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To the Department of Health and Aged Care

Re: Modernising My Health Record – Sharing pathology and diagnostic imaging reports by default and removing consumer access delays

Thank you for the opportunity to submit to the consultation on modernising My Health Record.

Scarlet Alliance is the Australian Sex Workers Association. Through our objectives, policies and programs, Scarlet Alliance aims to achieve equality, social, legal, political, cultural and economic justice for past and present workers in the sex industry.

Formed in 1989, Scarlet Alliance, Australian Sex Workers Association, is the national peak sex worker organisation. Our membership includes state and territory-based and national sex worker organisations and individual sex workers across uncaded Australia. Scarlet Alliance uses a multifaceted approach to strive for equality, justice and the highest level of health for past and present workers in the sex industry. We achieve our goals and objectives by using best practices including peer education, community development, community engagement and advocacy.

Scarlet Alliance is a leader when it comes to advocating for the health, safety and welfare of workers in Australia's sex industry. Through our work and that of our member organisations and projects, we have the highest level of contact with sex workers and access to sex industry workplaces throughout Australia of any agency. Scarlet Alliance represents sex workers on a number of government and non-government committees and advisory mechanisms.

While Scarlet Alliance recognises that investment in My Health Record is a key area of Australia's National Digital Health Strategy, and facilitates information-access for healthcare providers and consumers, mandated automatic and immediate information presents significant risks for sex workers.

It is vital that sex workers and other priority populations are able to maintain privacy and autonomy over the sharing of their health information, and receive competent and safe care from all levels of the healthcare system. This short submission outlines sex worker concerns relating to default sharing of pathology and diagnostic imaging reports to My Health Record from December 2024 (Part A) and the removal of the 7 day delay policy for sharing diagnostic imaging and pathology reports to My Health Record (Part B).

Please contact our CEO, Mish Pony on (02) 9517 2577 or mish.pony@scarletalliance.org.au if you have any further questions.

Background

Sex workers in unceded Australia experience stigma and discrimination in many contexts, including when accessing healthcare. Research conducted by the University of New South Wales Centre for Social Research in Health indicates that sex workers in Australia frequently experience stigma, both from the general public and when accessing healthcare, with up to a quarter of sex workers in 2022 reporting that they are 'often' or 'always' treated negatively by healthcare workers.¹

Further, sex work is regulated by the states and territories, with some forms of sex work or activities relating to sex work continuing to be criminalised in several jurisdictions. Criminalisation and stigma have been identified as significant barriers to sex workers accessing healthcare,² including sexual health prevention, testing and treatment.³ Sex workers who face multiple axes of marginalisation, (such as sex workers from culturally and linguistically diverse communities, sex workers in rural and remote areas, LGBTQI+ sex workers, sex workers who use drugs or Aboriginal and Torres Strait Islander sex workers) may experience compounding stigma and additional barriers to healthcare access.⁴

This context demonstrates that sex workers require sensitivity and discretion from healthcare workers, particularly in relation to the results of sexual health testing. Due to the stigma and discrimination outlined above, sex workers may choose to visit a different service for sexual health testing, and/or not disclose their sex work status to their other healthcare providers. Many sex workers do not disclose their work to partners, family members or the wider community, and inadvertent disclosure may be harmful to their safety and wellbeing.

Part A: Better access – sharing pathology and diagnostic imaging reports to My Health Record by default

While Scarlet Alliance acknowledges that default sharing of pathology and diagnostic imaging reports would enable improved access to clinical information for both healthcare professionals and consumers, this proposal generates significant privacy concerns for sex workers.

Outside of jurisdictions where consent is required before uploading health information (ACT, Queensland and NSW), a sex worker with a My Health Record who did not want to disclose their sex work status to their primary healthcare provider would be required to either:

¹ Elena Cama et al, '[Stigma Snapshot: Sex workers 2022](#)' (Summary Report, 2023).

² Kahlia McCausland et al, '["It is stigma that makes my work dangerous": experiences and consequences of disclosure, stigma and discrimination among sex workers in Western Australia](#)' (2022) 24(2) *Culture, Health & Sexuality* 180, 188-9.

³ Linda Selvey et al, '[Law and Sex worker Health \(LASH\) Study: A summary report to the Western Australian Department of Health](#)' (Final Report, May 2017) 20-21. See also Elena Jeffreys, Kane Matthews and Alina Thomas, '[HIV criminalisation and sex work in Australia](#)' (2010) 18(35) *Reproductive Health Matters* 129, 130.

⁴ See LASH Study Final Report (n 3) 6.

- a) instruct that their results not be uploaded at the time of the appointment (for a sex worker who accesses sexual health testing approximately every 3 months, each occasion of testing would require an instruction not to upload results), or
- b) restrict access to the results after each occasion of testing once they have been uploaded via the My Health Record/My Gov platform.

Both of these scenarios require the consumer to be familiar with My Health Record policy, with the latter also requiring internet access and navigating the My Health Record portal.

Sex workers are included as priority populations in the national strategies for bloodborne viruses and sexually transmissible infections (STIs), with access to safe, confidential and affordable STI testing and treatment playing a key-role in maintaining low levels of STI among sex workers and improving sex worker wellbeing.⁵ Default result uploading to My Health Record must not generate additional privacy risks for sex workers, nor disincentive access to sexual health testing and treatment by creating additional barriers.

To remedy these concerns, we would propose:

- a) Creating an exemption for dedicated sexual health services in all states and territories to not be required to upload results by default, and/or
- b) Creating targeted, culturally-appropriate and translated resources informing consumers that pathology records will be automatically shared, to inform consumers of the requirement to ask that their records not be uploaded.

Part B: Faster access – removing delays to accessing pathology and diagnostic imaging reports in My Health Record

While the removal of the 7 day delay between upload of pathology and diagnostic imaging reports and these being 'unlocked' for patients to view them may give consumers greater autonomy and lead to more streamlined care delivery, the discussion paper acknowledges concerns that access to abnormal test results without advice and support for a healthcare professional may be detrimental to consumer wellbeing, and may lead to disengagement with follow-up care.

Scarlet Alliance believes that consumers must be able to provide informed consent to receive immediate access to pathology and diagnostic imaging reports via My Health Record, with consent for immediate availability being obtained at point of testing. Further, consideration should be given to creating a list of exempt conditions where an abnormal pathology or imaging report would not result in automatic upload (regardless of consent) to ensure that results for complex or significant conditions are interpreted and explained to consumers by a healthcare professional, and follow-up care confirmed.

⁵ Basil Donovan et al, 'Improving the Health of Sex Workers in NSW: Maintaining Success' (2010) 21(4) New South Wales Public Health Bulletin 74.