RELATIONSHIPS

FAITH

SEXUALITY

GENDER

DISABILITY LABEL

CULTURE

BODIES

INTERSECTIONS

Healthcare Insights from People with Intersectional Needs

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HEALTH CONSUMERS NSW

ACKNOWLEDGEMENTS

Intersections: Healthcare Insights from People with Intersectional Needs

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This report and more information about The Intersections Project are available at www.hcnsw.org.au/intersections

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EXECUTIVE SUMMARY

Many people with a history of being marginalised report encountering healthcare access barriers and inequities. Research into these experiences is often limited to a single identity category. This can overlook the needs of people who experience barriers and inequities when accessing healthcare from multiple intersecting axes of marginalisation (e.g., disability, gender identity, and sexuality). The Intersections Project is a pilot community engagement initiative that collected health consumer narratives for people with intersectional needs seeking healthcare from public hospitals, NGO health services, GPs, and other providers. Most services were in metropolitan Sydney, but a few were in regional NSW or other states.

These experiences were evaluated against the Australian Charter of Healthcare Rights (2nd edition): access, safety, respect, partnership, information, privacy, and the right to give feedback. This project aimed to identify healthcare inequities experienced by people with intersectional needs. We believe the community wisdom and insights from people with lived experience featured in this report can inform and improve healthcare policy and practice across all health services.

Based on consumers' input, we identified five overarching recommendations for health services:

- **Co-design:** That health services apply a **co-design** approach to address the individual, provider, and systemic levels at which people experienced breaches of their healthcare rights. By incorporating insights from health consumers, healthcare providers, and system administrators, we can effectively address the dynamic interactions between these three levels.

- **Systemic feedback:** That health services develop ongoing opportunities for all stakeholders to give systemic feedback (consumers, carers, partners, family members, providers, and administrators). This includes inviting people to participate in and comment on policies, administrative processes, and other structural and systemic components that affect their healthcare experiences, beyond the level of experiences with individual providers.

- **Point of service feedback (POSF):** In addition to formal consultation processes and regular evaluation to assess how healthcare pathways address people's intersectional needs, health consumer opportunity for immediate participation and comment be made accessible through point of service feedback (see Gill et al., 2015). For example, POSF improved clinical outcomes at a service level in a national study of hospice/palliative care settings (Currow et al., 2015).

- **Social determinants of health (SDOH) analysis**: That healthcare system policies and processes evaluate the consequences of healthcare system design on other social determinants of health such as housing, employment, education, etc. That both providers and administrators consider how healthcare policies and actions can affect people in other domains of life and seek guidance regarding how to reduce the adverse impact on social determinants of health (e.g., a Clinic-to-Community Listening Forum). This includes evaluating the potential for indirect discrimination.

- **Ongoing intersectional assessments & point of service improvements**: That intersectional needs be integrated into existing healthcare system assessment processes (e.g., patient satisfaction surveys) at the healthcare provider, administrator, and system management levels. That policies and procedures allow frontline staff (e.g., reception, nursing, etc.) to be able to make immediate changes based on people's POSF.

Lack of safe and accessible healthcare has an impact on so many other areas of life, from employment to relationships to family life to housing.

HCNSW welcomes any opportunity to collaborate with health services interested in addressing the concerns of people with intersectional needs. We invite services interested in developing co-design processes with people with intersectional needs to contact us directly.

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INTRODUCTION

Background

The Intersections Project investigated the healthcare inequities and barriers that prevent people with intersectional needs from receiving safe, compassionate, equitable, and person-centred care. This project was inspired by the *Including Intersectional Identities (III)* report, a successful initiative of the Equality Network in Scotland co-authored by Equality Network's Intersectional Projects Coordinator Sam Rankin and Dr Gávi Ansara. The *III report* contained guidelines for health and social care professionals providing services for people with intersectional needs across protected characteristics, a term referring to characteristics for which people are legally protected from discrimination in the Scottish Equality Act: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, and sex. Different terminology is used outside of Scotland. This report attempts use terminology more consistent with Australian health policy.

Created from a partnership with South Eastern Sydney Local Health District (SESLHD), the Intersections Project aligns with and supports the values outlined in the district's strategy: The Journey to Excellence, which prioritises safe, compassionate, equitable, person-centred, and high quality healthcare that responds to and considers the various needs of the population. This emphasises protecting the most under-served in the population by establishing a culture of trust, respect, and inclusion.

Finally, the Intersections Project supports The National Safety and Quality Health Service Standards, which describe the level of care that should be provided by health service organisations and the systems needed to deliver safe and quality healthcare. Particularly pertinent is the over-arching focus upon person-centred care, which is embedded in each standard and prioritises the needs of people who may be at greater risk of harm, such as those with intersectionality.

Theoretical Framework

This project is based on the *intersectionality* paradigm, which was first popularised by Kimberlé Crenshaw's (1989, 1991) work in the fields of critical race studies and Black Feminist scholarship. Since Crenshaw's first publication in the field, intersectionality has been defined in a variety of ways. For the current community engagement project, we define intersectionality as "the interaction of multiple identities and experiences of exclusion and subordination" (Davis, 2008) and as "the relationships among multiple dimensions and modalities of social relations and subject formations" (McCall, 2005). For example, an intersex Autistic Muslim woman who uses a wheelchair has intersectional needs that are likely to affect her healthcare experiences.
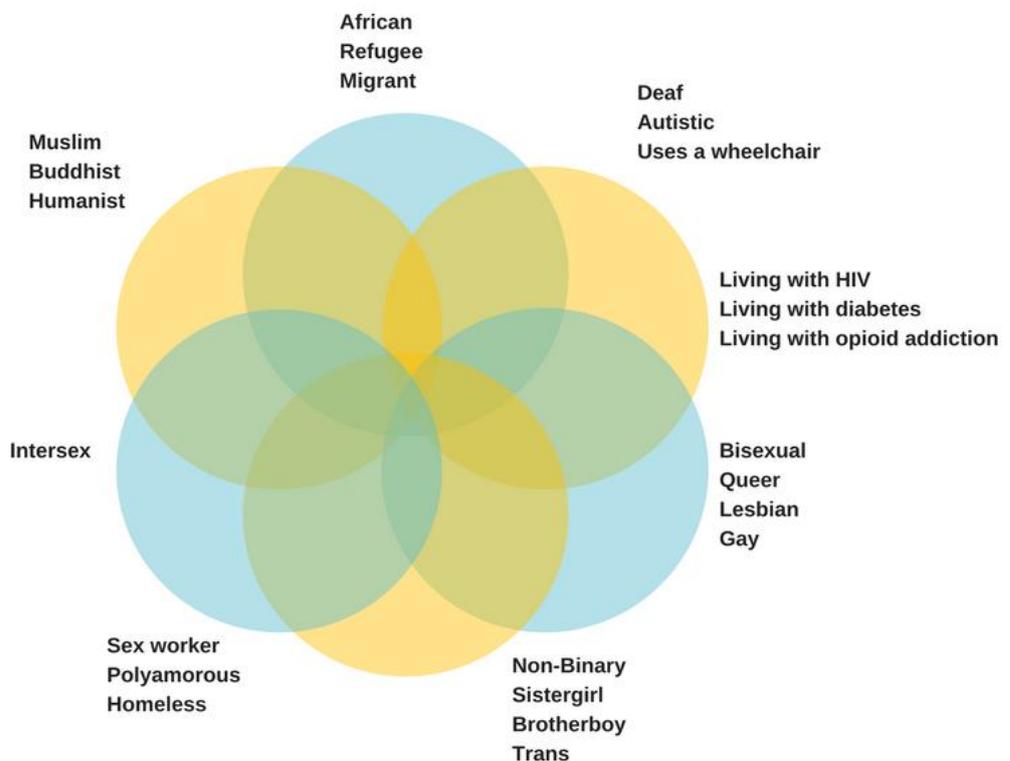
Intersectionality is a distinct approach that informs methodology and practice. Although this Intersections Project is a pilot community engagement initiative rather than formal research, Hancock's (2007b) standards for empirical research in the intersectionality paradigm provide useful guidance for our pilot. Hancock identified some key conceptual differences between the intersectionality paradigm and other more common research approaches to categorise 'difference' such as race, class, and gender. Some core distinguishing features of *intersectional* inquiry are:

- attention to multiple social categories
- categories matter equally rather than being rank-ordered in terms of attention or importance
- the relation between categories is an open empirical question rather than one that is predetermined
- the interaction between individual and institutional factors is viewed as dynamic rather than static
- the presumed makeup of each category is viewed as diverse, with recognition of politically significant variation between people with the same identity classifications or social categories
- individual and institutional levels of analysis are integrated within a single analysis
- the inquiry incorporates both empirical and theoretical components, with the view that the incorporation of multiple methods is both necessary and adequate.

Empirical evidence supports the use of an intersectional approach when examining access barriers and inequities in Australian healthcare contexts. For example, when Bastos, Harnois, and Paradies (2018) examined data from the 2014 Australian General Social Survey, a nationally representative survey of people aged 15 and older living in 12,932 private dwellings, they found that perceived racism in combination with other forms of discrimination predicted perceived barriers to healthcare. Unfortunately, the lack of intersectionality in research and community engagement initiatives can translate into knowledge gaps about the healthcare experiences of people who belong to more than one marginalised or excluded population. As Hancock (2007a) noted, a key focus for work using the theoretical framework of intersectionality is inclusion, which Davis described as "incorporating previously ignored and excluded populations into pre-existing frameworks to broaden our knowledge base regarding traditional questions".

Intersectional inquiry is focused on practical implications and applications. By acknowledging the interactions between individual, familial, community, and institutional phenomena, an intersectional theoretical approach "enables a comprehensive, multi-level approach that dynamically engages individual and institutional factors in policy-making across several relevant categories…" (Hancock, 2007b). The Intersections Project applied an intersectional approach to our community engagement initiative to increase health services' knowledge of the healthcare experiences of people with intersectional needs, who often experience exclusion and marginalisation when seeking or receiving healthcare. The aim of this project is not only to identify healthcare inequities experienced by people with intersectional needs but also to inform and improve healthcare policy to initiate a test of change.

Structural violence and systemic trauma

While people are sometimes marginalised through interpersonal interactions because of a particular person's prejudice, ignorance, or lack of empathy, people can also be marginalised through the effects of a system.

Public health advocate Dr Paul Farmer and colleagues (2006) used Galtung's 1960s term *structural violence* to describe the political, legal, cultural, religious, and economic societal structures that harm people by interfering with their ability to meet their basic needs. Farmer et al. explained that the word *structural* refers to societal structures that are normalised and often invisible due to how ordinary they seem, and that they are *violent* in the sense that they cause injury to people. For example, a woman of trans experience who was assigned male at birth was unable to get identity documents listing her as 'female'. As a result, she was unable to access her local women's refuge following an experience of intimate partner violence and instead ended up in a multi-gender environment where she was targeted for abuse and harassment and did not receive any support for her needs as a survivor of intimate partner violence.

Structural violence can lead to *systemic trauma*, which Goldsmith et al. (2014) defined as the contextual aspects of institutions, cultures, communities, and families that contribute to trauma, maintain post-traumatic stress, and affect post-traumatic outcomes. One form of structural violence that can lead to systemic trauma is *cisgenderism*, defined by Ansara (2009) and Ansara and Hegarty (2012) as the ideology (system of thought and action) that invalidates people's own understanding of their genders and bodies. Although cisgenderism can affect anyone, it is a common experience for women and men of trans experience and for non-binary people (people who do not identify as either women or men) when seeking healthcare. For example, when a man of trans experience waiting for a routine medical appointment is called 'she' by the receptionist and faces risks to his privacy and physical safety as a result.

Principles for Community Engagement

The Intersections Project applied a values-based framework based on seven core principles:

- **Moving to the margins**
  We prioritised recruitment of people who had not previously shared their healthcare experiences and people who were among the most marginalised within their intersectional demographics, rather than focusing on seeking contributions from people who were considered 'leaders'.

- **Internal diversity**
  We recognised that each person's needs and experiences will be different from other people who might check the same demographic boxes.

- **Self-representation**
  Our project is based on the slogan first made popular in South African disability rights activism, adopted by organisations worldwide that include the Sex Workers' Outreach Project (SWOP) in Australia, and recently adapted by social justice artist Ricardo Levins Morales to this:

  Nothing about us without us is for us.

This means we understand that we need to listen to people talk about their own healthcare experiences in their own words to make a positive difference to the healthcare system.

- **Accessibility and flexible responsiveness**
  To make our project as accessible as possible, we provided contributors with a variety of options to meet their accessibility needs. As explained in our recruitment material: "we will do our best to meet your needs. We can come to you or offer you a private space to talk. We can talk to you in person, through text chat or email, by phone, or through video. We can talk with you and your support people or with just you alone. We can talk for as long or as little as you feel comfortable. We can help you to share your story in any medium you prefer, from video to audio recording to written text. You can tell us if we need translation or adaptive aids. No information we share outside of Health Consumers NSW will contain your full name or any details that could identify you without your written permission."

- **Trauma-informed approach**
  Our project is designed in a trauma-informed way. This means we understand that sharing negative healthcare experiences can often be distressing or trigger people's unresolved trauma. For this reason, before people shared their experiences, we would chat with them to make sure that participating in this project seems emotionally safe for them. We also offered referrals to support services. In contrast to many data collection projects, we provided a supportive, empathic listening environment in which to share their healthcare experiences. We communicated the high value we placed on ensuring this project is culturally and emotionally safe for contributors.

- **Fair compensation**
  We also know that people in excluded and mistreated groups are often asked to give their time for free and what they give is not acknowledged or valued. For this reason, we showed that we valued each person by acknowledging contributors by name to the extent they permitted, and by giving each eligible contributor a $100 gift voucher.

- **Action-oriented focus**
  This project is not 'research'; it is a pilot community engagement endeavour for social change. We aimed to do more with people's stories than just listen to them. We aimed to use contributors' wisdom and insights to guide other people seeking healthcare services on how to deal with negative experiences, to educate health providers and health system authorities about the current gaps and problems with healthcare, and to make changes to what actually happens in the healthcare system

Healthcare Rights

Farmer et al. (2006) described healthcare as a human right. The Australian Charter of Healthcare Rights (2nd edition, 2019) identifies seven specific healthcare rights (the entire Charter is available on page 44 below):

- Access
- Safety
- Respect
- Partnership
- Information
- Privacy
- Give feedback

This report classifies contributor experiences in relation to each of these seven rights.

Purpose & Aims

The purpose of the Intersections Project was to identify specific service gaps, exclusion, and marginalisation experienced by people with intersectional needs when seeking healthcare. This project aimed to increase knowledge about people's intersectional needs and to use this knowledge to improve health policy and practice.

Participant Demographics

The Intersections Project focused on people who consider themselves to have at least two of these three areas of intersectional needs:

Bodies, Roles & Relationships

- **gender identity, experience, or expression** (including **but not limited to** agender, brotherboy, sistergirl, genderqueer, gender-fluid, trans, simply man or woman [who happens to have a trans experience or history], non-binary);

- **being an intersex person** (i.e., a person born with physical characteristics that are not considered strictly 'female' or 'male' in modern medical science;

- **sexuality** (including **but not limited to** asexual, bisexual, pansexual, queer, polyamorous);

  AND/OR

- **relationship(s)** (including **but not limited to** same-gender, polyamorous, and multi-partnered)

Faith, Culture & Citizenship

- **culture(s) or ethnicities** (being from an Aboriginal/Indigenous and/or Torres Strait Islander community and/or being from one or more linguistically and/or culturally diverse populations;

- **faith/belief(s);** AND/OR

- **citizenship status** (including **but not limited to** people born overseas, people seeking asylum, and people who have refugee status)

Marginalised life experiences
- a long-term or complex health condition
- homelessness
- living in community housing or a group home
- having low to no income
- ageing
- being given a disability label or living with a disability
- past or current sex work
- being autistic
- having another oppressed neurodivergence
- Rural or remote background
- Substance addiction
- Leaving care
- Time spent in juvenile justice or corrections facility

In recognition of the need to move beyond fixed social categories and potentially exclusionary language, recruitment materials emphasised the broad scope of intersectional identities, characteristics, and experiences we wished to include. As one recruitment pitch noted, "this is only a sample, not a complete list. We also want to hear from you if you don't see yourself mentioned here!"

Contributor Recruitment

The Intersections Project utilised a qualitative methodology designed to embody the seven principles in the Australian Charter of Healthcare Rights (2nd edition) and to address common concerns of people with intersectional needs when responding to community recruitment and research projects. We contacted trusted community leaders before and during the early stages of the project outreach. We use the term 'leader' to refer to an influential member of a community or a person who is viewed by that community as trustworthy and held in high esteem, recognising that formal titles and positions may not reflect community leadership accurately. Some of the trusted community leaders with whom we engaged included Chantell Martin, a case worker with the NSW Sex Workers Outreach Project (SWOP), Bec Johnson of Indigilez. Engaging and consulting with community leaders from the beginning of the project increased accessibility for contributors and allowed the project to reach a more diverse range of people, particularly those with prior negative experience with community outreach projects.

We conducted outreach through trusted community leaders, social media, word of mouth, hard copy postcards in community and service delivery settings, and through email list software.

Design

The Intersections Project was designed to provide contributors with flexible options to facilitate their engagement. In contrast to the limited scope of formal research questions, the project was designed to facilitate contributors' own identification of key topics and concerns they considered relevant to their intersectional needs within healthcare contexts. The project used a combination of semi-structured, open narrative interviews and non-directive, supportive dialogue to help contributors to identify topics of importance to them and to develop their narratives, rather than asking a series of fixed questions or using survey questionnaires that would set pre-defined limits on content scope. Contributors were encouraged to provide qualitative narratives in written, audio, and/or video format, depending on their preferences.

Materials & Procedure

Contributors contacted us through the HCNSW Intersections Project page contact form by Facebook, phone, email, WhatsApp, and text message. The Intersections Project was promoted via word of mouth, community leaders, community organisations, Facebook posts in closed and secret community-only groups, outreach postcards in community venues, and email lists. These diverse recruitment formats were part of our effort to avoid insularity and oversampling of people who have well-established contact with community organisations. We appear to have been largely successful in that effort, as multiple contributors noted that it was their first time sharing their healthcare experiences with people outside of their closest social or community networks.

Contributors were provided with four documents:

- an information sheet,
- an informed consent to participate form,
- a media release form, and
- a crisis intervention and suicide prevention resources sheet

The information sheet explained the aims of the project, discussed potential risks and benefits of participation, and stated contributors' ability to withdraw without penalty. The media release form allowed contributors to specify the content we could use, with options ranging from general descriptions without any direct quotations in our public materials or partial quotations without public sharing of full transcripts, to full video or audio transcripts shared on the Intersections website showcasing contributor experiences. Contributors were given the option of reviewing draft transcripts for approval before publication of the final report, an aspect of the project that demonstrated respect for contributor autonomy. Although this meant that some contributors took time to refine their narratives, changed their minds about the extent of the content we could share, or decided to change from using their names to using pseudonyms before giving final approval of the content, this option was necessary to maintain our trauma-informed approach. Contributors completed informed consent and media release forms.

Planning and Objectives

Some contributors proceeded to share extended narratives, while some were unable to do so due to health or other personal reasons. Contributors provided brief narrative self-descriptions of their intersectional experiences:

Selena (she/her/hers): *A 58-year-old woman currently living in a small country mining town in rural NSW and receiving basic health services in Sydney. I have 35 years of extensive medical experience as an intensive care paramedic and began identifying as a woman approximately two years ago.*

Alex (they/them/theirs): *I'm a young, nonbinary transgender, gray-asexual woman with multiple chronic illnesses, who has experienced discrimination and sexual harassment as a patient in NSW.*

Bella (she/her/hers): *An autistic parent that has a 21-month-old, I also have depression, anxiety and PTSD. I am in a sexually non-monogamous relationship with my partner and am active within Sydney's BDSM community.*

Daniel (he/him/his): *I am Intersex, Middle Eastern, from a traditional ethnic-religious background, aspy, and bisexual.*

Lavender (they/them/theirs): *A non-binary trans person who is autistic, lesbian, polyamorous, white, chronic illnesses.*

Leo S. (they/them/theirs): A 19 y/o queer agender person on the autism spectrum, also struggling with anxiety and depression.

Leo T. (he/him/his): *I'm a 41 yr old gay man, who is overweight, HIV+, has extensive interaction with the criminal justice system and does not fit into the stereotypical gay mould. I have experienced financial deprivation for most of my adult life combined with housing instability and drug dependency.*
MJ (they/them/theirs): *I'm an Intersex and trans Aboriginal person with a chronic illness, chronic pain and PTSD. I'm also a sex worker.*

Kip (they/them/theirs): *I'm a white Australian who grew up in America. I'm non-binary, queer Autistic and mentally ill.*

Pat (she/her/hers): *I am an Indigenous Australian lesbian, for quite some time I was a single parent. I was often made to feel invisible and was largely stigmatised and shamed. It was easier at times to stay in the closet, which increased my mental and emotional instability.*

Rachel (she/her/hers): *I am a Jewish, white, cis, queer, polyamorous woman who engages in BDSM and I am a mother of two.*

Tan (they/them/theirs): *I'm a non-binary and CALD young person. I also have a chronic illness (heart condition), which affects my hearing on one side, how I can/can't feel my body, and my ability to do normal young person things. I also have a trauma history.*

ACCESS

Contributors identified five key access barriers:

- hidden bureaucracy;
- interconnected logistics;
- exclusionary diagnostic and identity criteria;
- intersectional service gaps; and
- transient and complex living situations.

Contributors reported difficulties with healthcare access due to a combination of both direct and indirect factors, some of which resemble subtle and invisible elements characteristic of structural violence. As Leo T. (he/him/his) noted, when describing his experiences of healthcare access barriers:

> It's the hidden things, the bureaucracy that continually causes more and more drama that continues to discriminate against people and create health access barriers.

For example, MJ (they/them/their) described the hidden bureaucracy that resulted from their intersectional needs as an Aboriginal transgender person:

> I think that in terms of being an Aboriginal transgender person, there is the element of surprise a lot unless you're familiar with the community, like increasingly now we have a lot more awareness, but if you looked Aboriginal before but then you are queer-looking, then 'you're not Aboriginal'. If you're read as queer, then you're not seen as Aboriginal, because Aboriginal people are imagined retrospectively and in a past where there was only men's business and women's business, which is actually not the case. So that can impact how people treat you as well.

> Accessing Aboriginal healthcare services has a different array of issues. The reason for that is, largely speaking, confirmation of Aboriginality and the legalities around that, but also, there is a lot of evidence for trans and queer Aboriginal people not being able to access that documentation. So not only are trans and queer indigenous people not accessing those healthcare services, because many of us don't feel comfortable, is that we legally can't access some of them, so we legally find ourselves in a situation where there's Aboriginal healthcare services or there's queer healthcare services, but there's nothing in between for us.

Other contributors discussed how travel logistics, transient living situations, and administrative classifications had affected their healthcare access. These factors often intersected with contributors' limited finances to make needed services inaccessible. For example, Bella (she/her/hers) explained how economic hardship and administrative classification requirements had prevented her access to healthcare services:

> I can't access any NDIS or Autism-related services without a formal diagnosis, but I can't afford the cost. I shouldn't have to spend $1200 to get an adult diagnosis of Autism

Lack of awareness about people with transient living situations who may need services only available within a specific health system and who must travel long distances to reach services. As a woman with economic hardship who requires trans-informed medical care and who is living in a small country mining town in rural NSW, Selena (she/her/hers) explained:

> My town has very limited medical services, so I have repeatedly had to make the costly 7-10 hour drive to Sydney and pay for accommodation to receive basic health services.

Several contributors also commented on how existing services did not address the needs of people with transient living situations. Some of the populations whom community leaders described as travelling long distances for Sydney-based services included Aboriginal sistergirls from the Northern Territory, some of whom had felt forced to move to Sydney due to lack of adequate local services for medical gender affirmation; sex workers from states and territories without a Sex Workers Outreach Project or equivalent sex worker positive services; sex workers involved in touring for professional purposes; polyamorous/multi-partnered people from out of state with one or more partners living in NSW; and people with carer responsibilities to kin living in NSW.

SAFETY

Contributors identified four key safety concerns:

- misgendering due to both healthcare provider and systemic factors;
- exclusionary practices and policies within the local health system;
- inadequate consideration of trauma—including both intersectional forms of trauma and intergenerational and historical trauma common among Aboriginal people, refugees, and other historically marginalised populations—in healthcare service delivery and healthcare system policies; and
- common experiences of verbal abuse, neglect, and medically unnecessary, invasive physical examinations of marginalised people with intersectional needs.

Understandably, contributors had greater emotional difficulty sharing safety concerns than they did sharing information about any other healthcare right. Contributors described safety both in terms of feeling comfortable and in terms of being free from abuse and mistreatment. Contributors described healthcare experiences that ranged from verbal abuse and ridicule to more serious forms of physical and sexual mistreatment, only some of which had been reported through a formal complaints process. (Contributors who reported these experiences were notified of their right to file formal complaints.) For example, Lavender (they/them/their) was subjected to verbal abuse from a specialist physician and clinic medical director when they requested not to be *misgendered*—referred to using binary gendered language that disregarded Lavender's non-binary gender. *Misgendering* (Ansara, 2010; 2012) can also occur due to administrative classifications and policies. For example, several non-binary people described having experienced trauma by being placed in a binary gender ward of an in-patient psychiatric unit.

Multiple trans men who contacted us declined to contribute their full stories to this project. They reported invasive and medically unnecessary genital exposure and contact before being able to access gender-affirming hormones from medical providers. They expressed fear of retaliatory service denial if they shared more details with us. These forms of sexual assault persist, despite Australian and international treatment guidelines stating explicitly that invasive medical examinations are not medically necessary to prescribe hormones for gender affirmation (SBS, 2020).

Some participants felt unsafe due to their cultural and religious needs not being incorporated into healthcare systems or acknowledged by healthcare providers. These exclusions sometimes occurred as a result of inaccurate assumptions healthcare providers made about their intersectional needs. As Daniel (he/him/his) explained

> *I've also had clinicians assume that because I'm an LGBTI consumer, I don't care about the gender of clinicians. That can be very uncomfortable coming from a strict religious background.*

Despite the extensive trauma contributors attributed to their healthcare experiences, multiple contributors found that healthcare providers and systems appeared unaware that people had experienced these providers and their healthcare services as unsafe and traumatic.

Safety in healthcare contexts often requires providers to have basic knowledge and understanding. For example, MJ (they/them/their) encountered multiple healthcare professionals who were unfamiliar with the pivotal concept of *intergenerational trauma* and consequently unable to provide safe healthcare services for them as an Aboriginal person.

RESPECT

Contributors identified four key concerns about respect:

- discriminatory treatment by healthcare providers;
- administrative policies and processes that contribute to stigma and discriminatory treatment;
- ridicule and belittling by healthcare providers due to apparent discomfort and gaps in knowledge and skill; and
- gaps in policy and training regarding how to respect people's intersectional needs, such as the intersection of gender, sexuality, and body needs with cultural and religious needs.

Although respect in healthcare settings is often defined solely in terms of recognition of 'patient autonomy', Dickert and Kass (2009) found that patients defined respect as a combination of empathy, care, autonomy, provision of information, recognition of individuality, dignity and attention to their needs. Beach et al. (2007) had a similar critique of definitions of respect that are limited to autonomy, instead of defining respect in healthcare settings as "*recognition of the unconditional value of patients as persons*". This recognition can occur both *cognitively*, in terms of healthcare professionals' belief that people seeking healthcare have value, and *behaviourally*, in terms of healthcare professionals acting in a manner consistent with this belief. Beach et al. stress the importance of physicians providing this respect to all people seeking healthcare, regardless of their personal characteristics.

Contributors described both overt and indirect ways that healthcare systems disrespected them. Leo T. raised concerns that

> *The system is designed to stop people improving. They decided what box you fit into… for me, that's 'scumbag, drug addict, thief'. That's where they'll keep me. I'm not allowed to progress out of that box into a useful member of society.*

Rachel (she/her/hers) shared an example of more indirect communication of disrespect:

> *Anytime I mentioned any personal detail that she [the GP] perceived as out of the ordinary, she would chuckle and say, "You and [name] are such an "unusual couple". Initially, this was amusing, but it became less so as time went on particularly when it was in response to decisions that I had made as an individual (for example, to travel extensively for work, or to take up a new sport).*

PARTNERSHIP

Contributors identified five key concerns about partnership:

- the importance of partnering at both the individual and community level when seeking engagement with people with intersectional needs;
- pathways for partnerships often overlook people's intersectional needs and did not explicitly seek to engage with people with intersectional needs;
- the greater access to partnership and participation that results when healthcare providers and systems integrate consideration for logistical challenges and trauma into participation efforts;
- the barriers to partnership when people seeking healthcare are not provided with sufficient clinical and policy information to enable meaningful participation; and
- the pivotal role of flexibility and responsiveness by healthcare providers and systems.

Most contributors stated their desire to have greater partnerships in making decisions about their own healthcare. However, multiple contributors told us that the Intersections Project was their first experience in which a community engagement or healthcare project had explicitly sought to engage with them regarding their intersectional needs and experiences. In addition, most contributors commented on how challenging it was to make decisions about their healthcare or to make requests that challenged healthcare professionals and systems after having experienced marginalisation. Multiple contributors said they felt more comfortable if they knew that community organisations or other people with similar intersectional needs had already done so. This feedback highlighted the importance of combining collective engagement with existing individual engagement efforts to increase participation among people with intersectional needs (Tervalon & Murray-Garcia, 1998).

Most were very enthusiastic about sharing their stories with us yet found that their participation in this project required an extended time and involved lengthy delays. Contributors repeatedly told us that they could not have contributed to the project at all without our trauma-informed, flexible approach.

Daniel (he/him/his) echoed sentiments expressed by several other contributors:

> Sorry for the delay. I've had so many traumatic medical experiences that this has been really hard to be engaged with.

Bella (she/her/hers) concurred:

> I initially thought that my involvement with Intersections would take me 2-3 months at most. Instead, I'm still involved because I discovered that I have a lot to talk about and explain, and it takes a lot of time to do so in a way that isn't going to be detrimental to my health.

She further explained:

> While I am in a fairly good place mentally to be able to do this, I do also have very high stress levels. That means that I have to pick and choose very carefully when I use my free time to work on the Intersections Project. As a result, I have only started making final recordings 8 months after I began participating.

> Keep in mind with all of this that I only have about 6 years of experience with the health system here. I can't imagine how long it would take for someone with the same level of health needs or more, or who is a carer to someone with more complex health needs and has lived in Sydney their entire life, to go through their experiences.

> The thought of having to rush to finish talking about my experiences is distressing. I can't help but feel like this is my only opportunity to ever be heard in a way that respects my neurodiversity, my health needs and my personal needs without compromising my or my partner's privacy in the process, even though I logically know that it's not the case at all. Allow the process to happen naturally. I know there's a lot more I have to say, and I want to be able to say it in a way that means I only need to do this once, and not have to be involved in another project 5 or 10 years down the track because I didn't say it in a way that someone without autism or has never been mentally ill, or has never had to care for other people wouldn't understand. I imagine that's the case for the other participants in this project as well.

INFORMATION

Contributors identified four key concerns about information and communication:

- limited effectiveness of healthcare professionals' communication due to knowledge and skills gaps regarding people with intersectional needs;
- administrative, policy, and service delivery approaches that inhibited or prevented people seeking healthcare from sharing clinically relevant information;
- system-level gaps in awareness, skill, policy, and practice regarding their intersectional needs; and
- lack of consideration for how logistical factors (e.g., consultation time, sensory conditions, etc.) can affect healthcare communication.

Healthcare communication can promote or inhibit engagement by people with intersectional needs. Sometimes, information that attempts to reach marginalised populations can undermine this aim by highlighting gaps in healthcare organisations' cultural awareness. MJ (they/them/theirs) said

> *An example of this is [a Sydney-based LGBTI health services organisation's] sexual health marketing campaign that targeted Aboriginal people that was like 'HIV is deadly', and this is an example of people thinking that this is a cultural term and misusing the term 'deadly'. I think they were trying to make a joke about it, but it didn't carry. This is just an example of how people think they're making culturally specific services, but they're ridiculous services. It doesn't really matter how they're using it, they're still using it wrong, because if you're not Aboriginal and you don't use that word, then you don't understand what that word means. So even if you were like 'getting tested is deadly', it's still like you attempting to be culturally aware but it still doesn't come across that way. What it communicates to me is that you don't understand.*

Healthcare professionals' communications can determine which information people seeking healthcare feel comfortable communicating in return. Rachel (she/her/hers) said

> *Previously, I saw the same GP for more than ten years. Initially, she met my needs, but as my identities developed the mismatch deepened and I found that I wasn't able to honestly discuss my lifestyle and risk*

factors with her. I was dismayed at first that she seemed unable to remember my primary partner's name, and often cautioned me to be sure that I stay focused on the relationship so that he wouldn't have an affair or leave me for someone else. As a result, when my primary partner and I agreed to try polyamory, I felt unable to discuss issues such as STI testing with her.

Bella (she/her/hers) reported similar difficulty feeling able to communicate openly when seeking healthcare:

While distressed, I have to decide how much to disclose to hospital staff. I don't want to out my partner as polyamorous unnecessarily, but I encounter stigma the moment I disclose this vital piece of information.

Lavender (they/them/their) described the experience of being misgendered by a consultant as traumatic, explaining that this prevented them from feeling able to communicate medically relevant information.

Conversely, healthcare professionals who avoid misgendering can facilitate greater comfort and improve communication. For example, Daniel (he/him/his) expounded on how a positive experience with a specialist who avoided misgendering language about his body during a physical examination made him feel comfortable communicating about his healthcare needs:

She was really communicative and explained everything that was potentially problematic, as well as reasons why this or that might/might not be the diagnosis and what the options were going forward (some of which would have been in the main hospital and much more exposing). It was the epitome of shared decision making, and I also felt very at ease with the exam because of her level of communication and avoidance of gendered language for anatomy.

Multiple contributors critiqued a lack of communication by healthcare professionals itself as a concern. For example, MJ (they/them/their) described their experience in an in-patient emergency unit:

There have been many times when my health has been so bad from chronic illness and not being able to retain water that I've ended up in hospital and have not received proper treatment, but have been violently ill or

passed out, and those are examples of times when I can relate to other people with chronic illness, when they say they've gone to hospital in extreme pain or a very bad condition, and needed help, and felt powerless, so those would be times when I would say those were very confronting in terms of feeling powerless and not being able to get assistance.

There was one time when I went to hospital because I was so dehydrated that I was delusional and violently ill, and I spent maybe two nights or so there, and then the doctors wouldn't give me a medical certificate for my job… and that really impacted my wellbeing, because a) I was anxious about missing work, but then b) it impacted the future outcomes of my job opportunities because I had said that I was this unwell and there was no evidence provided for me to be able to provide my employer with it. So that would be an example of how even when I received healthcare, I wasn't able to receive it in the full capacity, because I guess my condition wasn't seen as severe or 'real', because it's a chronic illness and people don't think that those things are real conditions.

I find that there's not a lot of transparency in terms of what's going on. It was like this is what's happened, you're very dehydrated. You try to explain what the condition is, but that's not a real consideration I think, like a lot of things I find around intersexuality are not treated as medical conditions, rather as variations or prepositions of something that you should be able to prevent it getting to that stage, but maybe you can't because you can't access the appropriate treatment to prevent it from getting to that stage. So that's been my feeling generally speaking is that it's not actually a medical condition, it's like a predisposition that you're responsible for managing.

It was kind of like oh, don't worry, you've just got salt wasting and you're dehydrated, so you just need to sit here for a long time and you're fine. And I was like okay, that's good because I thought I was dying at this stage, but after a while and being rehydrated and receiving some sort of treatment, I was obviously okay, but I was

incapacitated and in hospital for two days, and I had no evidence to support that.

I asked the doctor and I asked the nurse to ask the doctor to write me a medical certificate. They both said no. They said something like 'we wouldn't call this need for you to take time off' or something along those lines.

At the time when they refused, I just felt oh, shit, now I have to think of an alternative or argue with someone, and probably I'll need to go to work after this unless I'm going to lose my job.

At the time, I don't think I was entitled to sick leave, but due to the work situation that I was in at the time, I needed to have evidence that I was unwell, for my job security.

I was in a contract position, but it was at a very bad time that I was unwell, so I needed that backup to be like, 'I actually was really sick, please don't think that I'm not reliable." It was a relatively new job as well, and I had just come from not being employed for quite some time, so I was very concerned about it.

Showing up at work without a medical certificate did have an impact. My employers' trust for me generally speaking or taking me seriously when I'm ill in the future. And even now, I still have some hesitation about calling in sick to work. I still have to be pushed to call in sick when I'm unwell because I'm worried that people won't take what I'm saying seriously.

Long-term, it has given me a lot of anxiety about going to hospital, but to be honest, I don't think I've ever had a good experience of going to one, and that is probably true for a lot of people, but I've never had a validating experience related to that when going to hospital, or even to a doctor, so I think I was quite accustomed to it by this stage to some extent, but that was very anxiety-inducing, particularly in relation to employment for me.

Nicolaidis et al. (2015) found that improving healthcare for autistic adults required providers to have knowledge of autistic people's verbal communication skills, sensory sensitivities, need for more processing time than typical for allistic (non-autistic) people, and autistic methods of non-verbal communication. For example, although many healthcare providers are trained to ask

open-ended questions, multiple communication guides informed by autistic people's own feedback caution providers to avoid open-ended questions. In addition, patient care is improved when providers are willing to correct incorrect assumptions about autistic people seeking healthcare, willingness to allow them to use written communication in healthcare interactions, use of accessible language and information-gathering methods, openness to providing other accommodations, and skill in appropriately integrating support people into the healthcare context. The authors also identified system-level factors such as the support person availability, complexity of the healthcare system, accessibility of healthcare facilities, and stigma about autism. This matched Bella's (she/her/hers) experience:

> *My autism makes it a challenge for me to communicate something direct and on point verbally, and to discern between what information is relevant or not.*

We note that it is not Bella being autistic that creates the challenge in her healthcare services, but the systemic not being designed to include autistic people and address their needs. In addition, healthcare providers and systems need to consider the internal diversity among autistic people, who can have a range of distinct experiences and needs. Some people also require extra time to ensure healthcare professionals understand their intersectional needs, particularly when these needs are excluded from educational and policy directives that inform healthcare professionals. As Bella (she/her/hers) explained,

> *I'm an autistic woman with anxiety, depression and PTSD. I am the carer of my partner (of 6½ years) with physical and mental health issues and in an open relationship, actively involved in Sydney's BDSM scene and parent of a 2-year-old son who is likely autistic. Any one of those things is a lot for someone to have to live with. I have to live with all of them. Engaging with someone like myself with complex health needs and copious caring requirements is going to take a lot of time, for reasons of prior commitments, mental and physical health management and wording and explaining things properly for someone that isn't involved in the autistic, chronic illness or kink communities.*

In addition to concerns regarding communication between people seeking services and healthcare providers, some contributors found that gaps in communication between administrators and providers led to discriminatory treatment.

Daniel explained that providers

often had to call the medical records dept (who often don't know legislation or what information is even available and argue with the provider "have you checked their Medicare card? the gender has to match their Medicare card")

PRIVACY

Contributors identified four key privacy concerns:

- privacy breaches due to lack of adequate recognition of how misgendering breaches people's privacy at both systemic and provider levels;
- inclusion of unnecessary and potentially stigmatising information in referral letters;
- inadequate consideration at both system and provider levels of how administrative factors (e.g., electronic database systems, intake forms, reception procedures, etc.) can affect privacy; and
- inadequate consideration at both system and provider levels of how logistical factors (e.g., appointment time, placement of reception area, signage, etc.) can affect privacy.

Contributors described privacy breaches that included misgendering, the inclusion of unnecessary personal details in referral letters, and a range of other experiences that demonstrated inadequate consideration of how administrative and logistical factors can affect privacy. Daniel (he/him/his) described some of his frequent experiences with privacy breaches in healthcare settings:

> *The main things that come to mind are inappropriate comments/touching about genitals and secondary sex characteristics and privacy issues. People who are not part of small communities don't realise how much people listen in public places or how connected people are to everyone else.*

Yet respecting people's privacy can be achieved by attention to these administrative and logistical factors, in recognition of how these factors can impact healthcare access, participation, and safety. For example, Daniel (he/him/his) told us*.*

I had to see a gynaecologist a few years ago, and she made a point of booking me in at the end of the day specifically because of the potential for confidentiality issues. I didn't even have to ask.

Rachel (she/her/hers) discussed the negative emotional consequences of a provider's breach of her privacy and unnecessary disclosure of private sexual information to reception staff during the referral process:

This irritation came to a head when I sought assistance after unsuccessfully attempting anal sex with my primary partner (a cis man). I already felt very nervous bringing it up with this doctor, but as it was something my partner and I both wanted I pushed ahead with it. She responded as detailed in the previous paragraph [which was using an incorrect name for Rachel's primary partner, laughing, and saying what an 'unusual' couple they were], which made me feel very uncomfortable like I was being judged by someone who should have been impartial. She did, however, provide me with a referral to a specialist physiotherapist. The physiotherapist herself provided excellent care, but I was deeply ashamed to discover that the GP had written about my concerns in more detail than I felt was necessary. This was then read by the physiotherapist's reception staff. I had not read the letter before my physiotherapist appointment so I had no idea until I was actually in that appointment. I felt that the GP had not sufficiently protected my privacy and that the physiotherapist's clinic could have had more discreet processes.

Multiple trans and intersex contributors shared similar experiences of having their privacy breached publicly when seeking healthcare, even before they begin interacting with their healthcare provider. Leo S. (they/them/theirs) shared that,

In regards to my trans status, many medical services are different, and while most strive to be accepting I've still had some really uncomfortable experiences. The one I get the most is because I have not yet changed my legal name, GPs will just read the legal name of the file and not the preferred name and then walk out and announce my birth name to the entire waiting room.

Daniel provided a variety of suggestions for how to improve this situation at a systemic level, advocating for:

- *ability for providers to change demographic information in systems,*
- *ability to have a preferred name in electronic record systems that shows up alongside legal name*
- *creating a culture where people check preferred name and gender before calling out in waiting rooms*
- *creating a culture of confidentiality (we still have a problem with clinicians talking about patients in coffee shops near hospitals, let alone in corridors and lifts in clinical settings) - we need to take examples from the US standards in this regard*

GIVE FEEDBACK

Contributors identified five key barriers to their right to give feedback:

- existing feedback mechanisms focused more on provider-level concerns rather than on systemic and policy complaints;
- concern regarding retaliatory service denial if they share their concerns, a negative experience that multiple contributors had experienced;
- perceived scarcity of available services to meet their intersectional needs (e.g., an intersex man being hesitant to complain about racism or cultural insensitivity within an LGBTI health service due to his limited service options); and
- lack of adequate awareness by healthcare providers, healthcare systems, and people seeking healthcare services of people's healthcare rights; and
- Inadequate understanding of how these rights can be applied to actual policies and practices when working with people with intersectional needs.

Multiple contributors discussed feeling unable to give feedback or raise concerns about their healthcare experiences. Three main concerns described by contributors were potential retaliation through service denial, perceived scarcity of available services, and lack of awareness of their own healthcare rights. Multiple contributors described experiences of being refused services following a complaint, as occurred to Lavender (they/them/their), when they asked a consultant and clinic director to avoid misgendering them. Similarly, the aforementioned anonymous trans men who divulged experiences of inappropriate genital exposure and touching by providers said they felt unable to complain due to the scarcity of providers to prescribe gender-affirming hormones and their fears about retaliatory service denial.

Multiple contributors stressed the importance of drawing on support people and utilising advance preparation to reduce the adverse impact of negative experiences. In terms of enabling people to raise concerns and to have those concerns taken seriously, Daniel (he/him/his) suggested that

> *It's difficult in an emergency situation, but if you have a choice, I always recommend getting word-of-mouth referrals from others who have similar life experience, taking a friend who is very with it, and having important information succinctly communicated in referral letters*

*that are sent ahead of time. Having to explain yourself
in the moment is never a good idea.*

KEY FINDINGS AND RECOMMENDATIONS

We identified key findings based on the seven rights defined in the Australian Charter of Healthcare Rights (2nd edition).

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS	Contributors identified…
Access the right to healthcare services that meet my needs	…five key access barriers: • hidden bureaucracy; • interconnected logistics; • exclusionary diagnostic and identity criteria; • intersectional service gaps; and • transient and complex living situations.
Safety the right to receive safe and high-quality healthcare that meets national standards. the right to be cared for in an environment that is safe and makes me feel safe	…four key safety concerns: • misgendering due to both healthcare provider and systemic factors; • exclusionary practices and policies within the local health system; • inadequate consideration of trauma—including both intersectional forms of trauma and intergenerational and historical trauma common among Aboriginal people, refugees, and other historically marginalised populations—in healthcare service delivery and in healthcare system policies; and • common experiences of verbal abuse, neglect, and medically unnecessary, invasive physical examinations of marginalised people with intersectional needs.
Respect the right to be treated as an individual, and with dignity and respect The right to have my culture, identity, beliefs and choices recognised and respected	…four key concerns about respect: • discriminatory treatment by healthcare providers; • administrative policies and processes that contribute to stigma and discriminatory treatment; • ridicule and belittling by healthcare providers due to apparent discomfort and gaps in knowledge and skill; and • gaps in policy and training regarding how to respect people's intersectional needs, such as the intersection of gender, sexuality, and body needs with cultural and religious needs.

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS	Contributors identified…
Information The right to have clear information about my, condition, the possible benefits and risks of different tests and treatments, so I can give informed consent The right to receive information about services, waiting times and costs The right to be given assistance, when I need it, to help me to understand and use health information The right to access my health information The right to be told if something has gone wrong during my healthcare, how it happened, how it may affect me and what is being done to make care safe	… four key concerns about communication: • limited effectiveness of healthcare professionals' communication due to knowledge and skills gaps regarding people with intersectional needs; • administrative, policy, and service delivery approaches that inhibited or prevented people seeking healthcare from sharing clinically relevant information; • system-level gaps in awareness, skill, policy, and practice regarding their intersectional needs; and • lack of consideration for how logistical factors (e.g., consultation time, sensory conditions, etc.) can affect healthcare communication.
Partnership the right to ask questions and be involved in open and honest communication. The right to make decisions with my healthcare provider, to the extent that I choose and am able to The right to include the people that I want in planning and decision-making	… five key concerns about partnership: • the importance of partnership and participation at both individual and collective when seeking engagement with people with intersectional needs; • pathways for partnership often overlook people's intersectional needs and did not explicitly seek to engage with people with intersectional needs; • the greater access to partnerships that results when healthcare providers and systems integrate consideration for logistical challenges and trauma into participation efforts; • the barriers to partnership when people seeking healthcare are not provided with sufficient clinical and policy information to enable meaningful participation; and • the pivotal role of flexibility and responsiveness by healthcare providers and systems.

AUSTRALIAN CHARTER OF HEALTHCARE RIGHTS	Contributors identified…
Privacy the right to have my personal privacy respected. A right to have information about me and my health kept secure and confidential	… four key privacy concerns: • privacy breaches due to lack of adequate recognition of how misgendering affects people's privacy at both systemic and provider levels; • inclusion of unnecessary and potentially stigmatising information in referral letters; • inadequate consideration at both system and provider levels of how administrative factors (e.g., electronic database systems, intake forms, reception procedures, etc.) can affect privacy; and • inadequate consideration at both system and provider levels of how logistical factors (e.g., appointment time, placement of reception area, signage, etc.) can affect privacy.
Give Feedback The right to provide feedback or make a complaint without it affecting the way that I am treated The right to have my concerns addressed in a transparent and timely way The right to share my experiences and participate to improve the quality of care and health services	… five key barriers to their right to give feedback: • existing feedback mechanisms focused more on provider-level concerns rather than on systemic and policy complaints; • concern regarding retaliatory services denial if they share their concerns, a negative experience that multiple contributors had experienced; • perceived scarcity of available services to meet their intersectional needs (e.g., an intersex man being hesitant to complain about racism or cultural insensitivity within an LGBTI health service due to his limited service options); • lack of adequate awareness by healthcare providers, healthcare systems, and people seeking healthcare services of people's healthcare rights; and • inadequate understanding of how these rights can be applied to actual policies and practices when working with people with intersectional needs.

Based on these findings, we have five overarching recommendations regarding how health services can address the above concerns about healthcare rights:

Co-design the healthcare system	Due to the individual, provider, and systemic levels at which people's healthcare needs were not met, that health services extend their co-design approaches to address the individual, provider, and systemic levels at which people experienced breaches of their healthcare rights. By incorporating insights from health consumers, healthcare providers, and system administrators, we can effectively address the dynamic interactions between these three levels.
Enable feedback on structural and systemic components	That health services provide ongoing opportunities for all stakeholders to give systemic feedback (consumers, carers, partners, family members, providers, and administrators). This includes inviting people to participate in and comment on policies, administrative processes, and other structural and systemic components that affect their healthcare experiences, beyond the level of experiences with individual providers.
Implement point of service feedback (POSF)	That in addition to formal consultation processes and regular evaluation to assess how healthcare pathways address people's intersectional needs, patient opportunity for immediate participation and comment be made accessible through point of service feedback (see Gill et al., 2015). For example, POSF improved clinical outcomes at a service level in a national study of hospice/palliative care settings (Currow et al., 2015).
Be aware how the healthcare system affects other systems	That all healthcare system policies and processes evaluate the potential consequences of healthcare system design on other social determinants of health such as housing, employment, education, etc. This includes considering whether a healthcare policy might constitute indirect discrimination. That both providers and administrators consider how policies and actions can affect people in other domains of life and seek guidance regarding how to reduce adverse impact on social determinants of health (e.g., a Clinic-to-Community Listening Forum).
Make systemic change to meet intersectional needs	That intersectional needs be integrated into existing healthcare system assessment processes (e.g., patient satisfaction surveys) at the healthcare provider, administrator, and system management levels. That policies and procedures allow frontline staff (e.g., reception, nursing, etc.) to be able to make immediate changes based on people's feedback at point of service.

GLOSSARY

Ace: An abbreviation for asexual.

Asexual spectrum: A spectrum of people on a sexuality spectrum. Some asexual people will engage in sex consensually when initiated by a partner. Some are interested in romantic, emotional, and/or affectionate relationships without sexual contact, while others are aromantic, meaning they are not interested in romantic relationships.

Anti-oppressive practice: A action-orientated meta-method of practice that prioritises challenging and avoiding oppression. Anti-oppressive practice is a key component of liberation psychology.

Bisexual: A person who is emotionally, romantically, sexually, affectionally, and/or relationally attracted to more than one gender of person, as well as anyone who self-identifies as bisexual.

Cisgenderism: An oppressive ideology—systems of thinking and practice—that delegitimises some people's own understanding of their genders and bodies.

Cultural humility: An approach that focuses on the life-long journey of reflective self-critique, examining one's own privilege, assumptions, and biases, and addressing inequitable power dynamics. Instead of seeking to gain "cultural competence" to become an "expert" in someone else's lived experience, a cultural humility approach treats health consumers and communities as the experts on their own lived experiences, while stressing the need for institutions and systems to engage in self-reflection, accountability processes, and reparations to address inequities and barriers.

Deadly: A positive term of praise or admiration used by Aboriginal people that has deep meanings not widely understood by non-Aboriginal people.

Endosexism: Ideology—systems of thinking and practice—that treat endosex (non-intersex) people as normative, desirable, or superior to intersex people.

Historical trauma: Trauma based on historical marginalisation of people with similar characteristics.

Intergenerational trauma: Trauma transferred from the first generation of trauma survivors to subsequent generations through complex post-traumatic mechanisms and effects.

Intersectional inquiry: Research or community consultation that considers the intersections of multiple lived experiences rather than focusing solely on one identity label or perceived group.

Intersex: An adjective (not a noun) to describe people with one or more of over 40 innate physical characteristics that are not considered strictly 'male' or 'female' according to modern medical or social norms. Intersex characteristics may be chromosomal, genital, gonadal, hormonal, or relate to other reproductive anatomy or features that emerge during puberty. See https://ihra.org.au/18106/what-is-intersex/ for more information.

Gray asexuality or **gray-ace:** A self-description used by people who lean more toward asexuality than sexuality, often by people who experience only occasional sexual attraction.

Man of trans experience: A term preferred by some men who were assigned female at birth and who consider trans to be an experience rather than their identity label.

Metamour: A term to describe the relationship between people who have one or more intimate romantic and/or sexual partners in common.

Misgendering: Language and behaviour that invalidate people's own understanding of their gender and body.

Neo-pronouns: Sets of third-person pronouns, generally singular, beyond those formally recognised as official language (e.g., xey/xem, fae/faer, ey/em). Some neo-pronouns are intended to reduce confusion with plural "they", whereas other neo-pronouns are intended to convey aspects of personality, kinship, or lived experience of importance to the person.

Non-binary person: A person who does not identify as either a woman or a man. There are multiple non-binary gender identities.

Pansexual: A person who is emotionally, romantically, sexually, affectionally, and/or relationally attracted to people of all genders.

Person-Directed: A model in which care is not only centred on people's needs and experiences, but where providers' role is to provide information to enable people to direct their own care in an informed way to the extent they wish.

Polyamorous: A person who is emotionally, romantically, sexually, affectionally, and/or relationally attracted to multiple people simultaneously. Polyamorous relationships involve ethical principles and informed consent from all partners, as distinct from the monogamous concept of "affairs" or "cheating". Polyamorous relationships can take the form of three-person relationships (triads), four-person relationships (quads), hinges or Vs (relationships that involve one person with two separate partners who are each other's metamours), and many other relational configurations.

Polycule: Any relational system or network that includes one or more polyamorous people, like a chemical molecule that contains distinct bonds between members. Some polycules include monogamous partners; some people raise children within their polycule.

Polycultural: The combination of cultural influences that emerges from the dynamic, interactive flux and interconnectedness between cultures. Unlike 'multicultural', this term acknowledges that people from multiple cultural backgrounds are likely to have interconnected and intersecting beliefs, practices, and lived experiences beyond the limits of any singular, static culture.

Pronouns: Words we use to describe other people in third person, such as she/her/hers, they/them/theirs, and he/him/his.

Queer: An umbrella term used by some people to describe their sexuality and/or gender beyond the limits of "LGBT". This term was once a derogatory slur used against people whose sexuality and/or gender expression were stigmatised. As a result, some older LGBT people may find this term triggering or offensive. Some people of trans experience who identify as heterosexual experience the imposition of the term "queer" onto them as a form of cisgenderism that has been called "coercive queering" (Ansara, 2010).

Repair: Addressing and healing rupture.

Rupture: A tension, breakdown, or interference in the collaborative relationship between a health professional and a person seeking or participating in healthcare services.

Social determinants of health: Socioeconomic factors such as employment, housing, education, and social support that research shows can increase or detract from the health of people and their relationships, families, and communities.

Stealth: A term sometimes used to describe the decision not to disclose one's marginalised characteristic to others, for a variety of reasons. This term is commonly used in trans communities.

Trans man: Someone who identifies as a man and who was assigned as female, typically raised as a girl. As many people with lived experience consider terms like 'female-to-male' and 'FTM' objectifying or inappropriate, nowadays this language is considered appropriate only when describing an individual who self-identifies using these terms. Not to be used if someone describes themselves simply as a man; not all people of trans experience are 'trans-identified'.

Trans woman: Someone who identifies as a woman and who was assigned as male, typically raised as a boy. As many people with lived experience consider terms like 'male-to-female' and 'MTF' objectifying or disrespectful, nowadays this language is considered appropriate only when describing an individual who self-identifies using these terms. Not to be used if someone describes themselves simply as a woman; not all people of trans experience are 'trans-identified'.

Trauma-informed: Ways of working with people who have experienced trauma that apply an understanding of trauma to provider safer and more appropriate services.

Woman of trans experience: A term preferred by some women who were assigned male at birth and who consider trans to be an experience rather than their identity label.

My healthcare rights

This is the second edition of the **Australian Charter of Healthcare Rights.**

These rights apply to all people in all places where health care is provided in Australia.

The Charter describes what you, or someone you care for, can expect when receiving health care.

I have a right to:

Access
- Healthcare services and treatment that meets my needs

Safety
- Receive safe and high quality health care that meets national standards
- Be cared for in an environment that is safe and makes me feel safe

Respect
- Be treated as an individual, and with dignity and respect
- Have my culture, identity, beliefs and choices recognised and respected

Partnership
- Ask questions and be involved in open and honest communication
- Make decisions with my healthcare provider, to the extent that I choose and am able to
- Include the people that I want in planning and decision-making

Information
- Clear information about my condition, the possible benefits and risks of different tests and treatments, so I can give my informed consent
- Receive information about services, waiting times and costs
- Be given assistance, when I need it, to help me to understand and use health information
- Access my health information
- Be told if something has gone wrong during my health care, how it happened, how it may affect me and what is being done to make care safe

Privacy
- Have my personal privacy respected
- Have information about me and my health kept secure and confidential

Give feedback
- Provide feedback or make a complaint without it affecting the way that I am treated
- Have my concerns addressed in a transparent and timely way
- Share my experience and participate to improve the quality of care and health services

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AUSTRALIAN COMMISSION ON **SAFETY** AND **QUALITY** IN **HEALTH CARE**

For more information ask a member of staff or visit safetyandquality.gov.au/your-rights

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About Health Consumers NSW

Health Consumers NSW is a membership-based, independent, not-for-profit organisation that promotes and practises consumer engagement in the NSW health sector. We create meaningful partnerships between consumers, the health sector and policy-makers. Our mission: Consumers shaping health in NSW. We promote the best quality, appropriate health outcomes for consumers of healthcare services. We believe that all perspectives are important and necessary to create better health outcomes for people. Consumer engagement leads to better health outcomes, more efficient and effective services, consumer-centred care and happier patients and staff. We work to ensure that health consumers are involved in the design and delivery of healthcare in NSW.

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HEALTH CONSUMERS NSW!

We invite you to join our network of NSW consumers, carers and staff of health organisations. Our shared aim is to create strong and sustainable partnerships in NSW.

By joining, you will become part of a network of skilled, connected people working together to make the NSW health system the best it can be.

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