Supplementary submission to Senate inquiry into rare cancers
Daffodil Centre, Sydney Cancer Partners (written submission 32)

Response to question on notice, taken at public hearing in Sydney, 31 January 2024

Paraphrasing the transcribed discussion, the following response aims to answer the question, "how can the health system improve data linkages and make better use of assets such as Australia's My Health Record to improve outcomes for people with rare cancers".

Background

Utilisation of patient data in mechanisms such as Australia's My Health Record is defined as "primary" or "secondary" – primary for the direct benefit of individual patients and secondary for deidentified and aggregated data used for research and public health purposes.

While we caution against inflexible application of the terms "primary" and "secondary" (e.g., public health research/algorithms can inform individual clinical decisions), we provide the following summary in relation to the two tiers of data linkage and usage.

Irrespective of this terminology, evidence shows that up-to-date, accessible, linked datasets, for use in both optimal care for individual patients and research to inform evolving treatment technologies and approaches, is increasingly important for improved patient outcomes.[1]

The problem

The challenges of data linkage and utilisation to improve clinical decision making, policy and practice are multifaceted and compounded by the complex mesh of federal, state/territory, regional/local, public and private healthcare services and databases. Moreover, in some of these parts of the system there is no effective data collection for leveraging to improve the design and delivery of services for Australia's growing cancer patient population.

We acknowledge that substantial work has been undertaken over the past 20 years aimed at addressing these problems, such as the introduction of Australia's My Health Record, Digital Health Agency and a range of government consultations and strategies.

While these developments are welcome, in our experience as clinicians, researchers and advocates working with consumers, they only scratch the surface of what could be achieved if there were fundamental changes in how patient data is collected, managed and accessed.

Key barriers to improved data-driven cancer outcomes include:

- The absence of linkages between Australia's large health datasets (e.g., Medicare, PBS, hospital separations data).

- Underreporting, and inconsistency in existing reporting frameworks, across the system against areas of best practice such as optimal care pathways for cancer.

- Vital technological developments in areas such as genetics and genomics, molecular profiling and artificial intelligence outpacing the system's capability for applying them through effective use of data to systematic improvements in patient outcomes.

- Disconnects between data on medical and supportive care, compromising the provision of person-centred multidisciplinary care and monitoring of outcomes.

---

[1] Chapter 10: Health information in Australia: an evolving landscape with an integrated future (aihw.gov.au)

- Concerns about data security (which could, in our view, be addressed by existing safeguards) sometimes used as a block to progress on improved data linkage and sharing to advance health policy, practice and outcomes.

- Fragmentation, inconsistency and gaps in patient data limiting the extent to which healthcare professionals can make rapid clinical decisions.

- Patient control of My Health Record, while a fundamental and necessary component of the system, limiting its utility for data collection and application to optimal care.

- Ongoing fragmentation and proliferation of datasets, as individual health services and networks and private data management providers seek to address their individual data needs with no national or intersectoral coordination.

- An emphasis on theoretical "strategies" rather than actionable (therefore more challenging, but necessary) plans to streamline data systems, mainframes etc.

Many of these challenges are captured in the Australian Institute of Health and Welfare's landmark report, *Health information in Australia, an evolving landscape.*[2]

Successful models

Despite these challenges, there are successful models of data linkage shown to improve healthcare outcomes in areas of high need. One example is the Territory Kidney Care initiative in the Northern Territory[3], a clinical decision-making system using data analytics to inform best practice to improve kidney health in Aboriginal communities.

The Territory Kidney Care initiative has shown that barriers can be broken down to integrate primary, secondary and tertiary patient data to develop algorithms that inform rapid clinical decision making and improvements in practice. Keys to its success include:

- Identification of high need in a priority population

- Support from clinicians, consumers and advocates at all points in the care pathway

- Data collection systems adapted to support ease of integration on a shared platform

- Patient-centred care supported by individual multidisciplinary clinicians informed by agreed guidelines

- A shared commitment from all stakeholders to achieving measurable outcomes, underpinned by goodwill and informed by extensive community consultation.

We acknowledge that the challenges are significantly greater for the cancer patient population. However, the principles remain the same – as do the facts showing that improved data management will be a key to improving outcomes for rare cancer patients.

Developments in other countries/jurisdictions (such as Portugal[4]), where data platforms are integrated and adherence to electronic reporting requirements is high, show that progress can be achieved if there is sufficient political will and evidence-based plans.

We also acknowledge the work underway through initiatives such as the Australian Rare Cancers Portal and a range of other studies and pilots highlighted in our original submission. However, these are largely disconnected and are not funded at a scale required to bring about system change to address the problems set out in this supplementary response.

---

[2] Chapter 10: Health information in Australia: an evolving landscape with an integrated future (aihw.gov.au)
[3] Territory Kidney Care (TKC) - Menzies
[4] Assessment of hospitals' websites in Portugal - PMC (nih.gov)

In supporting the objectives of this inquiry, data-driven solutions should recognise that:

- 'Rare' cancers also include complex subtypes of many primary cancers otherwise characterised as common by site.

- Improvements in the management of rare cancers can provide unique opportunities to enhance learnings (from biological science to improved targeted of care pathways to individual need) relevant to all cancers.

- Opportunities in emerging technologies such as proteomic and proteogenomic science may hold keys to major advances in pan-cancer control and will require agile use of patient information, at the individual clinical level and the use of deidentified data in epidemiology.

- Opportunities exist in areas such as wearable health devices, which could assist patients in managing their health data and could be integrated with health records.

Recommendations

Accelerated advances in the use and linking of health databases, including My Health Record, to improve cancer outcomes require a whole-of-government commitment, a willingness to overcome entrenched barriers and incentives for all stakeholders to adapt to consistent approaches to collecting and managing patient information.

These are large challenges, but not insurmountable if addressed urgently and through measures that are adapted as the health landscape evolves. Without action, many of the problems we have identified may worsen through increased fragmentation and an inability for data systems to keep pace with technological change.

Our advice to the committee is to recommend that Australian federal and state/territory governments take definitive actions to:

- Audit existing data collection systems and work across sectors to improve consistency of datasets to facilitate data linkages (at population level) and rapid clinical decision making (at individual patient level).

- Support clearly defined structural (rather than theoretical) improvements in data collection and management through the development of national protocols for all electronic medical record systems.

- Develop and trial more individual data-sharing models designed to improve outcomes in rarer, low-survival cancers, learning from successful models in the management of other disease types and in international electronic health systems.

- Establish frameworks for the collection and use of patient data to respond to rapid changes in technology, such as molecular profiling, proteomics etc., to adapt as the health science landscape evolves.

- Integrate multidisciplinary/supportive care into personal health records to provide a platform for monitoring interventions and outcomes that support all components of patient-centred care.

- Support systems that assist patients in the management of their own health data, including integration of wearable health devices into data platforms.

- Develop strategies for healthcare professionals to assist patients in managing their health information to improve overall quality of life.