



IMPLEMENTING ICHOM'S STANDARD SETS OF OUTCOMES: PARKINSON'S DISEASE AT ANEURIN BEVAN UNIVERSITY HEALTH BOARD IN SOUTH WALES, UK

MARCH 2017



IMPLEMENTING ICHOM'S STANDARD SETS OF OUTCOMES: PARKINSON'S DISEASE AT ANEURIN BEVAN UNIVERSITY HEALTH BOARD IN SOUTH WALES, UK

Authors: Dr. Jason Arora¹, Dr. Sally Lewis² and Mrs Adele Cahill²

Designer: Matthew Salt¹

¹International Consortium for Health Outcomes Measurement (ICHOM), London, UK

²Aneurin Bevan University Health Board, UK



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Aneurin Bevan
University Health Board



ICHOM

Boston
Scientific

HOW TO CITE THIS PAPER:

Arora J, Lewis S, Cahill A. Implementing ICHOM's Standard Sets of Outcomes: Parkinson's Disease at Aneurin Bevan University Health Board in South Wales, UK. London, UK: International Consortium for Health Outcomes Measurement (ICHOM), March 2017 (available at www.ichom.org).

Corresponding author: Jason Arora, MD, MPH; j.arora@ichom.org

SPONSORSHIP

We would like to thank Boston Scientific for sponsoring this case study to support the adoption of value-based healthcare (VBHC) across the industry.

ICHOM STANDARD SET IMPLEMENTER PROFILE

Location: Wales, UK

Standard Set: Parkinson's Disease

Standard Set complexity: Low

NHS (National Health Service) Wales is a universal, publicly funded health system free at the point of need and paid for through general taxation. The health system is divided into seven integrated payer-provider health boards that are each geographically distinct and responsible for the patients within their region. There are also three NHS Trusts that operate national services, such as public health and the provision of ambulances. Private healthcare is also available.

Aneurin Bevan University Health Board is the operational name of Aneurin Bevan University Local Health Board. The Health Board was established on the 1st October 2009 and achieved 'University' status in December 2013. The Health Board covers the areas of Blaenau Gwent, Caerphilly, Monmouthshire, Newport, and Torfaen, providing healthcare to an estimated population of over 639,000, approximately 21% of the total Welsh population. With a budget of £1.029 billion, the Health Board employs over 13,000 staff, two thirds of whom are involved in direct patient care. The Health Board is led by the Chairman, non-executive directors, the Chief Executive and other executive directors.

BACKGROUND

In 2014, the Welsh Minister for Health and Social Services laid down a set of principles to achieve more efficient health care across the country. This new set of principles, referred to as Prudent Healthcare, involved a greater emphasis on the co-production of health care between professionals and the public, caring for patients with the greatest health needs first, doing no harm, and reducing inappropriate variation through evidence-based approaches. Each of Wales' seven health boards would be tasked with defining a local strategy to achieve this over the coming years.

Dr Sally Lewis, Assistant Medical Director and Dr Paul Buss, Medical Director, at Aneurin Bevan University Health Board ABUHB, welcomed the new National Policy but felt there was a missing vehicle for the delivery of these new principles. Increasing financial pressures facing the Board and the repeated cost cutting exercises leaving staff feeling deflated across the organisation. There was a lack of visibility of both clinical and patient reported outcomes and detailed costing of patient pathways across the whole system, proving difficult to assess the value of healthcare provision to patients throughout the organisation.

Incidentally, Sally and Paul's colleague and Finance Director at ABUHB, Alan Brace, had just returned from a course at Harvard Business School on Value-Based Health Care (VBHC). Both Alan and Sally saw VBHC as the ideal vehicle for achieving ABUHB's goals. This would be an opportunity to engage in a dual focus on both of ABUHB's targets - outcomes and cost - with the potential to create a common language between clinicians, managers and financiers within the organisation whilst leveraging resources more efficiently. Thus, the senior leadership of ABUHB agreed to use VBHC as a vehicle to achieving Prudent Healthcare's principles in the coming years.

WINNING HEARTS AND MINDS FOR VBHC AT ABUHB

Alan Brace identified a senior managerial lead to programme manage the Value-Based Health Care approach; Adele Cahill, Deputy Director of Procurement Services for NHS Wales. The next job for the senior leaders was engaging the workforce across a range of disciplines within ABUHB. The Programme team identified genuine on the ground leaders through the different domains in the organisation; those who were most likely to drive change from below, organising 1-1 and group meetings across a range of teams including Finance, IT and Clinical areas.

It was vital to start with explaining the current state of affairs, and that relying almost entirely on process and structural metrics wasn't proving useful, there was a need for the organisation to shift towards using patient-reported outcomes, combined with cost as the true measure of success in health care provision.

One of the first key steps was to consider the language being used in order to get the workforce aligned, use of a common language between Clinicians, Finance and Managers, modifying as appropriate so that it was meaningful to all. This proved to be a lever for motivating clinicians and management, who in turn become more responsive to the approach.

Senior management emphasised that the VBHC approach would not belong to any one team, and that this was to become core business, owned and implemented by every unit of the organisation, working closely with the Health Boards quality improvement group, the ABCi (Aneurin Bevan Continuous Improvement team).

Once Sally and Alan had a critical mass of staff on-board for ABUHB's new strategy, the next key step was to identify how best to begin this transition.

IMPLEMENTING VBHC

GETTING STARTED

It was important to identify a department in which to pilot an ICHOM Standard Set on a small scale. This was essential to ensure feasibility and impact before scaling across the organisation. ICHOM's Parkinson's Disease Standard Set was identified as a relatively simple model to begin with.

Whilst there was excitement for the potential of the project, the Parkinson's Disease team had several initial fears. Some felt this would be a short-term project with no sustainability and no mechanism for timely troubleshooting. Others were concerned about an additional burden of data collection and a troublesome IT data collection platform without adequate support, resulting in a negative impact on clinic operations and quality of care. Finally, some questioned whether the outcomes data itself would be useful.

Nevertheless, the team proceeded with piloting the ICHOM Parkinson's Disease Standard Set in two of their clinics with the help of the ICHOM team and a dedicated internal resource allocation – the latter included a VBHC Project Team and Steering Committee involving experts from multiple disciplines, including clinical, informatics, administration and governance.

THE ICHOM STANDARD SET FOR PARKINSON'S DISEASE

In 2014, ICHOM facilitated the development of an holistic, globally standardised set of outcomes for Parkinson's Disease (PD). A summary of the ICHOM PD Standard Set is shown in **Figure 1**.

Parkinson's Disease

Parkinson's Disease is an incurable, progressive chronic disease of the nervous system caused by the degeneration of specific nerve cells in the brain. It generally manifests after the age of 50 and is characterised by a variety of neurological symptoms, including tremor, muscular rigidity, and slowness of movement. Parkinson's Disease also associated with numerous other physical and psychological symptoms, including depression and anxiety, falls, insomnia, pain, loss of sense of smell, and problems with balance.

FIGURE 1A | ICHOM STANDARD SET FOR PARKINSON'S DISEASE



Details

1. Includes cognitive impairment, hallucinations and psychosis, depressed mood, anxious mood, apathy, and features of dopamine dysregulation syndrome
2. Includes sleep problems, daytime sleepiness, pain and other sensations, urinary problems, constipation problems, light headedness on standing, fatigue, sweating, and sexual function
3. Includes speech, saliva and drooling, chewing and swallowing, eating tasks, dressing, hygiene, handwriting, doing hobbies and other activities, turning in bed, tremor, getting out of a bed, a car, or a deep chair, walking and balance, and freezing
4. Recommended to track via the Parkinson's Disease Quality of Life Questionnaire (PDQ-8)

Figure 1A: The ICHOM Standard Set for Parkinson's Disease outcomes wheel, detailing the outcome domains within the Standard Set.

FIGURE 1B | ICHOM TIMEPOINTS FOR PARKINSON'S DISEASE STANDARD SET

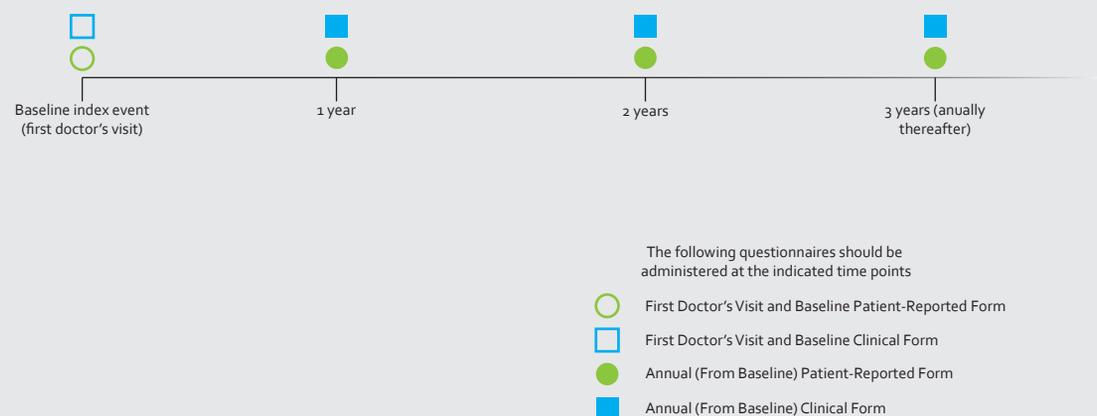


Figure 1B: Time points for data collection of the ICHOM Standard Set for Parkinson's Disease.

ABUHB MAPPED OUT 3 MAIN PHASES TO IMPLEMENT THE PARKINSON'S DISEASE STANDARD SET

1. Personnel and team formation

ABUHB first needed to secure both the support of the Parkinson's Disease clinical team and the capacity to operationalise the work. They knew that if the project were to be successful, then it had to be core business and resourced appropriately. An on-site Project Team was allocated for the day to day running of the work and a Steering Committee formed to give a clear governance structure.

The Steering Committee comprised Executive and Non-Executive Directors, a Lead Clinician, Assistant Director/Programme Manager, Head of Department, Head of Quality, Head of Nursing, Head of Administration, and Head of IT. Guardrails were put in place by the Steering Committee to ensure that if the implementation process negatively affected patient care, there was a system in place to pause and re-evaluate.

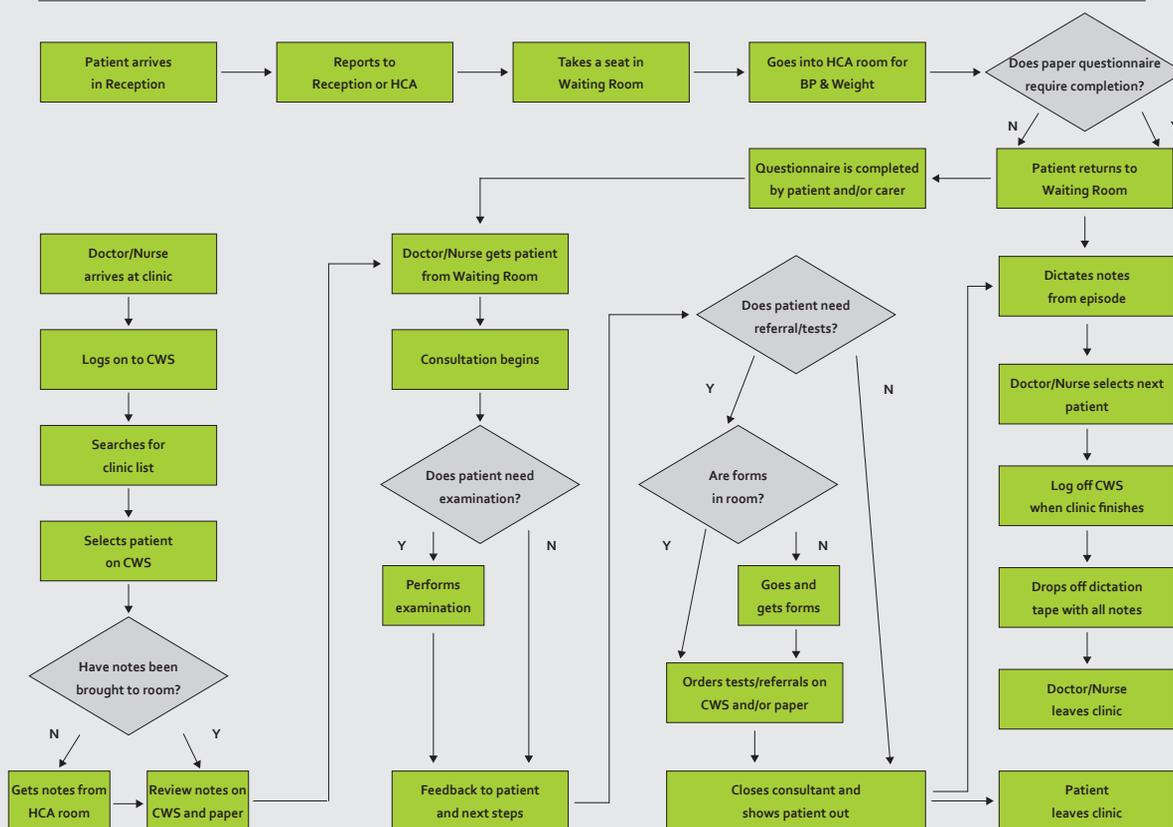
The Project Team would operate under the Steering Committee to drive the work on a day-to-day basis. This team comprised a project manager, quality team representative, directorate and administrative team representative, nurse representative, and IT representative. They would meet on a weekly basis to discuss progress and address course correction where appropriate.

2. Process-mapping

ABUHB subsequently process-mapped the pilot implementation clinics from patient, clinician and informatics perspectives. They produced a gap analysis of what, where and how each metric was measured. This allowed them to create a plan for any missing outcome metrics. Through process-mapping all three perspectives, the timing and manner of data capture was designed from concept to execution to cause minimal disruption to normal patient and clinician flow.

ABUHB found the process-mapping exercise extremely useful for both arms of the value equation. From a patient pathway perspective, it allowed ABUHB to explore different consultation models (e.g. telephone consultations), and the potential for redesigning services around cohorts – e.g. a full-day specialist clinic with a multi-disciplinary team to avoid duplicative patient visits and to provide high value for patients. This will result in improved control of the booking system and a reduction in patients lost to follow-up. Observations went as far as improving the clinic environment and clinic flow through very small investments in administrative and health-care assistant support staff and better signage for patients and their carers. There was a natural and significant shift to improving attention to detail. See **Figure 2**.

FIGURE 2 | PROCESS MAP FOR PARKINSON'S CLINIC



Process map for ABUHB's Parkinson's Clinic showing the patient journey through the clinic and opportunities for data capture.

HCA - Health Care Assistant, BP - Blood Pressure, CWS - Clinical Work Station

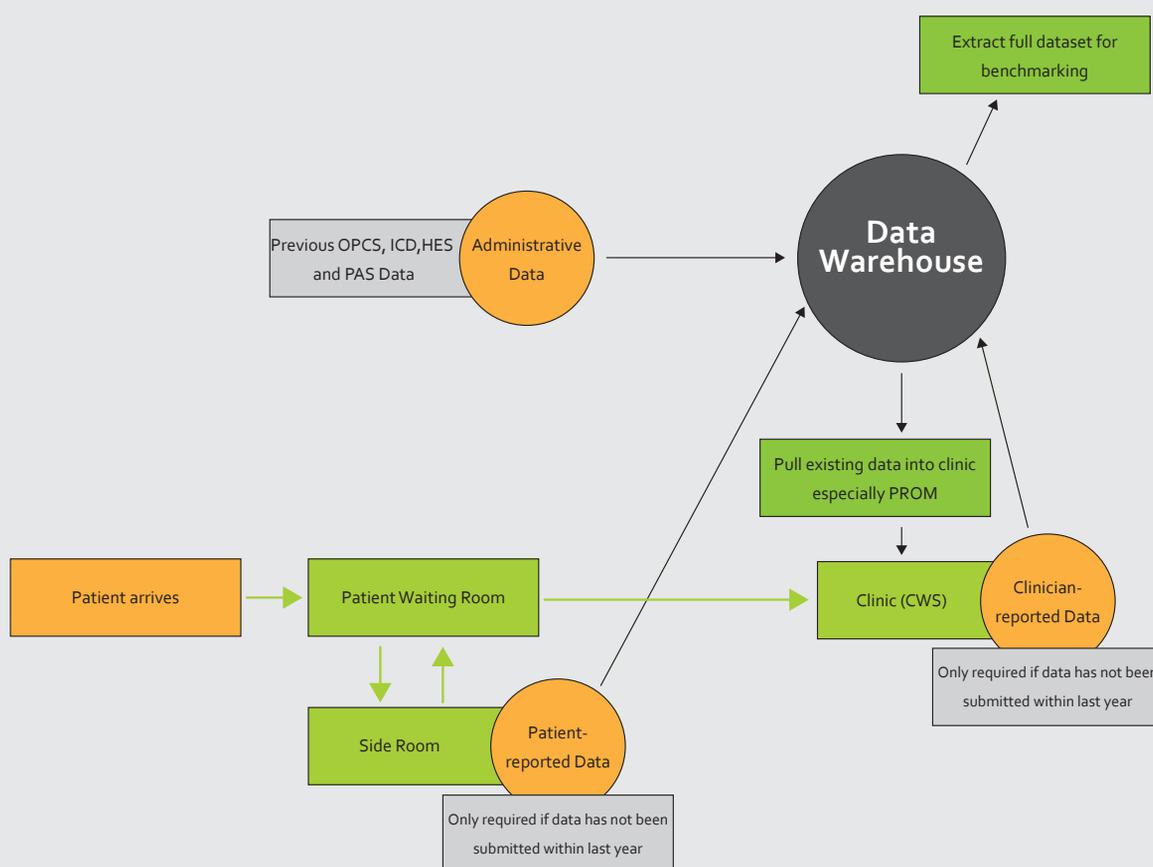
3. IT/Informatics restructuring

A data mapping and gap analysis exercise was undertaken in order to identify the data gaps between the ICHOM Standard Set for Parkinson's Disease and what the clinic was already collecting. This involved an investigation into where and how the various types of data were stored, and how these could all be pulled together. The biggest gaps in the Parkinson's Disease clinic between current data collection and the Standard Set were the use of patient-reported outcome measures (PROMs).

ABUHB developed a home-grown electronic data capture platform that allowed for the accurate capture of PROMs by the patient through the use of a tablet computer in the waiting room. The process mapping exercise had already identified that there was capacity within the role of the Health Care Assistant to help with this, and therefore, the additional resource cost to deploy this was minimal. The system was created with the Parkinson's patient population in mind, and the user interface designed to make data entry as easy as possible at every step. On deployment of the tool, weekly PDSA (plan, do, study, act) cycles and Project Team meetings to review the results of these cycles were held, until the process was perfected.

See **Figure 3** for the clinic's PD data map, which was key to understanding the flow of clinical, administrative and patient-reported data, from different sources, and in tandem with clinic operations.

FIGURE 3 | DATA MAP FOR PARKINSON'S STANDARD SET INFORMATION FLOW



Data mapping provided an opportunity to identify relevant data sources and design mechanisms for pulling this data together, in line with newly collected metrics (including PROMs) for the ICHOM Standard Set for Parkinson's Disease.

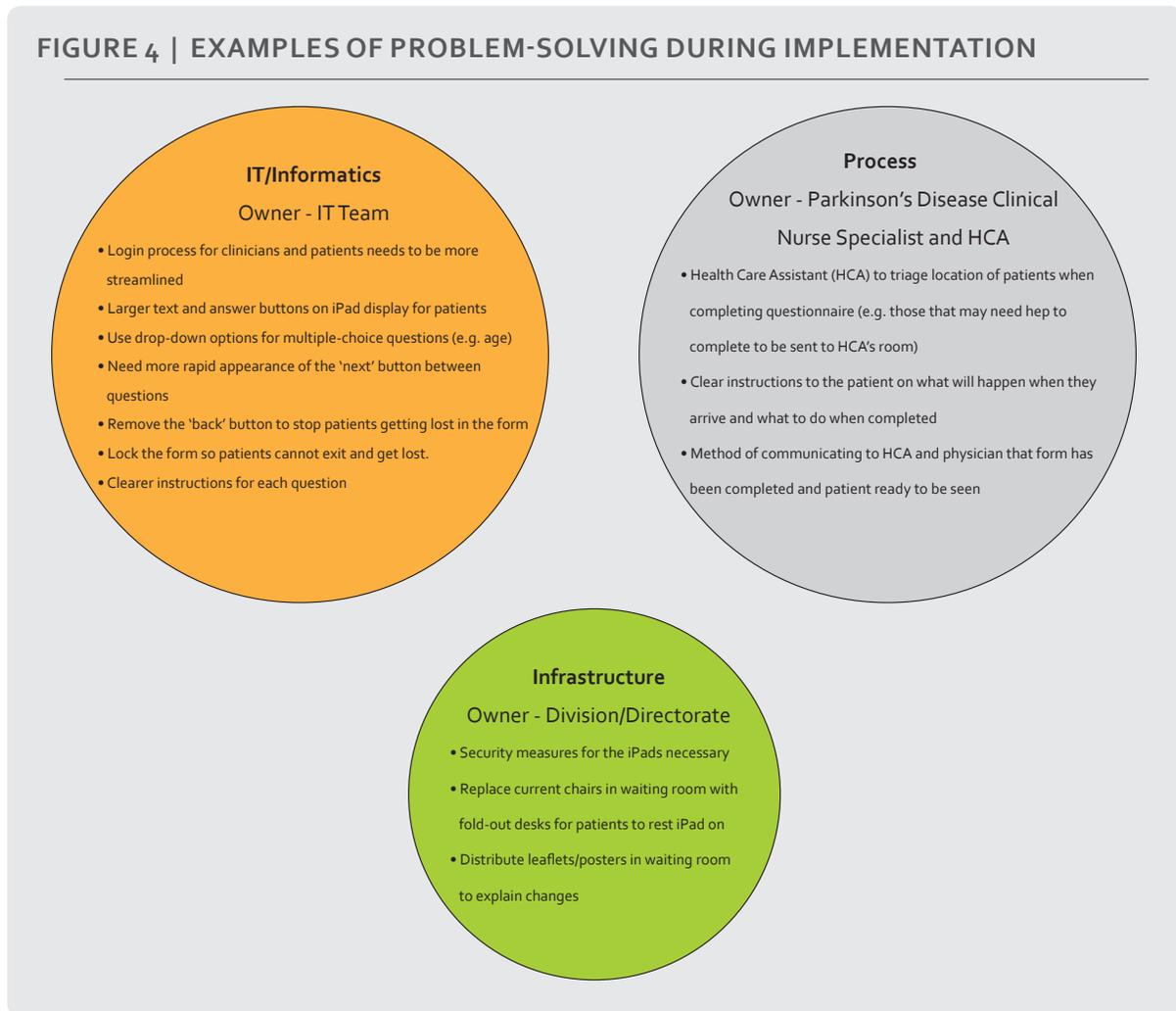
OPCS - Office of Population Censuses and Surveys Classification of Surgical Operations and Procedures (4th revision), ICD - International Statistical Classification of Diseases and Related Health Problems (10th revision), HES - Hospital Episode Statistics, PAS - Patient Administration System

PROBLEM-SOLVING DURING IMPLEMENTATION

The implementation process involved several iterations and continuous problem solving before arriving at a sufficiently streamlined outcomes data capture model. ABUHB's Parkinson's Disease clinic divided ownership of these problem categories into three disciplines, with input provided by other disciplines. For example, the IT and Informatics problem-solving is 'owned' by the IT team, with input from the clinical and project management teams. The improvements would be identified and then discussed at Project and Steering Committee meetings on a regular basis.

Figure 4 highlights some examples of problems encountered during the implementation process and some of the improvements made.

FIGURE 4 | EXAMPLES OF PROBLEM-SOLVING DURING IMPLEMENTATION



EARLY RESULTS

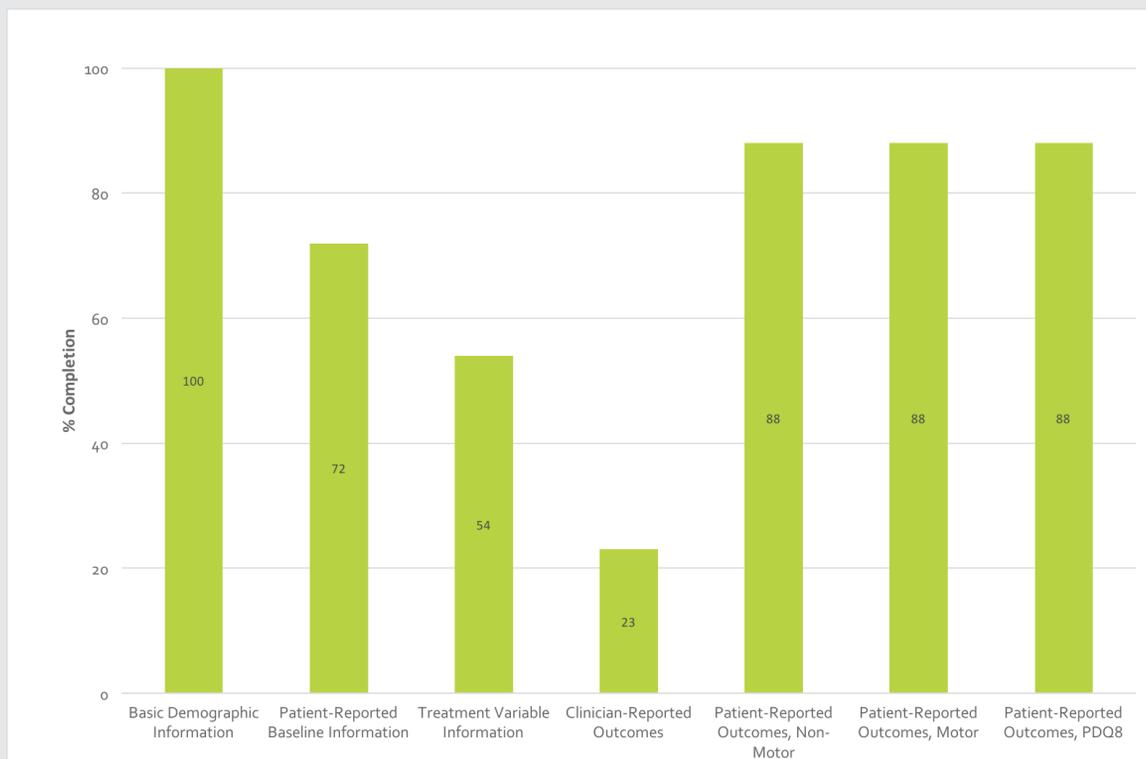
The early benefits were clear to all involved – patient information collated via PROMs was immediately available at the clinician's fingertips, streamlining history-taking and focussing the consultation on what matters most to the patient. There were limited delays within the clinic, as patient data collection occurred outside of physician-facing time, and remaining data items were pulled from pre-existing clinical and administrative data sources. In particular, the PROMs tool comprised an early question that re-ordered the subsequent PROMs questions based on what had been bothering the patient most in the recent past. Getting patients to complete PROMs questions on iPads in the waiting room was stimulating patient-patient conversation and helping them structure their thinking prior to their appointments. Other key pieces of information – such as drug adverse reactions and allergies - became more readily available and understandable due to a common data entry format across domains.

Through the process mapping exercise, ABUHB also decided to divide clinics by patient cohort. This will lead to the allocation of more specialised teams with a better understanding of patient cohort clinic needs (e.g. new diagnosis versus complex established diagnosis), and will mitigate the distress for new patients attending clinic with patients with visibly more complicated, severe diagnoses.

As of February 2016 – 9 months into the implementation process - administrative data capture of basic demographic information was 100%. Patient-reported data capture was very high, with 88% of Parkinson’s PROMs questions completed across all fields and 73% of baseline patient variable factors completed across all fields. Clinician-reported data capture initially had the lowest completion rate at 23% due to ‘crashing’ of the e-forms. Once this was resolved, clinician-reported data capture was 100%, emphasising the importance of an enabling IT system. Coding accuracy was satisfactory at 66% overall, indicating the need for further training of data abstractors. Fields simply need to be cleaned in order to render the data compliant for external benchmarking. For example, instead of listing gender as M or F, it needs to be listed as ‘1’ or ‘2’ as indicated in the Standard Set Reference Guide. Coding was, however, high quality for the majority of the patient reported data items.

LESSONS LEARNED

FIGURE 5 | COMPLETION OF PARKINSON’S DISEASE STANDARD SET DATA ITEMS



The percentage completion rate for each type of data item in the Parkinson’s Disease Standard Set. PDQ8 - Parkinson’s Disease Quality of Life Questionnaire-8

1. THE IT TEAM NEED TO BE ON THE FRONT LINE

In order to better understand and iterate the user interface, the IT team need to visit the clinic on a regular basis and see the technology in practice from both clinician and patient perspectives.

2. FRONT-LOAD SUPPORT SYSTEMS AND MANAGE EXPECTATIONS, ESPECIALLY IT

Support systems need to be front-loaded to facilitate early troubleshooting to give both clinicians and patients confidence. These systems can then slowly be dialled down as the process becomes more efficient and free of errors. As part of this, empower and enable front-line teams so that they continue to feel ownership.

3. 'OUT OF THE BOX' IT SOLUTIONS ARE LESS BURDENSOME

The ABUHB IT team decided to build their own e-forms for data collection. Complexities can arise (e.g. system-wide upgrades leading to 'bugs' in the e-forms) unexpectedly, which increases the burden on the IT team. The ideal solution is an affordable 'out of the box' solution that integrates with the hospitals IT system.

4. PROVIDE REAL-TIME DATA THAT CLINICIANS CAN USE IMMEDIATELY

Maintain the support and engagement of clinicians by providing them with actionable data, ideally in real-time. Frequently, clinicians are asked to support data collection for mandatory audits and other initiatives that may never get fed back to them, reducing their interest and support.

5. TOP-LEVEL COMMITMENT TO BOTH ARMS OF THE VALUE EQUATION

This sends a very powerful message to the organisation and acts as a 'call to arms' to all teams – not just clinicians – to modify their thinking. These must not just be stated as organisational priorities, but also operationalized to ensure action.

6. THERE IS NO 'TEAM' FOR THIS - IT SHOULD TRANSCEND ALL TEAMS

Don't over-define the team responsible for outcomes measurement and VBHC, because this may detract from it being core business across all teams. It is important for teams and individuals to be aware of their responsibilities, with matrix ownership allocation across domains. The VBHC Project Team and Steering Committee should act to support pre-existing teams until this becomes woven into routine practice.

7. SMALL, INCREMENTAL IMPROVEMENTS RATHER THAN MASS OVERHAULING

In order to change the way people work, it is important to take small steps. This reduces the risk of destabilising the organisation or departments, and facilitates incremental learning at every unit level – from individual to organisation.

8. FRAME THE INITIATIVE IN THE RIGHT WAY

Use of common language from the management played a big role in engaging clinicians, finance and managers, which is far more meaningful for teams and aligns interests across domains.

9. MAKE IT USER-FRIENDLY

If the clinician and patient-facing elements of the data collection system are not easy to use, they will not be used and data collection will be deprioritised. It is worth investing significant time and effort in, for example, the user interface.

10. TAKE A LONG-TERM VIEW

Even though no single team 'owns' an outcomes measurement initiative, it is important for individuals and teams to be brought in with a long-term view. Short-term projects often fail to significantly shift culture.

NEXT STEPS

Now that the project has been proven feasible and is already yielding early benefits, ABUHB are planning to integrate efficiency costing using time driven activity based costing (TDABC) and scale the work in Parkinson's disease to five other sites. They will additionally be expanding the programme to four further ICHOM Standard Sets (Heart Failure, Stroke, Cataracts, and Lung Cancer) so that they may identify similar benefits in other clinical areas. Finally, ABUHB will be part of ICHOM's first wave of international benchmarks in Cataracts, positioning them as front-runners in pursuing global comparisons of patient centred outcomes, moving them towards a collaborative, and value focused system.

ICHOM and ABUHB are now in discussions with other Health Boards across Wales to share the learning with the hope of creating national alignment around the outcomes that are being captured.

ACKNOWLEDGEMENTS

We would like to thank the following individuals for their generous contributions to the development of this case study:

Dr. Alistair Church, General Practitioner and Associate Specialist in Neurology

St. Woolos Hospital, Aneurin Bevan University Health Board

Ms Debbie Davies, Specialist Nurse

St. Woolos Hospital, Aneurin Bevan University Health Board

www.ichom.org
ichomteam@ichom.org

