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PCEHR/HI Discussion Paper Feedback
Department of Health
MDP 1003
GPO Box 9848
CANBERRA ACT 2601

17 July 2015

RE: Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

Thank you for the opportunity to submit our comments and feedback on the *Electronic Health Records and Healthcare Identifiers Discussion Paper* in light of the Australian Government's proposed changes to the personally controlled electronic health record (PCEHR) system and the Healthcare Identifiers (HI) Service.

Scarlet Alliance, the Australian Sex Workers Association, is the peak national sex worker organisation in Australia. Formed in 1989, the organisation represents a membership of individual sex workers and sex worker organisations. Scarlet Alliance and our member organisations and projects have the highest level of contact with sex workers in Australia of any agency, government or non-government. Through our project work and the work of our membership we have high levels of access to sex industry workplaces in the major cities and many regional areas of Australia. Scarlet Alliance and many of our member sex worker organisations and projects within Australia have CALD (culturally and linguistically diverse) projects employing bi-lingual project workers.

Scarlet Alliance is a member of the Australian Federation of AIDS Organisations (AFAO). AFAO has also made a submission to this process which Scarlet Alliance endorses.

2.1 Personally controlled electronic health record system

It is integral, if the PCEHR is to meet its aims in respect of people living with HIV and communities affected by HIV, that the rights to privacy and confidentiality of individuals are guaranteed. Sex

workers especially have unique privacy concerns, and it is imperative for this reason that individuals are able to personally control, limit, or exclude information on the PCEHR record, and that this is not undermined by efforts to strengthen the comprehensiveness of the information collected. Strong protection for individuals and an efficient and thorough complaints process are essential if the PCEHR is to protect sex workers, people living with HIV and communities affected by HIV.

3.3 Participation

If providers are to remain opt-in, but individuals will be opt-out, those providers opting in need to ensure that all consumers of their services are aware of what that means for them and are fully informed on how to opt-out and given reasonable time to do so. Community education campaigns regarding the trials, and targeted materials for particular communities and health providers, are an important part of this process, to ensure that people can make informed decisions about whether to opt-out or remain in the system.

3.4.6 Obligations to use PCEHR system

The changes proposed to require documents to be uploaded to the PCEHR system before payment for Medicare items relating to health assessments, comprehensive assessments, mental healthcare plans, medication management reviews and chronic disease planning items undermines the autonomy of the individual in controlling what information about their healthcare is recorded. This becomes particularly relevant to sex workers who regularly undergo comprehensive HIV and STI testing (in some states this is mandatory) if that testing is classed as a health assessment.

Records of regular STI screening can serve to “out” sex workers to general practitioners or other healthcare providers who access their records. Sex workers sometimes do not wish to disclose their occupation to healthcare providers due to stigma and discrimination faced by many sex workers in the healthcare industry.

3.5.4 Penalties for misuse of information

Serious misuse of PCEHR information can have grave consequences for sex workers. Privacy concerns are foremost in sex workers minds when their personal information is being collected and misuse of that information compromises the safety of sex workers. Sex workers with children may have child custody jeopardised if they are outed. In states where sex work is criminalised, particularly where it is an offense to sex work with HIV or an STI, misuse of PCEHR information of sex workers could have serious legal implications.

Scarlet Alliance supports the submission by AFAO that “serious misuses of PCEHR information should be subject to criminal penalties” under “a graduated framework of penalties proportional to the severity of the breach”.

Conclusion

Sex workers have unique privacy considerations when it comes to health and healthcare information. Due to stigma and discrimination against sex workers, often based on the false understanding of sex workers as vectors of disease, sex workers are cautious about the disclosure of their medical records and personal information where it may be used to target and criminalise workers. Particularly in jurisdictions where sex working with HIV or an STI is criminalised, sex workers are generally wary of collection of personal data related to healthcare.

It is crucial that changes to the PCEHR and HI allow individuals to personally control, limit, and exclude information on the PCEHR record, and that this is not undermined by efforts to fortify the completeness of the information recorded.

If you require further information please contact our Chief Executive Officer Janelle Fawkes on (02) 9690 0551.

Regards,

A handwritten signature in black ink, appearing to read 'Ryan Cole', with a long horizontal flourish extending to the right.

Ryan Cole
President