

Summary

A Healthier Wales, the Welsh Government’s Plan for Health and Social Care, sets out the need for services to transform so they can meet the challenges of the future and help deliver the best results. It indicates that the NHS needs to find new, flexible and smarter ways of providing services that make the best of existing resources. In particular health and care services should deliver better outcomes which matter to people. By talking to people about what they want, and what a treatment might or might not be able to achieve, health care becomes more personalised, and people feel more involved in decisions about their own care.

In most healthcare systems clinical data is routinely collected, however patients have limited opportunities to provide information on their own perception of outcomes, symptoms, priorities and experiences.

Patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) can be used to address this issue.

PROMs

Patient Reported Outcome Measures (PROMs) are questionnaires that have been designed and tested with patients and clinicians for either specific diseases or for your general health and quality of life. They look for changes in people’s health pre and post treatment and/or over time to understand changes in people’s quality of life.

An example of the EQ5D 5L general health/quality of life questionnaire.

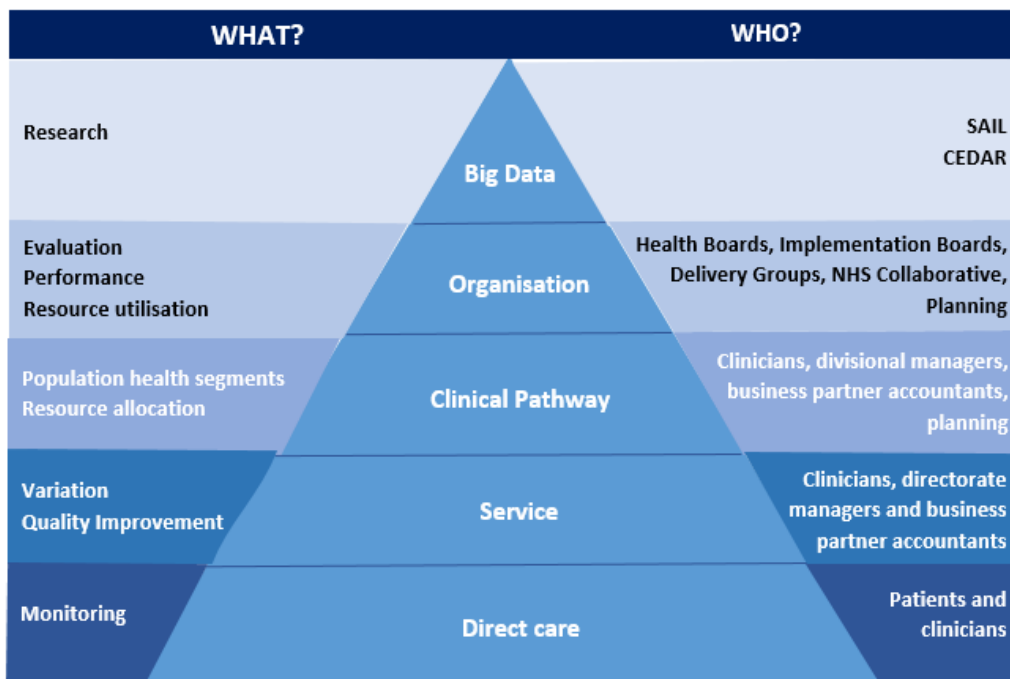
PROMs questions are usually multiple choice, with most questionnaires having a scoring system which converts answers into a single score. Each PROM may have a different number of questions, and scoring system, with answers to different questions being weighted according to their importance. Where available, combined scores act as a summary of the answers given in the questionnaire, making analyses more manageable. General health/quality of life PROMs are not specific to any condition in particular and therefore the scores of patients with different conditions can be compared. For



example, patients receiving treatment for hip arthritis and heart failure can be compared. This makes generic PROMs popular amongst decision makers to compare costs and outcomes for different treatment. However, condition-specific PROMs can only be used to compare between other hip patients or other heart failure patients. The detail provided in responses to condition-specific PROMs make them particularly useful to clinicians in order to understand their patients’ problems and therefore could become more useful for personalising care. (Palmer et al. 2020, translated by Palmer 2020)

PROMs use in healthcare

Outcomes are the important milestones in the lives of patients that matter to them and so we should measure this, to assess and meet their needs, to understand their experience of care and to improve services.



Triangulating PROMs with cost and audit data can help inform system wide effectiveness and quality improvement transformation.

The Value-Based health care strategy places the utility of PROMs at the heart of its vision.

“We seek to improve the health outcomes that matter most to the people in Wales.”
 “We will support this by asking people about their outcomes and creating a data-driven system which seeks to provide the timely information to citizens, clinical teams and organisations to inform the decision-making that leads to those outcomes in a way that is financially sustainable.”

PROMs collection

The focus for PROMs collection has previously been to support specific research studies or by clinicians when reviewing effectiveness of treatment for individual practice. Therefore, wide scale, consistent and standard collection across a nation, for use in direct care, is a fairly new concept.

However, the National PROMs Programme and more recently the NHS Wales Value-Based Health Care Programme, is looking to facilitate the consistent collection of PROMS around Wales by:

- Supporting the development of a bilingual electronic platform within the Wales NHS digital architecture, capable of collecting PROMs for a wide range of conditions with automated collection trigger points. (The national PROMs platform)
- Supporting the data flow of PROMs collected from different platforms across Wales to the national data resource.
- Facilitating national agreement on which PROMs are to be used within each condition through clinical reference groups.
- Helping to gain permission/licences and provide welsh translation, electronic conversion and validation of the chosen PROMs.
- Supporting health boards with implementation advice regarding embedding PROMs collection into direct care processes.

Clinical reference groups are available for each national clinical priority, bringing together healthcare professionals representatives and third sector patient advocates to advise and coordinate clinical engagement for PROMs and subsequent product roll out and maintenance. These groups are responsible for defining the purpose of collection and how the data is to be used. This is important as this will determine which questionnaires are chosen, the collection method and the focus for what analysis is required in the future.

To date 32 condition pathways have been nationally agreed by clinical reference groups and all pathways are currently available on the national PROMs platform. (See Figure 1)

Collection rates are notably higher when collection is embedded as part of the patients' normal care journey and is not seen as an extra step or separate process. Process mapping the patient journey is essential to identify the best touch points for collection.

PROMs use direct care

One of the most important uses of patient-reported outcomes should be to enhance the communication between a patient and healthcare professional. This can:

- Provide a defined structure to a consultation.
- Allows patients to consider what matters to them most before the consultation, prioritize and rank issues and also consider issues they may not have previously identified as relevant
- Facilitate the broaching of more difficult or sensitive issues
- Enhance the two way exchange of knowledge, expectations and goals, therefore assisting joint decision making and overall improvement of patient experience.
- Help manage patient expectations and the likely outcomes over time.
- Provide a tool to assist with more flexible ways to deliver individual care, i.e. remote monitoring/ virtual clinics assessments.

The VBHC strategy aims to operationalise a data driven system to allow the information collected to be used more efficiently and therefore more effectively, particularly for direct care.

It is important that information can flow and be used within NHS Wales therefore essentially allowing patients to be able to write back to their own electronic patient record. PROMs completed on the national PROMs platform are available timely within the electronic Welsh patient record (WCP) and the aim is that this would be extended to PROMs collected via any platform in the near future as a precursor of the National Data resource work (NDR).

The patient record will display the PROMs in document format and patient level visual tools are being developed for easier access and use of this data in a busy clinic environment. This will provide a clear trajectory of symptoms over time, which can help clinicians identify ongoing issues, needs, goals and next steps, while managing expectations. Tracking PROMs longitudinally will have a different meaning and purpose within each condition and the graphics will therefore be specific to each condition.

PROMs use for quality and improvement

Value-Based Health Care encourages the focus on meeting the needs, goals and preferences of patients through involving them in decision making while being able to support this decision making with the best evidence to hand. Therefore, supporting implementation and development of outcome measurement, costing measurement and analysis across Wales is key.

This work involves combining PROMs with clinical outcome (such as audit) and costing data and bringing this to life in dashboards for use across

PROMS Efficiency Framework

Wales. These dashboards will be made available to health boards and clinical teams to support direct care, quality improvement and service planning. The dashboards and the subsequent insights and analysis resulting from this combined data will assist with:

- Identifying low value practices and assist with reallocating resource into high value interventions
- Identifying areas of good practice and reducing unwarranted variation in care
- Assessing population needs and understanding whether those needs are met
- Further helping to support patient and clinician decisions using outcome data of local patients with similar conditions, comorbidities and lifestyle.
- Allowing clinical teams, to be stewards of resources by influencing high value care for the populations for which they are caring

Early analysis using PROM and audit data carried out within the VBHC team illustrates the value of using aggregated PROMs data and combing this with audit and other case mix data to assist with direct care, service planning and quality improvements discussions.

- **Figure 1** illustrates the effects of lifestyle choices (BMI) on health before and after treatment.
- **Figure 2** looks at responses to the individual oxford knee score questions and helps to identify expected outcomes within each domain which in turn will help manage expectations. For example, patients in this cohort tend to still have severe problems in kneeling down after surgery.
- **Figure 3** is an illustration that combines PROMs and prosthesis data and compares the average performance of prosthesis in knee replacement surgery. Similar analysis could be used for different clinic, clinicians, hospitals or health boards. This can help decision makers to improve services by helping us understand the overall outcome and quality of care that patients receive and can help clinicians to decide on choice of treatment.
- **Figure 4** is an illustration of assessment of longitudinal health gain following surgery and could help to provide evidence in support of remote monitoring for certain cohorts of patients

However, it is important that statistical analysis is carried out by those with the expertise to do, so that erroneous conclusions are avoided. There are many limitations to think about, such as:

- Dealing with missing data (either missing questionnaires or missing individual answers within a questionnaire)

PROMS Efficiency Framework

- Aligning each PROM correctly to the different stages on the individual patient pathway
- Removing bias by using case-mix adjustment and correcting for any confounders
- Dealing with the unavoidable 'subjectiveness' of PROMs by ensuring that there are enough numbers
- Considering, where possible, minimal clinically important differences etc. from the literature in order to determine whether any comparisons/differences are clinically significant
- Performing statistical tests to determine whether any comparisons/differences are statistically significant

All of these considerations can only be addressed with large collection numbers and it is important that PROMs are not used in isolation but triangulated with other clinical and costing data. This will help ensure that visual representations and analysis is meaningful to those requiring to use it.

Appendix

Fig 1 – Pathways available on National Platform

Sub-specialty	Pathway	Tools
Generic	PROM - Generic (Adults)	EQ5D, WPAI, 'About you'
	PREM	
Hip	Arthroplasty	Oxford hip score
	Non-Arthroplasty	IHOT12
Knee	Arthroplasty	Oxford Knee Score
	Non-Arthroplasty	KOOS
	ACL	IKDC + KOOS + Tegner activity Scale
	Osteotomy	KOOS + Oxford Knee Score + Oxford Knee Score APQ
	Patellofemoral conditions	Kujala
Foot and ankle	Arthroplasty	Manchester-Oxford Foot score
	Non-Arthroplasty	Manchester - Oxford Foot score
Shoulder	Arthroplasty	Oxford Shoulder Score
	Non-Arthroplasty	Oxford Shoulder Score
	Instability	Oxford Shoulder Instability Score
Elbow	Arthroplasty	Oxford Elbow Score
	Non-Arthroplasty	Oxford Elbow Score
Hand	Hand Arthritis -	Arthroplasty PEM + Brief Michigan
	Hand Arthritis Non-Arthroplasty	PEM + Brief Michigan
	Hand - Dupuytrens	PEM +URAM
	Hand – General (incl: non-wrist trauma)	PEM +Quick Dash
	Hand - Carpal Tunnel	PEM + Boston CTQ
	Wrist – Rheumatoid	PEM + PRWHE +Brief Michigan
	Wrist – General Conditions	PEM + PRWHE
	Trauma (Wrist /Carpal injury)	PEM + PRWHE
ENT	Tonsillectomy	T-14
	Rhinosinusitis	SNOT22
Ophthalmology	Cataract	CatQuest9 *switched to CatPROM5
Cancer	Lung Cancer	QLQ C13+ EORTC QLQ C30
	Neuro Endocrine Tumours (NETs)	GI NET 21 + Bristol stool chart
	Prostate Cancer	EPIC 26
Dermatology	General Dermatology (rashes)	Dermatology Life Quality Index DLQI
Cardiac	Heart Failure	(KCCQ-12) Kansas City Cardiomyopathy Questionnaire-Short Version + PROMS Physical Function- Short Form 4a + (PHQ-2) Patient Health Questionnaire

Fig 2 - ???

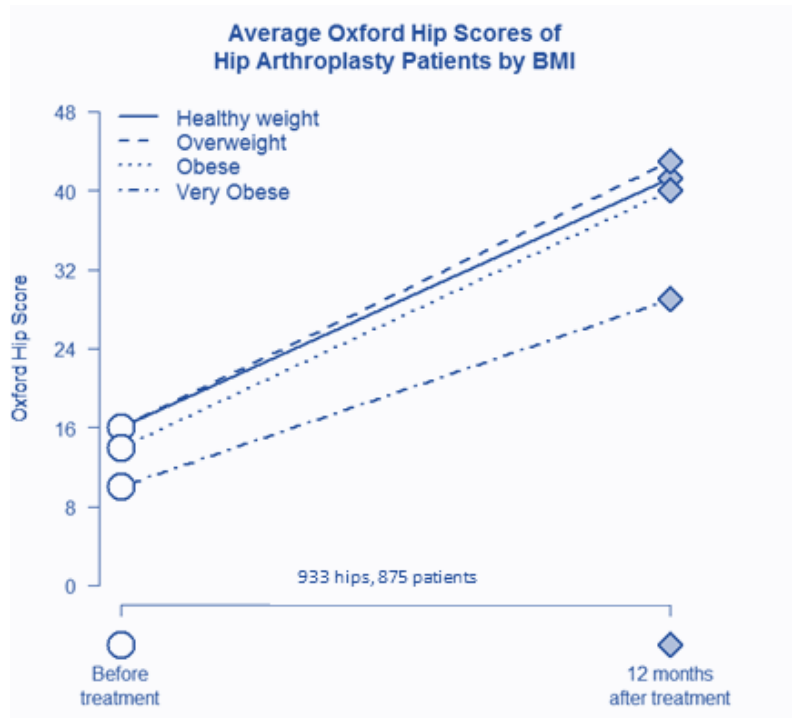
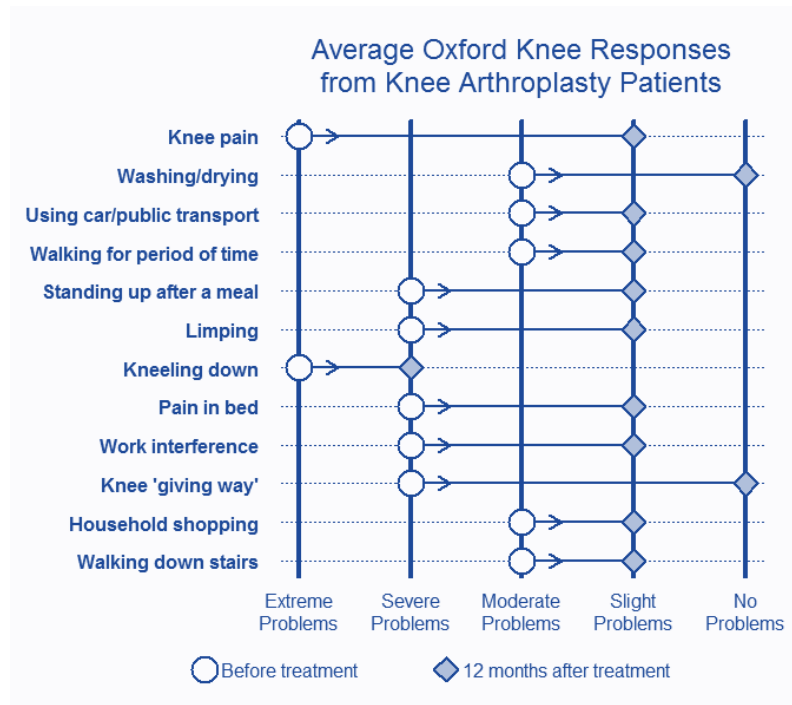


Fig 3 - ???



1007 knees, 939 patients

Fig 4 - ???

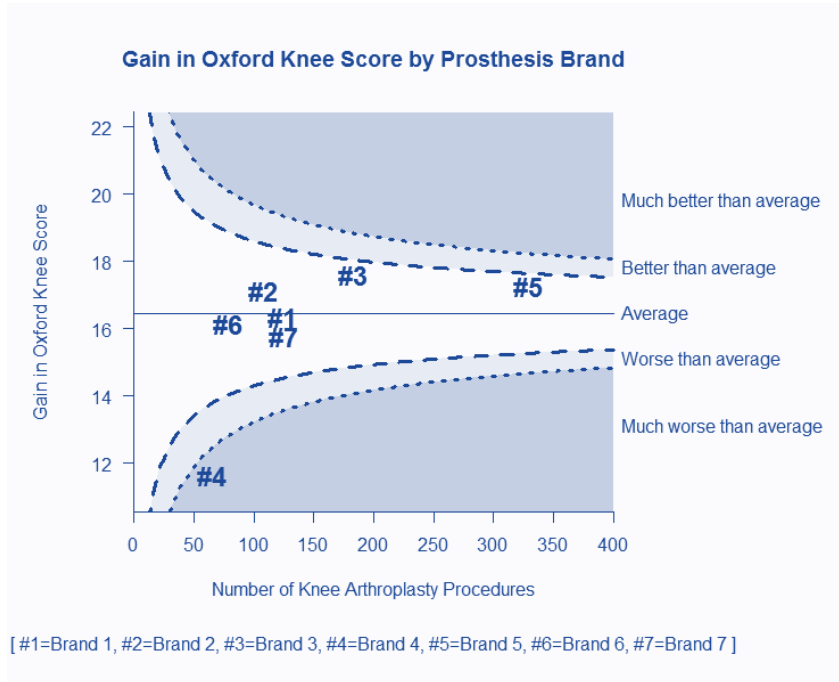


Fig 5 - Longitudinal gain for Oxford Hip scores

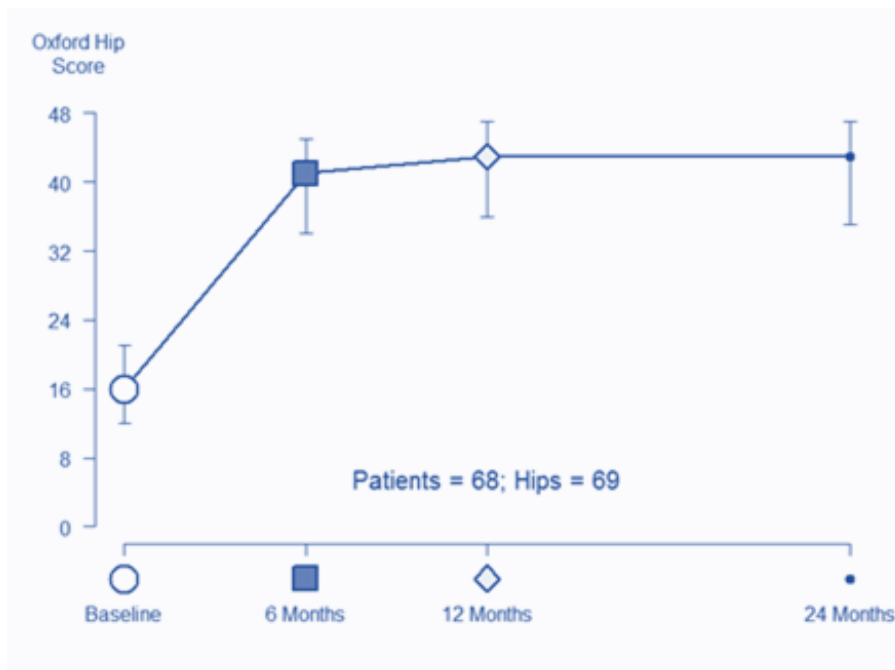
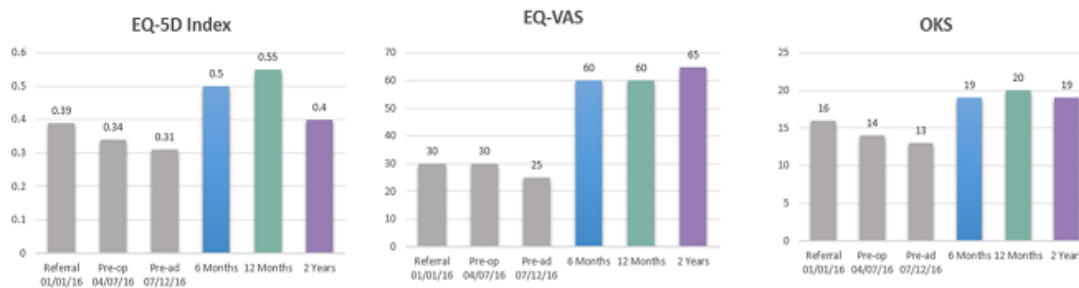


Fig 6 - Example of Knee Arthroplasty patient level graphic



Did you experience any of the following problems after your operation?

- Allergy or reaction - No
- Wound problems - No
- Bleeding - No
- Urinary Problems - yes

Have you been readmitted to hospital since the operation?

Yes/No/not answered

How would you describe the results of your operation?



Fig 7 - Example of Lung Cancer patient level graphic

Overall Quality of Life		Clinic Dates			
Score	16/05/2018	13/06/2018	08/08/2018	05/02/2019	
Global Health Status (QL2)	17	42	17	25	
Functional Status - Generic (QLQ-C30)					
Score	16/05/2018	13/06/2018	08/08/2018	05/02/2019	
Physical Functioning (PF2)	47	27	27	13	
Role Functioning (RF2)	0	33	17	0	
Emotional Functioning (EF)	67	67	75	50	
Cognitive Functioning (CF)	83	100	83	83	
Social Functioning (SF)	50	83	33	0	
Symptom Status - Generic (QLQ-C30)					
Score	16/05/2018	13/06/2018	08/08/2018	05/02/2019	
Fatigue (FA)	56	33	56	67	
Nausea & Vomiting (NV)	17	0	33	17	
Pain (PA)	100	67	67	100	
Dyspnoea (DY)	100	33	67	67	
Insomnia (SL)	33	67	33	33	
Appetite Loss (AP)	100	0	0	33	
Constipation (CO)	0	0	67	100	
Diarrhoea (DI)	0	0	0	0	
Financial Difficulties (FI)	0	0	33	67	

References

Robert Ieuan Palmer, Kathleen Withers, Amanda Willacott and Grace Carolan-Rees, 'Gwella gwasanaethau gofal iechyd â chymorth cleifion: Casglu PROMs a PREMs ledled Cymru', *Gwerddon*, 30, March 2020, 40–67. Accessed: <http://www.gwerddon.cymru/en/editions/issue30/article3/>

<http://www.gwerddon.cymru/en/editions/issue30/article3/> - Rob Palmers Welsh Publication on PROMS

[Link to Page on Dashboards](#)

[Link to examples of process map](#)

[Link to PROMS selection checklist](#)

[Link to TOR for clinical reference groups](#)