

PARLIAMENTARY INQUIRY QUESTION ON NOTICE

Department of Health and Aged Care

Senate Community Affairs References Committee

Inquiry into equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

01 March 2024

PDR Number: IQ24-000019

My Health Record in relation to support for people with particular conditions to find each other

Spoken

Hansard page number: 35

Senator: Louise Pratt

Question:

Senator PRATT: Surely, though, you should be able to see inside My Health Record if you're registered with any registries for particular conditions?

Ms Platona: I'm happy to take your question, Senator. My Health Record is not quite my area of responsibility, so I'll take it to people who are a lot more competent than I am, if that's okay.

Senator PRATT: Thank you. Are there any other officials with oversight of My Health Record?

Ms Platona: Not here today, but we're happy to take your question to our colleagues.

Senator PRATT: Okay. I guess I'm quite keen to see how results get in there and how My Health Record can be used to support people with particular conditions to find each other—for example, if you've been diagnosed with a rare cancer or a rare condition, whether the system flags peer support groups, clinical trials and things like that to accelerate people being able to find the support that they need, clinical or otherwise.

Answer:

A person's My Health Record (MHR) includes a summary of key health information including but not limited to immunisations, pathology and diagnostic imaging reports, prescription and dispensing information, hospital discharge summaries as well as advance care planning documents.

If a person has a MHR, health information is uploaded at the point of care by the patient's treating healthcare provider. Australians can also add health information they think is important in an emergency such as contact numbers, allergy information, organ donor information, preferred language, and personal health notes.

The MHR system does not currently include specific functionality that would connect a patient to peer support groups or clinical treatment pathways such as clinical trials. However, the MHR system can be used by clinicians to help determine treatment pathways as the MHR system allows information from a variety of source systems to help provide a more fulsome picture of a patient's treatment needs to guide clinical decision making.

In addition to supporting clinical care, the *My Health Records Act 2012* also prescribes a framework to support the collection, use and disclosure of de-identified data and, with the consent of healthcare recipients, health information, for research or public health purposes. In the future, legislative Rules could be established to support recruitment to clinical trials (e.g., identifying people whose capabilities may be suitable for a new product/service), development of new health services (e.g., identify service gaps and/or project demand for health services or workforce), improvement of existing health services (e.g. determine effectiveness and/or accessibility) or to support the development of government health policy (e.g. establish/refine the target population for a publicly funded service).