interoperability and data standards nationally defined for managing PROMs data. The framework will give flexibility to HBs across Wales allowing them to have a choice in PROMs platforms whist still adhering to a minimum standard of data collection. This will build on our existing experience and grow our ability to use PROMs as an effective communication tool.

Additional current developments within the Welsh Value in Health Centre focus on improving data flow and data visualisation to support shared, informed decision making. PROMs responses available within the patient record will allow clinicians to visualise an individual's PROMs responses over time and highlight where symptoms or problems are improving or worsening using data visualisations such as Red, Amber, Green alerts and up and down arrow systems. These can allow clinicians to easily see how symptoms are responding to treatment to help identify changes in aspects of health. It also provides a clear visual tool to support one-to-one discussions and shared decision making with patients in the clinic environment.

Current PROMs collection varies with most health boards collecting PROMs in specific conditions such as lung cancer and orthopaedics, while wide spread collection of generic PROMs has been implemented in one Health Board. Individual patient responses collected on the National Platform are available in the electronic patient record, and plans are in place to create additional data dashboards and visualisation tools. Patients using the National Platform are currently able to receive a copy of their response following completion, which can be printed. Their responses are automatically saved into their own patient record for clinical use on an individual basis, e.g. during the consultation. This information allows the patient to monitor their own health as a snapshot and over a period of time. As well as allowing clinicians to monitor changes, a data dashboard provides a clear visual tool to support one-to-one discussions and shared decision making with patients in the clinic environment.

Work has been piloted in lung cancer to develop PROM visualisation for daily clinical use in the management of lung cancer, and this is available within the patient electronic record in the Welsh clinical portal. The data view was conceptualised, defined, tested and approved in collaboration with an experienced data scientist and the clinical team collecting the data. The team at DHCW created an operationalised tool to allow clinicians to view patient PROMs as data visualisations. The model that was developed for these lung cancer visualisations is now being used as the basis of development for visualisations in other clinical areas. Visualisation tools are currently available for planned care areas including hip and knee arthroplasty, and chronic conditions such as heart failure with further areas in planning including palliative care. These visualisation tools have been developed and embedded within the Welsh clinical portal with the data refreshed daily. The ability to use PROMs during the clinic appointment is putting patients at the centre of care.

4.5 Current work

4.5.1 PROVis study

The recently published Patient Reported Outcome Visualisation (PROVis) study (Rutjes et al., 2023) aimed to improve the format of PROs by means of visualisation so that they can be more effectively integrated in patient care and clinician workflows. The need for this study arose after observing that patients were often asked to fill out detailed PROs and later would have to answer similar questions from clinicians, who preferred to gather these answers directly from patient interaction. Consequently, patients experience their detailed PRO reporting as a time-wasting activity.

Additionally, existing attempts at improving the format of PROs have not focused on creating a solution that meets the time requirements of clinicians.

To achieve integration in clinician workflows, this study followed a nine-stage “design study” methodology where visualisation researchers directly investigate a real-world problem in a target domain, design a validated visualisation solution for it, and reflect on lessons learned to refine guidelines. The setting for the study was a paediatric rheumatology department in a Dutch hospital. Following observations and semi-structured interviews with clinicians, it was decided that clinicians needed a quick and easily interpretable overview of the progression of PRO results of each patient over time while comparing these results to medication changes (Figure 10).

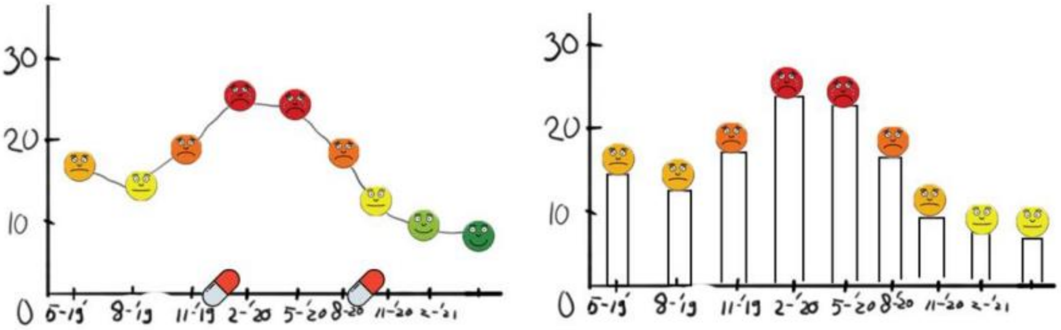


Fig. 10: Low fidelity sketches that illustrate medication changes (left) and medical data (right) with associated PRO scores over a time period (taken from Rutjes et al., 2023)

By comparison, interviews with patients indicated they had a preference for their doctors to show that they understood and remember their PRO data, so that they pose relevant rather than repetitive questions. Based on those observations PROVis was developed as a visualisation system that supports the clinicians in quickly learning the most important PRO data in a narrative summary and allowing for identified attributes to be plotted over time through line graphs and bar charts.

A focus group of four paediatric rheumatologists and a nurse followed by a thematic analysis evaluation demonstrated that PROVis allows clinicians to get a quick grasp of the PRO results as well as an understanding of the chronology of the PRO data. The report suggests that further studies should focus on including comparisons of PRO data with clinician observations.

4.5.2 PROVISION study

The PROm VISualisatION (PROVISION) study is a qualitative study being conducted by Cedar Healthcare Technology Research Centre. PROVISION is a preliminary study with three separate populations being recruited across South Wales. Patients are being recruited by clinical leads from three specialties; heart failure, epilepsy or hip arthroplasty. Through the use of a screening questionnaire the study aims to include a diverse group of patients with different clinical, social and personal demographics with differing health and IT literacy.

Focus groups of 4-8 participants will help answer the study research questions seeking to explore views and perspectives of patients, where the analysis will aim to define key themes and points of consensus or divergence gathered through interaction. Patients will be presented with example data displays and ask to provide their views. Transcripts from the focus groups will be analysed using thematic analysis and the themes will form the basis for recommendations to support the development of a model for visualising PROM data in direct patient care. This model hopes to ensure PROM data are properly utilised by both patient and clinicians by being easily understood and meaningful to patients. A protocol for the PROVISION study is available on the Cedar website here. The study is currently recruiting and due to finish in late 2023, with preliminary analysis available early 2024.

5 Conclusion

The use of PROMs in recent years has undergone a transition from being used primarily in clinical studies, data registries and healthcare policy, to facilitating shared decision making in routine clinical practice. With this, an appetite for optimising the way PROMs are visualised has emerged. This narrative review provides examples on the current landscape of PROM visualisation and provides examples of successful implementation at a local and national level. Bar and line graphs were a commonly preferred method of visualising PROMs but thought must be given to score directionality, axis-labelling and putting the score into perspective against the disease population. There is therefore not a one size fits all format when visualising PROMs and there are several methodological challenges that users need to consider if we are to move to a time where every patients’ PROMs data are able to be presented to them in an accessible and meaningful way. Ongoing projects such as the PROVISION study should build on this knowledge to help reach the long term goal of promoting patient-centered care by optimising accurate and meaningful interpretation of PROM data.

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