PATIENT-REPORTED OUTCOME MEASURES

Are they happy with the care?

How the measurement of outcomes is transforming private practice and how this affects your work as independent practitioners.

Dr Tim Williams (above), founder and chief executive of MyClinicalOutcomes.com, answers questions posed by *Independent Practitioner Today*

WHY SHOULD we collect patient-reported outcomes?

Traditional measures of healthcare quality focus on the processes of care, such as waiting times and length of stay, or the success of hospitals in avoiding unintended harm. These factors clearly need to be measured and managed, but they don't attest to the actual results of care from the perspective of the people that really matter: our patients.

'Outcomes', as defined by the International Consortium of Health Outcomes Measurement (ICHOM), are: 'the results people care about most when seeking treatment, including functional improvement and the ability to live normal, productive lives'.

Patient-reported outcome measures (PROMs) are structured condition-specific clinical assessments and are a key tool in measuring and tracking outcomes.

Systematic collection of PROMs regularly, remotely and throughout care helps:

- Patients to understand the benefits or otherwise of treatment and make more informed decisions;
- Clinicians to optimise the care of individual patients, including when to review face to face, when to treat or change treatment, as well as to understand the overall quality of care they are providing to different cohorts of patients;
- Managers and payers to ensure clinical resources are prioritised to patients that need it most and that ineffective or harmful activity is minimised.

What is My Clinical Outcomes?

My Clinical Outcomes (MCO) is an innovative web-based technology, created by clinician entrepreneurs, that allows doctors and hospitals to systematically measure and analyse PROMs as a routine part of care.

It has been used at over 70 NHS and private hospitals in the UK since 2011, with over 1,000 active clinicians and 20,000 patients.

MCO was borne out of a frustration of its founders about the lack of data on the impact of treatments and interventions to guide doctors and managers to organise

⇨ p26

clinical capacity most efficiently around the most effective treatments at a time where user-centred digital tools were becoming commonplace in day-to-day life.

The mission of the company then, as now, was to create a digital system to help healthcare organisations, doctors and their patients understand the results of treatment from the perspective of the patient in order to shape treatment decisions and ensure the highest-quality care for all patients.

How does it work?

MCO is implemented according to needs of individual clients to collect outcomes. This includes deciding which conditions, treatments and patient groups will be involved, as well as choosing appropriate PROMs and time-points for longitudinal data collection.

When data collection starts, patients are asked to register and are then served a combination of PROMs tailored to them as a baseline. The system automatically prompts patients to update their score at pre-defined future time-points via email.

Patients can log into their own dashboard at any time to review their progress; their doctors can review results as soon as the data is entered to help plan care and focus face-to-face consultations. Administrators can be given access to which patients are not-responding and pro-actively contact patients to ensure on-going high uptake.

Senior doctors and managers may then use the results in aggregate, depending on the specific arrangement with clients, to target available clinical capacity to those patients who need it most, and to ensure all patients are achieving the best outcomes, so that less effective activity may be reduced.

Patients can log into their own dashboard at any time to review their progress

Why should consultants do this?

The whole UK private sector is changing and is tasked to respond to new requirements set by the Competition and Markets Authority (CMA) to collect and transparently publish outcomes data. This is being done through the new information organisation for the sector, the Private Healthcare Information Network (PHIN).

This is to improve the ability of patients to make more informed choices of hospitals and clinicians, and for payers to ensure value for money.

The onus is on private healthcare providers to work with a partner supplier, or develop a solution in-house, to implement a compliant programme for outcomes measurement.

The first procedures selected are hip and knee replacement, shoulder replacement, carpal tunnel release, transurethral resection of the prostate, cataract surgery, nasal septoplasty, breast augmentation, rhinoplasty, abdominoplasty and liposuction, with data being required to be collected pre-operatively and once post-operatively so that the benefit of the surgery can be assessed.

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.

As well as bringing benefits in terms of long-term patient engagement and clinical utility, taking a digital approach to outcomes measurement allows clinicians and providers to monitor results as they are recorded.

A digital approach also ensures that the aggregate data that is eventually published will be as accurate and positively representative of clinical performance as possible.

What's happening in the NHS?

The NHS has had a nationally mandated outcomes programme since 2009 that authorises providers undertaking total hip or knee replacement to collect PROMs, before and six months following surgery.

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.

And engagement has often been rather poor, meaning that response rates are low with no mechanism or incentive to drive uptake by individual patients.

Finally, this resource-intensive approach means that the scope has remained narrow at just four interventions and two time-points of collection.

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.

What do patients think?

Patients find this record of clinical progress a useful reference to inform on-going decisions.

A long-term patient user sums up a common reaction: 'MCO is a great website and it is easy to use. I find it very reassuring that I am regularly reviewed by my consultant ...

'As much as I like meeting him face to face, I do feel that my life is so incredibly busy and taking time off from work is not easy, so this way I can be assessed without needing to take time off.'

For the first time, private patients, their relatives and, yes, even referrers will soon, through PHIN, be able to access comparable data about outcomes for the procedure, clinician and hospital they are choosing, to help make more informed decisions about their care.

This will result in overall quality of care rising as providers compete on the results they achieve for their patients. This new transparency will also result in a reduction in lower-quality activity. Ultimately, private healthcare will become better value for money for patients, whether funded through private medical insurance or self-paying.

Who is doing what?

PHIN has recently taken first steps on publication of outcomes and has released information about which providers of private healthcare are making the most progress towards being able to publish measures of the improvement patients experienced from common types of surgery.

Spire Healthcare, a client of MCO, was identified by PHIN as 'leading the way' (*Independent Practitioner Today*, February 2018).

MCO was established across Spire Healthcare in late 2016, with

⇨ p28

activity and scope growing, data being submitted to PHIN and NHS Digital.

More recently, The Hospital of St John and St Elizabeth and The London Clinic also became users of our system.

A programme manager at Spire Healthcare said: 'The MCO team is quick to respond to support queries, knowledgeable about their product and PROMS internationally and are keen to ensure that we get fantastic value from the system. Set-up was quick and easy, with minimal training required.'

MCO continues its longstanding relationship as an accredited supplier of PHIN. Matt James, chief executive of PHIN, has previously said: 'We found that the digital-first approach taken by MCO engages patients in the process of measuring outcomes, allows data to be used to inform clinical decisions and allows our members to cost-effectively expand the scope of collected data as necessary.

'We saw this as not only one of the best services available for compliance purposes, but as an approach that would move the whole market forward and add real value to the clinical process.'

PHIN will publish the first performance measures for individual consultants in private practice from summer 2018.

What does the future hold?

As well as the benefits of collecting and publishing PROMs, researchers in several disease areas have started to publish evidence for the specific clinical benefits of doing so, which, we believe, will only make the scope of their use grow.

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.

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 – or five months less – in the usual care group.

We saw this as not only one of the best services available for compliance purposes, but as an approach that would move the whole market forward and add real value to the clinical process
MATT JAMES

Matt James, chief executive of PHIN

To put that into context, this benefit was greater than for all but one of seven drugs approved by the US Food and Drug Administration 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 Tweet: 'Routine collection of patient-reported outcomes improves survival of patients with advanced cancer – so let's get on with it.'

Funding shift

Another shift we expect to see as a result of these new approaches is changes to the traditional fee-for-service funding model of the independent sector to one where demonstrable quality, in terms of the data a provider can produce to support it, is tied to the payment it receives.

This shift to so-called 'value-based healthcare' is widely anticipated as an antidote to spiralling health costs and variable quality, and it also provides opportunities for public systems to become more efficient and for the best private providers to thrive, being better re-imbursed for excellent activity and able to market that excellence to patients and payers to grow their market share.

In his 2014 book, *The Second Machine Age*, Erik Brynjolfsson noted that: 'In the next 24 months, the planet will add more computer power than it did in all previous history.' 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.

But that is changing and, as it happens, the potential is being realised for systematic digital outcomes measurement to transform patient care, clinical decision-making and service delivery and allow health systems to improve clinical quality while making costs more sustainable.

Ultimately, the aims of Boston surgeon Ernest Codman, widely acknowledged as the pioneer of outcomes measurement, will be realised when, as he wrote over a century ago: '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.'

The mandating of PHIN and thus the collection and publication or real long-term outcomes data is not only a point of change, but also brings huge benefits to patients and doctors alike.We believe it will increasingly help to show the real value and achievements of the UK independent sector. ■

Dr Tim Williams is founder and chief executive of MCO (www.myclinicaloutcomes.com), having previously worked in the NHS as a doctor and healthcare management consultant. He founded MCO in 2011 to help bridge the gap in patient-centred data available to inform clinical care.

He undertook Prof Michael Porter's Value-Based Healthcare 2014 seminar series at Harvard Business School and is committed to addressing the need for cost-effective digital technology to support the widespread adoption of value-based healthcare.

MCO is a technology affiliate of ICHOM and is accredited by PHIN.