My Health Record system Submission 19



# The My Health System and domestic violence survivors

Submission to the Senate Community Affairs References Committee By Women's Legal Service Queensland

#### **About Women's Legal Service**

Women's Legal Service Queensland (WLSQ) is a specialist community legal centre, established in 1984, that provides free legal and social work services and support to Queensland women. We assist women in the areas of family law, domestic violence, child protection and some aspects of sexual violence. WLSQ provide state-wide assistance through our state-wide domestic violence legal helpline, and have a designated rural, regional and remote priority line to increase women's access to our service in non-metropolitan regions. We undertake outreach work at the Brisbane Women's Correctional Centre and at Family Relationship Centres in Brisbane. We also conduct duty lawyer services at three Courts: Holland Park, Caboolture and Ipswich. Our specialist domestic violence units in Brisbane, the Gold Coast and Caboolture provide intensive case work and Court representation for our most vulnerable clients. We have just employed a First Nation's cultural liaison and support role at Caboolture which will in time increase First Nations women's access to our service.

We thank the Senate Community Affairs References Committee for the opportunity to provide this feedback.

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#### **Overall concerns**

Women's Legal Service Queensland's (WLSQ) submission to the Senate Community Affairs References Committee seeks to highlight how the proposed My Health Record roll-out may impact women and their children experiencing domestic violence.

Our overall position is that we hold significant safety concerns with the My Health Records system, in particular the automatic opt-out approach and the failure to have consulted with relevant specialist women's agencies in the development of this legislation and formulation of policy. Our preferred approach is for the roll out to be delayed until the safety of vulnerable women and their children is guaranteed.

### **Opt-out**

We are aware that Australia is one of the few countries in the world to create a digital health record system that allows the data to be viewed by patients and that the purpose of this was to create a system that is transparent and patient-centred. While WLSQ is supportive of initiatives that aim to enhance individual agency, we believe that the opt-out nature of the health records is inconsistent with a 'patient-centred' approach. WLSQ believe that informed consent must be a vital feature of the My Health Records system.

We believe the "opt-out" requirement is particularly dangerous if victims are unaware they have active My Health Records, the types of information contained on these records, and the potential for perpetrators to access this information. It is not uncommon for highly dangerous perpetrators to constantly monitor women's lives including who she communicates with, where she goes and her access to information. Perpetrators often have access to (and in fact demand) access to all such accounts including her passwords, controlling every aspect of her life. The media and controversy around the roll out has not only alerted victims to potential safety concerns but will also inadvertently alert perpetrators to a new possible way to enhance control over their victims and children.

We acknowledge that there will be some domestic violence victims who are comfortable with the My Health system and it may meet their needs if, for example they or their children suffer from chronic illness. However, we believe that the best practice approach is for patients to have free and informed consent about opting in so that their health and safety needs can be assessed in consultation with their doctor and other relevant professionals, for example a domestic violence social worker.

## **Consultation process**

The failure to consult with women's agencies is particularly concerning. This has caused confusion, anxiety and angst in the community as domestic violence victims are concerned what the roll out will mean for their and their children's safety. We would recommend that the government review its approach to such important policy and legislative formulation and include a step that specifically conducts a gendered analysis of the impacts on women, especially particularly vulnerable cohorts including domestic violence victims, children and older women. This analysis should inform the project from policy development phase and throughout.

## Domestic violence perpetrators creating children's accounts

It is our understanding that a loophole exists in the My Health Record system, which allows a parent who does not have primary custody to create a My Health Record on their child's behalf, without the consent or knowledge of their former partner. It is also not uncommon for perpetrators of violence to share custody with their former partner.

An abusive ex-partner can thereby gain access via the My Health Records system to details including the location of medical practitioners and pharmacies attended by the child with their primary caregiver, potentially narrowing down the location of victims in hiding. This has serious implications for victims fleeing violence.

Perpetrators of violence use power and control tactics to ensure ongoing control of women and children after separation. In addition to serious concerns about violent perpetrators locating victims, access to such information also means perpetrators can constantly question and second guess the primary parent's decision making about the child, or may use the information to instil fear and make victims feel the perpetrator knows their every action. Perpetrators are highly litigious and will often seek to use information of this nature against victims in family law and domestic violence litigation.

Many perpetrators retain shared parental responsibility of their children, even if domestic violence protection orders or family law orders are in place. Domestic violence protection orders frequently do not name children as protected parties or if they do they do not stop the perpetrator's contact with the child or affect their parental rights. Unless a primary caregiver has a Family Court order granting them sole parental responsibility in regard to medical treatment, which is exceedingly rare, a refusal of access by the Digital Health Agency would be unlikely to withstand a legal challenge.

We hold concerns that the current approach may create situations where a woman fleeing domestic violence may be forced to decide between either taking their child to a health professional and potentially identifying their location to the perpetrator or not seeking necessary treatment.

The My Health Record system as it stands places women and children fleeing violence at risk of serious injury and death.

## Coercive control safety concerns

Women experiencing high levels of control from abusive partners may be placed at greater risk by the proposed My Health Record system through its links to the MyGov site. It is not uncommon for perpetrators to have access to passwords or act as authorised persons on our client's MyGov accounts, but linking the data will grant them increased access to broader sensitive information.

There is widespread confusion in the community about what records are placed on the My Health Record system and victims of domestic violence may be deterred from disclosing for fear the information may be disseminated more broadly. We would not want to see situations where women may be deterred from disclosing domestic violence or seeking health care. As trusted professionals many disclosures of domestic violence are made to General Practitioners. Women experiencing reproductive coercion may feel they have no way of accessing contraception or terminations in a safe way that will not be shared with perpetrators and indeed with the opt-out approach this information may already be contained on their My Health Record putting them at increased risk

The opt-out approach means many women will not be aware their records exist. WLSQ counsels victims to immediately change their myGov password after separation, however many women, particularly those who do not contact a support service may not be aware of the need for this action. Women may access reproductive health services or make disclosures of domestic violence without knowing the information is shared through their My Health Record – alerting domestic violence perpetrators and putting victims at risk.

While we understand that protections are in place for women to password protect, or ask for certain data not to be added to their file, we believe that it is not appropriate for the onus to be on highly vulnerable victims of violence who may be experiencing trauma to make these requests.

It is sadly the reality of domestic violence that many victims live with very high levels of surveillance and control. As we stated previously, it is not unusual for perpetrators to have total control of victim's passwords, their bank accounts, email, phones and social media accounts. For this reason in many instances password protection is not sufficient to keep women and children safe.

From working with victims of domestic violence, we know that perpetrators are manipulative and persistent. There are risks both of hacking by perpetrators – and also a risk of officials releasing information to perpetrators.

### Vulnerable subgroups: children and older women

There are also issues regarding the safety and protection of the privacy of children. In My Health Record's current form, information about children may be transmitted to parents including abusive parents.

Our understanding of the My Health Record system is that parents remain the authorities for their children's record until the young person is 18 years old. This is at odds with the principle of Gillick competence (the legal rules that guide how and when health practitioners make assessments about the level of competency and maturity of young patients under 18 years to determine their capacity to provide confidential health instructions to health professionals).

We are not experts in young people and children but believe that it is unrealistic to place the responsibility on young people to advocate for their own right to confidentiality or to expect that young people will necessarily be aware that their information may be viewed in this way. In situations where young people are experiencing control or abuse from their parents, seeking medical advice may increase their risk of violence. Additionally, due to privacy concerns young people may be deterred from having important conversations with their GP regarding mental health, sexual health or their sexual and gender identity. Our understanding is that currently the Medicare system allows for children 14 years and over to seek medical assistance without their parent's consent or knowledge. There is therefore obvious inconsistency in relation to the Government's approach on this issue.

Older women may be particularly vulnerable to perpetrators accessing their My Health Records. According to the Australian Bureau of Statistics, only 55% of Australians aged over 65 are internet users (<a href="http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0">http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0</a>). More than 10% of women killed by a partner or ex-partner are aged 66 or over but they are the group least likely to leave their abuser and seek help (<a href="https://www.theguardian.com/society/2018/apr/25/domestic-violence-abuse-older-couples-increase">https://www.theguardian.com/society/2018/apr/25/domestic-violence-abuse-older-couples-increase</a>). It is likely more difficult for Australian women aged over 65 to optout of the My Health Record system. Due to lower rates of digital literacy among this cohort they may be particularly vulnerable to perpetrators using their My Health Records for abusive purposes.

#### **WLSQ Recommendations**

- 1) WLSQ advocates for an "opt-in" approach for sign up to My Health Records. We believe this is the safest option for domestic violence victims to manage their health information. An "opt-in" approach is also consistent with informed consent.
- 2) WLSQ supports proposed amendments that facilitate the option to withdraw from and delete My Health Records after the opt-out period ends.
- 3) WLSQ supports a delay to the roll out of the My Health Records approach until necessary changes are made to the system to ensure the safety of domestic violence victims and their children.
- 4) WLSQ supports the requirement for law enforcement and other government agencies to obtain court orders to access patient data. These measures will increase the safety of domestic violence and sexual assault survivors.
- 5) WLSQ supports the establishment of an urgent Digital Health Authority domestic violence roundtable with relevant stakeholders to discuss these concerns in greater detail.
- 6) WLSQ recommends the Government engage with young people's agencies to seek their expert view on the impact of the My Health Record system on young people seeking assistance and treatment from health professionals.
- 7) Reflecting the concept of Gillick competence and subject to the engagement of stakeholders who work with young people, WLSQ recommends a consideration that children's files are not viewable by parents once young people are considered to be and able to make their own health care decisions (i.e. 14 years of age).
- 8) When there are concerns regarding family court or domestic violence WLSQ recommends that records are no longer visible to either parent through the My Health Record system and instead are made visible only to health professionals and this arrangement is made explicit and easily understandable for people to action.
- 9) WLSQ recommends the Government review its process of policy and legislative development ensuring a gendered or at least a violence against women lens is included during the development phase ensuring that the needs of women and specifically domestic violence victims are considered from the commencement of the process.