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Utilising ehealth to support survivorship care

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Abstract
Cancer survivors represent approximately 3.5% of the Australian population. Physical and psychosocial issues experienced as a result of a cancer diagnosis and treatment persist into long-term survivorship. While oncology care pathways that routinely include comprehensive symptom and emotional well-being assessments have been shown to improve patient outcomes, such assessments are not routinely undertaken. Electronic Patient Reported Outcomes (ePRO) systems are increasingly used in cancer clinical care settings and are superior to paper-based PRO assessments, as they can facilitate assessment in a range of languages, as well as automated scoring and generation of real-time feedback reports to the care team. Linkage of ePROs into existing patient records integrates psychosocial information with other clinical information, enabling patient-centred care. In NSW, an ehealth system being developed and pilot tested, supports ePRO assessments which generate real-time feedback to the clinical team and access to self-management resources to assist survivors to better manage their own health and wellbeing.

Keywords
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UTILISING EHEALTH TO SUPPORT SURVIVORSHIP CARE

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Abstract

Cancer survivors represent approximately 3.5% of the Australian population. Physical and psychosocial issues experienced as a result of a cancer diagnosis and treatment persist into long-term survivorship. While oncology care pathways that routinely include comprehensive symptom and emotional well-being assessments have been shown to improve patient outcomes, such assessments are not routinely undertaken. Electronic Patient Reported Outcomes (ePRO) systems are increasingly used in cancer clinical care settings and are superior to paper-based PRO assessments, as they can facilitate assessment in a range of languages, as well as automated scoring and generation of real-time feedback reports to the care team. Linkage of ePROs into existing patient records integrates psychosocial information with other clinical information, enabling patient-centred care. In NSW, an ehealth system being developed and pilot tested, supports ePRO assessments which generate real-time feedback to the clinical team and access to self-management resources to assist survivors to better manage their own health and wellbeing.

In 2014, around 128,000 Australians were estimated to have been diagnosed with cancer, this is projected to rise to 150,000 cases in 2020.1 Approximately 65% of patients live longer than five years post-diagnosis, the vast majority cured from their cancer.2 With some of the highest cancer survival rates in the world,3 the prevalence of people living with cancer represents approximately 3.5% of Australians.4 Increased survival is associated with the persistence of treatment-related side-effects, higher rates of cardiovascular disease, diabetes, osteoporosis and functional decline post-treatment,5-12 and increased risk of diagnosis of a subsequent or treatment-induced cancer. Psychosocial issues also persist into long-term survivorship, including unmet needs relating to information about late-effects, managing fatigue, genetic risk to family and diet.13 In 2005, the landmark US Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition,14 highlighted deficiencies for patients undergoing and completing cancer treatment. Despite this report now being 10 years old, the provision of evidence-based survivorship interventions remains patchy.15-19

Person-centred care reflects a movement away from predominantly tumour-focused treatment toward care for the patient as a whole, acknowledging that cancer presents not only physical, but also emotional, social, informational, spiritual and practical challenges for patients and their families.20,21 Much psychosocial morbidity experienced by cancer patients is not detected by healthcare providers and remains untreated.22-25 Screening for distress has been advocated as one of the drivers to achieving person-centred care and oncology care pathways that routinely include comprehensive symptom and emotional wellbeing assessments have been shown to improve patient outcomes.26,27 However, the evidence is not unanimous in support of screening. Bidstrup et al reviewed seven randomised controlled trials,28 concluding that distress screening has limited effect on psychological well-being, though noting methodological weaknesses in several trials. However, they also concluded that screening could be clinically valuable if it was established “as part of a well-functioning total system,” where identification of those at risk was linked with a detailed, theory-based distress management plan and staff training. In a more recent review of 27 studies, Chen et al concluded that routinely collecting patient reported outcome (PRO) measures enabled better patient-centred care in cancer settings where a patient management plan was integrated with routine collection of PROs. There was strong evidence that well-implemented PRO systems with timely feedback improved patient-health care provider communication and patient satisfaction, and might also improve the monitoring of treatment response and detection of unrecognised problems.29

Electronic PRO (ePRO) systems, increasingly used in cancer clinical care settings, are superior to paper-based
PRO assessments in their potential accessibility in a range of languages, completion in the clinic or remotely, automated scoring of assessments, generation of real-time feedback reports to the care team, and linkage into existing patient records, integrating psychosocial information with other clinical information. Two Australian ePRO systems tested in randomised controlled trials reported some impacts on patient outcomes, or impacts only on sub-groups of patients, but both were limited by being ‘stand-alone’ systems. Their lack of integration into the clinic’s electronic health record limited their likelihood of routine adoption and at this point, neither has led to systematic clinic implementation beyond a trial.

**PROMPT-Care: a home-grown eHealth system supporting person-centred care**

With Cancer Institute NSW and BUPA Health Foundation funding, a collaborative partnership between the South Western Sydney Local Health District and the Illawarra Shoalhaven Local Health District has developed, and is piloting an eHealth system (PROMPT-Care). This project has considered some of the past ePRO attempts and has been well-informed by features identified as important to supporting a successful ePRO system (summarised in table 1) in a review of 33 ePRO systems (70% in the US, none from Australia) in 2013.

The departments participating in the PROMPT-Care development and pilot testing currently use an electronic oncology information system (OIS; MOSAIQ, version 2.4, Elekta Inc.) to routinely manage oncology patients in the clinic across all oncology disciplines, with all teams able to view the record. PROMPT-Care supports the electronic collection and importation of PROs directly into the OIS while patients are undergoing treatment and during post-treatment into long-term survivorship. Stored ePRO assessments can be used in routinely generated, real-time reports that inform the treatment team about patients’ reported symptoms, unmet needs and distress levels, as well as recommended care pathways uniformly referring patients for specific interventions based on their PROs. This system provides the advantages of supporting personalised care for each individual patient and sending alerts for patients with serious requirements. It will have the following key features:

- Facilitating routine risk-stratified and shared care by supporting more efficient and timely communication with the general practitioner in the survivorship phase as well as during treatment, and stratification of patients according to ongoing need.
- Facilitating self-management by delivering evidence based, tailored self-management information which is responsive to the types and levels of problems and needs identified by survivors, enabling them to take an active role in decision making and managing their ongoing care and recovery.
- Supporting survivors of culturally and linguistically diverse backgrounds by facilitating better communication with patients in their own language.

<table>
<thead>
<tr>
<th>System design features</th>
<th>Data collection features</th>
<th>Assessment reporting and workflow integration features</th>
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<tr>
<td>• Flexibility – allowing the system to: transition from treatment to survivorship; be able to be used at home as well as at clinics; specify assessment time points or have an open ended schedule (patient completing the assessment whenever they want to).</td>
<td>• User friendly for patients, staff, clinicians and researchers – option to save data when sessions are interrupted with easily understood page layouts and the ability to move quickly through questionnaires.</td>
<td>• Integration of PROs with electronic hospital records – allows linkage to automated scheduling and automated linkage/referral to other clinical care providers.</td>
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<td>• Integrates treatment-centred and patient-centred perspectives into one system: automatic integration of PRO content tailored to individual patient needs; flexibility in clinician report structure depending on patient need (e.g. treatment report providing detailed toxicity data; survivorship report providing more longitudinal monitoring); integration of patients’ self-identified concerns (PRO administration tailored to patient preference).</td>
<td>• Minimal burden on staff – ensuring the system includes automated alerts for follow-up assessments.</td>
<td>• Clinicians accessing and using the PRO reports: i) providing information that is actionable ii) quick and accurate interpretation of results iii) inclusion of general interpretation guidelines iv) identification of meaningful changes v) ability to report PRO scores in a numerical text-based format vi) ability to include graphical representation of PRO scores.</td>
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including systematic collection of their PROs and access to self-management resources in different languages.

- Developing the evidence base to identify gaps in care. PROs are increasingly incorporated into almost all clinical trials. Collection of PROs longitudinally through a flexible eHealth system enables assessment of whether subsequent interventions lead to improvement in patient outcomes, with patient-identified needs analysed across patient groups to determine the differential effectiveness of interventions.

While this pilot is the first step in this process, a number of groups have shown the power of developing this across treatment centres. For example, several US groups have reported significant investment in the development of very large database and research collaborations across many health centres, where a data collection model of routine PRO data collection is at the centre of the collaboration.35-41 The storage of ePRO data with the clinical record opens the possibility of correlating patient outcomes across the entire spectrum of the patient.

**Building cancer treatment and survivorship care for the future**

The PROMPT-Care project faces the twin challenges of developing a robust, secure, private infrastructure to transfer assessments between patient and institution, and a delivery system to transfer tailored care to specific patients when required. The system is not limited to cancer. However, its delivery of a completed assessment when required. The system is not limited to cancer. However, its delivery of a completed assessment into the patient’s electronic record is unique and opens up the possibility of initiating human contact, providing advice about online resources and prompting more specific surveys to delineate problems.

Personal smart device use facilitates patient contact before, during and after treatment, and collection of increased amounts of phenotypic data that may, in time, prove to be important. The use of the OIS as the repository for completed ePROs addresses many issues of security and privacy, and specification of healthcare providers within the OIS makes notification of patient information to other healthcare providers highly feasible.

Pilot testing of this eHealth system in a population of cancer patients initially involving English-speaking patients, will determine feasibility, including overcoming some possible information technology hurdles such as data traversing the hospital information system firewall, data flowing to the correct patient record and an e-report uploading to the clinician in real-time, for example, when the patient is. Other challenges include patient acceptance, clinician acceptance and the systematic issues that might be encountered in having patients enter data in the waiting room prior to being seen in a busy clinical area, or at home. Clinical advisory groups will guide appropriate initial questionnaire selection, with a focus on evidence-based, widely accepted and clinically validated tools, and care pathways prompted by PROs indicating high levels of need. Technical advisory groups will work on identifying and overcoming technological challenges of moving data from the assessment device outside secure hospital system firewalls and ensuring data are correctly placed in the OIS. The long-term plans will be to ensure that this system works across various different electronic OISs, with the intention to make this a state-wide rollout.

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