



PROMs in Practise

The integration of new technologies has become more intertwined with the analysis of patient care and practices. Using digital patient-reported outcome measures, healthcare organisations are now better able to measure patient outcomes and thus improve treatment value

Dr Tim Williams at
My Clinical Outcomes

As life expectancy rises and clinical investigations and treatments get ever more effective and complex, expectations of what health systems should deliver in terms of keeping people healthy for longer are, rightly, growing. However, the longstanding challenges of wide variation in access and quality, even within a single system, and spiralling costs are putting an ever greater strain on health systems and pose a risk to continued progress.

Today, healthcare quality is mainly understood in terms of process measures, such as waiting times, length of stay, and discharge rates as well as the unintended consequences or complications of care, such as hospital acquired infections and mortality. These measures are clearly important and need to be measured and managed, but they do not help patients or clinicians understand the actual results of care from the perspective of the patient. This includes information about which patients get better or worse or in what circumstances treatment is successful, whether it is generally done at the right time by a particular doctor or hospital and, if not, why not, how long the benefits last or the relative successes between treatments, doctors, and hospitals.

The International Consortium of Health Outcomes Measurement (ICHOM) define 'outcomes' as: "The results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives" (1). ICHOM was established in 2014 as a partnership between

Harvard Business School, Boston Consulting Group, and the Karolinska Institutet in Sweden to set a global standard for outcomes measurement at the level of the clinical condition.

The work of ICHOM is underpinned by a framework developed by Professors Michael Porter and Elizabeth Teisberg in their 2006 book, *Redefining Healthcare* (2). The 'Value Agenda' or 'Value-Based Healthcare' argues that the overarching goal of healthcare delivery has to be focused on increasing value for all patients, where value is the health outcomes delivered per dollar spent. Outcomes are measured and maximised at the level of the clinical condition and measured throughout the full cycle of care.



Figure 1: A clinician using remotely gathered, longitudinal patient-reported outcomes measures data to support patient consultation figures

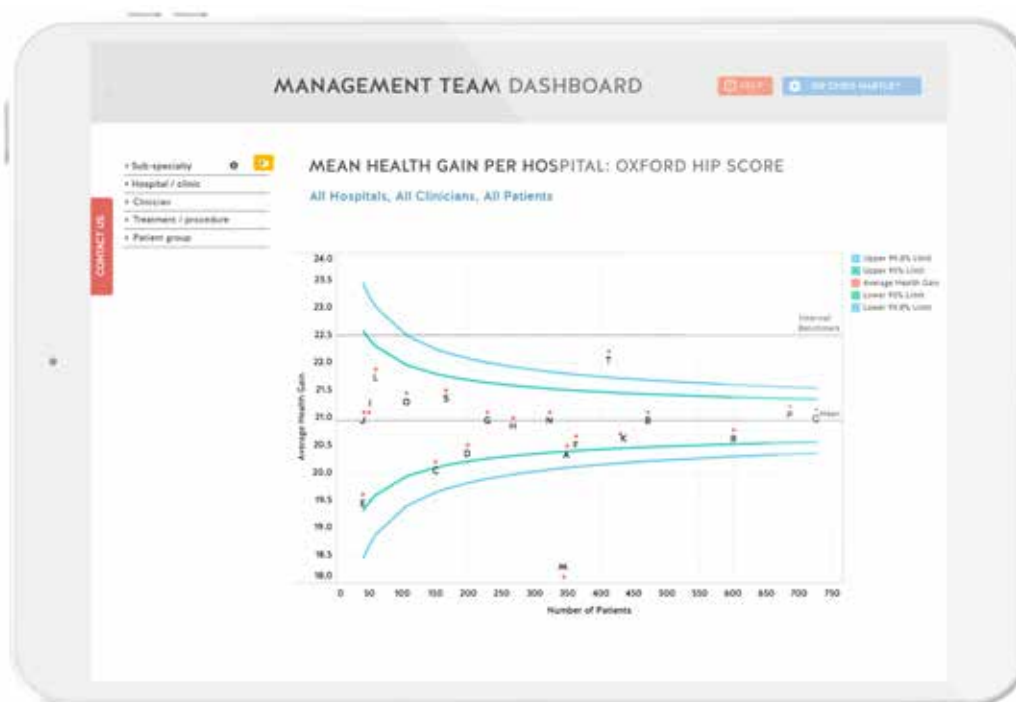


Figure 2: Aggregate outcomes data now available to clinical managers to benchmark performance, identify variation and support quality

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ICHOM have developed standard sets of outcomes, leveraging the experience and expertise of leading clinicians in their field, along with patient representatives, to draw on available best practice and research and discuss and agree what should be included in the standard set in terms of questions, time-points in the care cycle, and inclusion and exclusion criteria for comparison. To date, they have published standard sets for 23 conditions as disparate as coronary artery disease, dementia, and breast cancer that currently cover 54% of the global burden of disease, as defined by the WHO, and with a further 10 conditions in development.

Their mission is to “unlock the potential of value-based health... by driving adoption and reporting of these measures worldwide (1).” They already have a wide range of international supporters, and, in January 2017, health ministers from across 35 member countries of the Organisation for Economic Cooperation and Development met to discuss closer collaboration on healthcare reform and, as a result, signed a letter of intent to collaborate

with ICHOM (4). In April 2017, the World Economic Forum acknowledged Value-Based Healthcare as the only credible response to the unsustainable rise in healthcare costs across the world (5).

The UK Context

The UK NHS has had a nationally mandated outcomes programme since 2009, and the UK Private Sector has recently introduced a similar requirement. The NHS programme mandates that providers undertaking total hip or knee replacement collect patient-reported outcome measures (PROMs) before and six months following surgery. PROMs are clinically validated outcome assessment questionnaires that are completed by patients and provide a numerical score determined by the severity of their current health condition and its impact on their life. Collecting the data before and after surgery allows the benefit or ‘health gain’ of the surgery to be assessed.

The programme was introduced when digital technology was not widely available and data is, therefore, typically collected using pen and paper. This means that, while useful in terms of gathering data that allows aggregate provider-level analysis to spot outliers, reporting is delayed and individual results are not made available to patients and clinicians such that they may inform the care of those patients themselves. Furthermore, engagement has often been rather poor, meaning that response rates are low, with no mechanism or incentive to drive uptake by individual patients. Finally, the resource intensive approach means that the scope has remained narrow. There is



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now a mandate covering just two surgical interventions, and, with data collected one before and one following surgery, there is no longitudinal time-series data proving insight into the relative timeliness of operative decision-making, or sustainability of outcomes (longevity of benefit) between sites, pathways, clinicians, or devices for patients with similar needs.

Meanwhile, the UK private sector is responding to new requirements set by the Competition and Markets Authority to collect and transparently publish outcomes data through the designated Information Organisation for the sector – the Private Healthcare Information Network (PHIN) – to improve the ability of patients to make more informed choices about hospitals and clinicians and for payers to ensure value-for-money. The onus is on private healthcare providers to work with a partner supplier to implement a programme for measurement across an initial 14 conditions. The lessons of the NHS programme have been drawn on, and the emphasis is much more on encouraging providers to adopt a sustainable and clinically useful digital process for outcomes measurement. Many providers, such as Spire Healthcare have now been collecting PROMs data digitally for over a year now, and clinician-level reporting will begin through PHIN in early 2018.

Clinical Use

As well being useful in terms of identifying variation to improve service delivery, systematic collection of PROMs, including where they form part of the ICHOM Standard Sets, have the potential to act "...as a roadmap to restructure the clinical encounter by gathering and summarizing the information that is most meaningful to patients and thereby prioritising clinical information and care needs" (6).

A well-implemented outcomes solution improves the ability of multiple stakeholders involved in the care process to make decisions, for example:

- Patients themselves have better information about their own progress, can understand the benefits or otherwise of treatment, and can compare their progress with patients like them to shape ongoing care decisions
- Clinicians can use the data to make more informed treatment decisions about individual patients, including responding quickly to deteriorations or side-effects and prioritising

certain patients for face-to-face review (see Figure 1)

- Service managers can use the data in aggregate to understand variation in quality, reduce ineffective or harmful activity, and take out cost by better prioritising demand to the availability of clinical resources (See Figure 2)

The best digital systems for collecting PROMs wrap seamlessly around clinical workflows and integrate data with existing electronic medical records and business intelligence systems using standard protocols such as Fast Healthcare Interoperability Resources and open API architecture. They need to be configurable to local needs to overcome implementation and process barriers to adoption. Fundamentally, digital methods of collecting outcomes data are far more cost-effective because there is no incremental cost of collecting a greater number of data points from an individual patient (as adding additional cost of printing, envelopes, and stamps has in a paper process). Engagement is also greater, which results in better quality data across a broader scope of conditions and patient cohorts and more impactful analytics.

As well as these general clinical and service transformation benefits, researchers in several disease areas have started to publish specific clinical benefits. For example, in June 2017, Basch *et al* presented evidence of the survival benefit of electronic PROMs measurement for patients with advanced solid tumour cancer at the conference of the American Society of Clinical Oncology (7). In the work, 766 patients with advanced cancer were randomised to electronic PROMs monitoring during routine chemotherapy or a comparison group undergoing usual care. The study group had a median survival of 31.2 months compared to 26 months – five months less – in usual care group. To put that in context, this benefit was greater than for all but one of seven drugs approved by the FDA for advanced cancer in 2016, and, in a context where drugs that increase life expectancy by weeks can cost thousands of dollars, this approach clearly presents a highly cost-effective additional tool in the fight against cancer.

This research prompted Jane Maher, Chief Medical Officer of Macmillan, one of the largest cancer charities in the UK, to state on Twitter: "Routine collection of patient reported outcomes improves survival of patients with advanced cancer - so let's get on with it" (8).

The Future is Digital

In 'The Second Machine Age', Massachusetts Institute of Technology academic Erik Brynjolfsson notes that "In the next twenty-four months, the planet will add more computer power than it did in all previous history" (9). However, as rapid as the rise of the internet has been, health systems have been slower to embrace the potential of new technology than other industries. Indeed, in 2017, the NHS continues to routinely use pagers and fax machines to communicate and still spends £79 million a year on postage stamps. Smartphones, cloud computing, and global connectivity have created a universe of consumers accustomed to

managing their daily lives online, from checking bank balances and making purchases to watching movies on mobile devices. Increasingly, those consumers are expecting similar tools to understand and manage their health. As a result health systems, including the NHS, are now starting to invest seriously in digital healthcare and transformation.

As this happens, the potential of systematic digital outcomes measurement to transform patient care, clinical decision-making, and service delivery, as well as allowing health systems to improve clinical quality while making costs more sustainable, is being realised. Soon, all clinicians and hospitals will have the data and tools to truly understand the quality of care they are delivering from the perspective of the patient and will deliver care that is more patient-centred and higher value for all patients. Ultimately, the aims of Boston surgeon Ernest Codman, widely acknowledged as the pioneer of outcomes measurement in clinical care, will be recognised when, over a century ago, he wrote, "Every hospital should follow every patient it treats, long enough to determine whether or not the treatment has been successful, and then to inquire, 'if not, why not?' with a view to preventing similar failures in the future"(9).

References

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About the author



Dr Tim Williams is the Co-Founder and CEO of My Clinical Outcomes (MCO) – a technology platform that automates the collection and analysis of PROMs in clinical practice. MCO is an ICHOM TechHub technology affiliate and is accredited by PHIN. Prior to founding MCO, Tim studied medicine at Oxford University and Kings College London, UK. He worked as a doctor in the NHS as a strategy consultant and has undertaken the Value-Based Healthcare Intensive seminar at Harvard Business School, US.

Email: tim@myclinicaloutcomes.com