

Aide-Mémoire

Ovarian Cancer Register

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To:	Hon Simeon Brown, Minister of Health		
From:	Dr Richard Sullivan, Executive National Director - Clinical		
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Contact for further discussion (if required)			
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Purpose

1. This Aide-Mémoire addresses your request for advice about options to develop a national ovarian cancer register, including considerations through the current CanShare programme of work, and outlines the additional costs, benefits and risks of establishing a standalone register.

Background

2. New Zealand's cancer care system struggles with fragmented and non-standardised data, limited clinician access to essential information, and reliance on manual text-based reporting. Slow updates to national databases hinder planning and improvements. Inadequate data that is not timely makes it challenging to identify and address inequities in care or outcomes.
3. Several bespoke registries exist, often each are supported by specialised infrastructure and charitable funding, such as the breast cancer registry. The advantages that these registers bring include, being able to use proxy measures for quality as well as tracking, variation in care, and new and emerging trends within their specific tumour stream.
4. This bespoke development of registries has commonly occurred when clinicians and advocates, facing the absence of a national resource, have concentrated their efforts on specific tumour streams, resulting in inequities between tumour management. These registries often operate independently from other Health NZ data sources, are not widely accessible to clinicians, and rely on inconsistent funding sources.
5. Health NZ is moving to an approach where information will be stored in cloud-based repositories owned and operated by Health NZ. These systems are linked to other data sets, are easier to use and – importantly – can be automated. The outputs would provide the same data benefits as an individual registry while providing more cost-effective benefits. They are secure and real-time, and deliver much better clinical information to support the care of patients on the front line. Importantly, this also supports a pan-cancer approach so all tumour streams can benefit.

Discussion

Benefits of a registry

6. A register collects data on preinvasive and invasive cancer patients to support clinicians in improving diagnosis, treatment and outcomes. Registries provide individual-level details such as demographics, diagnoses, family history, risk factors, treatments, follow-up and care plans. They also allow for outcome tracking, identification of practice variations across New Zealand, monitoring of quality indicators and detection of emerging trends.

CanShare role in supporting cancer registries

7. CanShare is a national pan-cancer registry platform developed by Te Aho o Te Kahu that offers scalable, reusable infrastructure for collecting, sharing and analysing standardised cancer data in near real-time.

8. Although not yet fully implemented, the programme has underpinned projects such as Raurau Ngaehe (Northern Region oncology e-prescribing system) and the AI-Assisted Pathology reporting proof of concept. CanShare is designed to support clinicians, improve care delivery, facilitate equity-focused insights, and develop data infrastructure for the safe use of AI. Ongoing investment is necessary to support CanShare to achieve its objectives for a modern and efficient cancer care system.
9. CanShare will, if fully realised, replace multiple condition-specific registries, enabling clinicians, researchers and policy-makers to access detailed, interoperable datasets across tumour types for targeted and system-wide insights.
10. There is interest in a national ovarian cancer register, and this approach is best achieved through the CanShare infrastructure. CanShare is a unified, standards-based platform designed to collect and analyse high-quality data for all cancer types, including ovarian cancer, within an integrated system.

Benefits of a CanShare cancer registry approach

11. Embedding ovarian cancer data collection within CanShare ensures that it is captured in a way that is interoperable with data from other tumour types, improving opportunities for comparative analysis, equity monitoring and integrated care delivery. The CanShare model avoids the duplication of infrastructure and governance costs associated with condition-specific registers and supports more efficient use of resources.
12. Including ovarian cancer data collection within CanShare enables consistent and accuracy of data from other tumour types. This approach allows for comparative analysis, equity monitoring and integrated care delivery. The benefit of CanShare is that it does not duplicate infrastructure and governance costs linked with condition-specific registers and supports more efficiency of resources.
13. Importantly, CanShare enables near real-time access to cancer data at the point of care, supporting better clinical decisions, improved and more efficient patient care, and more responsive service planning. There is strong clinical support recognising that systems such as CanShare can reduce clinical workload, support improved health outcomes and improve the efficiency of the health system.

Risk of standalone registries

14. Health NZ does not support establishing a standalone ovarian cancer register. A separate ovarian cancer register would require extra resources for infrastructure, governance and staffing, which are not currently available.
15. Such registries often require additional manual data entry from frontline teams or incur higher costs if outsourced to an external provider. This manual approach increases the risk of data entry errors, causes delays and can result in incomplete records, all of which undermine data integrity.
16. Data collected in siloed systems is often retrospective, limiting its usefulness for timely clinical management. These standalone systems are frequently dependent on the expertise of a single person, making them vulnerable to disruptions.
17. Moreover, siloed registries can be expensive to establish and maintain, and they typically do not use standardised coding systems, making it challenging to compare data across different sets or integrate with other clinical information.

18. Security and data sovereignty also present additional concerns, particularly when systems are hosted outside of Health NZ, raising concerns over the level of protection afforded to patient information.
19. Health NZ is moving to cloud-based, owned data storage to streamline management, connectivity and automation. These secure, integrated systems offer real-time information, reduce manual handling and provide the same benefits as standalone registries while being more sustainable and fit-for-purpose for frontline care.

International registers

20. Australian cancer registries include Cancer Incidence Registries (CIR), which track cancer rates and mortality, and Cancer Outcome Registries (COR), which report on treatment outcomes. CIRs are typically government-run, while CORs are managed by professional societies or clinicians.
21. While integrating CIR and COR could benefit all stakeholders, registries have developed separately, leading to data gaps, inconsistencies and overlapping functions due to a lack of evidence-based guidance for cancer registry design. This separation slows development, and does not provide good use of funding and research¹.

Use of AI-assisted structured anatomical pathology

22. Te Aho o Te Kahu has developed an AI-Assisted Structured Anatomical Pathology (ASAP) reporting proof of concept that is a data and digital innovation aimed at modernising cancer pathology reporting in New Zealand.
23. In collaboration with Health NZ, ASAP is designed to convert free-text pathology reports into structured data, coded with SNOMED CT, for use in clinical care and national analysis.
24. An AI-enabled solution, ASAP outlines the limitations of current practice and is supported by the national infrastructure (CanShare, CanSoT, and CanTel). This initiative directly contributes to the Government's goals of strengthening digital infrastructure, modernising cancer services and using data to drive equitable care.

Next steps

25. Our goal is to deliver pan-cancer solutions, and we are close to achieving this. Rather than focusing resources on a single tumour stream, efforts should be directed toward broadening access to information across all tumour streams.
26. Investing in CanShare is key to enabling national data on cancers, including ovarian and other tumour types, by avoiding the expense of developing separate registries.

¹ [Cancer incidence and outcomes registries in an Australian context: a systematic review - Chong - 2023 - ANZ Journal of Surgery - Wiley Online Library](#)