



Submission

My Health Record system

Senate Community Affairs References

Committee

10 September 2018

Orygen, The National Centre of Excellence in Youth Mental Health welcomes the opportunity to provide a submission to the Senate Standing Committee on Community Affairs (Committee) inquiry into the My Health Record system.

About Orygen

Orygen, The National Centre of Excellence in Youth Mental Health (Orygen) is the world's leading research and knowledge translation organisation focusing on mental ill-health in young people. At Orygen, our leadership and staff work to deliver cutting-edge research, policy development, innovative clinical services, and evidence-based training and education to ensure there is continuous improvement in the treatments and care provided to young people experiencing mental ill-health.

Introduction

This submission addresses specific issues regarding the My Health Record system and vulnerable young people experiencing mental ill-health. The issues are:

- accepting presentation of a statutory declaration as satisfying requirements to act as a health recipient's authorised user
- whether vulnerable young people will be receiving the same opportunity to choose whether to have a My Health Record as their peers
- the lack of information prepared and provided to young people before and during the opt-out period
- the lack of information and support provided to health professionals to support them having conversations about the My Health Record and the possible impact on the privacy of young people, particularly for vulnerable young people
- the lack of appropriate channels of access available to young people.

Orygen has had some communication with the Australian Digital Health Agency (ADHA) including the offer to provide assistance and advice in developing targeted communication and providing technical advice and / or support to their internal clinical and policy areas around youth mental health and the My Health Record. Initial support to engage young people was requested and Orygen facilitated this and provided feedback from young people and ourselves on two draft information sheets.

There has been no subsequent communication from the ADHA until the 13th September 2018. Orygen via the same email also received a response to a formal letter of enquiry to the ADHA Chief Executive Officer dated the 30th August 2018. The responses to the questions raised unfortunately does not assuage Orygen's concerns.

Use of statutory declarations

Orygen is very concerned about the potential for the ADHA to be satisfied that a person is appropriate to be a health recipient's authorised user by presenting a statutory declaration if there is no known person with parental or legal responsibility or a relevant authorised professional. A statutory declaration would not usually be acceptable to give this type of authority and has the potential to leave a young person with a lived experience of mental ill-health vulnerable in relation to their personal health data.

In (a) what circumstances, and (b) where (i.e. a medical service, Medicare Service Centre) would a statutory declaration satisfy the ADHA that a person is appropriate to be an authorised representative for a health recipient (c) who will make this determination and (d) what additional skills and / or training will the decision maker have to assist them?

Recommendation

Orygen recommends the Committee takes the strongest action available to it to prevent young people's health records from being accessed on the basis of a statutory declaration.

Vulnerable young people

Orygen is very concerned about the opportunity provided to vulnerable young people to make a decision about having a My Health Record. Not all young people have the same opportunity to access information or the required access to enable them to opt-out of having a (or at a later date change the access settings for their) My Health Record.

Vulnerable young people include, but are not limited to those:

- experiencing mental ill-health
- living in out-of-home care
- living in secure welfare
- in detention, remand or prison.

The effects of mental ill-health can limit a young person's capacity to engage with systems that another young person may be more capable of.

Specific questions relating to issues regarding vulnerable young people have previously been asked of the ADHA by Orygen.

Who is the authorised representative for children and young people in out-of-home care and how will young people aged under 18 years in out-of-home care be able to opt-out if they would like to do so?

How will a young person (aged 12-25) who is in detention, remand or prison have the opportunity to opt-out if they would like to do so?

How will the government and / or the ADHA ensure that vulnerable young people have every opportunity to opt-out in the available opt-out period?

Recommendation

All young people be informed about the My Health Record and have access to an appropriate channel for opting-out of having a My Health Record if they wish to do so. If necessary the opt-out period should be extended to ensure vulnerable young people have every opportunity to opt-out. In the future the same information and access should be provided re control of their My Health Record.

Consideration of young people

Orygen is very concerned about the lack of timely and age appropriate information developed and provided to young people about the option to opt-out of a My Health Record before and during the opt-out period. An offer by Orygen to ADHA to provide assistance and advice resulted in Orygen facilitating the provision of feedback from young people on the information sheet after the opt-out period had opened.

While the term young people covers 12-25 year olds, there are particular issues regarding access and control of the My Health Record for young people aged 14-18 years. Young people should be collaboratively engaged in the development of information material and system access.

To be able to opt-out or have access to their My Health Record requires a young person to have access to their Medicare number. While young people can apply for their own Medicare card from 14 years of age, many young people will still be on their parent or guardian's Medicare card and, therefore, need to negotiate access with their parent or guardian. A second form of identification is also required.

Alternatively a young person (with ID) can opt-out at a Medicare Service Centre. Having to attend a Medicare Service Centre potentially presents issues for a young person, particularly someone aged 14-18 years. The location, travel and hours of opening of a Medicare Service Centre are examples of practical barriers. Stigma and confidence dealing with government agencies are also potential barriers. For a young person experiencing mental ill-health these barriers may be higher.

A 1800 number is provided for My Health Record information. While calls to 1800 numbers are free on landlines the calls are timed for mobile phones. It is highly likely that a young person who wants

to enquire about the My Health Record will do so from a mobile phone. The length of these calls and any waiting time may present a financial barrier to access for a young person.

Recommendation

The opt-out period needs to be extended to ensure all young people are informed about the My Health Record and have access to an appropriate channel for opting-out of having a My Health Record if they wish to do so.

Dedicated information needs to be developed and distributed that is age appropriate informing young people about the My Health Record and their option to opt-out.

Information and access channels need to be provided that do not present undue barriers to access for young people, including those who are at risk of increased vulnerability.

Information and access should be developed in collaboration with young people.

Contact details

For further information and follow-up relating to this submission, please contact:

Kerryn Pennell

Director, Strategy and Development

Orygen, The National Centre of Excellence in Youth Mental Health

Email: Kerryn.Pennell@orygen.org.au

Mobile: 0419 535 567