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### **Submission to the inquiry into the My Health Record system**

The National Mental Health Consumer and Carer Forum (NMHCCF) welcomes the opportunity to provide comment on the My Health Record system.

The NMHCCF is a combined national voice for mental health consumers and carers. We listen, learn, influence and advocate in matters of mental health reform. The NMHCCF was established in 2002 by the Australian Health Ministers' Advisory Council. It is funded through contributions from each state and territory government and the Australian Government Department of Health. It is auspiced by Mental Health Australia.

NMHCCF members represent mental health consumers and carers on a large number of national bodies, such as government committees and advisory groups, professional bodies and other consultative forums and events. Members use their lived experience, understanding of the mental health system and communication skills to advocate and promote the issues and concerns of consumers and carers.

The NMHCCF make this submission with particular reference to the Terms of Reference points:

- d. the Government's administration of the My Health Record system roll-out, including:*
  - i. the public information campaign, and*
  - ii. the prevalence of 'informed consent' amongst users;*
- e. measures that are necessary to address community privacy concerns in the My Health Record system;*

The My Health Record system roll out requires a public information campaign targeted to educate and inform people with mental health issues and their carers. The current generic information does not adequately address the challenges of understanding My Health Records nor the opt-out process. A tailored approach is required for consumers and carers to have access to plain English information in order to make an informed choice.

Current practices relating to privacy, confidentiality, information sharing and management of documents via technology are a significant concern for the NMHCCF. NMHCCF members are concerned about how records are uploaded (it is unclear if consumer consent is required), and there is confusion in the information regarding how consumers can control health professionals' viewing of their records, or individual sections/records. Management of a personal electronic health record requires written and verbal skills, education and computer literacy to participate. Concern is raised



over a consumer understanding when a document has been uploaded to their record, and how they can hide or delete that document if they require.

Technology can be problematic for consumers with mental health issues and the NMHCCF sees the need for greater and clearer information on the privacy controls consumers will have, and the measures they can take to secure their digital health data. Electronic accessibility can be limited for mental health consumers and carers, particularly for those living in rural and remote regions. The NMHCCF recommend strategies are implemented to ensure people who do not access or effectively use the internet can gain access to, and manage their My Health Record.

In sum, the campaign requires enhanced education and information for people with respect to potential risks to their privacy and confidentiality, together with accessibility.

Further comment:

We take this opportunity to highlight our concern for other vulnerable people in the community. For instance, people from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander peoples, the elderly, LGBTIQ people, children and youth.

The NMHCCF identifies a particular need for a public information campaign targeted at youth between the ages of 14 and 18 years, to advise that they will have a representative appointed for them and they need to actively take control of their record. This information should also include how the process works.

Protection and information also needs to be provided for people in domestic violence situations, child safety matters, or those with a history of alcohol and/or drug use/misuse. These particularly vulnerable groups may be placed at risk if their records are accessible to a perpetrator. An event summary in their My Health Records or shared care summary may affect their ability to gain medical care or to seek medical assistance.

Further, the NMHCCF is concerned the current opt-out period is insufficient for our constituency to be able to make an informed decision or have their concerns addressed as expressed in this submission. We highly recommend that a further extension to the opt-out period, to 6 months total, would benefit all Australians.

It is critical that Australians feel well informed when making decisions that relate to their health and to their security. On behalf of the NMHCCF, we thank you for the opportunity to provide feedback to this important inquiry.

Yours sincerely

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Consumer Co-Chair

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Carer Co-Chair