



National Digital Health Strategy Consultation

Submission from the Clinical Oncology Society of Australia and Cancer Council Australia

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The **Clinical Oncology Society of Australia** (COSA) is the peak national body representing health professionals from all disciplines whose work involves the care of cancer patients.

Cancer Council Australia is Australia's peak national non-government cancer control organisation and advises the Australian Government and other bodies on evidence-based practices and policies to help prevent, detect and treat cancer and also advocates for the rights of cancer patients for best treatment and supportive care.

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How well the current healthcare system works

What aspects of healthcare currently work well from your perspective?

Overall, the health of the Australian population compares well internationally. Life expectancy is among the highest in the world, with Australia ranked sixth highest in the OECD at 82.2 years. In addition, Australia's infant mortality rate is amongst the lowest in the world. Importantly, Australia is able to achieve good population health outcomes relatively efficiently, with health expenditure at 8.8% of GDP, which is on par with the OECD average of 8.9%.

The Australian health system has been shown to deliver better cancer outcomes than health systems in comparable countries. A recent study that compared survival rates for 11 common cancers across 67 countries has shown that survival rates in Australia were amongst the best in the world. Specifically, five-year net survival was high for all 11 cancers, in particular cancers of the colon, rectum, breast and prostate. Australia's world-leading cancer survival outcomes are likely to be due to the significant investments in screening, early detection and treatment that the Australian Government has made over many years along with a readily accessible public health system. There is also some evidence in cancer that clinical trials help to improve cancer outcomes overall and Australia has a long standing commitment to international trials of new therapeutics.

In Australia, there are three national population-based screening programs, for breast, cervical and bowel cancers, that help detect cancers early and, in some cases, detect early changes that could go on to become cancer. The introduction of population-based screening programs has resulted in significant reductions in mortality attributed to these cancers. The increased availability and quality of diagnostic services and treatment services, including timely access to the right combination of surgery, radiotherapy, and chemotherapy, have also contributed to improvements in cancer survival in Australia.

What aspects of healthcare need improvement?

There is evidence of variability in cancer outcomes by factors such as region, socio-economic status and ethnicity. The reasons for disparities are complex but the gap is not closing for low socio-economic status communities; relative survival is improving slowly in Indigenous Australians compared with non-Indigenous Australians.

If a patient is unable to travel to receive treatment at a public centre, they may be forced to pay a high premium elsewhere or choose suboptimal care. As a consequence, outcomes for patients living in rural and remote areas of Australia are inferior to those of their urban counterparts. It is critical that patient access to affordable, geographically accessible health services, including specialist services, is supported. Some of these issues are addressed by Australian Government investment in rural cancer centres but some are likely to be the result of an overlay of low socio-economic status in rural communities.

Population cancer registries are unable to explore unwarranted clinical variation in outcomes until stage, treatment and recurrence information is integrated in both clinical information systems and cancer registries. Thus a major area for improvement is enabling electronic health records to be integrated with national data collections. We welcome the Government's current approach to sharing MBS and PBS data to enable easier linkage of state and national data to help improve understanding of outcome variations.

Policies are needed to address increasing out-of-pocket healthcare costs, which comprise a significant portion of health spending compared with other OECD countries. Cancer patients in Australia experience significant out-of-pocket costs for their treatment. For example, in a study of cancer patients in NSW and Victorian hospitals, one in three said the out-of-pocket costs of their treatment imposed significant financial burden.

For the aspects of healthcare that you consider need improvement, what do you think are the barriers to improving performance in this area?

Alternative models of care have been put forward to help address the gap between rural and urban cancer outcomes in Australia. One such model involves the use of telehealth services such as videoconferencing (synchronous or real time telehealth) and store-and-forward technology (asynchronous telehealth) in cancer care. Despite its potential advantages, the uptake of telehealth services in Australia has been slow and inconsistent, which may be due to a number of factors.

Current telehealth-related MBS item numbers only cover real-time video interactions, while asynchronous store-and-forward telehealth services such as those used in teledermatology are not covered. Similarly, there are currently no MBS item numbers that cover patient consultations with allied health professionals. In addition, the level of telehealth-related knowledge and skills within the health workforce is limited. In services where staff turnover can be high, such as in rural and remote areas, and new staff are faced with a high initial workload and steep learning curve, enthusiasm for new ways of delivering health services, such as telehealth, may be limited.

Practical problems associated with scheduling, coordination, integration between public and private health services, as well as interoperability of equipment, have also been identified as barriers to the adoption of telehealth services in Australia.

Patients who travel long distances to access essential services, have limited mobility and/or a low socioeconomic status, experience a significant financial burden associated with hidden costs such as parking and transportation and lost wages due to carer responsibilities, +which may be reduced by the implementation of telehealth strategies. Government schemes aimed at subsidising expenses associated with travel to and from services do not adequately cover the costs borne by patients, and are falling short of supporting affordable access to essential cancer care.

Being in control of your healthcare

One of the Australian Government's key aims is to empower people to be in control of their own care.

What does 'being in control of your healthcare' mean to you?

We understand the phrase 'being in control of your healthcare' to encompass a number of components, including health literacy, shared decision-making and supported self-management.

An individual's *health literacy*, defined as the degree to which they have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions, is an important determinant of their ability to be in control of their healthcare. Health outcomes tend to be poorer, and hospitalisation rates higher, in those with low health literacy.

Shared decision-making is a process in which patients and healthcare professionals work together in order to make decisions about care and treatment based on both evidence-based best practice and the individual patient's preferences. A key part of shared decision-making is the acknowledgement that patients and healthcare professionals bring different, but equally important, skills and knowledge to the process. In the area of cancer care, shared decision-making has been identified as an important part of patient-centred care, and has been associated with improved patient knowledge about treatment options and increased satisfaction with the overall care experience.

Self-management is the active engagement of people suffering from chronic and complex health problems in the management of their own health. Self-management interventions in cancer may help patients manage the physical symptoms and psychosocial distress associated with the treatment phase of the cancer-care continuum, while interventions during the post-treatment phase may be focused on issues such as stress, depression, sleeplessness, fear, or changes in body image. Importantly, digital health initiatives such as the My Health Record, which enable patients to access their own health information, have the potential to help them better monitor and manage their chronic and complex health problems.

Digital technologies used in health and wellbeing activities

In recent times, digital technologies have changed the way we shop, travel, bank and socialise. To what extent do you agree with the following statement:

- Strongly Agree**
- Agree
- Indifferent
- Disagree
- Strongly Disagree

How would you like to see digital technologies change people's experiences of managing their health, and the way they interact with the healthcare system?

The widespread adoption of broadband and wireless technologies in the home, together with the availability of a variety of portable, smart devices, can improve care for patients in all phases of life, from wellness to acute and post-acute care. Individuals can now actively participate in the management of their own health, and interact with the health system in a variety of ways:

- Downloaded applications (apps) allow patients to track and record various symptoms including, pain, distress and anxiety, mobility and function. These apps can provide reminders for medication, as well as provide a patient with general health information. These activities can be undertaken between consultations to continuously capture accurate information about their health status and facilitate ongoing communication between the patient and their care team.
- Information from apps should be downloadable onto patient electronic health records which can be accessed by members of the care team. This facilitates self-management by the patient and alerts the care team to changes in the patient's condition.
- The vast amount of information provided to patients during a consultation with their healthcare professional can be overwhelming, and can lead to confusion and an inability to accurately recall and comprehend the information given to them. Apps such as [CAN.recall](#) function as a communication aid that allows patients to record

their consultation, replay it to improve their understanding of their specialist's advice and share it with family and friends as necessary.

- Through the My Health Record, patients should be able to access active prescriptions and referrals, which may reduce unnecessary consultations.

Healthcare professionals

What gets in the way of healthcare professionals being able to connect, communicate and coordinate with the right people?

Despite the fact that telehealth technologies have the potential to achieve considerable health system efficiencies and reduce costs, little progress has been made towards their widespread adoption for a number of reasons:

- There has been a lack of widespread support for the implementation of these technologies in clinical practice, as this requires significant planning and investment in both infrastructure and human resources, including training for the health workforce in how to effectively use these technologies.
- Resistance to adopt new models of care, particularly in a resource poor, busy healthcare environment, where there are many competing priorities.
- A lack of understanding of the benefits to both the health of patients and health professionals in their practice.
- Limited evidence on the clinical and cost-effectiveness of these technologies.
- Until recently, the absence of a comprehensive electronic patient record containing a medical history which can be used to support informed decision making regarding a patient's care.
- A lack of flexible funding and reimbursement pathways to support the widespread adoption of new models of care.
- Reluctance by health care professionals to engage with new technologies that hold patient information due to medicolegal and privacy concerns.

What do health professionals need to be able to effectively connect, communicate and coordinate with the right people?

In order for new models of care, such as telehealth, to make the transition from pilot projects and trials into mainstream healthcare delivery, a significant shift is needed:

- Training focused on new systems and technologies that health professionals will need to understand and utilise, in order to effectively manage the care of their patients.
- Integrating optimal care pathways into professional development programs offered through professional bodies, in order to increase awareness, understanding and application of up-to-date, evidence-based best practice which can be implemented within the local healthcare context.

- Endorsement and modelling by key opinion leaders or champions within a clinical speciality.
- Ideally, widespread adoption by health service organisations, both public and private.
- Routine collection, analysis and communication of outcomes data demonstrating the value of the technology over time, for patients, providers and the healthcare system.
- Ensuring processes are in place to capture and incorporate feedback from users regarding a wide variety of issues to inform systems improvement.
- Building relationships with peak bodies such as the Clinical Oncology Society of Australia, to more effectively communicate the benefits of integrating digital technology into clinical service delivery, as well as opportunities for training and skills development with their multidisciplinary cancer care membership.

Organisational priorities and digital health

What are your organisation's priorities in respect to digital health or eHealth?

Continuity of care is acknowledged as an essential characteristic of high-quality healthcare, and research suggests that continuity of care for patients with chronic conditions prevents hospitalisations and reduces healthcare costs; however, providing care that is coherent and linked, and is the result of good information flow, good interpersonal skills, and good coordination, is challenging. In the case of cancer, best practice care is delivered by a multi-disciplinary team, which ensures that the needs of the patient, including treatment, psychosocial, and supportive care, are addressed in a timely manner. For people diagnosed with cancer, survivorship care plans help ensure that the patient and all of the members of their healthcare team know what follow-up is needed, when it is needed, and who they should see for that care. The use of digital technologies such as the My Health Record will facilitate multi-disciplinary care, enabling the sharing of data across different healthcare providers and organisations, and may be particularly useful in areas such as cancer survivorship.

It is important that patient access to affordable, geographically accessible health services, including specialist services, is supported. This facilitates the utilisation of the most effective interventions to support the management of an individual patient's condition. In cancer, we know that access to services affects use of services, which in turn can impact on health outcomes. This is particularly relevant in regional and rural areas, where there is less specialisation of medical services, which influences treatment decisions and outcomes. The adoption of teleoncology models of care offer the opportunity for patients living outside of major metropolitan centres to access specialist treatment and eligible clinical trials closer to home, reducing the need for travel and increasing treatment options. This type of model also links healthcare professionals to support and ongoing professional development through upskilling and mentoring programs.

Data, technology, and improved health and wellbeing

How could data and technology be better used to improve health and wellbeing?

The availability of quality data is critical to the delivery of cancer care and cancer control services more broadly. In Australia, there are gaps in cancer data, where the data is either not available, incomplete, or not sufficient for national reporting purposes. For example, with advances in prevention, screening and treatment, many of those affected by cancer are now living longer, either free of disease or with recurrent disease; however, despite this, there is little data describing the quality of life of patients after treatment, intermediate and long-term toxicities, or the impact of new treatments and technologies. Therefore, improvements in the completeness, quality and availability of cancer data will help strengthen the evidence base on emerging cancer issues, current and planned cancer control interventions, and future trends.

Australia has a number of high value cancer datasets, which when linked, will enable better informed health policies and service delivery and more efficient use of health resources; however, one of the key concerns with data linkage is the protection of individuals' privacy. While the consideration of privacy standards is very important, it is also important to note that well-established linkage protocols that are capable of preserving individual privacy already exist in Australia. It is critical that government continues to fund initiatives such as the Population Health Research Network (PHRN), which is developing and testing leading-edge technology to ensure the safe and secure linking of data collections whilst working to protect people's identity and privacy. One such example is the Secure Unified Research Environment (SURE) system, a remote-access data research laboratory developed by the Sax Institute as part of the PHRN, that enables structured access for researchers to secure and sensitive datasets held on separate secure servers.

Priority initiative for My Health Record

What should be the immediate priority initiative for the My Health Record to ensure it delivers real value for clinicians and the public?

Personally controlled health records such as the My Health Record have many benefits, including helping consumers become more proactive participants in the management of their own health, as well as improved consumer-provider communication, access to data in medical emergencies and chronic disease management. In the case of cancer, best practice care is delivered by a multi-disciplinary team, which ensures that the treatment, psychosocial, and supportive care needs of the patient are addressed in a timely manner. The use of personally controlled health records will facilitate multi-disciplinary care, enabling the sharing of data across different healthcare providers and organisations, and may be particularly useful in areas such as cancer survivorship.

There are also challenges associated with the use of personally controlled health records. Individuals are able to remove clinical or Medicare documents from their My Health Record at any time, and as a result these documents may no longer be accessible, even in an

emergency. If individuals remove information without consulting with the relevant healthcare professional(s), this raises concerns about the accuracy and reliability of the data contained within the record. Australian Medical Association (AMA) president Michael Gannon has noted that 'Giving patients such control, as the My Health Record system does, is a big handicap to the clinical usefulness of shared electronic medical records'.

Individuals should have the right to access their My Health Record, including the right to request edits or corrections for reasons of accuracy; however, serious consideration needs to be given to the level of content control patients currently have, as it is likely to have an impact on how the record is viewed by healthcare professionals, and as a consequence its utility in clinical practice and its value to health and medical research.