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Committee Members
Standing Committee on Community Affairs
Office of the Senate

Re: Inquiry into the Equitable access to diagnosis and treatment for individuals with rare and less common cancers, including neuroendocrine cancer

Question on Notice - Senator Pratt
Chair, I just wanted to ask if the witnesses could take on notice the question I had about My Health Record. I would like to know the extent to which, if it was a more universal system, where diagnosis was reported and tumours were reported, we could connect the best trials and evidence more quickly.

We thank Senator Pratt for her question put to us when giving evidence on 31st January 2024. We took the question on notice, and provide a formal response below.

In our experience the My Health Record system is not regularly utilised for patients in public hospitals, which is to say it does not contain very much useful information for our patient cohorts.

It is difficult to see how My Health Record may be of benefit when trying to access new trials or evidence for childhood cancer. We have a very small field in Australia, and knowledge of current trials and therapies is disseminated by the national body ANZCHOG (Australian and New Zealand Children's Haematology/Oncology Group), as well as by clinicians' individual experience. Parents are also very motivated and will often bring any potential opportunities to the attention of the clinical teams.

For children with cancer in Australia, there are many avenues by which data is captured, including the Australian Childhood Cancer Registry, which provides appropriate data to identify the incidence and prevalence of cancer occurring in children in this country. This means there is already a national resource that can be accessed by academia and industry to consider new research. The ZERO program also includes banking of tissue samples, so most of the children in Australia will have a sample of their cancer collected and frozen, available for researchers both in Australia and around the world to pursue new ideas.

What may be a more useful role for the My Health Record is in our survivorship cohort, ie those children and adults who have survived their childhood cancer, and have long term side effects from their treatment. Having a record of what previous treatment patients have received would be beneficial when they attend their GP or local specialists' years after their cancer diagnosis. This may help drive screening and prevention, as well as help diagnosis of new problems when patients present years later.

We are happy to provide more information or answer any other questions the senators might have.

With Regards,

Dr Richard Mitchell
Haematologist/Oncologist