



**All enquiries**

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Hon. Roger Cook MLA  
Deputy Premier; Minister for Health; Mental Health  
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Dear Minister

**My Health Record – implications for young people**

I am writing to raise my concerns regarding the implications of My Health Record for children and young people in Western Australia.

As the WA Commissioner for Children and Young People, I have a statutory role to advocate for and promote policies, laws, programs and services that enhance the wellbeing of all children and young people in WA. My functions are set out broadly under section 19 of the *Commissioner for Children and Young People Act 2006*.

In performing my role the best interests of children and young people are my paramount consideration. I must give priority to, and have special regard to, the interests and needs of Aboriginal and Torres Strait Islander children and young people, and children and young people who are disadvantaged for any reason.

The Federal Government will automatically create a My Health Record for every Australian resident unless they choose to opt out before 15 November 2018.

I acknowledge the benefits of an online health records system to facilitate communication of consumers' health information and improve the efficiency and effectiveness of person-centred health care. However I hold concerns about the risks posed to children and young people through the use of My Health Record, in particular the potential for violation of their privacy and confidentiality.

Parents and carers are one of the most important influences on child and adolescent development and psychological wellbeing. For most children and young people their parents and carers play a positive role in supporting their wellbeing. However for some young people family relationships can create difficulties for them to access the care they need when there are situations of family conflict or different views and values between parents/carers and young people. It is particularly for these young people I am advocating the need for appropriate safeguards and processes to protect their privacy and support their wellbeing, as I discuss below.

When a My Health Record is created for people aged under 18 years, a parent or legal guardian will be the Authorised Representative of that record, not the child or young person. Once a young person reaches 14 years, their Medicare, Pharmaceutical Benefits Schedule and Immunisation Register information will no longer be automatically uploaded onto My Health Record. However the other components of My Health Record information (for example, health summaries or investigations) will continue to be uploaded onto My Health Record, which parents can see for any child under 18 years.

Young people can take control of their My Health Record at the age of 14 and remove parent/guardian access as Authorised Representatives, but it is not automatic. Once an individual turns 14, to take control of their record, they need to log in to My Health Record online and verify their identity, and may have to respond to questions about their Medicare enrolment and the timing of their last doctor's visit. Young people can also choose to opt out altogether from My Health Record once they reach 14 years. To opt out young people need their Medicare number (or access to their individual reference number on a parent's Medicare card) and a current driver's or learners license, ImmiCard or a Passport.

The requirement for this level of identification for these processes could prevent many young people from being able to exercise their right to opt out of My Health Record or to take control of their record. For some young people in particular, gaining access to their parent's or guardian's Medicare Card to use may not be possible if they are, for example; estranged from their family, their parent/guardian is uncontactable or their parent/guardian refuses them access to their Medicare Card.

The *WA Youth Health Policy 2018-2023* states:

*To increase trust and participation, young people must know their rights in relation to accessing and using health services. This includes the concept of consent and information about privacy and the confidentiality of their health information in addition to its potential limits.<sup>1</sup>*

It is essential young people are provided with information and support to understand their choices and rights in regards to taking control of their My Health Record at 14 years, and the level of privacy they will have over their health information.

Young people themselves often speak about the importance of understanding their rights regarding privacy and confidentiality and having these rights upheld.

*"Confidentiality is an issue because most young people do not know their rights. [It] needs to be addressed with more accessible youth focused information available in a range of formats." Young person<sup>2</sup>*

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<sup>1</sup> Western Australian Department of Health 2018, *WA Youth Health Policy 2018–2023*, Health Networks, Western Australian Department of Health, Perth.

<sup>2</sup> Consumer and Community Health Research Network 2017, *WA's Young People Have a Say: Community conversations report*, Perth.

Concerns have been raised about the risk of My Health Record data being misused by parents/guardians, or used to monitor children and families in domestic violence and other family conflict situations. Specific privacy concerns for children and young people in the care of the child protection system have also been raised.<sup>3</sup>

The Consumers of Mental Health WA group have identified a potential issue with the My Health Record process, whereby parents/guardians could potentially add themselves as an Authorised Representative where a young person's record is managed by the young person, posing a serious breach of the young person's privacy.<sup>4</sup>

I believe there are a number of risks for children and young people if they are not informed and supported to understand the My Health Record processes and how to take control of their record if they wish to. These risks include:

- Young people not knowing what health information is recorded and shared with providers and their parents/guardians
- Use of information to cause harm, abuse or neglect, such as where a family violence or child abuse perpetrator has access to their health record
- Unwanted disclosure of sensitive information to other health service providers, such as LGBTI status, mental health status, substance use, or sexual health information, which may be unnecessary information for the service they are receiving, or which may result in stigmatisation or a change in relation to the service they receive
- Compounding health inequalities for young people who may have lost contact with their parent or guardian, and who may lack the ability to access their own health records and identification documents.<sup>5</sup>

My key concerns regarding the current processes around My Health Records and the implications for young people are:

- It could discourage healthcare-seeking behaviour – Young people may be less likely to access health services for needs that are often stigmatised, such as mental health, sexual and reproductive health, substance use and gender diversity, because it will appear on their records which could be viewed by parents or guardians

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<sup>3</sup> CREATE Foundation 2018, *My Health Record System - Submission to Senate Standing Committees on Community Affairs*, 27 August 2018.

<sup>4</sup> Consumers of Mental Health WA 2018, *My Health Record System - Submission to Senate Standing Committees on Community Affairs*, 3 September 2018.

<sup>5</sup> Consumers of Mental Health WA 2018, *My Health Record System - Submission to Senate Standing Committees on Community Affairs*, 3 September 2018.

- Young people are not sufficiently informed - Currently there is a lack of targeted, accessible information for young people to support them to make informed decisions about their rights and use of My Health Record
- Requirements to exercise control of their rights may be prohibitive – The processes for young people to opt out online and to take control of their record may be complex and pose barriers for young people under 18 to do so, due to identification requirements.

I endorse the Australian Association for Adolescent Health (AAAH) calls for:

- The Government to automatically seek consent from young people aged 14 to 17 years before granting access to any part of their My Health Record to parents/guardians
- Organisations training current and future health professionals, and those providing professional development to all health professionals who work with young people, to ensure that young people's rights to confidential health care are maintained. This may involve having conversations with young people and their parents or carers about access to their My Health Record.
- Educators of young people, such as teachers, health promotion staff and peer educators, to proactively inform young people of how health information will be shared among health services under My Health Record.<sup>6</sup>

In addition I believe safeguards must be inbuilt into the My Health Record system to protect the rights of young people, rather than relying on the young person to activate the safeguards and speak up if they do not want their records uploaded or shared. This is particularly important for vulnerable young people who we know experience additional barriers to speaking up and raising concerns about their rights and safety.

It is essential to inform and support young people to understand the risks and benefits, and their rights, in order to make an informed choice regarding their control and use of My Health Record.

I would be happy to discuss these matters further with you.

Yours sincerely



COLIN PETTIT

Commissioner for Children and Young People

28 September 2018

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<sup>6</sup> Australian Association for Adolescent Health Ltd 2018, *Position Statement: My Health Record and young people's right to confidentiality*, 20 July 2018.

Cc: Hon Greg Hunt MP  
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