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Notifiable Data Breaches scheme draft consumer resources

The National Mental Health Consumer and Carer Forum (NMHCCF) welcomes the opportunity to provide comment on the two draft consumer resources in relation to receiving data breach notifications and what to do after a data breach.

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 currently 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.

Upon consideration of both documents the NMHCCF would like to raise the following comments and concerns:

Fear of a data breach

It is certainly important for people to know what to do following a notification of a data breach but it would also be helpful to provide information for people who fear a data breach. Information for people protecting themselves is important and we suggest a section or a fact sheet on how to protect yourself from a data breach (not just identity fraud), even when there has not been a notification or suspicion that this has occurred.

Support services

Under the Support Services section on page 4 of the 'What to do after a data breach', the NMHCCF request you remove the wording 'suffer from' and replace it with 'experience'. This is in keeping with the preferred language of the mental health sector.



Definitions and examples

On page 2 of 'Receiving data breach notifications' it is unclear what is meant by 'serious emotional harm'. How would this be defined and who would decide if an individual was experiencing emotional harm? From a mental health consumer and carer perspective, and informed by trauma informed care, any emotional harm is harm and its seriousness is subjective and depends on who is determining this.

Also on page 2 under agencies and organisations that must comply with the scheme, the definition of 'Health Service Providers' is slightly limited. The NMHCCF recommend traditional health service providers, such as private hospitals, day surgeries, medical practitioners, pharmacists and allied health professionals be included under this definition link.

In Example 2 on page 3, there is no mention of providing support to the individual student who has been subject to the data breach. The NMHCCF recommend this be included so it is clear the student is supported appropriately rather than simply being told about the breach.

Responsibilities of agencies and organisations

NMHCCF members made comment that there is little information in these resources concerning the responsibility of agencies or organisations to make restitution following a breach. Both documents focus on what the individuals have to do and what actions/steps they need to take but there is a lack of detail about what responsibilities or actions the organisation is responsible for.

Many individuals would want to know what will happen on their behalf when their information and records have been breached. How are they held to account for a breach and what can individuals expect from an organisation or entity responsible for the breach.

Contact and sensitive information

Under the contact information, the last dot point is about what to do if your physical safety is at risk (contact police). There is no reference of who to contact if your mental health safety is at risk (eg. contact GP, local crisis team, Lifeline etc.)

Under the section on sensitive information about sexuality, race etc. it is unclear how the information on being safe online fits and perhaps this needs further description. It was also suggested that the reference/ links to the support services section be added under this heading.

The actions to take fail to mention attending a GP (as an example), reaching out for support from family/ friends/ significant others, taking practical steps (as outlined in the paper) to protect individuals, It is also important for people to know that is OK not to be OK following such a breach.

In general, there is a need to understand that any data breach will have an impact on someone's emotional wellbeing, and we recommend attention be given to this at the beginning of the resources. The NMHCCF recommends more emphasis on the emotional distress and impact on wellbeing regarding a data breach. For example, these documents don't address the situation where someone may already be experiencing mental health issues, and the impact this may have on them.



On behalf of the NMHCCF, we thank you for the opportunity to provide feedback on these resources.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Lyn English'.

Lyn English
Consumer Co-Chair

A handwritten signature in black ink, appearing to read 'Elida Meadows'.

Elida Meadows
Carer Co-Chair