



# Collecting patient outcomes

Case study

Aneurin Bevan University Health Board  
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# Synopsis and key learning points

This case study provides information on the approach and framework used by Aneurin Bevan University Health Board to begin the collection of patient-reported outcomes. This will be incorporated into a value-based approach to services across the Health Board's portfolio.

## Key learning points

- Clinical engagement has been secured by focusing first on patient and care outcomes, followed by clinical pathway redesign. Only then, will service costs be included to complete the value-based approach.
- Using an established framework of outcomes enabled the Health Board to focus their resources on systems and methods of collection across a range of services.
- Access to clinical time within services has been a challenge, and so a multi-disciplinary central resource to support clinical teams was essential in driving this work forward.
- Systems for collecting patient outcomes need to be aligned to the way people access services.
- Although time and resources were initially invested in an in-house solution, it proved too complex to scale this up across all services. However, the learning proved extremely valuable in the effective procurement of a commercial system.

# Introduction

Aneurin Bevan University Local Health Board (ABUHB) covers the areas of Blaenau Gwent, Caerphilly, Monmouthshire, Newport, Torfaen and South Powys, encompassing a population of 700,000, around a fifth of the Welsh population.

ABUHB provides a range of acute, community and mental health services, delivered by 14,000 staff and a budget of £1.2 billion.

## Why a value-based health care approach?

In 2015, the Minister for Health and Social Services for Wales endorsed the Prudent Healthcare principles proposed by the independent Bevan Commission, following a year of vigorous discussion and debate.

The Bevan Commission's four key principles were:

- achieve health and wellbeing with the public, patients, and professionals as equal partners through co-production
- care for those with the greatest health need first, making the most effective use of all skills and resources
- do only what is needed, no more, no less; and do no harm
- reduce inappropriate variation using evidence-based practices consistently and transparently.

The key principles, however, were not reinforced by any specific methodology that health providers could adopt to achieve these outcomes.

ABUHB believed that research on value-based healthcare, undertaken by Michael Porter at Harvard Business School, could provide a structure upon which to deliver the Prudent Healthcare principles.

Porter's Value-Based Health Care Delivery is a framework for restructuring health care systems, with the overarching goal being value for patients; with value being determined by the outcomes reported by patients.

A partnership was therefore formed between ABUHB and the International Consortium for Health Outcomes Measurement (ICHOM), a non-profit organisation, which is working to develop a standardised approach to measuring and reporting patient outcomes across a range of conditions.

Key to the ICHOM approach is that the outcomes measured are designed to be those that matter most to patients; hence this framework supports the value-based healthcare approach.

## Setting up a value-based approach at Aneurin Bevan

The use of a value-based approach was driven by a joint clinical and finance partnership between the health board's medical director, assistant medical director, and finance director. All were supporters of the value-based health care (VBHC) model, believing it offered an opportunity to address ABUHB's cost and outcome targets.

A steering group was set up, with director level membership, and the Quality & Patient Safety Committee as programme sponsor. A Value-Based Programme Board was established with a dedicated senior programme manager, as well as clinical, information, and finance representation.

Programme board members were chosen not only because of their enthusiasm for moving to a way of working that valued the patient view on the value of service delivery, but also for their skills in facilitating change in those services which were receptive to developing an outcome-focused approach. The board members are a hands-on central VBHC resource, working with individual clinical service leaders and their teams to design and implement a tailored process to collect patient-reported outcome measures (PROMS), aligned to the ICHOM framework. This core VBHC team then provide practical support for implementation, such as design of collection proformas and IT solutions.

The critical dimension of the ABUHB value-based approach is that:

- outcome collection must be the priority, as that determines the impact of the care on the patient, and so needs to shape service delivery
- only then, can the focus move on to costing that model of service.

The patient- and care-focused approach helps to engage clinicians, especially those who like to use clinical data. In fact, rather than having to proactively sell the benefits of their work, the VBHC team report that that clinical teams are now approaching them, because they can see the benefit of using PROMs to improve care of their patients.

With finance being the secondary stage of the VBHC approach, this alleviates the fear that the approach is only about cost cutting. Only when outcome data collection is in place, and the results understood, do the VBHC team then work with the service on costing and service redesign. In fact, the VBHC team report that many of the clinical teams are then very enthusiastic about combining cost and outcomes to inform them about the best value way to deliver services.

Once this approach of collecting outcomes and combining with cost data is embedded as business as usual, the VBHC team withdraw to support a different service.

Work on the design and collection of data are now underway in the following services:

- Parkinson's Neurology and Parkinson's Care of the Elderly
- Dementia
- Gastroenterology
- Heart Failure
- Psoriasis
- Breast Services
- Pulmonary Rehabilitation/COPD
- Cataracts

The next two sections include a practical example of ABUHB's experience in applying this approach within the Parkinson's Neurology services, as well as an assessment of the key learning gained through collecting outcome data across a range of other services.

# Collecting outcomes – a practical example from the Parkinson's Neurology service

## The task

ICHOM have already developed an outcome framework set for Parkinson's' disease, so the challenge for the VBHC and the clinical teams was to put in place processes to collect ICHOM outcomes, and then use this data to identify the potential for service redesign.

## The process of designing outcome collection

- A process mapping exercise within two Parkinson's neurology outpatient clinics was done to define the patient pathway from both the user and the clinical perspective, and identify where outcome data could be captured.
- Data mapping and gap analysis against the ICHOM standard set showed which outcome measures were already collected, and where there were gaps. These were predominantly the patient-reported outcome measures.
- An in-house electronic tool to capture PROMS data was developed, which was specifically designed for people within this patient group.
- During the pilot process, the functionality and ease of use of the PROMS collection tool was reviewed and revised, with improvements implemented.
- As an additional benefit, the process mapping also provided information on where administrative clinic processes could be improved.

## How the outcome data is collected

- On arrival at the outpatient clinic, the patient and carer are met by a healthcare worker, whose role has been specifically funded to support the collection of PROMS. The patient is supported to answer a series of questions about their physical and mental health, as well about their abilities to undertake daily activities.
- The questions help the patient, and their carer, supported by the healthcare worker where applicable, prepare their thoughts ahead of their appointment with the consultant or other clinician.
- This information data is entered on a tablet via the in-house developed form, which interfaces with the clinical informatics system.

These are two examples of the questions patients are asked on arrival at the Parkinson's' neurology clinic

Mr.	Mr.	Mr.	Mr.	Mr.
Clinic Code: Clinic Date:				
Have you had difficulty getting around in public places?				
<input type="radio"/> Never <input type="radio"/> Occasionally <input type="radio"/> Sometimes <input type="radio"/> Often <input type="radio"/> Always or cannot do at all				

Mr.	Mr.	Mr.	Mr.	Mr.
Clinic Code: Clinic Date:				
Have you been told by a doctor that you have any of the following? Please tick all that apply.				
<input type="checkbox"/> - Heart disease <input type="checkbox"/> - High blood pressure <input type="checkbox"/> - Leg pain when walking due to poor circulation <input type="checkbox"/> - Lung disease <input type="checkbox"/> - Diabetes <input type="checkbox"/> - Kidney disease <input type="checkbox"/> - Liver disease <input type="checkbox"/> - Problems caused by stroke <input type="checkbox"/> - Disease of the nervous system (for example Multiple sclerosis) <input type="checkbox"/> - Cancer (within the last 5 years) <input type="checkbox"/> - Arthritis <input type="checkbox"/> - Depression <input type="checkbox"/> - Not Applicable				

Clinicians see a range of information on their screen, including a summary of questionnaire responses, and responses to the individual questions.

Mr.	Mr.	Mr.	Mr.	Mr.
Clinic: NLNEURSW Date: 18/10/2017				
<b>ICHOM Questionnaire Summary</b> Age patient diagnosed with Parkinson's: 53 Age of Onset Of Motor Symptoms: 52 History of impulse control disorders? <input type="radio"/> Yes <input checked="" type="radio"/> No Patient Category: <input type="radio"/> New <input type="radio"/> Maintenance <input checked="" type="radio"/> Complex <input type="radio"/> Palliative Main Carer: daughter not at home Driving Status: no Education level: Secondary Marital status: Divorced/separated Living status: I live alone Depression before diagnosis: No Anxiety before diagnosis: No Sleep disorder before diag: No Comorbidities: Leg pain when walking due to poor circulation Domain: Biggest Concerns Breakdown Non Motor Functioning: Sleep problems Answer Breakdown Motor Functioning: Eating tasks, Dressing, Hobbies, Turning in bed, Tremor, Balance and walking, Freezing, Speech Answer Breakdown Health Related Quality Of Life: Ability to work, Problems with getting around, Problems with dressing, Feeling embarrassment Answer Breakdown Cognitive And Psychiatric: Answer Breakdown Current Treatment: Stalevo 200mgs 1 five times a day Comments: Medication change to stalevo Referral Comments: POUK, Physiotherapy, OT Date Referral Sent: 2017-10-18 Back to menu				

Mr.	Mr.	Mr.	Mr.	Mr.
Clinic: NLNEURSW Date: 18/10/2017				
<b>Cognitive And Psychiatric Questions</b> Over the past week have you had problems remembering things, following conversations, paying attention, thinking clearly, or finding your way around the house or in town? <input checked="" type="radio"/> No cognitive impairment. <input type="radio"/> Impairment appreciated by the patient or caregiver with no concrete interference with the patients ability to carry out normal activities and social interactions. <input type="radio"/> Clinically evident cognitive dysfunction, but only minimal interference with the patients ability to carry out normal activities and social interactions. <input type="radio"/> Cognitive deficits interfere with but do not preclude the patients ability to carry out normal activities and social interactions. <input type="radio"/> Cognitive dysfunction precludes the patients ability to carry out normal activities and social interactions. Back to menu Next Nadex: User:				

## How the outcome data is being used

- Information collected on the tablet from the patient each time they attend the clinic is available to the consultant or specialist nurse at each appointment for that individual. This enables the clinician to focus on the current key problems and concerns.
- Essential pieces of information, such as medication and allergies, are available for viewing in a standard format.
- All data collected over the first 18 months of this project has been analysed to better enable the service to understand the needs of their patient cohort. In particular, there has been a focus on the proportions of new, maintenance or complex patients, and also on the range of comorbidities.

## The anticipated potential benefits of longer term use of ICHOM outcome measures

- More efficient clinic operations, with support staff using an established framework to collect patient data. Not only does this enable patients and clinicians to prioritise what they wish to discuss in the consultation, but it also helps promote shared decision making.
- Collection of outcome measures on a regular basis from people at home, which can enable remote monitoring, and hence clinic attendance only when required, rather than on a set schedule.
- Regrouping of clinics according to patients' category (new, maintenance, complex), enabling a better focus on the specific needs of each group.
- Establishment of full day multi-specialist clinic, with relevant services for specific groups, rather than scheduling sequential visits for patients.

*Patient feedback has indicated that overall the patients are enthusiastic about the implementation of the PROMs which allows the patients to have more input into the decisions made about their care and feel that the consultation becomes more direct and focused on their needs*



## Current status of this project

This was a pilot project that is now fully operational, with PROMS being collected at all ABUHB sites where Parkinson's neurology clinics are held.

The outcome data, as well as the process mapping results, are being used to inform a revised patient pathway. This is currently being reviewed by the clinical team managing this service.

Learning from the development of the in-house outcome collection tools is being used to inform the health-board wide introduction of the DrDoctor system. This will facilitate the larger scale implementation of outcome measure collection for all services from 2018 onwards.

In accordance with the ethos of ABUHB's value-based healthcare system, the costing of the revised patient pathway for Parkinson's neurology is the final stage of this approach and will commence once the revised patient pathway has clinical support.

*Patients said answering the questions on the tablet helped them to identify areas that they may not have associated with the condition or had forgotten to bring up in previous appointments*

## Taking on board the learning from this programme

Although ABUHB was convinced by the evidence of the benefits of collecting patient-focused outcomes, and has been supported through the partnership with ICHOM, in reality they did not know if the practicalities of the data collection would make this ambition feasible.

Pages 6-9 above provide some detail on just one of the projects the VBHC team has led over the last two years, but across those projects some common themes have emerged:

- Although the team has dedicated resource to do this work, the greatest barrier has been access to clinical time within the services. As the VBHC team includes clinical, managerial, and financial skills, they have been able to work in a way that maximises the clinical input from the service team.
- Although the in-house approach to outcome collection was very effective in the Parkinson's neurology service, it has proved to be very difficult to scale up across a broader range of services. Hence, this was the only in-house solution across all the VBHC workstreams. Wider integration of ABUHB systems with the commercial system, DrDoctor is a very large task which is estimated to take a further 6 months.
- Developing the inhouse e-collection system did, however, teach the team much about the functionality needed to scale this approach up across a large organisation, and across multiple clinical services and sites. Although the commercial product is now being procured, the learning from the in-house approach has been essential in effectively identifying the requirements for such a system. The team now builds their own e-forms to link into the commercial software.
- Collecting outcome data from patients works best when it is synchronised with the way patients normally access the service, especially for the remote collection of outcome questionnaires. The team found that when people are reassured that this is directly connected to their care, higher response rates are achieved.
- Whatever the approach chosen for the collection and presentation of outcome data, it is essential that there is integration with clinical systems, and easy access for clinicians to review information; ideally a single sign on for both clinical and outcome information.
- Interoperability with other platforms is key, but this does take time to get in place.
- Access to business intelligence and data analytical capability is essential, especially at the stage of using outcome and costing data alongside each other.
- It is important to avoid overburdening with 'too much measurement'. It is better to focus on fewer, more focused outcome measures.

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ICHOM website <http://www.ichom.org/>

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