Patients’ Experiences and Perceptions Study
Patients’ Experiences and Perceptions Study (PEaPS) Report

Justice Health and Forensic Mental Health Network
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Foreword

The Justice Health and Forensic Mental Health Network (the Network) has demonstrated itself to be a leader in the implementation of evidence-based healthcare service provision. Key to this responsibility is the Network’s commitment to improving patient health by conducting high quality research to inform decision making, service delivery and planning, patient care and policy development.

The patient-centred approach of engaging with patients and including them in evaluating healthcare services provides the Network with the opportunity to collect data on key performance indicators and patient experience data relevant and useful to monitor our patient population as well as assist the Network in designing health care that directly benefits the patient’s health care experience and outcomes. Patient experience was assessed for the first time in 1996, originally as part of the Inmate Health Survey, before the Network developed a stand-alone patient satisfaction survey in 2011.

In 2016, the Research Unit commenced Phase 1 of the Patients’ Experiences and Perceptions Study (PEaPS), revising the methodology used in previous surveys, to undertake a collaborative study with patients as research participants to help the Network better understand our patient’s experiences with healthcare services while in custody. With the Network’s strategic direction of providing a values-based, innovative model of care, the qualitative component of this study, using focus groups as a means of collecting data is an effective way of partnering with patients and engaging with them to drive improvement in health care. Phase 2 of PEaPS will focus on the development of a survey instrument to quantitatively measure the patient experience of health care in custody.

Results from Phase 1 of PEaPS identified that many patients believed they were being treated respectfully by healthcare professionals, while recognising that some staff were hardened by past experiences. They understood the powerful position Corrective Services NSW (CSNSW) officers held in their ability to gain access to health care. For patients who did not regularly access health care outside of custody, many stated that being in a correctional centre gave them an opportunity to do so and improve their health care. Patients identified that accessing healthcare services, particularly long wait times, and some medications are an ongoing challenge. Access to health care can be more difficult for some cohorts of patients than others. Patients who work, those serving shorter sentences and those seeking health care while in maximum security reported more difficulty accessing health care. Overall, patients recognised that their lack of autonomy resulting from incarceration has an impact on their ability to maintain and manage their health.

Our commitment to providing the best possible health care to our patients remains our key focus. We are confident that by using the evidence from Phase 1 of PEaPS to inform policy and practice, the Network will be able to continue to deliver improved health outcomes for patients in custody in NSW.

Chris Puplick AM
Board Chair

Gary Forrest
Chief Executive
Executive Summary

Annually, Justice Health and Forensic Mental Health Network (the Network) provides care for over 30,000 inmates that are incarcerated within the NSW justice system. This health care begins upon entry into this system where every inmate receives a health assessment. Continued health care is provided by general and specialist health care workers through a custodial clinic model, with other health services including mental health, drug and alcohol, dental care, optometry, podiatry, and sexual health services also provided on-site. Patients with health issues that require more specialised care are treated at a dedicated correctional facility hospital or the hospital in the local area.

To monitor the quality of health care provided to patients and to proactively respond to identified patient needs the Network has undertaken surveys of patients’ experiences with healthcare services since 1996. These surveys have focused on health centre access, patient satisfaction, confidentiality, Aboriginal healthcare services and information provided at reception. However, in 2015 the Network identified the need to design a contemporary survey that would accurately capture patients’ experiences of health care in the changing custodial environment. This report represents Phase 1 of this initiative.

Phase 1 has involved undertaking qualitative research to define the areas of concern as reported by patients in the custodial system. These areas of concern will be used to develop a patient experience and perceptions survey that is tailored for the custodial environment (Phase 2). As such, this report depicts the healthcare system in the custodial environment through the eyes of the patients who use it, providing one perspective regarding how it operates. It is acknowledged that the staff within the system or the administrators who oversee the system may have differing views regarding its operation. The reader needs to bear this in mind when drawing conclusions from this report.

Understanding how the patients perceive the health care they receive in the custodial environment is a first important step to understanding opportunities to improve, as well as ways to remove barriers to health care. Patients’ experiences and perspectives are increasingly being recognised as an important factor in helping to develop and improve quality in healthcare services. Patients are uniquely positioned to provide insightful views about their care and healthcare management including problems they may have encountered, the coordination of their care and the treatment they have received.

This report identified access to healthcare services as the core issue, with over 20 other issues identified as enablers or barriers to this access. Many patients believed they were being treated respectfully by healthcare professionals enabling their access to healthcare services, while recognising that some staff appeared hardened from previous bad experiences and thus acted as barriers to access. They understood the powerful position CSNSW officers hold in their ability to gain access to health care. For patients who did not regularly access health care outside of custody, many stated that being in a correctional centre gave them an opportunity to do so and improve their health. Patients identified long waiting times to receiving treatment, and accessing some medications as an ongoing challenge.

Access to health care was identified as more difficult for some cohorts of patients than others. Patients who work, those serving shorter sentences and those seeking health care while in maximum security reported more difficulty accessing health care. Overall, patients recognised that their lack of autonomy resulting from incarceration had an impact on their ability to maintain and manage their health. The issues identified in this report will be used in Phase 2 of this study to inform the development of a survey instrument that will examine these issues in quantitative manner.
Glossary

The definitions in this glossary are contextualised for this report and may not reflect a formal definition of the word.

**Bag:** A bag containing a patient’s daily allocation of medications.

**Bell-up:** The use of the call system in the cell to request assistance (usually medical) from corrective service staff. ‘Bell-up’, ‘Buzz-up’ and ‘Knock-up’ are used interchangeably.

**Bluey:** A blue form filled in by inmates when requesting health care.

**Buy-ups:** Weekly shopping from an approved items list that are purchased by inmates inside the correctional centre.

**Buzz-up:** See ‘Bell-up’.

**Category:** Higher level concept under which analysts group lower level concepts that then become its subcategories.

**Cellie:** Referring to another inmate sharing the same cell.

**Classo:** The grade of security classification assigned to an inmate or correctional centre section.

**Communicable disease:** Disease able to be transmitted from person to person.

**Concept:** A word that stands for interpreted meaning of data, the conceptual name enabling researchers to group ‘raw data’ with other ‘raw data’ that share a common meaning or characteristic. When concepts are linked to a category they become subcategories.

**Core category:** A notion that summarises in a few words the main ideas expressed in the study.

**Custody:** Incarceration at a correctional centre.

**Focus group:** A small group of people brought together to discuss a topic or issue with the aim of ascertaining the range and intensity of their views.

**Incarceration:** Imprisonment. The state of being confined in a correctional centre.

**Inmate:** Person sentenced or remanded into custody.

**Knock-up:** See ‘Bell-up’.

**Muster:** Correctional security roll call. The officer will undertake a head count of inmates. This is typically done prior to inmates being locked into their cells.

**Officer:** Corrective Services New South Wales (NSW) officer.

**Participant:** Patient who partook in the study documented in this report.

**Patient:** Inmate who has or is receiving healthcare in the custodial environment.
**Pill parade:** Patients collecting their medications from nursing staff by queuing up in front of the medication dispensing room situated on the wing of the correctional centre.

**Reception:** The first location an inmate will come in contact with when they are taken into custody or transferred into a correctional centre.

**Remand:** An inmate taken into custody but not sentenced. They may be awaiting bail, court appearance or sentencing after arrest.

**Screws:** Officer.

**Segro:** Segregation. This is where an inmate is kept isolated from others due to charges and/or behavioural issues.

**Sentenced:** An inmate who has been convicted of a crime and given a punishment within the possible punishments set by state law.

**Supervised medication:** Medication that is administrated under the direct supervision of a nurse. The nurse will witness the consumption of the medication and the patient must show that it has been consumed.
### Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td>CSNSW</td>
<td>Corrective Services New South Wales</td>
</tr>
<tr>
<td>LBH</td>
<td>Long Bay Hospital</td>
</tr>
<tr>
<td>OST</td>
<td>Opioid Substitution Treatment</td>
</tr>
<tr>
<td>PEAHS</td>
<td>Patients' Experiences and Perceptions Study</td>
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<tr>
<td>The Network</td>
<td>Justice Health and Forensic Mental Health Network</td>
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</table>
1. Introduction

Justice Health and Forensic Mental Health Network (the Network), is a Statutory Health Corporation established under the Health Services Act (New South Wales) 1997 and is funded by NSW Ministry of Health to provide health care to adults and juveniles in contact with the criminal justice and forensic mental health systems. The Network cares for over 30,000 inmates annually, a health community that is unique in NSW.

Upon entry into the justice system, every inmate receives a health assessment, provided by the Network, which revolves around four key areas. These key areas are an assessment of self-harm, drug and alcohol dependence, current and past medical issues, and population health (communicable diseases, sexual assault). This assessment is overseen by nursing staff and forms the basis for ongoing care provided to the inmate while in custody. Consent to obtain health information from their community health care providers is also sought. If an inmate experiences a new or acute condition while in custody, they can seek healthcare services through a self-referral system.

Healthcare services for patients in correctional centres is provided by the Network as they no longer have access to the community Medicare system. Healthcare services provided by the Network include mental health, drug and alcohol, including addictions medicine, dental care, midwifery, optometry, allied health services, pharmacy services, radiology, orthopaedics, ophthalmology, dialysis, podiatry and population health services including hepatology, sexual health and harm minimisation services. For specialist healthcare needs, patients may be transferred to the Long Bay Hospital for inpatient pre and post-operative care, inpatient mental health care or assessment and rehabilitation services for older patients. Outpatient services for adult males and females are facilitated by the Integrated Care Service and Medical Appointments Unit who liaise with the relevant Local Health District. Emergency presentations are facilitated by the individual health centre, with patients sent to the closest Emergency Department.

The Network has undertaken surveys of patients’ experiences with healthcare services provided by the Network since 1996. This has been undertaken to monitor the quality of care provided to the patients and to proactively respond to identified patient needs. These surveys historically have focused on health centre access, patient satisfaction, confidentiality, Aboriginal health services and information provided at reception. However, in 2015 the Network identified the need to design a contemporary survey that would accurately capture patients’ experiences of health care in the changing custodial environment. As such the Network has undertaken a study using 24 focus groups at a variety of metropolitan and rural correctional centres in NSW with the aim of identifying all issues, from a patients’ perspective, regarding their interaction with healthcare services in the custodial environment.

This report represents Phase 1 of a broader initiative – to quantitatively measure patients’ experiences and identify potential workable and non-workable practices within the custodial environment. The qualitative nature of the results in this report mean caution should be placed on the weight given to each of the issues identified in the study. Phase 1 (this Report) is concerned with identifying the issues while Phase 2 (Quantitative Analysis) will examine how common the issues are within the custodial population.

This report depicts the healthcare system in the custodial environment through the eyes of the patients who use it, and as such provides one perspective (one side of the story) regarding how it operates. It is acknowledged that the staff within the system or the administrators who oversee the system may have differing views regarding its operation. Therefore the depiction of the healthcare system in this report should not be considered as the ‘true’ system but rather an interpretation of the system that is constructed from the patients’ experiences, culture and life circumstances. The ‘true’ system may in fact lie somewhere between this perspective and the perspectives of staff and administrators. Therefore the results presented in this
report should not be presented as an absolute truth, but rather framed within the context from which they were collected, that is, the patient’s perspective. It is nonetheless important to understand the perspective of the patient in order to better determine and address their concerns – a primary outcome of this report.

Understanding how the patients’ perceive the health care they receive in the custodial environment is an important step to understanding opportunities to improve, as well as ways to remove barriers. The patients’ experiences and perspectives are increasingly being recognised as an important factor in helping to develop and improve quality in healthcare services\(^1,2\). Patients are uniquely positioned to provide insightful views about their care and healthcare management including problems they may have encountered, the coordination of their care and the treatment they have received.

### 1.1 Purpose

The purpose of the Patients’ Experiences and Perception Study (PEaPS) is to develop a survey instrument to measure patients’ experiences and perceptions of healthcare services using a mixed methods two Phase approach. Phase 1 involved undertaking qualitative research to identify and define the areas of concern as reported by patients in the custodial system (this Report). These areas of concern will be used to develop a patients’ experience and perceptions survey that is tailored for the custodial environment (Phase 2). The goal of the survey is to provide repeatable measures that can be compared within the custodial environment to inform continuous quality improvement.

### 1.2 Aim – Phase 1

The aim of the current study and subject of this report was to gauge patients’ perspectives on health care provision in a range of adult correctional and juvenile detention centres across the state. Specifically, participants were asked to provide qualitative feedback on their perception and experience of healthcare service provision, across a number of themes drawn from previous surveys and a content analysis of existing literature.

The current study (Phase 1) aims to capture the breath of patients’ perceptions and experience of healthcare service provision rather than providing a quantitative analysis, which will be captured in Phase 2.
2. Methods

This study had an exploratory qualitative design using focus group interviews as the primary means of gathering data. Focus groups were chosen because it enables participants to elicit issues that they deem to be important and significant. Focus groups also encourage participation among those who cannot read or write, and helps to address concerns among potential participants who do not feel comfortable being interviewed on their own.

Within the context of the custodial environment, focus groups also have advantages over one-on-one interviews because it offers the opportunity for respondents who are acquainted with one another to remind or prompt each other’s experiences with the healthcare system. Rich data can also be drawn from interaction between respondents as there are opportunities to challenge each other’s reasons for holding a certain view.

Focus groups are useful in highlighting different perspectives, particularly where there is a power differential because decision makers may have very different ways of thinking to the participants they are trying to serve. The chosen approach ensures that participants are inclusive to the research design process and that improvements to healthcare services will directly benefit patients themselves. Further, patient involvement is also in line with the Network’s strategic directions. That is, to foster a ‘collaborative, person-centred and integrated health care experience for custodial and forensic mental health patients’ and to ‘partner with patients to understand their experiences of care, and redesign services to improve health outcomes’.

Ethical approval for this study was obtained from Justice Health and Forensic Mental Health Network and Aboriginal Health and Medical Research Council Human Research Ethics Committees, while Corrective Services New South Wales and Juvenile Justice NSW provided study endorsement. The anonymity and confidentiality of all participants was assured.

2.1 Data Collection

In February and March 2017 two focus groups were conducted in 15 correctional / juvenile centres purposively selected to cover both rural and metropolitan New South Wales, and to capture all classification of inmates including remand and sentenced, adult men and women, and juvenile offenders. However, due to logistical issues and problems obtaining parental consent for juvenile participants, juvenile detention centres were excluded from the study. This left 12 correctional centres with two focus groups per centre, a total of 24 focus groups for this study. To ensure anonymity in this report, these focus groups were randomly assigned a focus group number from 1 to 24. To provide some context the security level of the correctional centre where the focus group took place was assigned to the focus group number.

Focus group eligibility criteria included the participants’ ability to speak English, comprehend and consent to the study procedures, and use of healthcare services within the last 12 months. Potential research participants were randomly selected via a patient list and through self-selection from promotional posters that were located in the health centres and on wings of the selected correctional centres several weeks prior to data collection. Focus groups were carried out in the consulting rooms in the health centre, or in general visitor areas under the surveillance of CSNSW officers (officers). The researchers explained the purpose of the study and provided the ground rules regarding confidentiality prior to the start of the focus group. A semi-structured interview guide was used based on key areas of health care most commonly identified in literature and those identified in previous surveys (Appendix A).
Two members of the research team were assigned to facilitate each focus group with the number of participants per focus group ranging from three participants to nine participants. The focus groups lasted between 27 and 58 minutes with a mean time of 39.5 minutes. All focus groups were audiotaped and subsequently transcribed verbatim by a professional transcription company for data analysis. Quotes provided in this report from these transcriptions have been de-identified. Assignment of participant number to a quote is specific to that quote only. Therefore ‘Participant 1’ in one quote is not necessarily the same person as ‘Participant 1’ in another quote with the same focus group number.

2.2 Data Analysis

Data analysis was undertaken using inductive constant comparison techniques to explore patterns and semantic categories based on the work developed by Strauss and Corbin\(^\text{(6)}\). Text analysis included identifying initial concepts followed by axial coding where connections between concepts and categories were made and patterns of interactions were linked and identified. Using selective coding, the core category of access was identified and systematically related back to the other categories and subcategories. To enhance trustworthiness and reliability, peer checking of the developing categories and relationships in the data occurred\(^\text{(7)}\). Peer checking involved reviewing the transcripts of the groups and a list of draft categories independently and then as a group. Peer checking took place on several occasions.
3. Findings

3.1 Study Sample

The participants ranged in age from 18 to 72 years (Table 1). A total of 128 participants provided written consent to participate in the study. Of these 99 were males and 29 were females; with 25% of males and 31% of females identifying as Aboriginal (the term Aboriginal in this report is inclusive of Aboriginal and Torres Strait Islander peoples).

Table 1 – Participant Profiles

<table>
<thead>
<tr>
<th>Gender</th>
<th>Correctional Centre Security Levels</th>
<th>Legal Status</th>
<th>Identified as Aboriginal</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Minimum</td>
<td>Medium</td>
<td>Maximum</td>
<td>Remand</td>
</tr>
<tr>
<td>Male</td>
<td>36</td>
<td>17</td>
<td>46</td>
<td>27</td>
</tr>
<tr>
<td>Female</td>
<td>10</td>
<td>0</td>
<td>19</td>
<td>10</td>
</tr>
</tbody>
</table>

3.2 Category Analysis

Category analysis using selective coding resulted in the induction of the core category: Access to Healthcare Services. Three categories were identified that describe the factors influencing access to healthcare services. These included:

1. The prison construct,
2. The healthcare services construct, and
3. Personal factors.

These three categories each consist of a series of sub categories or concepts that describe the factors participants identified when navigating access to healthcare services. These factors are explored throughout the report and specific quotes are provided for illustration. These quotes are provided verbatim to retain fidelity with the original intent of the participants. Many of the concepts are interrelated and this report has attempted to explore the key interrelationships, as voiced through the participants.

Figure 1 presents the diagrammatic representation of the selective coding. It provides the integration of the identified categories and concepts. Appendix B highlights the concepts presented in an infographic format.
Figure 1 – Relationship between the Identified Categories and Concepts
3.2.1 Access to Healthcare Services

From the participants’ perspective, access to healthcare services (core category) is influenced by three categories, their prison construct, their health system construct and a series of personal factors. Beneath these are a series of subcategories and concepts that detail the participants’ experiences.

3.2.2 Prison Construct

The category, Prison Construct, represents a mental construction of how the inmates ‘see’ the custodial system as it pertains to influencing access to healthcare services, and therefore their ability to access or not access these services. The prison construct does not have to reflect the ‘actual’ custodial system as defined by those who work in it or administer it, as the study is about understanding how issues are perceived from the patient (participant) perspective. Participants’ experiences are described in this category through the concepts of custodial security classification and officer interface.

3.2.2.1 Classification

Participants reported that the security classification of the correctional centre influenced access to healthcare services; and being in maximum security made it more difficult to access treatment. A participant who was now in a pre-release correctional centre, recalled access to healthcare in maximum security correctional centres being more difficult compared to their current experiences:

Even at work here, you go and see the screw, he’ll tell you to go to the clinic. In max though, you’ve got to bell-up, nobody bells-up. [Transcript from Focus Group 21, Minimum Security]

Accessing it at super max, they won’t let you to the clinic. In max they’re banged up 19 hours a day. In here, if you need something go and knock on the door. [Transcript from Focus Group 21, Minimum Security]

3.2.2.2 Officer Interface

Participants reported the issue of officers being the interface to healthcare. Participants described their first contact with accessing health care commonly involved engaging with officers. Officers had the ability to facilitate health referrals by encouraging participants to seek health care and potentially bypassing the ‘bluey’ system or acting as conduits in passing requests to health staff. They also had the ability to deny participants access to health centres. Participants recognised the powerful role officers played within the healthcare system. Access to healthcare services was reported by some participants as dependent on the individual officers.

Yeah well we’re in the yard most of the day, and we can just go to the gate and say to the officer, if he’s a good officer, we’re going we need to go and see the nurse. And generally they’ll just get you straight in. [Transcript from Focus Group 15, Maximum Security]

And the officer too sometimes. Some do, will do the bare minimum they have to. Others will go that extra and they’ll make the phone call for you and get you in the clinic. It really depends who’s on.

Participant 1: And the officer too sometimes. Some do, will do the bare minimum they have to. Others will go that extra and they’ll make the phone call for you and get you in the clinic. It really depends who’s on.

Participant 2: It all comes back down to the officers and their …

Participant 3: I’ve seen that too because I’ll go up there and say, ‘I need to see the nurse, they forgot about me,’ and a couple of the officers, ‘No worries.’ They’ll get
straight on the phone. They'll ring the nurse and say, ‘Look, you missed [Participants name] appointment,’ or something. ‘Okay, I’ll give him a ring.’ They might ring the next week. Yesterday I said, ‘I need this done,’ and he rung up in front of me and a couple of times we’ve been up there they go, ‘Yeah, we’ll get to it,’ and that’s it. [Transcript from Focus Group 12, Maximum Security]

Participant 1:

Let’s say we’ve finally made our way up there so generally you will speak to a nurse and that’s when, you know, you tell them what your situation is and I found that they more or less address whatever the issue is in that regard. The main issue is just actually getting, getting up there, you know because you can’t get up there unless the officer sends you.’

Participant 2: The breakdown is the officers. It’s not the clinic. They’re not getting what they’re meant to get from us. [Transcript from Focus Group 12, Maximum Security]

3.2.2.3 Staff Interactions

After making first contact with officers, participants identified an interactive relationship between officers and Justice Health staff. This interaction was a significant pathway in their ability to access treatment. Participants reported a breakdown in communication between these staff members as a barrier to accessing health care.

If the officers would work more with the nurses and that so you can get your blue forms through instead of just them not giving a fuck. [Transcript from Focus Group 15, Maximum Security]

Yes, it’s … yes, in some ways it is because … again, I think it’s a breakdown between corrections and Justice Health because information isn’t passed on. [Transcript from Focus Group 11, Maximum Security]

Further, they reported situations where they considered corrective service staff were working with Justice Health staff to provide their health care.

Participant 1: And a lot of the time the nurse asks the officer, is that alright to give to [Non- Participant’s name]. And the officer goes what is it? And they say oh, you know Endone. No, no you can’t give them that.

Participant 2: Officers, they don’t know - they have no experience and are given the final decision [Transcript from Focus Group 1, Medium Security]

Finally, suggesting a solution to the situation was to take the officer out of the health access process.

You could just fix it by cutting out the middle man, cutting out the officers. You know, have a nurse come down to the wing every day or like someone that floats around that can [come] round and collect the forms and assess people as they need, you know, and put them on a number scale and they get seen to sooner rather than later because it’s the officers that let it down and it’s only a phone call. [Transcript from Focus Group 12, Maximum Security]
3.2.3 Healthcare System Construct

The category, Healthcare System Construct, represents a mental construction of how the inmates 'see' the healthcare system in the custodial environment and through this perception choose to access or not access these healthcare services. This construct may not reflect the 'actual' health system in the custodial environment as defined by the clinicians who work in it or administrators who operate it, rather it is how the participants reported they perceived its workings, and through these perceptions develop biases that influence the way they choose to engage with it. The concepts within this category provide examples of how these cognitive biases have formed, for example a previous experience of long waiting time led to a negative bias towards engaging the system in that way again. For the Healthcare System Construct three pathways emerged. One pathway where health conditions have been identified and treatment plans put in place (noted as ‘Diagnosed Health Conditions’) a second pathway of self-referral and a third emergency pathway.

3.2.3.1 Diagnosed Health Conditions

Participants reported that access was facilitated by having a health condition that has been diagnosed and was known to both officers and health staff. Formally diagnosed health conditions were either established through a verified patient history, diagnosed by the clinic staff themselves, or an inmate having gone through critical or emergency care during their incarceration and then followed-up by health staff. For participants known within the custodial and health system to have a diagnosed condition, receiving treatment reinforced their status as a legitimate patient, thereby increasing their ability to access services and ensure continuity of care.

A participant who previously experienced difficulty in accessing the healthcare services reported a change after being diagnosed with cancer while in custody. Having a diagnosis legitimised the participant’s need for accessing healthcare services in the eyes of both the health staff and the officers:

I'm pretty lucky in one way at the moment, I’ve been pretty crook. All I’ve got to do is go down and say I want to see someone down there - cancer and other rubbish, so they’re right on top of it at the moment. [Transcript from Focus Group 20, Medium Security]

Similarly, participants who were known by the custodial system and health staff to have a chronic condition such as diabetes or a heart problem found access to healthcare services relatively easy:

I'm type 1 diabetic so I go down every day. Personally I find it quite easy. I might be a bit more alone in that, but I find it easy. I go down and get my things done… personally I find it fine. I've never had any issues at all waiting for any extended periods of time. [Transcript from Focus Group 20, Medium Security]

I think that the particular issues that they take particular care, for me, my blood pressure needs to be checked, for example, and they’ve been right on to that. I have not had my blood pressure checked so much as what I’ve had in the last two weeks. So, yeah, and they’re really monitoring that. Yeah, so that’s been a really good thing. [Transcript from Focus Group 11, Maximum Security]

Being on a forensic community treatment order was also reported to legitimise a participant’s status and increase their access to healthcare services:

I am on a community treatment order and I get extra attention through the healthcare services they tend to respond to me pretty quickly. [Transcript from Focus Group 20, Medium Security]
Treatment

Participants with diagnosed conditions reported that their treatment and health issues were well managed in custody. Participants with diabetes reported positive experiences with the health centres in the custodial environment as they had established channels of referral to specialist diabetic care. Additionally, holistic care for participants with diabetes including monitoring, diet and treatment were reported to be equivalent to community standards:

Yeah probably every three months, which again they organise that and it’s much the same as it is on the outside. So like I said, I’ve been off to Prince of Wales a couple of times as well just to see an endocrinologist and stuff there. It’s as often as on the outside anyway... [Transcript from Focus Group 20, Medium Security]

I find in here - like I said before - my HbA1c for diabetes have been as good as those I’ve had in the last four-ish years I’ve been on the outside...... The control has been pretty much the same. [Transcript from Focus Group 20, Medium Security]

He comes over here and sees how we’re doing and thanks to him, thanks to him done a blood test on me one day. I’m diagnosed with diabetes now and I’m ... I’m on tablets which made it come down and yeah, only for him I wouldn’t knew at all. Yeah. [Transcript from Focus Group 7, Medium Security]

Quality of Care

Quality of care in this context revolved around perceived clinician competence, empathy and communication. Within the diagnosed health condition subcategory participants who utilised mental healthcare services reported extremely positive experiences with their clinician while in custody:

Participant 1: I don’t know whether you’re talking about the psych. Are they part of ...
Facilitator 1: Yeah.
Participant 1: Oh, they’re fabulous.
Participant 2: The psych people are lovely.
Participant 1: I walk out of there and I feel better. I feel ... I just feel really good. I’m going in there and I don’t particularly want to be in there. I think that they ... when I first came in, you’d talk about your past. You’d bring up a lot of traumatic stuff and you’d rip the band aid off. That was your 10 minutes up. Oh, my God, there’s been no closure. But of late I would say the last six months of my year and a half incarceration I’ve got a new psychologist and she’s fantastic. I go in there and for the last couple of minutes we bring it back in to the surroundings and the mindfulness and so you’re not walking out with a band aid ripped off and feeling like, oh my God, how do I deal with this. Yeah, have had some really, really good experiences with the psych’s here, fabulous. [Transcript from Focus Group 13, Maximum Security]

...I’ve been seeing healthcare professionals on the outside for years, since I was 13, and they could never diagnose but I’ve been in here for two years and I’ve had diagnosed what it is, things calmed down. Being transgendered was never brought up on the outside. [Patient diagnosed with bipolar while in custody, Transcript from Focus Group 4, Medium Security]
However a number of participants reported not receiving follow-up consultations or feedback of results.

I went for a mammogram. They are saying that I’ve got a lump in my breast but not quite sure. I haven’t seen the doctor yet from October, I think it was. I haven’t seen the doctor for that yet. The x-ray for my legs, it’s got pins and plates in it. I think two of the pins are loose and I can feel it when I’m walking. Sometimes I limp on it. I haven’t seen the doctor for that either. [Transcript from Focus Group 6, Minimum Security]

Well when they call me up it is but if I ask say the people behind the desk, they say, ‘Okay, we’ll ring the medical and say you need help,’ it never happens. Like my leg’s infected and I got a bad gash in it and it’s supposed to get changed every two or three days and they missed it and I asked the people downstairs, the screws or whatever you want to call them. ‘Yeah, we’ll ring and ring and ring.’ They just never get through. [Transcript from Focus Group 12, Maximum Security]

Medication

Participants with diagnosed health conditions reported easy access to medications except for medications prescribed by an outside (community) doctor, especially for pain or mental health conditions. For some participants having a diagnosed medical condition validated the participant’s need for medication in the management of their health. A participant who was taken out of the correctional centre to a public hospital to be treated for diabetes reported receiving his medications immediately upon return to the correctional centre.

No I got my medication straight away. I didn’t go to the hospital with that. My medication come with me when I got picked up. Then when I came in here turn it into the nurse, and then she said, ‘Is that all yours?’ I said, ‘Yeah, that’s what I’m on.’ I had the script and all that too. ‘Oh yeah ok then, have you had ‘em today?’ And I said, ‘Yeah I’ve already had ‘em today just um tomorrow mam?’ ‘All right I’ll see you tomorrow. [Transcript from Focus Group 22, Minimum Security]

Other participants with medical conditions known to health staff and officers generally received their medications through the medication dispensary system. While it varies between correctional centres, all patients on regular medication for diagnosed health conditions queue up in front of the medication dispensing room situated on the wing and are given their medications by nursing staff. The process of lining up to collect medication is known colloquially as the ‘pill parade.’ Patients with diagnosed health conditions expect to receive their medication through this system and generally reported easy access to their medications.

They have allocation times for … well, what’s it called, supervised medication…which is great. Thank you for providing that service for the [inmates] because I’m sure that it does assist them. [Transcript from Focus Group 6, Minimum Security]

However, mistakes in this process were raised:

Yes. I’m on monthlies now which is good because I can see what’s in the box because they give you boxes. But before I was getting a daily until they put me on the monthly. I only get issued three pills for the blood pressure. Sometimes sporadically there’ll be a fourth pill in there, I’ll say what’s this? Or what’s this, this is a different colour this doesn’t look right. They say oh okay that’s wrong, and they take it back off me and fix it up. [Transcript from Focus Group 4, Medium Security]
There was movements every morning. We’d all come up and we’d get our pills. Now, it is that the nurses come to us at night, so all our supervised pills, any pills that we take, we get them at night. Quite often, girls don’t get their right medication, so you go without that medication until the next [day]… because they don’t let you come up. If you have missed out on your Seroquel or your antidepressant and you let them know, more often than not they don’t come back to you at night. Then the next morning, they go, ‘Well, we’ll come up in the morning and get them at the window.’ The thing is that you’re not allowed to come up. The whole process of us coming up to the window was stopped. That’s why the nurses have brought the pills to our door but the nurses aren’t dispensing or whatever our pills correctly, so more often … no, not more often than not. Sometimes we go without, which is frustrating. [Transcript from Focus Group 13, Maximum Security]

Participants reported having an understanding that healthcare services operating within the custodial environment had to comply with strict medication rules. However, this understanding faltered when participants were unable to access medications in custody that they had been previously prescribed prior to coming into custody. Participants reported that medication was taken off them when they entered or returned to the correctional centre. Some participants reported that they were not provided with an explanation for why they could not continue with their prescribed medication and this caused resentment. They reported that they felt health staff prioritised order and compliance with correctional service policy over the participants’ individual health needs and the staffs’ concern was more related to fear of medication diversion or misuse.

Facilitator: So the pain medication that they’ve given you for a broken neck is Panadol?
Participant 1: Yeah, Panadol, that’s it. I was prescribed something - I took a fall in the shower, got taken to hospital, got given a range of medication for a week, they fucking put it in the shredder as soon as I got back here, ‘You’re not getting that. Here’s some Panadol.’ [Transcript from Focus Group 17, Minimum Security]

Participant 1: There’s only so much they can do and you know what they can honestly do for us? Give us Panadol. That’s about as far as what they can fucking do. I tell you, that’s it.
Facilitator: Do you find that happens a lot?
Participant 1: Oh yeah. I’m supposed to be on pain relief medication. I’ve got it in my property. It says [Participant 1’s Name], like prescribed from my doctor. [Transcript from Focus Group 2, Maximum Security]

Entering a correctional centre was a significant time point where participants reported delays or discontinuity to their prescribed medication, particularly for those diagnosed with mental health issues. Interruptions to regular medication after entering a correctional centre were reported to exacerbate an inmates’ mental state at a time when the inmate felt most vulnerable.

I take antidepressants every day and it took me four days. I was in there … [Name] is my cellmate. I was physically sick. I’m saying I’m going to vomit. I need to get my medication. I have been on these for 11 years. Eleven years, I’ve been on my medication and you don’t understand. It’s withdrawals, for starters. It’s the fact that I’m all over the place. I’m crying and then I’m … my emotions are all over the place, my anxiety … [Transcript from Focus Group 11, Maximum Security]

When I was in clinic there was a girl who was schizophrenic and she’s usually on risperidone and lithium and she hadn’t had it and I know she hadn’t had it because I was there with her
and I saw the nurses bring medication. She said she hadn’t had her medication for four
days and with each day that went past I could see her mental state deteriorating and her just
talking more crazy things and just strange things. I noticed her behaviour was deteriorating
with each day. [Transcript from Focus Group 11, Maximum Security]

I’m still not on all my medication, my mental health medication, and I’ve been in custody for
a month. I’ve been here for two weeks. I asked the ... one of the staff members this
morning, when they called me up for the pregnancy test if they could check on the system
because I’ve tried at the window but been sent away. [Transcript from Focus Group 8, Minimum
Security]

Along with entering into a correctional centre, moving correctional centres was also identified as impeding
access to medication.

Something little as an asthma pump, I was given an asthma pump at [Correctional Centre 1]
and I come to [Correctional Centre 2] and they said, ‘Yes, all right.’ When they went back to
[Correctional Centre 1], they said, ‘It wasn’t on the system.’ But they were the ones that gave it
to me in the first place. Still now, I haven’t got the asthma pump. [Transcript from Focus
Group 8, Minimum Security]

Yeah. So generally I just find for people that are in a transit wing, it becomes very difficult,
especially if you come from one gaol to another and you’re waiting there, you put in a form and
you wait and wait and nothing happens, and then all of a sudden they transfer you to another
gaol, and you have to redo the whole process again. And you can wait for sometimes one
or from two weeks up to a month and it could be a common problem. You know you’ve got a
headache from a common cold. So yeah, other than that, yeah. [Transcript from Focus
Group 19, Minimum Security]

A number of participants from a particular centre questioned the efficiency of the stock control practices in
the clinic’s pharmacy.

Yeah, very. I just went down there asking for anti-inflammatories for a sore back, which
was already been written down in the file. And she quickly told me that they had no anti-
inflammatories at the moment, and to come back Tuesday. But very abruptly and rudely,
there was no need to speak to me like that. [Transcript from Focus Group 17, Minimum
Security]

...with medications or asthma puffers, fuck I shouldn’t have to wait two days until you get -
until the truck comes in, you know what I mean? I’m having an asthma attack for fuck’s sake.
[Transcript from Focus Group 17, Minimum Security]

For some participants, they believed the delay in access to medication was an institutional problem and not
the fault of the health staff who were advocates for their physical and mental wellbeing. Some participants
reported that health staff were doing their best while expressing discontent with the institutional culture and
the limited capacity of staff to be able to improve their position.

I think it’s the process of it, that when you come in and you have to sign so that they can
contact your doctor on the outside to actually know that you’re on this medication but for me it
took a week and I wasn’t on antidepressants. When I saw the doctor, she said that’s not good.
Yet you’re not getting any … it’s a process, so it’s not necessarily the nurses. I don’t know. It’s
the process of ... that it takes far too long, when it’s especially antipsychotics, antidepressants,
anything like that, any mood-altering substance, when particularly you get here and then you are judged on your mood and what you’re doing and your behaviours. Something like that can really make a huge effect and then it slows down the process and it becomes a frustration because we’re not getting the medication we need in order to stabilise us. Yet it’s at such a crucial time. In society one of the biggest things that causes depression and all that is being in gaol. Yet you’re not getting medicated for that. So, therefore, there’s a huge issue in that process of coming in. [Transcript from Focus Group 11, Maximum Security]

3.2.3.2 Self-Referral

Participants seeking primary health care reported greater difficulty accessing health care compared to those with diagnosed health conditions. These participants were those who were not regulars to the health centres, not chronically ill, did not require follow-up and in some circumstances had newly developed symptoms for a diagnosed health condition.

To access primary health care in a health centre, participants are able to self-refer in two different ways. For non-urgent issues, participants submit a blue paper form known colloquially by inmates as a ‘bluey’ and for circumstances where inmates require attention while in their cell they may ‘buzz-up’ or ‘knock-up’. ‘Buzzing up’ or ‘knocking up’ involves pressing a buzzer located in each of their cells with the purpose of getting the attention of officers. Their use is therefore generally reserved for more critical health concerns.

The ‘bluey’ needs to state the reasons for seeking health care such as pain, stress, medication issues, or to talk to the nurse. The application form is then either placed into a locked box on the wing or delivered to the clinic by inmates. However, some participants reported this may be undertaken by officers. These forms are then collected by the nurses who read and triage the requests.

Participants’ experiences with the ‘bluey’ application system were generally negative, characterising it as inefficient and paper-chasing. It was perceived that multiple applications frequently went missing. Lack of acknowledgement that application forms were submitted to health staff made participants suspicious that their requests were deliberately destroyed:

And so obviously the problem is whether we have blue forms getting there. So they must have like a drawer stacked of them and one day they say oh it’s over full, we might as well just throw them down there. [Transcript from Focus Group 15, Maximum Security]

Treatment

Participants reported varying degrees of access to treatment, depending on their presenting symptoms. Access to the clinics was reportedly easier if participants presented with easily identifiable health conditions.

Even when we do manage to get over to the circle clinic, they just say, ‘We can’t get you over there.’ Unless you’ve got stab wounds or something it’s like really bad care. [Transcript from Focus Group 24, Maximum Security]

Participants who did not have overt or obvious health conditions but required further investigations from primary care practitioners were more likely to be placed on a waiting list or given paracetamol by the nursing staff to relieve their pain symptoms in the interim.

I’ve got really bad teeth. I’m on the waiting list for oral health and that, and like, you can’t get a Panadeine when you need it…there’s days when you don’t have access to the nurse. [Transcript from Focus Group 14, Medium Security]
Participants reported difficulty accessing drug and alcohol services while in custody. At the time of interview, inmates who were on an Opioid Substitution Treatment (OST) program upon entry into custody continued to receive their treatment. Other inmates wanting to access to an OST program needed to meet the criteria for priority or fast track access. These criteria were patients confirmed to be pregnant, HIV positive, and in some cases Hepatitis B carriers. For all other inmates, they could only commence an OST program via a pre-release program 7 days prior to their confirmed release date. This made it significantly more difficult for patients to access the program. Participants expressed dissatisfaction with the stringent criteria to use these healthcare services.

Participant 1: When I first come in I had a bad heroin problem and I tried to get on the methadone, and they said they weren’t going to put me on it at all until I had 12 weeks left. I’ve got four years.

Facilitator 1: Why did they say you had to wait until you’ve got 12 weeks left?

Participant 1: Because they’re apparently not putting anyone else on methadone in gaol, unless they’re previously on it.

Facilitator 2: So if you’re previously on it when you come into gaol you can get it, but if you’re not on it when you come in you don’t get it until about 12 weeks…

Participant 1: Yeah. I probably wouldn’t worry about it by then. [Transcript from Focus Group 23, Minimum Security]

Some participants also reported the supply of inappropriate physical health aids which were not properly fitted or customised to suit its intended purpose. For example, one male participant accessed optical services to get prescription glasses but was sent women’s frames. While the participant’s health care needs were addressed, the product received was not considered optimal. This result may also prevent other inmates with similar issues from accessing optical services because they believe this to be the standard of care they would receive.

Participant 1: Well I had to go and get me eyes checked, and I had to pay for it. It cost me $75, I paid to go in and see the eye specialist. Then I wanted to buy me own glasses. Justice Health said no we’ll get them for you. They sent me up girl’s ones. [Laughter]

Facilitator 1: That’s helpful isn’t it?

Participant 1: I’ve got to walk around with these turtle shell girl’s glasses on, do you know what I mean.

[Later in the conversation]

Participant 1: They said no we’ll look after it. I thought, oh yeah I’ll get a free pair of glasses out of it and they sent me up these girls ones, so I would’ve been better off buying me own.

Facilitator 2: What happened when you went back to the health centre and said these are girl’s glasses, can I...

Participant 1: Oh they don’t care.

Facilitator 2: Did you ask them to change?

Participant 1: No. They don’t care they just have a little giggle and say get on with it. Yeah,

Participant 3: that’s not good. [Transcript from Focus Group 21, Minimum Security]
Further, participants reported a lack of access to physical health aids, particularly if the health care request conflicted with the security needs of the correctional centre (for example the aid could be used as a weapon).

Participant 1: Yeah, they gave him one crutch.

Participant 2: It took me a week to get one crutch and then a week later they gave me a second crutch so I could get round. But it was getting to the point where I was going to have to cancel visits from my family, all that sort of shit.

Participant 3: He almost broke his back the other week falling over because he only had one crutch and it was raining.

Participant 2: I went, yeah, hopping down to the yard, went balls up and smashed myself. [Transcript from Focus Group 24, Maximum Security]

While participants recognised their right to seek health care, many also accepted the inherent tensions between access to health care and the security concerns of the custodial environment resulting in patients not being able to receive health care as they might in a community setting:

Yeah I think generally I’ve been able to speak to them about anything I needed to. But when you bring up an issue with them, you may not get a resolution but that’s because of the security environment. So you don’t always get what you want in gaol, that’s just the way it is. [Transcript from Focus Group 4, Medium Security]

Quality of Care

Within the subcategory of self-referral, some participants reported quality of care (perceived clinician competence, empathy and communication) exceeding community standards while others expressed poor experiences with their quality of care.

I thought the doctor was good too that I saw because that same thing, they went and … actually took the time to find the history and ask questions and make sure what treatment I’ve had and what I may need and I thought that was really good. [Transcript from Focus Group 11, Maximum Security]

They address all my issues that I ask them to and they do it really well. I just think they’re a great service. [Transcript from Focus Group 4, Medium Security]

All they seem to have in front of them or have a look at is the sheet that’s got the name that they have got to call up next and whatever’s the comment next to it, so whatever the problem is on that day, that’s it. They don’t look on the computer to see the past stuff. When you go to the doctor’s surgery outside, they actually go into our file. They read … do you know what I mean? [Transcript from Focus Group 8, Minimum Security]

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I think what I’ve noticed in my experience with them is they concentrate on what they’re dealing with at the moment. I’ve never [been] asked for anything else except for what I was dealing with at that present time, but they never gave me any feedback either. They don’t ask ‘how you’re feeling’ or ‘how you’ve been travelling,’ are there any other issues that you want to attend to’. It’s always one - they go up and down the form of what I asked for, that’s what they’re mainly concerned about. [Transcript from Focus Group 4, Medium Security]

I was going to the clinic every day. I thought I was having a heart attack, you know. I had no idea what was wrong with me and all they could do was put me on an ECG machine and there was no [indication] on the ECG, so obviously there’s nothing wrong with me. They were, they were more or less trying to say I was making it up, you know. So they gave me like three different lots of medication that only made it worse and in the end – what it took for me to actually be seen again on the fourth time was for me to threaten legal action and I, I, I put in a complaint threatening legal action and I had to get someone on the outside like to do that as well, to be seen by a doctor and, and then that’s when the doctor worked out it was [condition x], you know. All my other, like all the other symptoms that I was having, they were disregarding it. They weren’t taking it into consideration. [Transcript from Focus Group 12, Maximum Security]

A lack of proper communication was also raised as an issue by some participants.

When I first came out here they pulled heaps us in for a pap smear and I hadn’t had one for years and so I had one and got given this big turbo thing of antibiotics, full on antibiotics and I was on them for five days, three times a day. I didn’t know what it was for. I had to end up pulling the nurse up out here. She told me what it was for and I had to Google it – I thought I had some sexually transmitted disease or something and it wasn’t. It was just some bacterial infection or some shit like that but I was on antibiotics, didn’t know what it was for. Never got told, called up, anything. I just got abused for not going and picking up the pills I didn’t know I was meant to be on. [Transcript from Focus Group 7, Medium Security]

Yeah, because I’m at clinic every morning. I’m on Suboxone. When I got my dose this morning, the nurse give me a bag with a tablet in it with my name on it. I took it but I didn’t know what it was for. Then afterwards, at 10 o’clock, when the pill window is open, I went and I give it to her and I asked her what it was for. She said, ‘Doesn’t it look familiar to you?’ I said no. Then she just told me that it was an antidepressant’ [Interviewer asks if participant knew they had been prescribed anti-depressants.] Participant: ‘No, I had seen last week the mental health nurse. She just asked me how I was coping and that. I just said I can’t sleep and that. That must be it. I don’t know the name of it. I don’t know anything about it. [Transcript from Focus Group 6, Minimum Security]

Participants reported positive interactions with optometric professionals.

I had the optometrist guy come in and he was excellent. He done me eye test and that, and was fairly thorough for in here. I was pretty well impressed with him, he did that much. [Transcript from Focus Group 20, Medium Security]
On the other hand, participants reported negative experiences with dental professionals while in custody including having to perform self after care service:

Participant 1: And the dentist, the dentist is just ridiculous inside, because there’s teeth that can be fixed, they’re like 75% fixable, and they just say I’m just going to take it out. They don’t do fillings and that, it’s just ridiculous. Like they just want to…

Facilitator: So they just pull the tooth out instead of giving you a filling or a crown.

Participant 1: Yeah.

Participant 2: Not proper health care ay bro. [Transcript from Focus Group 15, Maximum Security]

Participant 1: Sometimes they pull out the wrong tooth too.

Facilitator: Really?

Participant 1: Yeah it’s happened to me.

Facilitator: They pulled out the wrong tooth?

Participant 1: Yeah they were supposed to pull this one out and they pulled that one instead. Then I lost all me teeth up here.

Participant 2: The thing is but, he hasn’t even done - I don’t know how he can just - he’s like a psychic dentist, because you can tell your tooth is - the bacteria and everything underneath without even looking at or getting an x-ray. Because I’ve had the actual thing, like a root canal and I had the actual filling come out. So there’s actually no nerve underneath there, so it can be like treated and sealed off. He’s like ‘nah mate, I can’t seal it off’. Because when I rang Justice Health, they said look before you go see him, speak to the clinic, and they’ll get you a course of antibiotics so it’s not inflamed when you go see him. So I got the antibiotics, and I got - I went to go see him, because there’s no inflammation there - the infection’s gone. All he had to do was just cap it and to finish it off. He couldn’t even do that, so I go just don’t worry about it. [Transcript from Focus Group 15, Maximum Security]

Yeah and I ended up getting it out and that and I kept going around it with my tongue up the back. I could feel something there. I actually pulled it out myself. It was a long skinny piece of tooth. It wasn’t a good job what he done in town. [Transcript from Focus Group 3, Minimum Security]

I have to say the same thing happened when I was at [Correctional Centre]. There’s a dentist on site there. A little bit later it was the same, like the skin had grown over it but there was something sticking out of it, so you just pushed down on it. It started bleeding and then you pull it out. It’s horrible and it stinks too. [Transcript from Focus Group 3, Minimum Security]

Medication

Many participants in the focus groups reported dissatisfaction with the perceived limited range of analgesic medication available for patients in custody under the self-referral system. Across the focus groups conducted, the majority of participants believed that paracetamol was given as a quick fix for patient’s health issues and universally prescribed for all conditions irrespective of their pain levels.
They're good, they've very cooperative. They ask questions, but the problem that we have here sometimes, you put forward the case, like say you have sickness or some kind of sickness, the nurse sometimes, you can tell from her voice that she doesn't have the answers, but what she does is to just keep you done and dusted. She just describe [sic] Panadol for you [LAUGHS]. It happens in many cases. The nurses are very nice, they're very nice and they're trying to help, we understand their intention, but sometimes there are some cases I need to be looked up and be seen by someone, a specialist. And what they do, they say okay Panadol will do the job. And it happened not in one case, if you do your survey you will see that there are many, many people, all the people will give you the same answer. That's the problem that we have here, Panadol is the answer. [Transcript from Focus Group 5, Maximum Security]

Yeah, when you do get to the clinic like in a C classo gaol, like up at [Correctional Centre], I was going down there and told them that, 'I've got a cold and that.' And they just give you Panadol. What's Panadol going to do? You know what I mean? It's not going to get rid of your cold. ‘Oh here's some Panadol.' You know, it's not going to help you really. It may be good for a headache, yeah. I went there the other day and I said, 'I've got a broken toe.' Gave me some Panadol. [Transcript from Focus Group 19, Minimum Security]

Participants in some centres felt that there would be repercussions if they complained about their access to medications.

Participant 1: If you want them to issue it [a medication prescribed in the community], they usually tell you to call up the Justice Health people and make a complaint. If you do that, as soon as you call that number, they will call you to the clinic, ‘why the fuck did you call up for.’

Participant 2: We get in trouble, we get in trouble bad.........And you know why, because we’re chasing a bit of help.

Participant 1: And then they come back and the officers will be like don’t call that number again.

Participant 3: I’ve been told a few times not to ring that. The last time I got told that, he told me I spent three days filling forms out for you, and if I have to go see it again, you will go segro.

Facilitator: Again, so corrections officer that told you that, or Justice Health?

Participant 3: No Justice Health, he’s the boss of Justice Health.

Participant 1: The NUM. [Transcript from Focus Group 17, Minimum Security]

Yard Program

Participant dissatisfaction with the perceived limited range of analgesic medication lead some to access stronger pain relief through the informal yard program. This program is where medications are sourced from other inmates.

Participant 1: Or it’s too hard to get like with our friend [Non-Participant 1], by the time he saw a doctor – I don’t think he’s still got pain killers but it’s sort of like they’re just trying to scam us to get OxyContin or they’re trying to scam us to get some actual pain relief.

Participant 2: They gave him Panadol and he could barely walk.
Long Waiting Time

A key issue reported by participants seeking health care was the long and unpredictable waiting times. Participants reported that waiting times varied depending on the healthcare service required. A majority of participants acknowledged that access to the nurses was relatively easy and efficient, but if participants wanted to seek health care from a doctor, secondary care or specialist consultation, waiting times were thought to be substantial. Outside of the nursing staff, participants reported waiting times to see a doctor, dentist or psychiatric service as anywhere from ‘three days’, ‘two weeks’, or as long as ‘six months’.

I guess in a nutshell it’s the timing. It’s the waiting. It’s frustrating. Then you’ll get the bluey and they will return the bluey to you and it says on the waiting list. Big deal and that means what? I mean, that could be 200 days. [Transcript from Focus Group 13, Maximum Security]

Previous poor experiences with healthcare services, particularly long waiting periods for care had implications on both the participant’s health seeking behaviour and their health outcomes. These participants became disillusioned by the healthcare system and did not bother putting in an application to get their health issues addressed.

When you’re at [Correctional Centre], you don’t even bother. You put in the form and wait a couple of months to get in and see them. [Transcript from Focus Group 14, Medium Security]

I’m just really stroppy with everything. Once bitten, twice shy. You just don’t ask for nothing anymore. [Transcript from Focus Group 13, Maximum Security]

I waited about six months for mine. And I just went like two weeks’ ago, but it was about eight or six months’ ago. I didn’t even want to ask them anymore. I couldn’t be bothered anymore so I just left it. [Transcript from Focus Group 18, Minimum Security]

This sentiment was widely adopted by many inmates, as noted by one participant who is also an Inmate Development Committee delegate. As a delegate, this participant is privy to the inner problems and concerns of fellow inmates regarding programs, activities and services within the correctional centres:

The opinion of a lot of the inmates here is they ... I will say to them, like, they might come up and say ‘My foot’s aching.’ I’ll say, ‘Come on, you should go to the clinic.’ ‘What’s the use, [Participant 1]? Why should I go to the clinic? They are not going to do nothing.’ That’s the attitude that we have all adopted. [Transcript from Focus Group 6, Minimum Security]

For some participants who felt that their health issues were not being met by healthcare professionals due to the long waiting times, these participants reported alternative ways to manage their own symptoms. This included engaging in unsafe, do-it-yourself health practices. One participant reported having to take matters into his own hands by pulling out his own infected tooth because he could no longer manage his pain symptoms while waiting for the dentist:
In 2012 and I was in area [x]...it took me four months to see - I had a bad tooth, and I had to pull it out myself basically. I got it out myself, before like the dentist even...even though I was telling them that it was that bad, and ended up pulling it myself and it was a month after that that they seen me, and then they ended up pulling out the tiniest little bit of bone or something, I don’t know what it was. [Transcript from Focus Group 15, Maximum Security]

While another participant performed his own podiatry services:

Participant 1: Yeah I had a bad ingrown toenail and I tried to cut it out myself and made a mess of it. Then I went over there and then…
Facilitator: So it got infected?
Participant 1: Yeah and then they said we’ll put you down to see a doctor on Wednesday or whatever it was a couple of weeks ago. And then the doctor never called and I haven’t had a call since.
Facilitator: Wow, and that’s how long ago?
Participant 1: Three weeks ago.
Facilitator: How is it now?
Participant 1: Yeah it’s not as painful, but yeah I pretty much done it all myself, because yeah, they won’t do anything about it. [Transcript from Focus Group 1, Medium Security]

Finally, some participants reported a lack of timely response to a ‘knock-up’ or ‘buzz-up’.

You press the buzzer and they take about 45 minutes to an hour to come to your cell. [Transcript from Focus Group 13, Maximum Security]

Yard Program

Participants who felt they could not receive immediate help from the health centres turned to the informal networks for medication to manage their health problems. Participants reported saving their medication for tough times when health care was not easily accessible.

Participant 1: You just save your excess pills and just go ask your neighbour like, ‘Have you got any Panadol?’ [Transcript from Focus Group 15, Maximum Security]

Having excess pain medication on hand allowed participants to provide medication to others even if there was a risk of getting caught by Corrective Services Officers:

Participant 1: Sometimes I’ll give my Panadol to someone else you know what I mean, if they’ve got a real bad headache or toothache, I’ll give them a my Panadol Osteo, give them even though we’re not supposed to, but that’s the only way they can get it.
Participant 2: But we could get on a charge for that if we don’t tell the nurse with had Panadol then get a dirty urine from Panadol.
Participant 1: In a way it’s the wrong thing but we’re only looking out for each other. [Transcript from Focus Group 18, Minimum Security]
And I could understand if you were caught misusing a drug or you’ve been caught in the past but none of us have... If any of them talked others out, ‘cause as I’ve been saying ‘cause they’re genuine – I’ve had a mate with his face swollen like that and given him two of my codeine just being a friend but God forbid if I was caught. That wouldn’t matter about how bad his tooth was. It’s just a matter of I gave out my medication and that just automatically gets me cut off. I would get nothing. [Transcript from Focus Group 16, Maximum Security]

Some participants felt their health conditions were not taken seriously by health staff and therefore turning to fellow inmates for treatment was an easier option.

Participant 1: Yeah it's hard in here.
Participant 2: That's why a lot of the boys don't even worry about going over there because they know the answer. So they start - they're getting one of the boys to rip their tooth out, or cutting their ingrown out with a dirty razor.
Facilitator: So boys are looking after each other’s health.
Participant 2: Pretty much, yeah.
Facilitator: Wow that’s pretty intense!
Participant 3: It helps. Better than feeling - we’re just animals in here or something. [Transcript from Focus Group 1, Medium Security]

Communication

Breaks in communication and the absence of feedback were identified by some participants as elements which hindered their ability to access and receive health care. These participants often felt that they were ‘in the dark’ regarding healthcare services as well as aspects of their own health. They felt unclear on how they could access health care, what care was available to them, how long it took to be seen, the processes relating to waitlisting, accessing test results and follow-up care.

You could put something in the box and you don’t even know until you’ve actually made the list. They're not giving us that feedback, no feedback to tell us. They say - even if you did get to see the nurse, they might say oh we’re going to refer that to the doctor and then you don’t even - you’re sitting back in your cell for months on end going yep, they’ve told me I’m on the doctors’ list, so you just go twiddle, twiddle with your thumbs over the next couple of months, and you might see the doctor, and then you might not. [Transcript from Focus Group 4, Medium Security]

Participants reported that they wanted feedback from the appointment system. They wanted to be advised whether an appointment would be arranged or how long they would have to wait:

If you put a clinic form in, they don’t go, ‘Okay, we’ve received it,’ so you’re like fuck, I’ll put another one in and then you stop because you’re like fuck, am I bugging them? Do they think it’s not serious enough? So you’re sort of like hesitant to put in any other forms. You still don’t know whether they’ve got it or not and then you start sitting there thinking, ‘Oh shit, I must be just bugging them.’ They just don’t even want to know. [Transcript from Focus Group 24, Maximum Security]
Yeah I think it's just that general acknowledgement that okay yeah, we recognise you put a form in ..... We know you've put a form in, we'll get back to you as soon as we can, and just keep on updating us when we could go and see them possibly. [Transcript from Focus Group 4, Medium Security]

I think if everyone got something to say that yes you're in the system and you'll be looked at, at this point, and give you a little bit of a timeframe, whether it be one month or six months, that would help a lot. [Transcript from Focus Group 20, Medium Security]

Participants also reported that some physical communication systems were inadequate and lead to delayed access of health care.

Participant 1: The big problem is when they call our name over the PA, they say they call your name...
Participant 2: But you don't hear it.
Participant 1: But we don't hear it. It’s a big centre, we could be anywhere, we could be doing buy ups, we could be in the yard. The officers - the nurse will tell the officers, the officer says yeah we'll chase it up, they're doing 1000 things, they don't come and see us. The PA doesn't necessarily work, and then they say we called you five times where were you. And you say well I didn't hear it. Then they go well bad luck, see you later. [Transcript from Focus Group 1, Medium Security]

Work Around

Work arounds are an informal system that the participants have identified and used to streamline access to the clinic. This involves participants providing information to the officers about going somewhere else in the correctional centre and then heading to the clinic instead, or skipping work, or exaggerating symptoms.

Facilitator: When you say that you steer your way there, can you explain what that means?
Participant 1: Yeah, like I’m meant to be going to programs, and then you just like...
Participant 2: You veer off to the right [LAUGHS].
Participant 1: Exit stage left [LAUGHS].
Participant 3: I only got seen the other day straight away because I snuck out.
Participant 4: Yeah, that’s what you’ve got to do, you’ve got to sneak out, say you’re going to the library or something and you divert, dart and duck. [Transcript from Focus Group 15, Maximum Security]

Another work around participants used to access a nursing staff and to avoid the bluey system was to tag along with those lining up for their regular medications.

Participant 1: You go there at 1 o’clock pills in the afternoon they’ll usually get you in, you go to pills.
Facilitator: If you’re on regular medication?
Participant 1: Yeah, you can just like tag along there, and sometimes you can get to see someone. But with the form, like when I got here, I waited like about five weeks before I even got called. [Transcript from Focus Group 15, Maximum Security]

3.2.3.3 Emergency

Participants reported that emergency and critical care needs were adequately addressed if they were clearly identifiable such as severe loss of blood or loss of consciousness. Having an identified emergency meant quick access to the health centres located within the correctional centre or community hospitals outside the correctional centre.

Participant 1: The only thing I guess is when I had my face all busted up, they were pretty quick to get onto that, get me to the hospital and x-rayed.
Facilitator: So when there was something that was more of an emergency they were onto it.
Participant 1: They were onto it, but anything else...
Participant 2: Yeah but you see...
Participant 3: If they have an emergency here, they'll take you to hospital. [Transcript from Focus Group 17, Minimum Security]

Something can happen between you and another inmate, and they will rush you straight to hospital. [Transcript from Focus Group 17, Minimum Security]

For cases that were less identifiable, it was at the discretion of the officer to determine the urgency of the concern. A concern perceived to be an emergency by the participant, was not necessarily perceived as such by the officer.

Participant 1: No the buzzer will just go. You ring them for an hour or so, and then they’ll say I’ll let the nurse know and no one ever comes. I buzzed up two nights ago because I kept fainting, and I kept my - my heart would start racing. It just kept buzzing, ringing, ringing, ringing.
Participant 2: It just kept buzzing, ringing, ringing, ringing.
Participant 3: Yeah I could hear it buzzing, buzzing.
Participant 1: And when they do, they say oh we’ll get onto that or whatever and nothing happens, so you don’t buzz-up again because you think they’re going to do something then nothing happens.
Participant 3: But sometimes they don’t even answer the thing at all. It’s like two hours later. It should be within 10 minutes. [Transcript from Focus Group 15, Maximum Security]

The difference in participant and corrective services or health staff perceptions of urgency led one participant to report taking drastic action to obtain attention.

Previously when I was in [Correctional Centre] last year, no actually 2015 I was there, they wouldn’t take me to hospital. At the time I had a broken hand, this hand actually again. It was broken and they didn’t take me to hospital so I actually swallowed [foreign object] to get to hospital because they wouldn’t take me to hospital. I was in that much pain I actually swallowed [foreign object]. I have been stupid. [Transcript from Focus Group 24, Maximum Security]
3.2.4 Personal Factors

The category, **personal factors**, represents personal circumstances and experiences that influence the way the participants chose to access or not access the healthcare services within the correctional centre. The concepts within this category represent factors reported by participants that influence decisions on how they do or can seek health care. Some of these factors lead to the development of positive or negative biases for future decision making while others describe how the custodial and health system impacts them personally in the form of enablers or barriers to accessing health care. Personal experience means many participants drew on comparisons with the outside (community) health systems in this category.

3.2.4.1 Sentence Length

Participants reported that sentence length had an influence on available healthcare services and treatment options. Some participants with shorter sentences or those at the end of their sentences reported feeling that their health care requests were being deflected by healthcare staff because enquiries into their health concerns could not realistically be met before their release date.

The other day I went to the clinic. I was supposed to get an x-ray on my fingers because two fingers are dislocated. They didn’t even give me an x-ray. They just said, ‘No, you’re right. Just wait until you get out.’ Because I get out in five weeks they said, ‘There’s no point in x-raying it. It’s not going to do any good.’ [Transcript from Focus Group 24, Maximum Security]

… I waited seven weeks to see the dentist, and I came in with an abscess. Get to see the dentist and he’s like, ‘I don’t know which way to go bro’, and he says, ‘How long are you doing? Are you doing a whack? Over six months?’ Yeah maybe…well then I can get some dentistry. And then he’s like, ‘Oh no, we’ll have to pull it out.’ And I said, ‘Well what about if I’m doing a short term?’ He goes, ‘If you’re doing short term, it’s good because you just wait to get out and get it fixed, can’t do nothing for you.’ So what do you do? So I just go don’t worry about it. [Transcript from Focus Group 15, Maximum Security]

This issue worked both ways. Sentence length also influenced participants’ reported health-seeking behaviour. Participants serving shorter sentences or those due to be released from custody within the foreseeable future preferred to wait, choosing to pursue treatment outside in the general community. When the interviewers asked participants if they wanted them to put in a referral form on their behalf, participants declined stating that they would seek health care upon release.

Facilitator: So you’ve got numbness in your feet?
Participant 1: Yeah I’ve still got it, I still can’t feel my foot properly.
Facilitator: Have you spoken to somebody about that here?
Participant 1: No I’ve been waiting two and a half months to speak to someone about that.
Facilitator: Okay. We need to make a referral about that.
Participant 1: But don’t worry about it, because I’m getting out in a month, I’ll see me own neurosurgeon. I’m not going to wait for these gynomos. [Transcript from Focus Group 17, Minimum Security]
Facilitator: We can do a report to the health centre if you like? We can identify these issues for you?

Participant 1: Yeah I’m getting out in four and a half months anyway, so I’ll get it done myself. I even told the nurse I would pay for it myself, $2200 or something.

Facilitator: Did you want us to complete one of the reports after the session?

Participant 1: No that’s alright. [Transcript from Focus Group 21, Minimum Security]

In contrast, participants who had more time remaining in custody were more likely to seek out health care.

Facilitator: So if you don’t get to see the doctor or the dentist when you first want to see them, are you likely to go back or are you just…

Participant 1: Not really.

Participant 2: It depends how long you have really. With me I’ve got a couple of years. There’s no point me waiting a couple of years to get something sorted. If I’ve got to get it done, I’ll get it done while I’m in here. [Transcript from Focus Group 23, Minimum Security]

3.2.4.2 Cost

Participants reported that they did not regularly engage with community healthcare services due to the high cost of accessing care on the outside:

Depends on the circumstances too you know, if you’re on the dole and you’ve got to pay for it yourself. I’ve got to pay a fortune to see my doctor, $180 or something just to see the doctor. So I hardly ever go unless I’ve got my fingers chopped off or something you know. [Transcript from Focus Group 21, Minimum Security]

Participants who did not regularly access health care in the community due to the financial costs reported that access to care was easier inside a correctional centre. As healthcare services in a correctional centre are free of charge, the financial constraint is no longer a barrier for participants.

Facilitator: Do you guys have better access to health care while you’re here in the centre or out in the community? Would you make more use of the healthcare services while you’re here then you do in the community?

Participant 1: Yeah well me personally, yeah.

Participant 2: You get it for free here. [Transcript from Focus Group 9, Medium Security]

3.2.4.3 Time

Participants felt that having more time on their hands gave them more opportunity to use healthcare services on the inside. Participants who did not have time on the outside to access healthcare services reported greater use of health care while in custody and these participants felt their health was better managed in custody and the care received was equivalent to community standards.

Participant 1: I don’t see doctors on the outside. I’m always too busy. I never have the time so I do it in gaol. I always get everything done in gaol.

Facilitator: All right, so better?
Participant 1: Yeah.
Facilitator: And you think better as well?
Participant 2: Yeah.
Facilitator: Why do you think it’s better?
Participant 2: The same, I can’t remember the last time I seen a doctor other than when I’m in gaol.
Facilitator: Okay. What about you guys? Would you say it’s managed better or worse?
Participant 3: What’s that?
Facilitator: That your health care in prison compared to in the community.
Participant 3: The same. They do the usual thing, check your blood pressure.
Participant 4: I think it’s better. [Transcript from Focus Group 5, Maximum Security]

3.2.4.4 Reglementation

The reglemented nature of custodial life was viewed by some participants as an enabler allowing them to take control of their health. Other participants reported a lack of autonomy acted as a potential barrier to them accessing healthcare services.

Control of Chaotic Lifestyle

For many participants community living meant violence, excess consumption of alcohol, smoking and drug-taking were everyday experiences that had a negative impact on health. Participants reported that breaks from their chaotic lifestyles on the outside, and having access to health care on the inside made them feel more committed to taking care of their health needs.

Participant 1: I worry about myself more in gaol.
Facilitator: You worry about yourself more in gaol?
Participant 1: Yeah, out there because I’m a drug user. I just don’t ever go to the doctors or anything except for me pills. I take me pills religiously but that’s it. When we come in here, that’s our chance to go to the dentist and get things seen to that we don’t always do on the outside.
Participant 2: Because I was scattering and couldn’t pick up my medication, they wouldn’t give them to me when I come in here.
Facilitator: What about the rest of you girls? Do you use health care more when you’re in here?
Participant 3: Yeah.
Facilitator: Why is that? Why do you use it more?
Participant 3: Because in here we have pap smears and get our blood tested and everything. Outside we just don’t care, you know.
Participant 4: You don’t worry about it until you’re in places like this.
Facilitator: Why don’t you worry on the outside?
Participant 5: Drugs.
Participant 3: Drugs and alcohol abuse. [Transcript from Focus Group 7, Medium Security]
I’m a mother of seven children and I’ve worked and I’ve been so busy in my life. I’ve been a drug addict all my life. My health never mattered to me. What I can say about coming to gaol for me personally is that I’ve seen more psychologists, more doctors, more nurses here than I ever would have and may still ever would in my time outside. For me, there are a few silver linings in coming here to gaol. My health, although I have put 60 kilos on since I have come here, in saying that, I have got a lot more care and worried a lot more and addressed my issues medically and emotionally and mentally here than I ever have, ever. So, that’s a real positive for me. [Transcript from Focus Group 13, Maximum Security]

The structured nature of custodial life and restrictions from drug and alcohol use allowed some participants to regain control of their health. Participants reported that they had seen an improvement in their health since coming into custody where there was access to regular meals, a stable routine, physical activities and health interventions such as free vaccinations and treatment services.

Participant 1: I don’t know whether it’s training, it’s just lack of drugs.
Participant 2: Yeah I train, but I don’t train hard.
Facilitator: So do you reckon it’s because of not being on drugs in here?
Participant 3: Yeah I suppose so, and you’re having meals around a certain time, so your metabolism or whatever it is, is right because you’re having three meals a day, snacks and that. You’re not just eating one meal a day and that, so your body gets used to it and starts getting happy with the nutrition so you start putting the weight on. [Transcript from Focus Group 23, Minimum Security]

A number of participants reported that their physical health had improved since the introduction of the smoking ban in August 2015. While many participants felt disgruntled by the imposed changes, a number of participants reported that restrictions to smoking had incidentally improved their health and health management. When the interviewer asked participants if they had noticed any changes in health since the introduction of the smoking ban, participants reported the following:

Participant 1: Yeah, I can breathe.
Facilitator 1: Breathe a lot better?
Participant 2: Yeah breathe a lot better. Like I was doing stair runs there the other day. When I first started there I’d be flat out doing 10 and I done 30 there. Just breathe a lot better.
Participant 3: Opens your lungs.
Participant 4: I sleep better.
Facilitator 2: Anything else?
Facilitator 1: You’re training more. Some of you said you’re training more now that you’ve stopped smoking. How many hours a day would you train or are boys training?
Participant 5: Usually they train about twice a day hey. Like they train once in the morning for say an hour when they lock us out and then they do a session in the afternoon. So half an hour, an hour, so probably two hours a day. But when I was here before I was training every day like now this time I’ve come back I’m more laid back I haven’t been training much. But probably two hours a day what do you reckon boys?
Participant 2: Yeah. [Transcript from Focus Group 9, Medium Security]
Fear

Some participants reported that prioritising health on the inside was done out of necessity rather than to utilise the healthcare services offered at the correctional centre. They reported that they could not afford to be sick in custody in part due to the nature of the carceral environment where they believed they were at higher risk of transmission of infection. They felt they could not rely on the healthcare services to adequately address this issue. Some participants also reported the need to keep healthy to prevent them becoming vulnerable to other inmates.

Facilitator: Are you guys more focused on looking after your health when you’re in here or on the outside?
Participant 1: In here I reckon.
Participant 2: Probably In here.
Facilitator: Why’s that?
Participant 1: In here you could catch anything you know.
Facilitator: So you’re quite health focused when you’re in here. So what sort of things do you…
Participant 1: You can’t afford to get sick here, you know what I mean? Not when the health care like it you know as much as you expect them to... You gotta look after yourself.
Facilitator: Why can’t you afford to get sick in gaol, what’s the main reason?
Participant 3: Because you can’t just go to the doctor, you’ve got to – and it gets spread around real quick.
Participant 2: Yeah you just pass it on to everyone... when you’re sick outside you stay away from everyone, you stay in bed and you get fixed. But here you just get kicked out of bed and have to do what you’re told to do.
Participant 4: It makes it a little bit harder as well when you’ve got a problem. I knew a couple of people in [Correctional Centre] that had like rashes and stuff, and it was taking them six or seven days to see the nurse. By the time they went to see the nurse, instead of it just being on their arm it would be all over their body. [Transcript from Focus Group 18, Minimum Security]

Facilitator: Some of the other blokes said to us that it’s important to keep fit in prison, you can’t afford to get sick in prison.
Participant 1: Yeah.
Facilitator: Why is that?
Participant 2: It’s the waiting list.
Participant 1: Yeah.
Participant 3: You can be real sick and stay in bed all day but you’ve still got to wake up early for musters and stuff.
Facilitator: Does it make you more vulnerable if you’re sick in prison as well?Yeah.
[Transcript from Focus Group 23, Minimum Security]
Lack of Autonomy

Participants reported that the loss of autonomy in custody had an impact on their ability to maintain and manage their health. They described that it was more difficult to care for themselves in custody due to restrictions on everyday items that they could access on the outside such as appropriate footwear, hand sanitiser, band aids, clean sheets and sunscreen.

Participant 1: There’s not enough infection control in here.
Participant 2: The yards and all that and the cells aren’t that clean at all. It’s not a real hygienic place.
Participant 1: Our Fincol runs out – I think it lasted us a week, it’s meant to last...
Facilitator: What’s that sorry?
Participant 1: Fincol - it’s our disinfectant we get.
Participant 1: You can’t buy things like Dettol. Even if they put Dettol on the buy ups. Hand sanitiser, Dettol...if you get a cut in the yard, a tiny little scratch, you’re not going to go over to the clinic for it.
Facilitator: So there’s no hand sanitiser anywhere?
Participant 1: No, there’s no personal disinfectant.
Participant 3: Especially out here, to wash your hands there’s nothing. [Transcript from Focus Group 24, Maximum Security]

...It said on the thing you must use thongs to go in gaol and you don’t even get thongs when you first walk in. So I was walking in and out of those showers with no thongs. Got the tinea on my toes. Started scratching my toes. Picked it up in my nails. [Transcript from Focus Group 16, Maximum Security]

Participants wanted more access to healthcare items to assist in the management of their own personal care and to uphold the environmental health of the correctional centre. Female participants discussed the lack of items available for new inmates to maintain personal hygiene which was a health issue that impacted on others.

Female 3: I think fresh inmates should have a pack of deodorant and stuff like that, shampoo because they just get like soap and that’s it.
Female 1: You get soap and that’s all.
Female 6: Soap and a little gaol toothpaste.
Female 4: Yeah, it should be a necessity that they give those, like a protocol yeah.
Female 3: I see fresh inmates come in asking for shampoo, conditioner, like deodorant.
Female 1: We don’t get socks, undies, crop tops.
Female 6: Well I never got told about the razors or the toothbrushes, things like that. It’s an issue, personal hygiene.
Facilitator: That’s pretty intense isn’t it?
Female 4: Yeah, it is, especially when don’t get family support and that while in gaol. [Transcript from Focus Group 7, Medium Security]
Externally for me [responding that health care out of custody was preferable]. Because - well not because of the fact that we’re here, but more just preferring to go and buy what you need. Example say a guy’s got a toe nail fungus, so he wants to go buy something to put on there or something like that. You still have to do the same thing; fill in a form to try and get a cream. Or what they do now is do the screenings, and it takes a while. Health can take up to a month, two months and by that time your nails probably gone. [Transcript from Focus Group 19, Minimum Security]

While some participants were positively affected by the smoking ban introduced in 2015, many of them reported that the structured nature of the correctional centre with the enforced smoking ban had a negative impact on their health and daily life in the correctional centre. Smoking was considered by participants as a way to relieve stress and an activity for emotional regulation. They reported increased violence and deterioration of health, particularly weight gain due to overeating.

Facilitator: Have you found that you are substituting anything else for not being able to smoke tobacco?
Participant 1: For sure.
Participant 2: Yeah.
Facilitator: Examples, like, do you buy more junk food on buy ups and stuff like that?
Participant 1: Fizzy drink and chocolate and …
Participant 2: I eat.
Participant 1: Chips …
Facilitator: You have given up for two years. How long have you been given up for?
Participant 1: I've only been since January.
Participant 3: Six months, seven months.
Facilitator: Have you seen any changes in your health since you’ve given up?
Participant 1: I’ve gotten fat.
Participant 4: Gotten fatter, yeah. [Transcript from Focus Group 6, Minimum Security]

The only legitimate option available in the correctional centre was the purchase of nicotine lozenges from Corrective Services buy-ups. Some participants did not find this option appealing due to the perceived inefficacy and high cost. They found a lack of help offered by the health centre to get through the transition and reported potentially unhealthy ways of managing withdrawal symptoms such as smoking tea leaves. When asked about the helpfulness of the healthcare service, participants reported the following:

Participant 1: Shit.
Participant 2: Shit.
Participant 1: They don’t even give you a patch.
Participant 2: You have to buy your own Nicorette out of your own buy up and if you are only on $15 a week unemployment …
Participant 1: They are like $10.95.
Participant 2: They take three quarters of your pay a week.
Participant 3: I gave up before it came in because I thought it will make me give up.
3.2.4.5 Work and Programs

Some participants have coveted jobs within the custodial system or are enrolled in an offenders program that must be completed prior to release. These participants reported difficulty accessing health care due to their commitments. For some participants who had highly coveted jobs, they placed greater importance on keeping their jobs over managing their health. The issue of access was especially apparent when clinic hours were limited and generally coincided with work hours.

The easiest way to see the nurse here is just take a day off work. If you really want to see them. You run the risk of being fired from your job. [Transcript from Focus Group 20, Medium Security]

I had to organise a list because I worked seven days a week. I can't get to the window readily available when other workers can. When I was going to ask for any help that I need, I was getting abused by the nurses for not being a regular inmate. I work and I actually work off compound, so I can't get here as readily as they want me to. [Transcript from Focus Group 6, Minimum Security]

A number of younger participants reported choosing to forego specialist health care appointments if it meant being transferred to another correctional centre, particularly if participants missed out on completing their correctional program as part of the rehabilitative requirement. Correctional programs can be largely based on group work and participants recognised that interruptions to their place in a program may potentially mean re-entering the program with a different group dynamic. There was a sense that participants preferred continuity of their program and to remain at the same correctional centre over seeking health care.

Facilitator: Do they tell you about any other services, like Quit Line or …
Participant 4: I rang them yesterday. They wouldn't even give me an information pack. They’d only send it to the outside.
Facilitator: When you call Quit Line …
Participant 2: They wouldn’t send her any information pack into the gaol. ‘We can’t send it into a gaol. We have to send it outside.’
Participant 4: The day I come in, the first time, it was the day before the patches stopped. I didn’t know that. They were like, ‘Do you want a patch?’ I’m like ‘No’. The next day I asked for a patch, ‘No, they stopped today.’ I was like, ‘Are you fucking for real right now?’ [Transcript from Focus Group 8, Minimum Security]

Facilitator: Say you had to go to Sydney to see a specialist, would you likely agree to go or not?
Participant 1: Probably not.
Participant 2: It depends if it’s going to jeopardise our program, like I said some of us are on young offenders. If we leave, we’re going to miss a part of the program. Like we’ve got [name of a course program] this week, and if we miss that we’re going to get a back class, it’s another extra month... [Transcript from Focus Group 18, Minimum Security]
3.2.4.6 Misuse of Health Resources

Participants reported that there were a number of non-legitimate patients who were inappropriately using healthcare services. These patients were described as malingerers who feigned sickness to obtain medication, get out of work or their cell.

...they’re dealing with 170 inmates here per week and there’s definitely got to be a few in here that are crying wolf. Want a day off work, they’ve heard it all before, seen it all before. They’ve still got to look at it all, why a lot of people get Panadol I think because of the ones that do cry wolf. [Transcript from Focus Group 21, Minimum Security]

Participants recognised that misuse or misallocation of healthcare services placed constraints on time and resources meaning those who had a legitimate health need potentially missed out on getting health care.

Facilitator: Do you reckon a lot of people bung it on?
Participant 1: Oh a few.
Participant 2: Oh yeah, yeah.
Facilitator: Is that they’re trying to scam medication?
Participant 1: Oh just to get out of the cell probably.
Facilitator: Just for something to do?
Participant 2: Yeah.
Participant 1: But then it does, it pushes people with a genuine need for medication ...
Facilitator: Further down the queue?
Participant 1: Exactly. [Transcript from Focus Group 12, Maximum Security]

They took me to the doctor, and I - when I first come I hadn’t been given me methadone for three days and me blood pressure was up, so they wanted to monitor me blood pressure, which came good in a couple of days. But for the next fuckin’ 10 days or something, yeah I seen a doctor to get me blood pressure done, you know when somebody – [with] an actual medical concern could have seen that doctor. The nurse could have took me blood pressure. [Transcript from Focus Group 5, Maximum Security]

Participants reported that the large numbers of non-legitimate patients trying to access health care resulted in staff becoming hardened and less sympathetic to the health needs of other patients.

They think we’re all lying. Like when we walk up there to ask them, they think we’re just bullshitting because they’ve heard it all before. That’s their excuse. Because we’re in gaol, we’re all criminals apparently - well, we are in gaol [LAUGHTER]. Yeah, but they just generalise because someone’s bullshitted them before and tried to get something they think everyone’s doing that. [Transcript from Focus Group 18, Minimum Security]

Participant 1: It’s just a job mate...I am the same when I work. You know, you know, you can’t expect them to care too much about 900 fuckin’ people.
Facilitator: Yeah.
Participant 1: Yeah and half of them are hypochondriacs and shit. [Transcript from Focus Group 5, Maximum Security]
I'm not a whinger. If I'm that whinger, you know it's a legitimate reason, believe me. I believe half these girls are too. They are there because they do have problems. [Transcript from Focus Group 6, Minimum Security]

Some participants felt that once hardened, health staff were not interested in their concerns. The participants reported that health staff questioned the appropriateness of their request for health care and believed the participant was only seeking care to access medication for inappropriate reasons.

I was prescribed S8s and that, yeah like I said before, I know it's a security issue in the gaol, but you can’t tell me that if I drink them and sit there for 20 minutes if that's what they want, and it’s not going to be dissolved in my stomach. You know what I mean? Like I'm not trying to divert just so I can get what, two fucking cigarettes. Please! [Transcript from Focus Group 17, Minimum Security]

Not interested you know what I mean? And I’m pretty sure I speak for most of the people who’ve got injuries. We want it for ourselves, we don’t want to divert to some other gronk. [Transcript from Focus Group 17, Minimum Security]

As the boys were saying, you go to a window and ask for Panadeine, you’re looked at like you’re a fucking junkie. [Transcript from Focus Group 14, Medium Security]

3.2.4.7 Privacy and Confidentiality

Participants reported lack of privacy was an issue when accessing healthcare services. Participants cited examples where they felt that patient confidentiality was compromised:

We can and I have done, but it’s not possible all the time because officers are always sitting outside the door of the clinic. You don’t want them listening to personal things, it’s like it should be confidential between you and the nurse. It's very hard when you’ve got custodial staff sitting outside the nurses’ door listening to everything you say. [Transcript from Focus Group 4, Medium Security]

I also have the other problem with custodial staff. That’s a problem if the doctor calls me in to see them, I think there should still be that doctor patient relationship confidentiality and I find it off-putting when custodial staff interfere or make comments about what I’m discussing and that sort of thing. [Transcript from Focus Group 4, Medium Security]

Participants also perceived that nursing staff were breaching confidentiality by enquiring about their wellbeing while collecting their medication at the dispensary in front of other inmates:

I get my pills at the window when I go there. I’m not on… I’m on supervised … there are different ways... I think they try to engage me in conversation while I’m getting pills and ask how are you doing which is quite often a quiet thing but at the same time I find it a bit sort of annoying because of the privacy issue you know if I’m really going to sit down and discuss how things are in gaol and I’m not going to do it when there are guys waiting in line. It’s almost I don’t know I find the person side of it …a little bit of a conflict and at the same time I think you know obviously if everything is good it does feel good to share. [Transcript from Focus Group 20, Medium Security]
Lack or knowledge of healthcare services and how to use them can act as a barrier to the use of healthcare services. Participants reported getting more information on health, processes and systems from the informal system rather than through the formal health channels, with the understanding that this information may not always be correct.

Facilitator: Where would you guys find information about the services provided at the clinic?
Participant 1: You don’t.
Facilitator: You don’t?
Participant 1: Nothing apart from whatever’s stuck up on the bulletin board.
Facilitator: What kind of things get stuck up on the bulletin board?
Participant 2: Not much.
Participant 3: Mostly it’s like that. [pointing/referring to very simplistic primary school level posters]
Participant 2: Hep C stuff.
Participant 3: Hep C stuff, you know. Nothing else
Participant 4: Word of mouth.
Facilitator: Word of mouth, yeah. Do you find that word of mouth is always right?
Participant 2: No.
Participant 1: No.
Facilitator: Depends who you’re talking to?
Participant 2: 75% of it might be right but 100% of it’s not.
Participant 3: Sometimes you might write it down for certain things, a stab in the dark if you ask me.
Participant 4: I get more information, from the boys in green, about how to go about doing things and getting to the clinic.
Participant 1: Everyone’s treated differently so you can’t really go off another person’s experience. [Transcript from Focus Group 12, Maximum Security]
3.2.4.9 Staff – Patient Interactions

Participant experiences interacting with health staff was mixed. Many participants reported positive experiences with the way health staff interacted with them. Participants felt that healthcare staff were sensitive to their needs and treated them with respect and dignity. This was reported across all focus group discussions.

The nurses are really empathetic. The nurses I’ve seen, once they realise my situation, maybe it’s because I have something in common, obviously working in the healthcare field, they spent way more time than they had to with me. They talked to me for ages. It wasn’t just about my pregnancy or heart problems. They just talked to me about everything. They went beyond what they had to. That’s my personal experience. [Transcript from Focus Group 11, Maximum Security]

Yeah, they treat you with courtesy and respect. [Transcript from Focus Group 7, Medium Security]

You have to go - they’re very good people, the way they read and speak. I’ve never seen any harm or any disrespect. They’re very good people the nurses here and in every centre, I went to lots of centres. [Transcript from Focus Group 5, Maximum Security]

I have as well. They’re very respectful, they don’t treat me like I’m a criminal. They treat me like a normal patient as they would on the outside going to a clinic or in hospital.

They don’t discriminate. If you say you’re using needles or something they don’t go well you’re an idiot or something like that, they try and help you as much as they do. [Transcript from Focus Group 15, Maximum Security]

Some participants reported that some health staff had poor attitudes towards them.

Participant 1: Yeah they’ve pretty much got no respect for us in green, you know what I mean. Just because we’ve done a crime or something like that, they’ve got no respect for us. Like don’t get me wrong there are a couple of good nurses out there that actually do something, but the majority of them are a bit rude to you and they don’t really care. Like you tell them what’s going on and then they don’t even take note of it sometimes. Like one of the boys has bad asthma and that, he couldn’t breathe and she just said go eat some concrete, harden up.

Facilitator: Did she really say that?
Participant 1: Yeah.
Facilitator: Go eat some concrete and harden up.
Participant 2: And harden up, yeah.
Participant 3: She pretty much said the same thing to me about me leg when I kept going up to get Panadeine.
Facilitator: Why do you think they respond to you like that?
Participant 4: Because we’re criminals.
I saw the doctor and I was supposed to be on light duties, and they put me back up there in mill. I’m the one with the [complaint that will require surgery], I’m just in pain and I got bought up with pain. Just every now and again when I’m standing up there all day, [the condition] is aggravated. It actually does hurt, I went down and saw the nurse, and she said ‘get back to work’. [Transcript from Focus Group 21, Minimum Security]

Participants who interacted with health staff on a regular basis reported positive experiences.

I’ve never really had any issues with them, but I get to know them because I go there a lot, so that probably makes it easier to get issues dealt with. [Transcript from Focus Group 4, Medium Security]
The Justice Health and Forensic Mental Health Network Research Unit undertook 24 focus groups at a number of correctional centres in NSW with the aim of identifying issues of concern, from patients’ perspectives, regarding their interaction with healthcare services in the custodial environment.

A cognitive model (a model of how we mentally process the world around us) has been developed which outlines the key concepts participants have identified that either advance or impede their access to health care in the custodial setting. For some of these concepts, the participants have a choice and this choice is influenced by a number of factors including past experiences, knowledge and trust. For the other concepts, they represent what the participants have identified as enablers or barriers to health care access.

The results in this report are the participants’ perceptions of the health care system in the custodial environment. It is acknowledged that these perceptions are influenced by numerous factors and may not reflect the perceptions of staff or administrators of the Network or Corrective Services NSW. Many of the participants present from socially and economically disadvantaged backgrounds. The participants interviewed in the focus groups are, by the virtue of being inmates, in a position of restricted liberties and this experience can lead to the development of negative biases towards a system that is incarcerating them. Previous research has discussed the negative biases that may influence an inmate’s perception of health care systems in a custodial environment[6-10]. The reporting of the participants’ perceptions may also have been altered as a result of officers being present at the time of the focus group interviews – a necessary security measure. While focus groups are a good way of eliciting information, it should be noted that the results obtained may be influenced by the informal hierarchies that often exist amongst inmates. Depending on the group dynamics within individual focus groups, it is possible that some participants may be reluctant to raise opinions that do not align with points already raised by inmates of higher status/influence within the prison culture. Requiring participants to have the ability to communicate in English and including some non-randomly selected participants may limit the generalisability of the study findings somewhat due to sample bias. This report may not have captured all of the views and issues from people of culturally and linguistically diverse backgrounds. Regardless of these limitations, it is important to understand the patients’ perspective to ensure improved quality of healthcare services[1] and to align with the Network’s strategic directions[5].

The patient-centred approach of engaging with patients and including them in evaluating healthcare services provides an opportunity for the Network to redesign health care that directly benefits the patient’s health care experience and outcomes. This report has identified key concepts around the evaluation of healthcare services drawn from the experiences and perceptions of patients in custody. Being in custody provides an opportunity to promote better health practices, prevent disease and administer health interventions to a population that may not otherwise engage with the healthcare system[11]. Participants in the study cited factors such as high cost of health care and lack of time as barriers which prevented them from seeking health care on the outside. Participants felt being in custody gave them an opportunity to address health needs previously ignored on the outside. For many inmates living in the community meant violence, excess consumption of alcohol, smoking and drug-taking were normalised experiences, these experiences being shown to have negative impacts on health[12]. Participants reported that breaks from their chaotic lifestyles on the outside, and having access to health care on the inside made them feel more committed to taking care of their health needs. They reported access to regular meals, a stable routine, free healthcare check-ups, health screenings, healthcare interventions such as vaccinations and abstinence of substance use were positive features of the custodial system. These findings are consistent with other qualitative studies exploring inmates’ health experiences and evaluations of healthcare services while in custody[8, 13-15].
While participants reported that time in custody provided opportunities to access health care, they also recognised that the nature of the custodial environment created challenges in health care access. Medical treatment in the correctional settings is managed within a restrictive environment and patients are subjected to constraints not experienced in other social and medical contexts\(^\text{16}\). Owing to this, environmental stressors such as risk of communicable disease and lack of autonomy have been raised in published research as factors that may impede access to health care\(^\text{9, 17, 18}\). Consistent with this research, participants perceived an increased risk of communicable diseases along with a loss of autonomy as factors they believed impacted their ability to maintain their health while in custody. Participants recognised that their lack of autonomy in custody made access to health care more difficult than what they would normally experience on the outside. Yet many also understood the inherent conflict between wanting greater freedom to manage their health needs and the security restrictions of the custodial system.

Participants identified personal factors that were enablers or barriers to accessing health care in the custodial environment. Published literature has referred to some of these identified factors in terms of an open or closed custodial climate. An open custodial climate being where staff were responsive to inmates’ needs and complaints, while a closed custodial environment was perceived with a lack of support or advocacy by custodial staff along with an atmosphere of strictness and control\(^\text{19, 20}\). Participants reported that where staff appeared to be more empathetic and approachable, this enabled their access to health care. However, poor attitudes of staff, along with an atmosphere of maintaining control and order were reported as barriers to accessing health care.

Another personal enabler or barrier raised in the literature and by participants in the study was sentence length. Condon, Hek\(^\text{13}\) found that inmates serving shorter sentences perceived clinical staff deflected healthcare requests due to time limitations. This perception was also described in the current study where participants reported remaining time in custody not only impacted their perceived access to health care but also influenced their own decision to pursue health care.

Having a diagnosed health condition known to both officers and health staff facilitated participants’ access to medication and treatment. It was perceived that regular contact with the healthcare system in custody reinforced the patient’s status as a legitimate patient which further increased their ability to access the health centres. Participants with diabetes perceived their treatment to be positive and in line with community standards, a finding consistent with a qualitative study on inmates managing long-term conditions in custody\(^\text{8}\).

Another common theme reported by participants in this study was the delays or cessation of regular medication taken by participants outside in the community when entering or returning to custody. These interruptions to medication were reported to have a negative impact on participants’ physical and mental health. This finding is consistent with a qualitative study conducted by Bowen, Rogers\(^\text{21}\) who explored medication management and practices for inmates with mental health issues.

Participants seeking health care for undiagnosed symptoms reported a number of barriers to accessing that health care. A large proportion of the participants reported long and unpredictable waiting times to see a doctor. Many felt the current process in place to seek health care for undiagnosed symptoms was arduous and did not meet their needs in a timely manner. This perception was universally reported amongst all focus groups and is consistent with qualitative studies exploring inmates’ experiences with healthcare services while in custody\(^\text{9, 13, 14, 22}\).

Previous research has identified a relationship between a poor healthcare service experience and lack of future engagement with the healthcare service\(^\text{8}\). This was the case for many participants who reported disillusionment with aspects of the healthcare service provided and subsequent withdrawal from applying for care. This led to several participants managing their health by self-treatment or turning to the informal networks for medication, treatment, or health information. The heavy reliance on information from other inmates or receiving health care in the yard has important safety implications for participants due to its unregulated nature.
5. Conclusion

This report documents specific patients' perceptions of healthcare services in the custodial environment. These perceptions revolved around the ability to access the health care. Factors reported that enabled access to health care included healthcare cost, lifestyle and time, while long waiting times, poor communication and a lack of privacy were seen as barriers to accessing health care. Further quantitative research is now needed in order to determine how common these perceptions of healthcare services are amongst patients in custody and this will be undertaken in Phase 2 of the study.
6. References


Appendix A – Interview Sheet

Patients’ Experiences and Perceptions Study

FOCUS GROUP INTERVIEW SCHEDULE

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**QUESTIONS**

**Thinking about the times you have been to the health centre (clinic):**

1. How easy is it to get health care in prison?
   - Who did you report your illness to?
   - What happened next?

2. Where would you find information about the services provided at your clinic?
   - What sort of information was given to you?
   - Who gave you the information?

3. What do you think about the length of time you waited to see a nurse or doctor?
   - If it was too long was the delay explained to you?
   - What was the reason for the delay?
   - Did you get better or worse during the delay

4. What were the best things about the healthcare service?
   - What else?

5. What were the worst things about the healthcare service?
   - What else?

6. How is your health managed in prison compared to the community?
   - Is it managed better or worse in prison?
   - Have any of your health issues been diagnosed for the first time in prison?
   - Have any of your health issues been managed / treated for the first time in prison?

7. What sort of things would have made your experience with the healthcare service better?

**Smokers Only**

8. Did you find the clinic staff helpful after the implementation of the Smoke Free Prisons Policy?
### Focus Group B

**Date:**
(DD/MM/YY):

**Centre:**

**Group Facilitator:**

**Group Scribe:**

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### Questions

**Thinking about the times you have been to the health centre (clinic):**

1. **Do you think you were treated with respect by the clinic staff?**
   
   **A)** What were the things that the clinic staff did that made you feel respected / disrespected?

2. **Were you given the opportunity to discuss your health needs with the staff?**
   
   **Do you feel you were listened to when you discussed your health needs?**
   
   **If not why not?**
   
   **Were you able to freely discuss issues with clinic staff?**
   
   **If not why not?**

3. **Did you feel the clinic staff worked as a team in your care and treatment?**
   
   **Did you get the same information about your condition and treatment from different staff?**
   
   **Did you have to repeat yourself to different staff?**

4. **What were the best things about the healthcare service?**
   
   **What else?**

5. **What were the worst things about the healthcare service?**
   
   **What else?**

6. **How is your health managed in prison compared to the community?**
   
   **Is it managed better or worse in prison?**
   
   **Have any of your health issues been diagnosed for the first time in prison?**
   
   **Have any of your health issues been managed / treated for the first time in prison?**

7. **What sort of things would have made your experience with the healthcare service better?**

---

**Smokers Only**

8. **Did you find the clinic staff helpful after the implementation of the Smoke Free Prisons Policy?**
This low security prison is really good, they see you
I have time in here to access healthcare services
The staff treat me with respect and that makes me want to access healthcare
It doesn't cost me to see someone in here, so I'll seek treatment
I can't access what I want, when I want
The chief listens in on my appointment
Some of the staff know their stuff, but others are terrible
I can't miss a day of work to go to the clinic; otherwise I'll lose my work
I hate using the bluey system. I put in a thousand applications. They never tell me what's going on, you wait forever and I just end up seeking treatment in the yard
Too many people bunging it on means it takes forever to get seen at the clinic
I'm in a high security prison, I'll never be seen
I get more health information from other inmates
Prison gives me structure around my life, which allows me to get healthy
I've been diagnosed with a chronic health condition; the staff are really good with my treatment
My short sentence means I'll be told to wait to get my issue sorted till I get out
The staff think I'm a junkie, when in fact I'm sick or in pain and need meds
The staff think Panadol fixes everything, no matter what my concern or how much pain I'm in
The staff take all my outside meds off me, leaving me with nothing to treat my condition
My main concern is around my access to healthcare services
I better get healthy, prison is tough
Patients' Experiences and Perceptions Study
## Appendix C – Focus Group Size

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