Vixen Collective (Victoria's peer only sex worker organisation)

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PCEHRHI Discussion Paper Feedback
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17th July 2015

To whom it may concern,

Vixen Collective is a non-funded organisation run by sex workers volunteering their time and energy in the absence of a funded peer only sex worker organisation in Victoria.

We appreciate your assistance in with regard to an extended timeframe for our submission.

We look forward to engaging throughout this process and encourage you to contact us if you require any further detail or if you wish to discuss any part of this submission..

Sincerely,

Jane Green
On behalf of Vixen Collective

Vixen Collective - PCEHR/HI Discussion Paper Feedback 2015

Vixen Collective - Victoria's peer only sex worker organisation

Vixen Collective is Victoria's peer only sex worker organisation. Through our objectives and work we promote the cultural, legal, human, occupational and civil rights of all sex workers.

Victoria has a proud history of sex worker rights. With the advent of HIV in the 1980s, Australia led the world by deploying a community based response - money was given to key communities (sex workers, gay men, injecting drug users, etc) to form their own organisations to contribute to the fight against the virus. Melbourne was the first place in the world to commit funding to a sex worker organisation - the Prostitutes Collective of Victoria (PCV). The PCV were pioneers in sex worker organising. However in 2001 the PCV was taken over by a community health service and it ceased being an organisation of sex workers.

It was in this environment of Victoria lacking a sex worker run organisation, that Vixen Collective was formed in 2005. Vixen Collective was started by a group of Victorian sex workers and launched at the 2005 Scarlet Alliance (Australian Sex Workers Association) national forum. Later gaining membership of Scarlet Alliance in 2007, Vixen Collective has continued to engage in sex worker rights organising, building participation by local sex workers, as well as developing links to state and national sex worker organisations.

Vixen Collective continues to work fiercely on sex worker rights in Victoria, through:

a) being a proud peer only (sex worker only) organisation
b) encouraging local sex worker participation
c) consultation with Victorian sex workers on key community issues
d) peer education and peer support to local sex worker community
e) education initiatives with broader non sex worker community
f) advocacy and lobbying to government
g) working to break down stigma and promote positive media on sex work
h) work with other community organisations eg. VAC, ISCHS
i) HIV/AIDS advisory work (as a key population)
j) work with the Victorian Police
k) public education eg. Festival of Sex Work

This submission has been produced by Vixen Collective, through ongoing consultation with Victorian sex workers.

Vixen Collective remains an unfunded organisation and is run solely through the volunteer energy of Victorian sex workers.

Vixen Collective Objectives

I. Vixen promotes the cultural, legal, human, occupational and civil rights of all sex workers.

II. Vixen believes that sex workers have the right to work under legislation that promotes our rights and occupational health and safety. Vixen seeks to challenge any legislation, implementation thereof or its enforcement, where it infringes on the rights and/or occupational health and safety of sex workers.

III. Vixen seeks to engage with current government, regulators, officials, policy makers and those who implement government policy to lobby for the rights and safety of sex workers, without accepting the status quo if it does not support sex workers rights or safety, specifically challenging those that infringe on the rights of sex workers.

IV. Vixen affirms that the model of sex work regulation it supports is the *full decriminalisation of sex work* and that we will not accept other discriminatory models or legislation that infringe on the rights of sex workers.

V. As sex workers we should be able to work how, when and where we choose - including (but not limited to) street based sex work, brothel based sex work, private sex work, escort sex work and opportunistic sex work.

VI. Vixen recognises and values our members' diversity, we are committed to promoting the wellbeing and rights of sex workers from diverse backgrounds.

VII. Vixen works to create and facilitate means by which current and former sex workers' voices are heard, both within and outside sex worker community, and specifically to government.

VIII. Vixen works to combat stigma and whorephobia via a range of mechanisms:

a. Vixen provides training and presentations on sex work to community groups, educational institutions, sex work forums and government bodies.
b. Public events, to demystify sex work and allow the public to gain understanding for our work.

c. Producing positive media on sex work and addressing negative media when necessary.

IX. Vixen plays a role, as a key population, in informing Australia's response to HIV/AIDS.

X. Vixen seeks to empower Victorian sex workers through the provision of community and peer support.

XI. Vixen disseminates information on sex work to sex workers through the Vixen Website, Vixen Facebook, Vixen Twitter, as well as regular meetings and consultations.

XII. Vixen connects with other sex worker organisations nationally and internationally.

Executive Summary

Vixen Collective has concerns regarding the introduction of the PCEHR/HI into Victoria, when the licensing model of sex industry regulation already significantly disadvantages Victorian sex workers in terms of:

- exercising autonomy in accessing healthcare
- the compiling of health records on both individuals and sex workers as a community

both of which lead to stigma and discrimination against sex workers in Victoria.

The licensing model itself as well as its implementation and enforcement, both cause and contribute to multiple violations of the human rights and labour rights of sex workers, as well as being an ineffective and costly system of regulation.

- Licensing involves a significant burden to the state in terms of bureaucracy to administrate and enforce.
- The costs associated with licensing are not adequately recoverable through the fees brought in by the system, making it prohibitively expensive to the taxpayer.
- Because of disincentives to participate in licensing (stigma, outing, etc) a two tiered effect is created where part of the sex industry is compliant and part non compliant.
- Sex workers rights are infringed upon as the licensing system treats us as intrinsically different from other workers, requiring monitoring and control.
- Sex workers health and safety are undermined because sex workers in the non compliant part of the sex industry are less accessible to health, outreach and sex worker organisations.
- The licensing system reduces transparency in the sex industry and undermines anti-trafficking initiatives.
- Sex workers are placed in an oppositional role from police in a licensing system making it difficult for sex workers to access assistance as other members of the public do when victims of crime.

- Licensing affects the most marginalised among sex worker community most; street based sex worker, trans* sex workers, ATSI sex workers and others are all disproportionately affected by both the intersectional stigma that comes from multiple marginalisation, and the struggles of working within or outside the licensing system.
- Because the licensing system restricts how and where sex work may occur, sex worker autonomy and the control that sex workers have over their workplaces is reduced.
- Interactions with police and the courts for working outside the licensing system (or in parts of the sex industry that remain criminalised) lead to records with the state that are deeply stigmatising for an already marginalised population - such records can prevent sex workers accessing public housing, affect child custody and have many other far reaching consequences.

It must be made clear that licensing is a system that harms sex workers and cannot be updated, modified or 'improved' such that it's fundamental flaws could ever be erased.

Sex worker organisations worldwide call for the full decriminalisation of sex work as does Vixen Collective here in Victoria.

- Decriminalisation is the removal of all criminal laws relating to the sex industry, allowing sex work to be regulated like any other business - this does not mean no regulation, but that the sex industry should be regulated like other businesses.
- Decriminalisation is recognised as the worlds' best practice model for sex industry regulation - by the United Nations[1], the World Health Organisation[2], Australia's HIV Strategy[3], multiple medical studies[4], and sex workers representative organisations.

[1] The United Nations Population Fund, United Nations Development Fund and UNAIDS support the decriminalisation of sex work and note that legal empowerment of sex worker communities underpins effective HIV Responses.

[22] *"Countries should work toward decriminalization of sex work and elimination of the unjust application of non-criminal laws and regulations against sex workers."*, Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations, World Health Organisation, July 2014, pg.91.

- Decriminalisation recognises sex work as work, helping to break down stigma against sex workers and reduce discrimination.
- It has been shown that STI rates and safe sex outcomes are maximised under decriminalisation[5].
- Under decriminalisation there is less waste of police resources on enforcement and sex workers are better able to access assistance when in need because of improved relations with police[6].
- It has been shown that sex work as regulated under decriminalisation has little to no amenity impacts.[7]
- Access to justice is improved for sex workers under decriminalisation, including an improved ability to pursue criminal cases against those who perpetrate violent or sexual offences against sex workers, but also civil protections (such as restraining orders).
- Decriminalisation would give sex workers better access to workplace safety, including state apparatus such as WorkSafe Victoria and the Fair Work Ombudsman.
- Decriminalisation would give sex workers greater ease to access health services, without the requirement to 'out' themselves - as is required due to mandatory testing under current licensing regulations - which has been shown to lead to discriminatory treatment and exclusion from medical services[8].

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[3] Australian Government Department of Health and Ageing, Sixth National HIV Strategy 2010-2013, Commonwealth of Australia, Canberra, 2010 at 6.4.

[4] For example: C Harcourt, J O'Connor, S Egger, C Fairly, H Wand, M Chen, L Marshall, J Kaldor, B Donovan, 'The Decriminalisation of Prostitution is Associated with Better Coverage of Health Promotion Programs for Sex Workers', Australian and New Zealand Journal of Public Health, 2010, 34:5 pg 482.

[5] National Centre in HIV Epidemiology and Clinical Research, *HIV/AIDS, Viral Hepatitis and Sexually Transmissible Infections in Australia Annual Surveillance Report 2010*, National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales, Sydney, NSW; Australian Institute of Health and Welfare, Canberra, ACT. 2007.

[6] *"The nature of sex workers' contact and interaction with police determines whether they feel confident making complaint to police regarding crimes of violence",* Scarlet Alliance and the Australian Federation of AIDS Organisations, Unjust and Counter Productive: The Failure of Governments to Protect Sex Workers From Discrimination Sydney, 1999, pg 14.

[7] Prior and Crofts, 'Effects of sex premises on neighbourhoods: Residents, local planning and the geographies of a controversial land use', New Zealand Geographer, v68, 2012, pg.130.

[8] The Sex Industry in NSW: A Report to the NSW Ministry of Health, 2012, pg.23.

- Decriminalisation would remove the impediment to testing and treatment that licensing, remaining criminalisation of street based sex work, and HIV criminalisation present for sex workers[9].
- There is no evidence of organised crime within the sex industry under decriminalisation.[10]
- Greater industry transparency under decriminalisation aids anti-trafficking efforts[11].
- Decriminalisation has been shown not to result in an increase in the numbers of workers participating in the sex industry[12].

Decriminalisation is a first step to recognising sex worker rights - many more issues remain to be addressed beyond how the sex industry is regulated - including; anti discrimination protections, recognition of sex workers as key stakeholders and experts in our own lives and work, funding for peer sex work organisations.

It is essential that government take that first step - the full decriminalisation of sex work - in recognising sex work as work, in recognising sex workers rights and in focusing on the health and safety of sex workers as a key component of the laws that affect us.

It is the firm opinion of Vixen Collective that introducing the PCEHR/HI into an environment in which sex workers rights are already fundamentally compromised can only compound the discrimination Victorian sex workers currently experience.

[9] The UNAIDS Guidance Note on HIV and Sex Work 2012 recognises that criminalisation poses substantial obstacles in accessing HIV prevention, treatment and support.
[10] As recognised by the Land and Environment Court in *Martyn v Hornsby Council*, cited in Nothing About Us Without Us, 'North Sydney Council Prohibits Home Occupation (Sex Services) in All Zones under the New Draft LEP', accessed at http://nothing-about-us-without-us.com/tag/urban-realists/ on 30 October 2014.
[11] It has been shown that decriminalising sex work does not cause an increase in trafficking, New Zealand decriminalised sex work in 2003 and continues to be ranked in Tier 1 by the United States State Department Trafficking in Persons Report. United States Department of State. Trafficking in Persons Report, (2010).
[12] *"…the number of sex workers in New Zealand has not increased as a result of the passage of the PRA…"* Report of the PLRC on the Operation of the PLA 2003, page.29.

Response to - Electronic Health Records and Healthcare Identifiers: Legislation Discussion Paper

At present the PCEHR/HI operates on an "opt-in" basis:

"The PCEHR system currently operates on an opt-in basis where individuals who want a PCEHR register for one and give consent for their information to be uploaded to their PCEHR by healthcare providers and Medicare.."[13]

It is of significant concern that as part of a drive to increase participation there is intent, to first run "opt-out" trials, and to then move completely to an "opt-out" model:

"An opt-out model of participation, as recommended in a review of the PCEHR system, will be included as part of these trials, that is, individuals in certain trial regions will automatically be registered for an eHealth record ***unless they advise that they do not want an eHealth record****.*

While opt-out participation means that the PCEHR system ***will no longer be relying on the consent of individuals but on legal authority****, the system will* ***continue to offer the same level of personal control over a PCEHR*** *and will* ***continue to give information the same level of privacy and security protection****..."*[14](emphasis added)

This change has significant implications for marginalised populations, including but not limited to:

- Sex workers
- Trans people
- Drug users
- People living with HIV
- Aboriginal and Torres Strait Islander peoples
- People living with homelessness
- People living with mental health/neuroatypical status
- People with culturally/linguistically diverse backgrounds

[13] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 1.
[14] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 1.

Vixen Collectives' submission deals with the issues these changes to the PCEHR/HI would present to sex workers, but with the recognition that there are those within sex worker community that may face multiple intersecting marginalisations, and therefore may be more profoundly affected due to this factor.

It should be noted that the very foundation of the PCEHR/HI and the intention behind its establishment seems to overlook the possibility that there are inherent issues within the health system itself for marginalised populations:

" It is a national system for providing access to individuals' key health information, intended to:

- *"..help overcome the fragmentation of health information in Australia;*
- *improve the availability and quality of health information;*
- *reduce the occurrence of adverse medical events and the duplication of treatment; and* ***improve the coordination and quality of healthcare provided to individuals*** *by different healthcare providers..."*[15] (emphasis added)

For marginalised populations, including sex workers, where the information held in their health records may in fact lead directly to both stigmatising treatment and/or discrimination against them in health settings the above is demonstrably untrue.

Statements to the effect that individuals are in control of their own PCEHR/HI information are very much mitigated by the issues many individuals in marginalised populations face, for example:

> *"The PCEHR system places the individual at the centre of their own healthcare by enabling access to important health information where and when it is needed by individuals and their healthcare providers. The individual can choose to limit access to their PCEHR and to particular documents in their PCEHR, can add their own health notes, and can remove documents from their PCEHR if they choose."*[16]

This is problematic as there exist <u>extensive barriers for those in marginalised populations</u>, including sex workers, in accessing their PCEHR/HI records:

[15] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 4.
[16] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 4.

- Accessing information on/having awareness of the PCEHR/HI
- Feeling able to challenge government/authority figures in relation to accessing, updating or removing parts of their PCEHR/HI information
- Access to internet/internet charges re inquiries and/or changes to PCEHR/HI being made via online mechanisms
- Access to telephone/telephone charges (with potential long wait times) re inquiries and/or changes to PCEHR/HI being made via telephone
- Navigating the bureaucracy surrounding the PCEHR/HI
- Accessing information on the PCEHR/HI and all of the above for culturally and linguistically diverse members of marginalised populations

Although it would appear that there has been extensive consultation within the health sector itself, there is little indication of direct consultation with marginalised populations or of any group with specialised health needs[17].

Definitions

Refer - 3.1.2 Definitions, pg 8-10 Electronic Health Records and Healthcare Identifiers Legal Discussion Paper

There are a number of concerns around the unclear nature of definitions relation to terminology employed within the current PCEHR/HI -

Identifying information

What exactly does this/is this intended to constitute for individuals? Reference is made to:

[17] Groups listed as "selected stakeholder groups" include *"..individuals; healthcare providers... ; health software vendors; private health insurance providers; medical indemnity insurance providers; private hospital representatives; healthcare providers and community workers working with Indigenous and remote communities.."* Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 6.

"A telephone number is defined to be identifying information of an individual healthcare provider but not an individual. Further, the definition of "identifying information" in relation to individual healthcare providers and healthcare provider organisations allows regulations to be made to prescribe additional information that is identifying information. However, it is not possible to make regulations prescribing additional identifying information for individuals. These ***restrictions are preventing the handling of information in ways that would enhance the utility of the PCEHR system****. For example, it is not currently possible to collect and* ***use individuals' mobile telephone numbers or email addresses to enable the PCEHR System Operator to send them messages****..."*[18] (emphasis added)

This seems to imply a desire to move to a system by which the PCEHR/HI would be able to collect and utilize both an individuals' email addresses and mobile telephone numbers.

This has significant implications for marginalised populations in a number of areas:

(i) Marginalised populations, including sex workers, have not been consulted or allowed to provide feedback on the specific issues unsolicited calls and messaging services have for their communities, potential impact (including impacts on safety) on them or how it will affect their use of health services prior to implementation.

(ii) The use of unsolicited calls and messaging services has implications in terms of confidentiality, particularly with modern smart phone technology (including the text message preview feature of many cell phones).

(iii) For many marginalised groups, including sex workers, who suffer from discrimination and stigma, there is a risk of 'outing' that may be attached to having to explain an unsolicited call or text message. There are also risks attached to other assumed implications from attending a health service (whorephobia, homophobia, transphobia, etc) and these can be profound.

(iv) For sex workers there are other associated work place related risks, such as venues demanding to see results (for example results of STI testing) that have been sent as a text message. This is why services that offer outreach or health services to sex workers are encouraged to access representative peer sex worker organisations such as Vixen Collective

[18] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 10.

or Scarlet Alliance (Australian Sex Workers Association) to receive feedback on legislative change such as this directly from sex worker community.

(v) It is also of note that when automatically "opted in" to the PCEHR/HI, it is only those with knowledge of their ability to "opt-out" and access/means to do so that will be able to prevent themselves receiving contact of this nature - refer extensive barriers for those in marginalised populations (see pg 12 of this submission).

(vi) In other jurisdictions (for example the U.K.) where notification of patient results have moved to text messaging, and in trials in Australia (for example Melbourne Sexual Health in Victoria) concerns have been raised that health service users may become aware of positive test results in the absence of post test counseling and support. We would raise these concerns here in regard to any move toward this policy for general results notification across Australia as part of the PCEHR/HI.

In regard to privacy and security of an individual's health record:

" The technical settings in the PCEHR system ensures that a healthcare provider or other authorised user can only access an individual's PCEHR if the individual has granted them access, except in emergency circumstances. ***Individuals cannot prohibit emergency access to their PCEHR by healthcare providers.***

Individuals can elect to be notified (by email or by SMS) when certain activities occur in relation to their PCEHR, including when a healthcare provider accesses their PCEHR by asserting an emergency exists or when their nominated healthcare provider uploads a new shared health summary..."[19]

Where members of marginalised communities, for example sex workers, face ongoing discrimination on the basis of being identified as a member of that community then having medical records in which that status may be recorded able to be accessed without the persons active consent is in itself a form of discrimination.

[19] Factsheet for Individuals - Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Australian Government - Department of Health, 2015, pg 2

An Opt-Out PCEHR System

Refer - 3.3.1 An opt-out PCEHR system, pg 12-15 Electronic Health Records and Healthcare Identifiers Legal Discussion Paper

Difficulties with opting out:

*" **Individuals choosing to opt-out of the PCEHR system would need to verify their identity with the System Operator**. This is necessary so that the System Operator can be certain that they are opting-out the correct person. The System Operator would subsequently write to that person at the latest address held by Medicare confirming that they have opted out. This is designed to prevent third parties being able to opt-out individuals when they have no authority to do so. .."*[20] (emphasis added)

The requirements for verifying identity to allow an individual to "opt-out" are as follows:

"*..the **unique reference number of the individual's driver licence, passport or Immicard**, and the type of credential (driver licence, passport or Immicard) – this would allow the PCEHR System Operator to collect this information, and disclose it to the Document Verification Service, in order to verify the identity of an* individual *who chooses to opt-out. The System Operator will not store this information once it has been used to verify the individual's identity.."*[21] (emphasis added)

For some individuals in marginalised communities, including sex workers, access to and retention of up to date identity documents can be challenging. This can potentially put individuals in the position where they do not wish to participate in the PCEHR/HI, because of the difficulties it raises for them as a member of a marginalised community, but leaves them with no ability to "opt-out" of the PCEHR/HI.

[20] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 13.
[21] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 10.

Individual Consent:

With the change to an "opt-out" system there is no longer active consent in relation to an individual's health records being brought into the PCEHR/HI.

"It will not be practical for the System Operator to obtain the consent of all individuals in trial areas who do not opt out. Therefore, in opt-out trial areas it is proposed that, ***in place of consent, for those who do not choose to opt-out, the legislation would authorise the registration of individuals and uploading of records by healthcare provider organisations and Medicare (including up to two years of historical Medicare data).*** *The authorisation in relation to uploading records to an* individual's *PCEHR would be subject to the same exceptions that currently exist – for example, the* individual *would still be able to tell a healthcare provider to not upload a particular record and would still be able to stop their Medicare data being uploaded. Authorisation is required because* individuals *won't have the opportunity to give consent..."*[22]

This means that depending on the effectiveness of public awareness campaigns about trials and the eventual full move to the PCEHR/HI there may be many individuals left unaware that their health records have been migrated to the PCEHR/HI without their consent, this effect is only magnified within marginalised communities.

The listed steps to address individuals privacy concerns:

- "..set access controls to control who can access what information in their PCEHR, including restricting access to their Medicare data and removing documents;
- tell healthcare providers on a case-by-case basis to not upload certain documents;
- monitor activity in their PCEHR using the audit log or via messages alerting them that someone has viewed or used their PCEHR;

[22] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 14.

- make a complaint if they consider that there has been a breach of their privacy; and

- cancel their registration if they wish, that is, cancelling their PCEHR.."[23]

All of these steps face the same barriers already raised earlier in this report, namely the difficulties that marginalised populations have with:

- Accessing information on/having awareness of the PCEHR/HI
- Feeling able to challenge government/authority figures in relation to accessing, updating or removing parts of their PCEHR/HI information
- Access to internet/internet charges re inquiries and/or changes to PCEHR/HI being made via online mechanisms
- Access to telephone/telephone charges (with potential long wait times) re inquiries and/or changes to PCEHR/HI being made via telephone
- Navigating the bureaucracy surrounding the PCEHR/HI
- Accessing information on the PCEHR/HI and all of the above for culturally and linguistically diverse members of marginalised populations

This is with the additional challenges of being required to produce identification (drivers license, passport, Immicard) to withdraw from the PCEHR/HI presents, and the fear of challenging an authority figure over making a complaint or telling them not to upload a certain document.

It would be reasonable to expect that community organisations, for example peer sex worker organisations could conduct work within their own communities to raise awareness and pass on information about the PCEHR/HI to mitigate the effect of some of these issues. However there is no indication of whether there will be funding available to carry out this work and quite obviously community organisations cannot be expected to cut service delivery work to publicize the PCEHR/HI.

[23] 'Electronic Health Records and Healthcare Identifiers Legal Discussion Paper', Commonwealth of Australia, 2015, pg 14

It is also noted that with regard to State and Territory law:

".. if the document to be uploaded relates to certain matters prescribed in state and territory laws that have been preserved by PCEHR Regulation 3.1.1 (known as preserved privacy laws). For example laws relating to the disclosure of HIV/AIDS or communicable diseases information. In these cases, ***the provider will still need to obtain consent from the individual before uploading a record, in accordance with the relevant state or territory law****..."*[24] (emphasis added)

This relies on individual medical practitioners beings both aware of and up to date with relevant State and Territory laws. It has been consistently reported by sex worker community that this is not that case at present (ie medical practitioners are not aware of relevant State and Territory law) and as the local representative peer sex worker organisation we have significant concerns that in the absence of relevant knowledge of these laws a mixture of information from the media and personal prejudice is being used. This is particularly concerning given that not only are the laws under which we work accessible, but a large body of medical research exists in Australia indicating sex workers have low rates of STI's (lower than the general population).[25]

<u>Secondary Use of Information</u>

What constitutes "de-identified information"?

Are there additional identifiers in the PCEHR/HI at present that identify those in marginalised populations?, such as:

- Sex workers
- Trans people
- Drug users
- People living with HIV
- Aboriginal and Torres Strait Islander peoples

[24] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 14.
[25] *".. condom use for vaginal and anal sex exceeds 99%.."*, Improving the health of sex workers in NSW: maintaining success, Donovan et al, NSW Public Health Bulletin 2010, pg. 74

- People living with homelessness
- People living with mental health/neuroatypical status
- People with culturally/linguistically diverse backgrounds

If there are additional identifiers in the PCEHR/HI for any of these marginalised populations then it is recommended that the relevant representative peer based organisations be consulted for feedback as part of the ongoing PCEHR/HI consultation process.

The collection of and research on marginalised population without consent or consultation with either individuals or the representative peer organisations of the communities would be of significant concern.

Note: Confirming Opt-Out

For individuals living with homelessness the requirement that to "opt-out" one must also receive a letter from the 'System Operator' to confirm registration is cancelled, is a barrier to being able to exit the PCEHR/HI.

There needs to be an alternative option so that individuals that do not have the ability to maintain and/or provide an address, can still "opt-out" of the PCEHR/HI without going through this part of the procedure.

"An individual (or their representative) will continue to be able to cancel their registration at any time. ***The System Operator would write to the individual to confirm that registration will be cancelled.*** *This is designed to prevent third parties from being able to cancel other individuals' PCEHRs..."*[26] (emphasis added)

[26] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 19.

Collection, Use and Disclosure of Information

Refer - 3.5.3 Collection, use and disclosure of information, pg 20-22 Electronic Health Records and Healthcare Identifiers Legal Discussion Paper

Marginalised populations, including sex workers, have a history of making use of both:

- anonymous clinics
- free clinics (that may require Medicare information but do not charge)

Often these clinics are facilitating health testing, including STI/HIV testing in environments where workplace and/or legal penalties may apply for those returning positive results.

Any consideration of extending the use of PCEHR/HI identifiers to other records (for example blood testing records, contact tracing etc) would raise significant barriers to current successful community participation in testing and treatment.

*"**Consideration is being given to allowing certain other records to use healthcare identifiers to ensure the owners of the records are accurately identified**. Any additional use of healthcare identifiers would be tightly restricted – for example, for use in records relating to the provision of healthcare or for closely-related purposes.."*[27] (emphasis added)

Interaction of the PCEHR/HI with sex work and the licensing system in Victoria

The licensing system for sex industry regulation already provides significant issues for sex workers managing their health care and medical records in Victoria.

The primary legislation that affects sex workers with regard to the Victorian sex industry regulatory system are the 'Sex Work Regulations 2006' and the 'Sex Work Act 1994', specifically the sections therein:

- 18A Sex workers and clients must adopt safer sex practices

[27] Electronic Health Records and Healthcare Identifiers Legal Discussion Paper, Commonwealth of Australia, 2015, pg 21.

- 19 Permitting sex worker infected with a disease to work in a brothel etc
- 20 Sex worker working while infected with a disease

(Refer below for a longer discussion of these issues in 'Excerpt from Vixen Collective Submission to the Review of the 'Sex Work Regulations 2006')

Excerpt from Vixen Collective Submission to the Review of the 'Sex Work Regulations 2006'

(From the Vixen Collective submission to the CAV regulatory review, April 2015)

Laws that apply criminal sanctions or penalties to a sex act that would be otherwise legal, except that the sex involved is paid, are arbitrary and contrary to the findings of substantial medical research.

Sex workers undertake education in sexual health and safer sex both as peer educators within their own community and with clients. This is reflected not only in low STI and HIV rates for sex workers in Australia, but in high uptake of safer sex practices[28].

The sections (19 & 20) of the 'Sex Work Act' which amount to 'mandatory testing'[29], cause a significant number of issues for the rights and safety of sex workers:

- Mandatory testing is unnecessary with regard to STI and HIV rates within sex worker community, as medical research consistently reports rates for sex workers that are as low or lower than that of the general community[30] regardless of the regulatory regime in place.
- Over testing of sex workers is a waste of tax payers money and uses health resources that could be better devoted to high risk groups, or to free up overcrowding in anonymous services.

[28] *".. condom use for vaginal and anal sex exceeds 99%.."*, Improving the health of sex workers in NSW: maintaining success, Donovan et al, NSW Public Health Bulletin 2010, pg. 74

[29] Sex Work Act 1994, Victorian Government, 13th August 2013, Part 2, Regulation 19 & 20, pg. 32-35.

[30] *"Among the 140 LASH participants in Sydney who were tested for four common STIs – chlamydia, gonorrhoea, trichomoniasis, and Mycoplasma genitalium infection – the prevalence of these conditions was at least as low as would be found in women in the general population"*, The Sex Industry in NSW: A Report to the NSW Ministry of Health, 2012, pg.23.

- Having to attend a GP or medical centre, to obtain a medical certificate, 'outs' workers to doctors which is stigmatising and can lead to intrusive and/or inappropriate comments and questions.
- The requirement for provision of medical certificates leads to unnecessary compiling of data on sex workers both by medical staff and at sex industry businesses.
- There is only one confidential service in Victoria that sex workers can attend, Melbourne Sexual Health (MSH), located in central Melbourne. This is not accessible to many sex workers, especially rural sex workers, and it is a drop-in clinic (appointments cannot be made) meaning waiting times are lengthy - often between three to five hours.[31]
- Sex workers attending medical services report that doctors do not have standard guidelines in place when conducting consultations in relation to mandatory STI screening, that many doctors do not clearly understand which tests are required in order to comply with the licensing legislation.
- Sex workers attending non confidential services (such as a GP or medical centre) report that many doctors are unsure of the exact requirements of providing medical certificates (for example - may insist on writing them in a sex workers full legal name, not the sex workers business or 'working' name). This, as previously mentioned, contributes to the unnecessary compiling of data on sex workers, as well as risking 'outing'.
- It has been reported by sex workers attending non confidential services (such as a GP or medical centre) that they have suffered discrimination in the form of refusals (an individual occasion of refusal of treatment) and exclusions (permanent exclusion as a patient of the practice) due to sex worker status. This is due to a doctor learning of a workers' status as a sex worker and then refusing "on conscience" to provide treatment to them.
- Sex workers attending GP's or medical centres are increasingly finding that doctors will not process their visit or the resulting blood work and/or swabs on Medicare. This has left sex workers with medical bills of hundreds of dollars just to comply with the licensing

[31] Sex worker consultation on the review of 'Sex Work Regulations 2006', Vixen Collective, 11th April 2015.

requirements[32]. The lack of Medicare coverage for sex workers tests has also been cited by doctors as ground for refusal of treatment[33].

- Sex workers attending medical services for STI testing and to obtain a certificate report facing inappropriate questions[34] and discriminatory treatment.
- Laws that mandate that sex workers who test positive to an STI or HIV cannot work create the following issues:
    i) loss of income
    ii) disconnection from support networks
    iii) discourages testing, especially if symptomatic, for fear of testing positive
    iv) discourages treatment, for fear of a record of treatment while working

  STI and HIV criminalisation ignore safer sex practices and beg the question - if we do not criminalise sex with an STI or HIV for the general public then how can the criminalisation of the same for sex workers be anything less than discriminatory?

  When medical research has proven sex workers sexual health is at least the same or better than the general public, and our use of safer sex techniques much greater, how is the requirement for mandatory testing of sex workers in Victoria anything less than discriminatory?
- Due to window periods when testing for STI's mandatory testing does not indicate a sex workers actual sexual health status.
- Mandatory testing can give a false sense of security and increase requests for unsafe practices from clients.
- Having sex worker status recorded on a persons' medical records can lead to stigma and discrimination. This is likely to have a greatly increased impact with the eventual move to electronic records management for medical records in the near future.

[32] This issue is consistently reported to Vixen Collective, a report was taken as recently as Sunday the 19th April 2015 from a sex worker who had migrated to Australia and on undergoing STI testing was presented with a bill in excess of $800.

[33] Sex worker consultation on the review of 'Sex Work Regulations 2006', Vixen Collective, 11th April 2015.

[34] *"..were you abused as a child?.."*, from interaction with doctor as reported in, Sex worker consultation on the review of 'Sex Work Regulations 2006', Vixen Collective, 11th April 2015.

Most importantly sex workers should have the same rights to bodily autonomy and the same ability to exercise choice regarding their health and healthcare as other members of the public in Victoria do.

Victorian Sex Industry Licensing and the PCEHR/HI

At present government legislation and health policy are both based not on reality (that sex workers have better sexual health and lower STI rates than the general population[35]) but on the stigma that sex workers are "vectors of disease". The current legislation and resultant policy in Victoria also perpetuates this stigma.

Mandatory testing is not just a burden on taxpayers and a use of health resources that could be better distributed to at risk groups - but it places sex workers in the position of "outing" themselves (indicating their status as sex workers) to medical professionals. This is in order that sex workers obtain the necessary paperwork to work (a certificate indicating testing has occurred). However, having "outed" themselves sex workers may now face discrimination.

At present Victorian sex workers already report the following in medical settings:

- Intrusive and/or inappropriate comments and questions
- Discrimination in the form of refusals (an individual occasion of refusal of treatment)
- Exclusions (permanent exclusion as a patient of the practice)
- Will not process their visit or resulting blood work and/or swabs on Medicare
- Lack of Medicare coverage for sex workers tests has also been cited as ground for refusal of treatment
- Sex workers attending medical services for STI testing and to obtain a certificate report facing inappropriate questions and discriminatory treatment

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[35] *"Professor of Sexual Health at Melbourne University, Christopher Fairley, said research showed monthly testing was unnecessary and a waste of public health resources because sex workers have much lower rates of STIs than other people."* 'Monthly sex worker tests are ridiculous, health experts say', The Age, May 31st 2011, http://www.theage.com.au/victoria/monthly-sex-worker-tests-are-ridiculous-health-experts-say-20110530-1fctn.html#ixzz3g5HbFFLr

With the advent of the PCEHR/HI, sex worker status would be reflected in an individual's PCEHR/HI if they are a sex worker (due to licensing) in either of the following ways:

1) Explicitly - through medical practitioner/s notes indicating a person's status as a sex worker
2) Implicitly - able to be implied because of regular three monthly STI/HIV testing history (required due to Victoria's licensing regime)

With the intent of the PCEHR/HI being that an individual's records are accessible by any medical practitioner, if information is entered into an individual's record that is a basis for potential discrimination then the flow on effects of this are significant.

Current Stigma and Discrimination Against Sex Workers in Australia

It is already the case that sex workers face stigma and discrimination in Australia. This stigma and discrimination is magnified in environments where sex work is either criminalised or regulated via a licensing system.

Being identified as a sex worker can have implications[36] not limited to impacting:

- Interpersonal and interfamilial violence when 'outed'
- Can affect school age and/or older children if a parent or carer is 'outed'
- Outcome of child custody cases
- Other future employment
- Access to housing and accommodation
- Goods and services (including banking, insurance and online commerce)
- Entry to clubs or hotels
- Education (including exclusion from courses on 'morals clauses')
- Medical treatment (incl. compiling of medical records)
- Research on sex workers (sex workers are an over-research population who often have little input into the research conducted on their community)

[36] Refer Scarlet Alliance and the Australian Federation of AIDS Organisations, Unjust and Counter Productive: The Failure of Governments to Protect Sex Workers From Discrimination Sydney, 1999.

- Membership of trade unions
- Stalking and harassment from anti sex work groups and their members, including outing to family and in social media
- Restriction of movement and identification of travel documents
- Reduced access to police when victims of crime
- Reduced ability to access justice through the courts
- Excessive and/or vilifying coverage in media of sex work related news, court cases and the deaths of sex workers

Given the profound harms (as outlined above) that result from stigma and discrimination against sex workers it our belief that it is critical to move to the full decriminalisation of sex work prior to fully adopting the PCEHR/HI.

Vixen Collective Recommendations

It is critical that the voices of sex workers be heard, in order that the rights of sex workers be recognised and the safety of sex workers given protection by law.

It is imperative that sex workers be recognised as the key stakeholders regarding our own lives and work, that government consult with our representative organisations, peer sex worker organisations accordingly.

Vixen Collective recommends that the Commonwealth Government - in consultation with sex workers and their representative sex worker organisations - do the following:

1) ***Join Victorian sex workers in recommending to the Victorian State Government that the licensing system in Victoria must be replaced as the regulatory model for Victorian sex work****, as licensing as a system of regulation is inherently stigmatising and discriminatory to sex workers****.***
2) ***Join Victorian sex workers in recommending to the Victorian State Government that the only acceptable model of sex work regulation is the full decriminalisation of sex work,*** *and that it is the full decriminalisation of sex work that supports sex workers health, safety, human rights and labour rights.*
3) ***Recognise that the current "opt-in" model of the PCEHR/HI offers a better protection of individual's rights than an "opt-out" model, especially regarding the rights of those individuals from marginalised populations, including sex workers****. Individuals from marginalised populations often already face significant barriers to accessing healthcare and the discrimination they currently suffer is perpetuated in all government records that reference their marginalised status (including health records).*
4) ***Recognise the need for direct consultation with marginalised populations, specifically the representative organisations of marginalised populations - in the case of sex workers, peer representative sex worker organisations****, such as Vixen Collective - so that there is direct*

feedback on the impact of proposed changes to the PCEHR/HI to Government from these communities.

5) ***If a decision is made to move forward with an "opt-out" model for the PCEHR/HI, <u>which we strongly recommend against</u>, then it is critical to consider:***
    a. *The **need for consultation specifically on the issue of use of the use of identifying information** and the multiple challenges this presents for marginalised populations, including sex workers. Specifically in the areas of safety, confidentiality, 'outing', workplace risks, post test counseling/support, and technology.*
    b. ***Reconsider the requirements for opting out, as currently these present significant barriers**, particularly for those in marginalised populations, including sex workers, as some parts of community may have difficulties with access to and retention of up to date identity documents.*
6) ***We ask the Commonwealth Government to provide clarity on the current identifiers intended for use in the PCEHR/HI. Are there any identifiers relating to the following marginalised populations and if so what they are?***
    a. Sex workers
    b. Trans people
    c. Drug users
    d. People living with HIV
    e. Aboriginal and Torres Strait Islander peoples
    f. People living with homelessness
    g. People living with mental health/neuroatypical status
    h. People with culturally/linguistically diverse backgrounds
7) ***We ask the Commonwealth Government to provide clarification as to whether the use of PCEHR/HI identifiers will be extended to other records** and if so, to what records?*
8) ***We ask the Commonwealth Government to provide clarification regarding the PCEHR/HI being reliant on medical practitioners knowing relevant State and/or Territory law - is there an intent to ensure that this is the case?** As there is considerable evidence at a local level (in Victoria) to indicate that this it is currently not the case that all medical practitioners are aware/sufficiently aware of relevant State and/or Territory law .*

9) ***We ask the Commonwealth Government to provide clarification regarding the budget for the PCEHR/HI. Is there any allowance for specifically training medical practitioners on working directly with marginalised populations, such as sex workers?*** *Such training, at a minimum would need to be on:*

   a. *Stigma and discrimination faced by sex workers*
   b. *Specific medical requirements for sex workers under law (by State or Territory)*
   c. *Issues faced by sex workers with regard to medical records*
   d. *Issues raised for sex workers by the PCEHR/HI*

      NOTE - this training would need to be conducted in partnership with peer sex worker organisations

10) ***We ask the Commonwealth Government to provide clarification regarding the budget for the PCEHR/HI. Is there any allowance for funding for peer sex worker organisation to publicize the PCEHR/HI (and the relevant issues it presents) within their own communities?***

Glossary of Terms

Non Peer - A non sex worker. When used to describe an organisation this means that although there is the possibly that there may be some sex worker staff it is not a sex worker only organisation.

Peer Only - Sex worker only. When used to describe an organisation this means that everyone involved in the organisation - all staff, management, board members and volunteers - are current or former sex workers.

Private Worker/s - This is the sex worker term for someone who under the licensing law in Victoria is called a small owner-operator sex work service provider, ie an individual sex worker working for themselves rather than in a brothel.

Sex Workers Representative Organisations - In each state and territory of Australia sex workers participate in their representative organisations, for peer support, health promotion and to lobby for law reform. These are peer only organisations.

Whorephobia - The act of holding and/or disseminating stigmatising attitudes towards an individual sex worker or sex worker community.