



Capturing Cancer Evidence

The use of patient-reported outcome measures in clinical practice and clinical trials is continuously evolving and adapting leverage for new approaches to data collection and analysis. The latest research and practice of patient-reported outcome measures are able to benefit patients in real time, as well as assist services in reorganising around the perspective of patients

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The Clinical Case

In June 2017, Basch *et al* published randomised controlled trials evidence of the benefits of using a digital platform to remotely measure patient-reported outcome measures (PROMs) – clinical assessments that capture the impact of a condition on a patient's life at a time point – alongside the usual processes of care for patients undergoing chemotherapy for advanced cancer. The study group were found to survive an average of five months longer (which translated to an absolute five-year survival benefit of 8%) than the control group. Additionally, 31% reported quality of life benefits at six months, and emergency room visits were 7% lower (1).

These surprising results were better than those reported by the majority of recently licensed chemotherapy drugs, were more impactful on quality of life, and contributed positively to overall care efficiency and cost effectiveness.

The reasons for the benefits are because of how the technology allowed the service to better meet the needs of patients. Using remotely collected symptom and outcome data, specialist nurses could monitor patients between appointments and look for treatable problems that may otherwise have escalated and mean patients could no longer tolerate a hospital visit for further doses of chemotherapy, or worse, deteriorate to the point that they are admitted to hospital and deteriorate further.

In monitoring patients remotely, action could be taken proactively to improve patients' individual circumstances, and seemingly small interventions could be additive, such that more patients received more of their chemotherapy and lived significantly longer as a result.

This result was presented as one of the keynotes at the 2017 American Society of Clinical Oncology and has had an understandably high profile in the UK, as well as the US.

The UK Landscape

Following the US research, NHS Scotland announced the Cancer Innovation Challenge funding programme to search for organisations working to develop solutions in this space (2). Launching the programme, the Chief Medical Officer in Scotland, Dr Catherine Calderwood, said: "Getting accurate information

from patients about their symptoms at the time they are experiencing them is... particularly pertinent for people with cancer. How they feel really matters. Patient-reported outcomes (PROs) tools will enable doctors to weigh up the risks and benefits of individuals' treatments. It takes the pressure off the patient having to remember how they felt a week or two ago when they are coming in for their next appointment. Using such tools has the potential to enhance the quality of life for patients while they are going through treatment. Ultimately, it is about improving services, treatments and outcomes for people with cancer."

As a result of the challenge, oncologists at a first health board, NHS Ayrshire and Arran, are now collecting data remotely between chemotherapy appointments. Roll-out has initially focussed on haematological malignancy patients, with breast cancer patients and other tumour types being added.

While still in its infancy, the programme is being embraced by patients who report feeling more closely looked after in between appointments. Both patients and clinicians find it saves time by shortening or even replacing face-to-face or telephone reviews. Clinicians are finding that the data is more comprehensive than they used to receive, that it allows the right clinical decisions to be made at the right time, and that comparisons can be more easily made between patients to make sure everyone is looked after as well as possible.

The approach is expected to scale across the region, launching next at the Beatson West of Scotland Cancer Hospital, UK, with more NHS Scotland health boards coming online thereafter.

Meanwhile, the NHS in England is now more than halfway through implementation of its five-year strategy, 'Achieving World Class Cancer Outcomes', which is focussed on reducing preventable cancers, increasing cancer survival, and improving patient experience and quality of life. It includes investment in technology, the introduction of a new quality of life metric, focus on improving waiting times, making care pathways more effective and efficient, and the establishment of nineteen geographic Cancer Alliances to coordinate investment and transformation at a regional level.



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Service Benefits

Technology and the systematic and routine use of PROMs are being explored as a key enabler of service transformation at several Cancer Alliances, offering the potential to:

- Improve standardisation of care: by using PROMs to inform treatment decisions and ensure timely interventions, as well as to identify and reduce unwarranted variation, multidisciplinary teams can use data to ensure optimal allocation of resources throughout the care pathway at an individual patient and cohort level, including using data to restructure resource allocation to meet the needs of different patient cohorts
- Monitor long-term outcomes following surgery and radiotherapy: this includes adverse physical and psychological side effects associated with cancer care and treatment, enabling signs of relapse and treatment side effects to be monitored, facilitating self-management by patients, and direct referral back into care pathways according to symptoms reported
- Support patients 'living with and beyond cancer' and enable supportive care in stratified follow-up pathways: this includes redistribution of outpatient capacity and more focus for people with complex needs while all patients continue to receive appropriate support and symptom management
- Understand and improve long-term quality of life for all patients: this can be achieved through measuring and comparing longitudinal outcomes data
- Access better data to inform commissioning, provision, and accountability: with potential in future aligning payment and incentives – for services and specific treatments – with outcomes that matter the most to patients, understanding patient-report outcomes associated with care enables an accountable cancer network

Cancer charities and Royal Colleges are also supporting the adoption of these approaches. In one project, Macmillan Cancer Support and the Royal College of Radiologists have joined forces and begun to use digital PROMs to monitor for potential late-toxicity effects in patients undergoing pelvic radiotherapy. Here,

the use of PROMs is used to support the long-term follow-up of patients whose treatment has finished and for whom cancer services do not typically have the capacity to provide routine monitoring. In this case, all patients are routinely asked outcomes questions that screen for the symptoms of potential toxicity, and the 5-10% of patients who are flagged at some point are then directed back into the cancer service with contact information. The benefit of this approach is that these symptoms often go undiagnosed or untreated for many months, causing significant undue anxiety and distress or unnecessary and prolonged investigation.

International Standards

In terms of the data themselves being used in these initiatives, multiple academically and clinically robust resources and libraries are available, such as the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life tool, EORTC qlq-30, elements of which are being used by NHS Scotland; the three item ALERT-B screening tool to detect gastrointestinal symptoms after pelvic radiotherapy; and the international Standard Sets produced by the International Consortium of Health Outcomes Measurement (ICHO) that now include lung, breast, prostate, and colorectal cancer.

ICHO was first established in 2014 as a partnership between Harvard Business School, US, Boston Consulting Group, US, and the Karolinska Institutet, Sweden, to set a global standard for outcomes measurement at the level of the clinical condition. The work is underpinned by a framework developed by Professors Michael Porter and Elizabeth Teisberg. The 'Value Agenda' or 'value-based healthcare' argues that the overarching goal of healthcare delivery has to be focussed on increasing value for all patients, where value is the health outcomes delivered per dollar spent.

The Standard Sets of outcomes developed by ICHO leverage 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.

As healthcare organisations around the world are now agreeing and adopting standards for outcomes measurement, such as those produced by ICHOM, further opportunity is available to benchmark and learn from the best in the world. Ultimately, the providers embrace these developments that will thrive; outcomes data will be used to market and differentiate on quality and value to win on reputation and market share in competitive markets.

The Technology Imperative

In the UK, the healthcare landscape has never been better for technological innovation. After years of high-profile and expensive failures, fragmented approaches and small-scale pilots, Matt Hancock, the new Secretary of State for Health and Social Care, who has a background in technology and has set out a clear vision for technological transformation in the NHS, stated in a recent speech delivered to a NHS health technology conference: "I intend to bring my knowledge and experience and, frankly, my unsurpassable enthusiasm for tech to Britain's health and social care system... and boy do we need it." In this environment, and with organisations working to adopt best practice and reinvigorate care pathways, as well as growing clinical evidence for the benefits of outcomes measurement in cancer,

greater adoption of systematic, longitudinal digital outcomes measurement can be expected to support the transformation of cancer services and improve outcomes for all patients.

References

1. Basch E *et al*, Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment, *JAMA* 318(2): pp197-8, 2017
2. Visit: cancerchallengescotland.com/funding-calls/new-approaches-record-and-integrate-cancer-proms-and-prems/proms-prems-phase-2

About the author



Dr Tim Williams is the Co-founder and CEO of My Clinical Outcomes – a technology platform that automates the collection and analysis of PROMs in clinical practice. Tim previously worked as an NHS doctor and strategy consultant and has a keen interest in how technology can help improve healthcare services, having also undertaken Professor Michael Porter's Value-Based Healthcare seminar series at Harvard Business School, US.