



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Abertawe Bro Morgannwg
University Health Board



Meeting Date	7th June 2018		Agenda Item	5c
Report Title	Patient Reported Outcome Measures (PROM) Up-date			
Report Author	Kerry Broadhead, Head of Strategy & Value Dr Sue Morgan, PROMs Clinical Lead			
Report Sponsor	Hamish Laing, Executive Medical Director			
Presented by	Hamish Laing, Executive Medical Director			
Freedom of Information	Open			
Purpose of the Report	This paper summarises the National PROMs context, the good local progress made and challenges being overcome to take PROMs data collection and usage forward in the Health Board.			
Key Issues	<p>Issues relating to; Delivering excellent patient outcomes, experience and access and; Demonstrating value and sustainability</p> <ul style="list-style-type: none"> • Routine PROMs collection is central to delivering value based health care • ABMU has started to make progress in collecting PROMs data and make plans to expand this • A PROMs platform, centralised storage and analysis facility would greatly improve collection & usage of data • Central funding for Health Board PROMs Clinical Leads ceased in May 2018, an internal solution is being developed • Welsh Government have re-prioritised the future PROMs collection areas of the National PROMs & PREMs Platform to the National Value Based Healthcare priority areas 			
Specific Action Required <i>(please ✓ one only)</i>	Information	Discussion	Assurance	Approval
		✓		
Recommendations	<p>Members are asked to:</p> <ul style="list-style-type: none"> • Note the progress made to date • Consider the key challenges identified • Endorse the planned actions 			

PROMS UP-DATE

1. INTRODUCTION

This paper summarises the National PROMs context, the good local progress made and challenges being overcome to effectively take PROMs data collection and usage forward in the Health Board.

It is intended for discussion regarding progress and the proposed actions for taking the work forward.

2. BACKGROUND

2.1 Value Based Healthcare

Value Based Healthcare (VBHc) approaches optimise patient outcomes through service improvement, based on the collection and analysis of clinical and patient reported outcomes linked with cost data. ABMU are working to embed these approaches into health board plans and work streams, including identifying clinical variation to support our Delivery Units in tackling this where it is inappropriate. The strategic intent is for ABMU to become a VBHc organisation prioritising optimisation of health outcomes for our patients and communities.

Welsh Government has recognised our progress and ambition and recently awarded ABMU additional funding to add to our capacity. This includes resource for clinical leadership, which will be hugely beneficial in supporting the health board take forward increased collection and use of PROMs data.

2.2 PROMs collection in ABMU

The total activity around PROMs in ABMU has not to date been well described. We know clinical teams are contributing data to national registries (e.g. Orthopaedics, Dietetics, Renal and Speech and Language); or collecting their own data which are felt to be clinically important (e.g. Podiatry, Paediatric OT).

Clinicians are using either nationally/internationally recognised and validated tools or locally developed tools. Locally developed tools are less likely to be robust for standardisation and validation. The data being collected independently by clinicians typically are stored on individual computers and their analysis is dependent upon skills of individual staff. The fact that our clinicians are doing this demonstrates the importance they place on this data and the potential they see in its use.

ABMU is in discussion with Welsh Government about the procurement of a platform to enable us to increase the scale of PROMs collection across the Health Board.

2.2. NHS Wales & ICHOM

The International Consortium for Health Outcomes Measurement (ICHOM) aims to support transformation of health care systems through measuring and reporting patient outcomes globally in a standardised way. PROMs are a part of the data collected through the ICHOM approach. ICHOM have developed over 25 standardised outcome data sets which are freely available on their website www.ichom.org

In March 2017, NHS Wales formed a Strategic Alliance with ICHOM for the roll out of outcomes data collection across all Welsh Health Boards in three internationally validated outcome data sets; *Lung Cancer, Cataracts and Heart Failure*.

Staff in ABMU are also involved in several other areas of work with ICHOM outside of the Strategic Alliance these include; contributing to the development of a data set for Overall Adult Health and proposals to lead on the development of an Asthma data

More recently we have been selected to participate in an International ICHOM & All.Can Outcomes Study in Breast Cancer due to launch in June 2018.

NHS Wales is actively supporting Health Board adoption of VBHC approaches through a range of national initiatives including the recent appointment of a National VBHC Clinical Lead. In addition Public Health Wales, the Medical Directors and individual clinicians are developing Atlases of Variation for Wales, starting with “heart disease”. Swansea University is partnering with ICHOM and other European undergraduate Health schools to develop undergraduate value-based curricula.

2.3 National PREMS, PROMS and Effectiveness Programme

Welsh Government funded a National PROMs, PREMs and Effectiveness Programme (National Programme) rapidly to deploy an all Wales solution for capturing and analysing patient reported outcomes. The aspiration being to create an effective interface with existing technology being used in all the Health Boards across Wales. This included development of a system for results to be shared back with patients and clinicians.

The solutions in development include both *in-clinic* and *at-home* data capture approaches. The PROMs tools currently available for use by clinical teams via the national programme can be seen at Appendix 1.

Some of the advantages to the Health Board of the National Programme include management of licence arrangements and associated costs, a centrally coordinated IT infrastructure for linking clinical systems with the PREMs and PROMs data collection (supported by NWIS), and use of standardised tools across Wales to facilitate benchmarking and shared learning opportunities.

Recently Welsh Government have reviewed and amended funding and priorities for the National Programme to align with the national value based healthcare priorities; lung cancer, cataracts and heart failure. As such ABMU has been in discussion with

Welsh Government about the procurement of a platform to enable us to increase the scale of PROMs collection across the Health Board.

2.4 ABMU Progress with the National programme

The National Programme is currently working with Morriston Hospital to support *In-Clinic* collection of paediatric tonsillectomy PROMs data and Lung Cancer (as part of the ICHOM data set).

To date, (March 15th 2018) 71 patients have completed the PROMs questionnaires, through the National Programme. These are for Tonsillectomy (40) and Lung Assessment (21). Plans are in place to initiate further PROMs collection with the National Platform for;

- Lung Cancer (extending to Singleton & Neath port Talbot Hospitals)
- Cataracts
- Heart Failure

Learning from PROMs collection via the National Programme includes;

- *The Collection at home* solution generates letters to ask the patient to go on-line to complete a PROM questionnaire which can be viewed by the clinician. The patient needs a unique email address and a computer or tablet at home which for some patients isn't possible. Additionally it is not always technically possible or timely in more urgent cases to generate a letter e.g. lung cancer and therefore we have needed to consider *in-clinic* alternatives.
- *The Collection in clinic* sees one of the clinic team ask the patient to complete the questionnaire, either on paper or a laptop/iPAD. Where on paper this raises administration capacity issues and if iPads are available in clinic, security issues to be addressed. Additionally for patients with limited eye sight, dexterity or IT skills someone needs to read the questions and help submit the answers. Volunteers have been tested with some success in this role.
- Consideration of timing of collection is also key for example the Lung Cancer PROM takes approximately 15-20 minutes to complete and therefore unsuitable to be done in the diagnosis consultation.

The learning from these early implementation projects is helping to inform considerations for future projects ensuring that collection is both convenient for patients whilst not adversely impacting patient flow or staff capacity.

2.3 Clinical Leadership

The National Programme provided funding in 2016/7 to each Health Board of one session per week for a PROMs Clinical Lead. The role provided leadership and

guidance both to the national programme and the health board for the National Programme.

Due to recent changes to the National Programme, funding for this role is no longer available. See section 3. ABMU is currently preparing the redesign of our Value work stream in light of our success in securing additional Welsh Government Funding. This includes funding for clinical leadership which is focused on collecting and using clinical and patient reported outcome data to inform patient care and service improvement.

2.5 Key Issues we are addressing

- 1] Understanding all the PROMs activity being undertaken across the Health Board and creating access to a platform to support collection, centralised storage, clinical data view and aggregated analysis of PROMs data outwith the National Programme.
- 2] Identifying solutions to support patient participation to complete PROMs where clinical sessions do not allow e.g. working with the ABMU volunteer programme
- 3] Joining forces with Aneurin Bevan Health Board to understand tools and capability requirements to start to link PROMs, clinical outcomes and cost data to provide meaningful insights for clinical teams
- 4] Identifying how we can support teams with mapping complex pathways to facilitate identification of appropriate PROMs collection triggers
- 5] Identifying solutions to facilitate data submitted to PROMs national registries to also be retained within the Health Board, through “do once” data entry for two or more platforms.

2.6 Key Actions being taken forward

- 1] Exploration of options with Welsh Government for the procurement of a platform solution for internal health board use. In the interim work will take place to develop a PROMs data repository for the Health Board – promotion of this will hopefully also help to identify clinicians independently collecting PROMs data
- 2] Discussions with the ABMU Volunteer Manager regarding volunteer support for PROMs collection with patients. We have trialled this in lung cancer the learning from which is informing on-going discussions
- 3] ABMU and Aneurin Bevan will be working together to scope feasibility of linking PROMs, clinical outcome and cost data using QlikSense.
- 4] Scoping of the cataracts pathway and feasibility for the collection of pre and post-operative PROMs data.

3. GOVERNANCE AND RISK ISSUES

Clinical leadership - due to funding changes with the National Programme the Health Board PROMs Clinical Lead sessions have been stood down as of May 2018.

Mitigation

- Additional funding secured from Welsh Government will include clinical leadership for Value Based Healthcare

National Programme Limitations – will reduce support for development of new PROMs collection areas.

Mitigation

- Procurement of a platform solution for ABMU.

Learning – absence of an internal mechanism to facilitate data storage and access reduces clinical engagement in PROMs collection and/or opportunities to learn from the data that is collected

Mitigation

- Creation of a central PROMs warehouse will promote PROMs collection and facilitate access to the data

4. FINANCIAL IMPLICATIONS

It is intended to secure national resource to procure the PROMs platform solution however should this be unsuccessful the cost of this would become financial implication of the proposed actions.

5. RECOMMENDATION

Members are asked to:

- **Note** the progress made to date
- **Consider** the key challenges identified
- **Endorse** the planned actions

Governance and Assurance							
Link to corporate objectives (please ✓)	Promoting and enabling healthier communities		Delivering excellent patient outcomes, experience and access		Demonstrating value and sustainability		Securing a fully engaged skilled workforce
			✓		✓		
Link to Health and Care Standards (please ✓)	Staying Healthy	Safe Care	Effective Care	Dignified Care	Timely Care	Individual Care	Staff and Resources
			✓	✓		✓	
Quality, Safety and Patient Experience							
Collection of PROMs data needs to be actively encouraged and facilitated by the Health Board as a vehicle for improving quality of care and patient experience.							
Financial Implications							
There are no financial implications in the proposed actions.							
Future funding arrangements for Health Board PROMs clinical leadership should be considered as part of discussions for the development of PROMs within the Health Board going forward.							
Legal Implications (including equality and diversity assessment)							
Patient confidentiality is incorporated into the National Programme data collection programme along with Caldicott and data sharing consent arrangements. Any local collection of patient PROMs data is subject to existing patient data requirements.							
Staffing Implications							
Lack of dedicated Health Board clinical leader for PROMs to shape and inform PROMs development within the Health Board and act as a clinical point of contact for colleagues. Collection of PROMs within clinic settings may be hampered by staff capacity to support patients with questionnaire completion. Informatics, Finance and Analytical capacity is required if we are to successfully link PROMs data							

Informatics capacity is required to both establish and maintain a PROMs repository																												
Long Term Implications (including the impact of the Well-being of Future Generations (Wales) Act 2015)																												
VBHc & PROMs collection support both the Long Term and Involvement ways of working within the Well-being of Future Generations (Wales) Act 2015																												
Report History	No previous report has been submitted. This report has not been received at any other forum.																											
Appendices	<p><u>Appendix 1: Tools currently available through the National Programme</u></p> <p>For a PREMs or PROMs tool to be included on the National Programme it must</p> <ul style="list-style-type: none"> • be nationally recognised and validated. • a consistent tool that is agreed across Wales through the disease specific network • not be a stand-alone entity when using condition specific tools, but as an additional measure used to complement the generic questionnaire. • be able to identify patients (pathways) through existing items. <p>Table 1: National PREMs & PROMs Programme Tools currently available</p> <table border="1"> <thead> <tr> <th>Specialty</th><th>Tool</th></tr> </thead> <tbody> <tr> <td>Hip</td><td>Oxford Hip Score</td></tr> <tr> <td rowspan="3">Knee</td><td>Oxford Knee Score</td></tr> <tr> <td>KOOS non-arthroplasty</td></tr> <tr> <td>IKDC (ACL)</td></tr> <tr> <td>Elbow</td><td>Oxford Elbow Score</td></tr> <tr> <td rowspan="2">Shoulder</td><td>Oxford Shoulder Score</td></tr> <tr> <td>Oxford Shoulder Instability Score</td></tr> <tr> <td>Foot/Ankle</td><td>Oxford Foot/Ankle Score</td></tr> <tr> <td rowspan="3">Hand</td><td>PEM (Patient Evaluation Measure)</td></tr> <tr> <td>PRWE (Patient Rated Wrist Evaluation)</td></tr> <tr> <td>Boston Carpal Tunnel Questionnaire</td></tr> <tr> <td rowspan="2">ENT</td><td>T-14 (Tonsillectomy)</td></tr> <tr> <td>SNOT22</td></tr> <tr> <td>Ophthalmology</td><td>CATQUEST 9SF (Cataract)</td></tr> <tr> <td rowspan="2">Lung Cancer (pilot)</td><td>EORTC QLQ C30</td></tr> <tr> <td>QLQ C13</td></tr> </tbody> </table>	Specialty	Tool	Hip	Oxford Hip Score	Knee	Oxford Knee Score	KOOS non-arthroplasty	IKDC (ACL)	Elbow	Oxford Elbow Score	Shoulder	Oxford Shoulder Score	Oxford Shoulder Instability Score	Foot/Ankle	Oxford Foot/Ankle Score	Hand	PEM (Patient Evaluation Measure)	PRWE (Patient Rated Wrist Evaluation)	Boston Carpal Tunnel Questionnaire	ENT	T-14 (Tonsillectomy)	SNOT22	Ophthalmology	CATQUEST 9SF (Cataract)	Lung Cancer (pilot)	EORTC QLQ C30	QLQ C13
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Appendix 2: Overview of Health Board engagement in National Programme

Health Board	Site	System Used	Forms Used
Betsi Cadwaladr UHB	Ysbyty Gwynedd	In-Clinic	Hip Knee Generic
	Ysbyty Glan Clwyd	In-Clinic	Hip Knee Generic
	Ysbyty Maelor	In-Clinic	Hip Knee Generic
	Central	At-home	All orthopaedic pathway General Surgery/ Colorectal
Aneurin Bevan UHB	Nevill Hall	In-Clinic	Hip Knee Generic
	Royal Gwent	In-Clinic	Hip Knee Generic
Cardiff and Vale University Health Board	Across Whole UHB	At Home	Generic Shoulder
	ALAS Mobile Hand new patients	In-clinic	Generic
	Haematology	In-clinic	Generic
Hywel Dda UHB	Bronglais General Hospital	In-Clinic	Hip Knee Generic
	Withybush General Hospital	In-Clinic	Hip Knee Generic Lung Cancer
	Glangwili General Hospital	In-Clinic	Hip Knee Generic
Abertawe Bro Morgannwg UHB	Morriston Hospital	In-Clinic	Tonsillectomy Lung Cancer
Cwm Taf UHB	Across Whole UHB	At Home	All hip and knees pathway
Velindre		In-Clinic	Urology (using generic)
Powys			Within UAT environment with Cataracts

