

## EDITORIAL

**Evidence for the routine collection and clinical utilisation of patient-reported outcomes is compelling: It is time to jump on the bandwagon**Afaf Girgis, BSc(Hons), PhD<sup>1,2</sup><sup>1</sup>University of New South Wales (UNSW Sydney), Sydney, NSW, Australia<sup>2</sup>Ingham Institute for Applied Medical Research, Liverpool BC, NSW, Australia*J Med Radiat Sci* **68** (2021) 108–110

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This issue of the Journal of Medical Radiation Sciences includes three papers which are highly pertinent to the field of medical radiation sciences, on the very topical issue of systematic collection and clinical use of patient-reported outcomes (PROs). In the past decade, evidence of significant benefits associated with systematic use of electronic PRO (ePRO) systems has been accumulating. Whilst these systems have differences, their key features are similar. These include patients completing ePROs (e.g. symptoms, distress, other toxicities), and the treatment team (e.g. nurses, oncologists) receiving automatically generated alerts of above-threshold scores, prompting them to review and action ePRO reports in line with treatment and referral pathways. Some systems also automatically generate information for patients to support self-management of their issues of concern.

Although study designs have differed substantially, their findings have consistently shown significant benefits from well-implemented ePRO systems. These include improved patient satisfaction and health-related quality of life, reduced emergency department presentations and hospitalisations, and increased survival.<sup>1–3</sup> However, realising these benefits on a larger scale requires moving beyond the research setting and determining strategies to optimally embed ePRO systems into routine patient care across entire health systems. Internationally, the adoption of ePRO systems as part of routine oncology care has been limited, and health services often struggle to efficiently and meaningfully use ePRO data to tailor care to individual needs.

A critical first step to supporting oncology institutions to implement and use PROs in routine care is to fully understand the barriers to this occurring. In their literature review of 14 eligible studies, Nguyen et al<sup>4</sup> identified barriers at the patient, health professional and

service levels. As detailed in their paper, the patient barriers include time, incapacity, and difficulty using electronic devices to report their outcomes. Health professional barriers include lack of time and insufficient knowledge to interpret PROs, integrate them in their practice and respond to the PRO data. At the service level, the barriers predominantly relate to inadequate technology infrastructure and challenges integrating PROs into existing workflows. This paper is important as it provides a framework for individual services to map out their particular barriers and to develop a plan for how these can be addressed locally. It is expected that cancer services will experience different barriers depending on the populations they serve (e.g. levels of literacy, access to technology) and their resources (staffing, technology, etc.). Therefore, identifying centre-specific barriers is quite important and should be undertaken early in the implementation process. Inevitably, some barriers will be more challenging to address and may require significant resources (e.g. infrastructure), but others can potentially be addressed more readily, through strategies offered by Nguyen et al<sup>4</sup> in their discussion.

To address a patient-level barrier, Nguyen et al<sup>4</sup> recommend completion of PRO assessments by a proxy (e.g. carer, spouse) on the patient's behalf in cases where a patient is either too unwell or unable to complete it for another reason (e.g. low literacy). Carers often play a critically important role in patients' care, including accompanying patients to their oncology appointments, and are therefore an important source of information about patients' physical and psychosocial well-being. However, it is well documented that carers often report higher and more persistent distress than the cancer patients themselves<sup>5</sup>; hence, there is a growing impetus to also routinely assess their physical and psychosocial well-

being. Whilst systems have been developed for electronic capture of patient-reported outcome measures (PROMs) in a clinical setting, there has been little work to date focusing on developing equivalent electronic systems for carers (eCROM). The Wishart et al<sup>6</sup> paper addresses this important area, reporting on the implementation of ScreenIT Carer, an eCROM system to monitor the prevalence and nature of general and mealtime-specific distress in carers of patients undergoing (chemo) radiotherapy (C(RT)) for head and neck (H&N) cancer. This study of 135 carers, who completed a total of 434 assessments over the course of the patients' (C)RT treatment, is important for a number of reasons. First and foremost, it highlights the expectedly high levels of carer distress, with clinically significant levels of general distress noted by 59% of carers and mealtime-specific distress reported by 46% of carers, as well as the trajectories and predictors of that distress.

Second, it demonstrates the feasibility of carers completing eCROMs, whilst also highlighting the need for a more systematic approach to reaching all carers. In this study, carers' adherence rates for completing the assessments were on average 41%, which may have been in part due to lack of opportunity to complete the eCROMs in cases when carers did not accompany the patient to treatment. The authors suggested that another possibility is that carers may have elected to complete the assessments when their distress levels were higher, hence potentially over-inflating the levels of distress reported in this paper. Whilst this is a limitation of the study, the levels of distress are not inconsistent with published literature; hence, this should not be an undue concerning limitation. Clearly, further work is required to better understand the distress carers experience in different contexts. Overall, this study presents some interesting findings, not just confirming the distress experienced by carers of H&N cancer and the trajectory of distress over the course of treatment, but also in relation to the potential gains from implementing an eCROM system to systematically collect important information to better support carers in undertaking that critically important role.

Another important factor with PRO implementation is considering whose role it is. In much of the published PRO literature, the role of facilitating PRO assessments and reviewing and acting on the reports has largely fallen to oncology nurses and specialists. In this issue, Arnold et al<sup>7</sup> report the results of a study which explored the role of radiation therapists (RTs) in routine screening of cancer patients' symptoms and distress. Whilst this group has not traditionally undertaken this role, the authors make a strong case for their suitability to undertake PRO screening, given their regular contact with cancer patients

undergoing radiotherapy treatment during potentially high-stress phases of their care. Whilst the small sample size is a limitation, 37 of the 39 eligible RTs in the two cancer centres which adopted this very specific model of care participated (95% response rate). Importantly, the study identified a reasonable level of support for PRO screening and RTs felt relatively confident with some of the more psychosocial aspects of care including discussing psychosocial issues and recognising anxiety and depression. However, RTs confirmed a number of the health professional barriers identified by Nguyen et al,<sup>4</sup> including lack of time and insufficient knowledge regarding implementing PROs. It is important to note that the majority of RTs had not received any psychosocial (86%) or emotional cues (77%) training, and lack of education on psychosocial concerns was the highest-ranking barrier to undertaking PRO screening. Nguyen et al<sup>4</sup> highlighted the importance of incorporating staff training, education and guidelines into the early stages of the implementation process, and this was reinforced by Arnold et al.<sup>7</sup> Importantly, training programmes are effective in improving confidence and skills, including a communication skills and emotional cues training programme which is specifically developed for RTs and previously reported in this journal.<sup>8</sup>

Together, the three papers discussed here make a compelling case for health services to consider implementing PROs. For centres which have not yet adopted ePRO systems, a very pragmatic starting point is to undertake an assessment of their local barriers, guided by the Nguyen et al<sup>4</sup> review, and involve staff at all levels within the centre in workshops to identify potential strategies to address barriers. Another important factor with PRO implementation is considering whose role it is to administer and act upon PROs. The published evidence for routine collection and clinical utilisation of PROs is compelling. It is time to jump on the bandwagon.

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