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Patient-reported outcomes and personalised cancer care

Putting the patient at the core of personalised cancer care delivery remains the elusive final frontier

Over 20 years ago, the Australian House of Representatives Inquiry into the management of breast cancer recommended that cancer care should be delivered using a multidisciplinary approach.[1] Ten years later, an article published in this Journal articulated how to put multidisciplinary care into practice,[2] paving the way for the concept to be embedded into clinical cancer practice and policy of today.[3] One of the key recommendations made in the article, and since adopted as national policy, was for the patient to be included "as a member of the multidisciplinary team". But as of today, multidisciplinary care does not routinely include input from patients themselves. Patients do not attend multidisciplinary meetings. Rather, their circumstances are discussed and treatment recommendations are made. They may subsequently make a shared decision with the clinician, but their input tends to occur after the multidisciplinary discussion and it is uncommon for the patients' perspectives to systematically inform these discussions.

Putting the patient at the core of personalised cancer care delivery thus remains the elusive final frontier. The potential benefits of such an approach are well established and include a greater alignment of care with individual patient goals, better understanding of needs, and better patient outcomes and satisfaction.[4] Health care providers are poor surrogates for assessment of patients' symptoms, needs and experiences and patient-reported outcomes (PROs) collection is a way to systematically integrate patients' perspectives into assessment, treatment planning, and ongoing monitoring.[5] PROs report on patients' subjective perception of health, functional status, unmet needs, and quality of life and are collected directly from patients either online, via a smartphone, or through paper-based means. While there are many sets of questions that are relevant to any patient with cancer, specific questions can be tailored to particular cancer types, populations, or different phases of cancer trajectory.[6] PROs as a concept are not new and not unique to cancer. However, while they have been used extensively in research, including clinical trials, their adoption in routine clinical care has received much less attention, with only one article on the topic published in this Journal over 10 years ago.[7] This article summarises the current evidence supporting the use of PROs in cancer as an example of their potential of relevance to broader health care delivery, and argues for their routine adoption into practice.

The evidence for the utility of PROs in cancer care is compelling. A single-institution randomised controlled study of 766 patients included participants with multiple metastatic cancers and assigned them to a usual care group or a group that reported on their symptoms using an electronic portal.[8] The study found that patients reporting PROs had longer survival, with a median prolongation of 5.2 months; comparable in effect size to many effective, novel cancer therapies.[8] In Ontario, where PROs have been routinely collected since 2007, administrative data analysis has shown survival improvement irrespective of the phase of cancer treatment, as well as reduced hospitalisation and emergency department presentations.[9] Two systematic reviews concluded there was strong evidence that implementation of PROs improves patient–provider communication and patient satisfaction.[10,11] PROs are recommended by the Australian Commission on Safety and Quality in Health Care, have been advocated for by the Clinical Oncology Society of Australia, and have been included as a critical element of care in the Australian Digital Health in Cancer Care Roadmap.[12] But to date, their adoption into routine clinical practice has been limited.

Like multidisciplinary care 20 years ago, a significant barrier to their integration has been the ability of the health system to operationalise routine collection and response to PROs data. In 2020, we finally have technology for efficient, real-time collection, reporting of, and response to PROs through customisable portals and dashboards and integration with the electronic medical records. But technology alone is not sufficient and its roll-out, especially with regards to electronic medical records, has been slow and fragmented. Similar to the approach to multidisciplinary care,[2] it is time to articulate the principles and outcomes necessary to integrate PROs into the routine clinical workflow (Box 1). Where multidisciplinary care called for a core team of experts, the PROs collection requires a core dataset. While a dataset using a generic PROs measure, such as the Edmonton Symptom Assessment System Revised (ESAS-r) used in Canada, may be most appropriate for screening for unmet needs in any clinical setting, more specific measures may be required for assessment of different cancer types, different phases of disease (ie, at diagnosis *v* end of life) or for different populations, such as Indigenous patients.[13] There is a need for a clear communication framework involving relevant heath care providers in a timely fashion, with feedback communicated to the patient. The process must be accessible to patients irrespective of technology, rurality, remoteness or language barriers. Lastly, the collection of PROs needs to be underpinned by agreed standards that clearly articulate and support the role of the patient in this process.

While the barriers to adoption of PROs in clinical practice are significant,[14] they are not insurmountable. System redesign may be required to integrate PROs collection and feedback into the routine workflow, with clear pathways to inform a standardised approach. PROs collection should not become an additional task but rather be considered part of a realignment of workload and services to meet patients' needs, reduce care variation, and optimise resource utilisation. A systematic approach to identification of needs is critical to supporting self-management, an essential component of patient care, as it assists the patient in knowing what symptoms are unexpected, what to report, and how to seek support when needed.[15] Data from existing PROs systems show that rapid, real-time feedback to health care providers facilitates timely response, reducing the likelihood of issues escalating or remaining unaddressed. In many cases, this response may only require reassurance and/or advice on self-management, with only the more severe issues necessitating referral and/or hospital admission. With advances in technology, patients and health care providers can obtain visual summaries of trends over time that may assist further in decision making, while aggregated data derived from individual cases can be used to drive health system improvement and plan services to meet demand.

Are we ready for this final frontier? PROs can become an important part of value-based care delivery with support through relevant drivers, such as reimbursement and accreditation. But we need to build capacity through training and a community of practice to share learnings, resources and tools. Many tools already exist (Box 2), with technology fully capable to support rapid processing of data and linkage to electronic health records; although it is important to note that PROs collection can be achieved using paper-based surveys or simple reporting such as text messaging.

As we reflect on the 20 years of multidisciplinary cancer care in Australia, it is worth remembering that multidisciplinary care is not just about multidisciplinary meetings. Similarly, PROs are not just about PROs collection tools. Together, these two complementary approaches put into practice the principle of personalised care. It is the focus on the patient that enables us to realise the full potential of the multidisciplinary care through framing multidisciplinary recommendations in the context of what the patient identifies as their main issues, needs or concerns. It is time to reach this final frontier and make personalisation of cancer care through PROs an achievable standard in Australia.

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[Insert boxes]
[Box 1]

1 Principles of clinical use of patient-reported outcomes (PROs) in cancer care

Principle	Outcome
Core data	Agreed core dataset appropriate for patient, population or setting
Communication framework	Relevant information is communicated to relevant team members in a timely fashion through agreed channels
Access	Systems established to ensure access for all users irrespective of distance, technology, language, literacy level, or completion method
Standards of care	Patients and clinicians are aware of PROs and support their use at key points in clinical care pathway through: ▪ best practice protocols; ▪ stratified alert systems; ▪ reporting framework; ▪ professional development opportunities; ▪ adequate resourcing to allow collection, scoring, review, response and feedback and re-screening; and ▪ feedback and co-design opportunities
Patient involvement	Information and education Self-management support Feedback and co-design opportunities

[Box 2]

2 Examples of clinical practice resources for patient-reported outcomes (PROs) use in routine care

Australian Commission on Safety and Quality in Health Care (https://www.safetyandquality.gov.au/our-work/indicators-measurement-and-reporting/patient-reported-outcome-measures)	General information on PROs, including list of validated measures and guides for implementation
International Consortium for Health Outcomes Management (https://www.ichom.org/)	Multiple resources and standard datasets for multiple conditions including cancer
Cancer Care Ontario, Patient Reported Outcomes and Symptom Management Program (https://www.cancercareontario.ca/en/cancer-care-ontario/programs/clinical-services/patient-reported-outcomes-symptom-management)	A system of PROs screening for patients with cancer, including clinical pathways and guides for patients and health care providers
Clinical Oncology Society of Australia, PROs Think Tank report (https://www.cosa.org.au/media/332504/cosa_pros_think_tank_report_final.pdf)	An overview of evidence, current practice and recommendations for PROs uptake into cancer care in Australia