

**THE HEALTH NEEDS AND HEALTHCARE EXPERIENCES  
OF WOMEN LEAVING PRISON**

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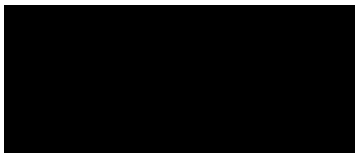
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## **Statement of Authentication**

I, Penelope Anne Abbott, hereby declare that this submission is my own work and that it contains no material previously published or written by another person except where acknowledged in the text, nor does it contain material which has been accepted for the award of another degree.

I understand that if I am awarded a higher degree for my thesis entitled "The health needs and healthcare experiences of women leaving prison" being lodged herewith for examination, the thesis will be lodged in the University Library and be available immediately for use. I agree that the University Librarian (or in the case of a department, the Head of Department) may supply a copy of the thesis to an individual for research or study or to a library.



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## **Abstract**

This thesis examines healthcare access for women in contact with the criminal justice system, as experienced both in prison and in the community, with a particular focus on primary health care. There were two main research objectives. The first was to examine the healthcare needs of women leaving prison and their experiences in accessing health care. The second was to examine continuity of care across the interface between prison and community-based health services, in particular, general practitioner (GP) care.

Three distinct studies were undertaken: a retrospective medical record review of the health records of women in prison, a qualitative study using pre- and post-release interviews and a scoping review of published literature reporting on qualitative research with prisoners.

For the first study, prison health records from 231 periods of incarceration of women released between 2013 and 2014 from prisons in New South Wales (NSW), Australia, were reviewed. Data were collected in predefined categories relating to healthcare delivery in prison, health information transfer and continuity of care arrangements across the interface between prison and community health services. Qualitative data relevant to these themes were also collected.

The review showed that most women in prison had multiple contacts with healthcare providers and, at release, most women required ongoing management for substance misuse and mental and physical health problems. Hearing health was often not recorded despite a third of records being of women from an Aboriginal and Torres Strait Islander background, a high risk group for ear problems. Health management plans generated in prison were not always completed before release. Reasons for this included custodial factors and waiting times for appointments. Except for women with certain priority health conditions, continuity of care arrangements and health information transfer appeared to occur infrequently outside formal transitional programs.

For the second study, 69 semi-structured interviews were conducted with 40 women while they were in prison and with 29 of these women after their release in 2014 and 2015. Inductive thematic analysis was undertaken. Most of these women had histories of substance misuse. Women perceived that they were not considered legitimate patients because of their drug use histories, and this impeded their access to health care. For women in transition between prison and community, health care could be experienced as 'medical homelessness' in which women felt caught in a perpetual state of waiting and exclusion during cycles of prison- and community-based care. Their healthcare experiences were characterised by ineffectual attempts to access care, transient relationships with healthcare providers, disrupted medical management and a fear that stigma would prevent access to health care, even in the event of serious illness. Women perceived that GPs lacked interest in their wellbeing beyond physical ailments and needed more skills in substance misuse management. Women often chose not to disclose their prison health care due to fear of differential treatment, decreasing the value of health care initiated in prison due to lack of follow up in the community.

For the third study, a scoping review of methods used in qualitative interview and focus group research with prisoners published between 2005 and 2017 was undertaken. The review aimed to investigate considerations when conducting ethical and rigorous research in prison settings, with a focus on recruitment, sampling and data collection. Strategies used by researchers to manage coercion risk, informed consent, recruitment, sampling, confidentiality, privacy and working with prison-based intermediaries were identified, and key considerations highlighted.

The findings presented in this thesis provide new information to support the changes needed in order to release healthier, well-supported people into the community and to provide community-based care which meets the needs of people leaving prison. Promoting the confidence of healthcare providers to manage people who have a history of substance misuse, facilitating timely care in prison and supporting continuity of care at release will increase access to health care for those in contact with the criminal justice system.

## Abbreviations

AMS	Aboriginal Medical Service
AOR	Adjusted odds ratio
AUD	Australian dollar
CALD	Culturally and linguistically diverse
CI	Confidence interval
CNSP	Care Navigation Support Program
CSNSW	Corrective Services New South Wales
GP	General Practitioner
HCP	Healthcare provider
JH&FMHN	Justice Health & Forensic Mental Health Network
NSW	New South Wales
OST	Opioid Substitution Therapy
RACGP	Royal Australian College of General Practitioners



## **Organisation of thesis**

In this thesis I present the published work that arose from this research, together with a narrative commentary. After an introductory chapter in which I set the scene to the research, the key components are four published papers and a fifth manuscript which is under peer review. These papers are arranged as chapters with their own reference lists. I close with two chapters in which I discuss the work as a whole.

Chapter One is an introduction to the thesis and, in providing a rationale for the research, presents an overview of health needs of women in contact with the criminal justice system and healthcare delivery to women in prison. It concludes with a personal reflection on my motivations and positioning within this research.

Chapter Two and Three are the publications resulting from the first phase of my research, namely a retrospective review of medical records of women in prison. Chapter Two relates to findings on the health needs which were identified when women entered prison and on the health care delivered during their prison stays. Chapter Three presents an analysis of continuity of care between prison and community.

Chapters Four and Five are publications arising from the qualitative component of the research. Chapter Four focuses on the experiences of women in accessing community-based general practitioner care. Chapter Five presents a broad analysis of the challenges of access to health care for women in contact with the criminal justice system.

Chapter Six comprises the scoping review of literature arising from qualitative interview or focus group research with people who are prisoners, focusing on key challenges of qualitative research in this context.

In Chapter Seven I reflect on my experiences within the research, returning to the beginnings described in Chapter 1, 'Conceiving the research', to interrogate how the research and my perspective as a researcher changed over time. Chapter Eight is a discussion of the thesis findings as a whole with recommendations on ways to improve healthcare access for people in contact with the criminal justice system, followed by concluding remarks.

## Chapter 1: Introduction

### Background

#### Prison in Australia

Women make up 8% of the Australian prison population and the incarceration rate for this group continues to grow(1). New South Wales (NSW), the most populous Australian state, has the highest proportion of the Australian prison population, with over 13,000 people in prison at any one time, of which approximately 1000 are women(1). In Australia, women are usually in prison for less than 6 months and re-incarceration is common, with women's offences frequently related to problematic substance misuse(2, 3). In NSW, 37% of the women in prison in NSW are of Aboriginal and Torres Strait Islander background(1), despite under 3% of the NSW population being Aboriginal and Torres Strait Islander people(4). This distressing disparity occurs on a background of historical and systemic disadvantage(1, 5). In addition, a quarter of female prisoners in NSW surveyed in 2009 were born outside Australia and more than 20% spoke a language other than English at home(2).

Women are housed in seven state-run correctional centres in NSW, often moving between centres for custodial reasons. The three largest centres are women-only prisons situated in Sydney and its outskirts(6), and these were where the qualitative research presented in this thesis was undertaken. Health care in these centres is delivered by the Justice Health & Forensic Mental Health Network (JH&FMHN)(7), the largest prison health service in Australia. JH&FMHN is a Board-governed speciality network of the NSW Ministry of Health. Delivery of health care by JH&FMHN requires close collaboration with Corrective Services NSW (CSNSW)(8), another state government agency with responsibility for custodial care. CSNSW facilitates healthcare delivery in the prison by providing support and custodial security to JH&FMHN

operations. CSNSW provide some limited health-related services themselves, primarily psychology and re-entry programs targeting issues such as substance misuse and family violence. These are separate to health care delivered by JH&FMHN.

### **The high health needs of women in prison**

People in prison have substantial health needs(9-11). Mental health disorders(12, 13), substance misuse(14), blood-borne viral disease(15), sexually transmissible infections(16), chronic disease and its risk factors(14, 17) and risk factors for cervical cancer(18) are examples of health problems which are more common in people in prison.

Women in prison have particularly high levels of social disadvantage and life experience of trauma(19-22). Many report their health to be poor(9, 19). In a survey of people in prison in NSW in 2015, 29% of women considered their mental health to be fair to poor and 24% rated themselves as having fair or poor physical health(9). High numbers had experienced violence, with 70% of women in prison in NSW having witnessed or experienced violence and 18% having experienced sexual violence(9). Such experiences of trauma, and of isolation and social disconnectedness prior to incarceration, can exacerbate the stress on the mental health and wellbeing of women both when they are in prison and after their release(3).

### **Health services in prison**

Healthcare delivery in prison is affected by the high and complex needs of people in prison and by the custodial environment(23, 24). Use of primary care services is often high, and some people access more health care in prison than when they are in the community(2, 25-27). This may be due to community-based barriers to care, such as healthcare costs or substance misuse, or to competing priorities and difficult personal circumstances(27). Prison systems subsequently facilitate access to health care for some people(24). Incarceration can offer opportunity for systematic preventative care and medical treatment to an underserved group. In this way, prison health services are sometimes in the position of seeking to make up for neglect experienced in the community(28).

However, access to healthcare services in prisons can also be suboptimal. Mechanisms which create barriers to effective health care include distrust of prison health services(29) and custodial barriers such as waiting lists and loss of autonomy and ability to self-manage health issues(24, 27). Furthermore, the prison environment is not ideal for promoting positive health change due to the trauma and disempowerment associated with incarceration(22, 28).

### **Health risks at release**

The vulnerability of people after release from prison has been repeatedly demonstrated in national and international studies, including studies which report a high risk of hospitalisation and death after release(30-37). The findings of some studies suggest risks after release can be particularly high in Aboriginal people and in women(30, 33, 38). The extent of the health differential between some populations of women recently released from prison and the general community can be striking. A Western Australian data linkage study identified a significantly increased risk of death for all prisoners in the first 6 months after release, with non-Indigenous women being 69 times more likely to die than their counterparts in the general community(38).

The transition between custody and the community is thus a pivotal time. Although sometimes presented as an opportunity for a 'fresh start', release from prison more often serves as another complication in an already difficult life(39). Health and wellbeing can be unstable, exacerbated by homelessness(40, 41), disconnection from family and community(21, 42, 43), poverty(44, 45), lack of employment(46) and return to a an unsupportive environment(47).

### **The social needs of women leaving prison**

Focusing on the health needs of people leaving prison without consideration of other crucial needs such as housing, financial support, employment and re-establishment of social networks(48-50) is unlikely to be successful. Understandably, material support will be prioritised over treatment needs on leaving prison, even in the presence of

serious illness(51). Competing demands, particularly those relating to family wellbeing, are also prominent challenges for many women leaving prison(21, 52).

Programs which aim to support people leaving prison must therefore attend to their immediate welfare needs and also increase opportunities for improved longer term wellbeing, such as by ensuring people are housed and have adequate living skills, financial support and employment opportunities(43, 53-55).

Social support, including opportunities for interacting with others who can provide respect, concern or can give needed information, has been shown to promote wellbeing, prevent poor health and promote recovery after illness(56). The social support needs of women on leaving prison may be very high because their family and social networks have been disrupted or dysfunctional prior to incarceration(57). In another disruption of social networks, people are commonly released to completely different communities as a custodial condition of release, and so need to establish themselves in unfamiliar areas.

### **Access to health care at release**

Both those who have high utilisation of prison health services and those who do not have their health care needs met in prison need to be well connected to health care after release. Those who were closely tied to prison health services are likely to have continuity of care requirements and a need for ongoing health support, while those who had little connection in prison are likely to have unaddressed needs. However, the interface between prison and community-based health services can be complex and challenging to traverse. It is influenced by patient, system and healthcare provider factors both within the prison health environment and the community(58, 59).

In Australia, a strong interface between prison and community-based GPs is important. People leaving prison commonly access GP care early after release(60), supported by Australia's universal health insurance system. However, the extent of therapeutic engagement with these GPs is unclear and has been little researched in Australia. Studies in the United States and the United Kingdom suggest that fear of stigmatised attitudes, distrust of the health system and lack of previous positive relationships with

healthcare providers may impede the development of therapeutic relationships on release from prison(58, 61-63).

## **Conceiving the research**

My doctorate research objectives were derived from professional experiences as well as the evident gap in the literature. My positioning within the research commenced with my understanding of my professional self as a community-based clinician with an interest in research. My motivation to undertake a doctorate was in part a pragmatic decision that I needed more skills in research if I were to continue to work as a researcher. I had undertaken several research projects in the preceding 5 years aligned with my longstanding position as a GP delivering clinical services within an Aboriginal Medical Service (AMS) in Sydney, NSW. In that role I was also a member of a team which focused on health promotion in chronic disease. The research I had been part of related to our health promotion activities.

I had also been a visiting GP in different prisons for women for most of my career, variously working one to two days a week. I had not had any research or leadership roles within the prison health service, and had considered it a career interest that was secondary to my main clinical role in Aboriginal health. I had attended a particular women's prison in the outskirts of Sydney for 6 hours a week for many years. Nevertheless, I often felt like a guest within the prison health system who didn't need to fully understand the bigger organisational picture or the frequently changing systems. The primary clinicians in the prison were nurses, who would triage more complex patients to me and would themselves manage the day-to-day healthcare operations. As such, the nurses were the ones in charge, and I perceived myself as a visiting clinician who liked the challenges of the clinical work and believed in equity of care for people in prison.

My interest in research had increased over the years, particularly in the areas of collaborative, action-focused, health-promoting research and evaluation. I had found qualitative research particularly rewarding, valuing the opportunity to more deeply

understand the beliefs and life experiences that underlie health behaviours. These activities created a career trajectory when I was offered a position at a newly established general practice department within a young School of Medicine at Western Sydney University. Although I had not consciously planned this additional career thread it was welcome, and I started to take on responsibilities in supervising the research of medical students and junior doctors. Realising that I needed to upskill myself, I started this doctorate as an experienced clinician with some understanding and experience of research.

In choosing a research direction, I looked for a topic which mattered and which utilised the skills and knowledge I already had due to my mid-career change of focus. I was aware of the high health needs of women in prison and also of the need to strengthen connections between prison and community health services. As a GP in both the prison and community sector, this was a familiar interface. On further investigation I identified there was little Australian or international research examining the engagement of women leaving prison into effective general practice care.

Therefore, I began my research with two planned objectives. I wanted to examine what the women viewed as their healthcare needs upon leaving prison and their experiences of health care, in particular community-based general practice care. Secondly, I wanted to examine continuity of care across the interface between prison and community-based health services, with a focus on GP care. As the research developed further, as I discuss in Chapter 7, my research aims expanded. The data, and my emerging understanding, dictated that I more broadly examine healthcare access for women in contact with the criminal justice system.

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## **Chapter 2: Healthcare delivery for women in prison**

This publication presents data from the medical record review describing the health needs identified when women entered prison, and healthcare services delivered to these women in prison.

- ***Abbott P, Magin P, Hu W. Healthcare delivery for women in prison: a medical record review. Australian Journal of Primary Health. 2016;22(6):523-529.***

## Healthcare delivery for women in prison: a medical record review

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**Abstract.** When women come into prison, many have unmet health needs. In this study we examine the health care provided to women in prison and their identified health needs, and discuss opportunities for improved healthcare delivery. We undertook a medical record review of women released from a minimum 6-week period of incarceration in New South Wales correctional centres between May 2013 and January 2014. Records from 231 periods of incarceration were reviewed. At reception, 52% of women were identified as having anxiety or depression. Hearing health was not documented despite 30% of records being of women from an Aboriginal and Torres Strait Islander background, a high-risk group for whom hearing screening is recommended. Most women had multiple in-prison clinical contacts, including interactions with general and specialised nurses (97%), general practitioners (65%) and psychiatrists (35%). At release, 49% were on psychotropic medication and most required ongoing management for: mental health (71%), substance misuse (65%) and physical health (61%) problems. External specialist appointments were pending in 7% at release. Health management plans generated in prison were not always completed before release for reasons including custodial factors and waits for hospital-based appointments. Provision of effective health care in prison requires improved integration with community health services, including timely access to a wide range of health services while women are in prison, and continuity of care at release.

**Additional keywords:** health services, hearing, integrated care, mental health, nursing care, primary care, prisoners.

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### Background

People in prison have high and often complex medical needs, with mental health disorders, substance misuse and chronic disease all more common than among the general population (Butler T *et al.* 2007; Australian Institute of Health and Welfare 2010; Indig *et al.* 2010). Women in prison have poor self-reported health and healthcare needs that are often different to those of men, including particularly high levels of social disadvantage and experience of trauma (Hockings *et al.* 2002; Harris *et al.* 2007; Indig *et al.* 2010).

Approximately 8% of people in prison in Australia are women (Australian Bureau of Statistics 2014). Aboriginal and Torres Strait Islander women are over-represented in custody, making up ~30% of women in New South Wales (NSW) prisons (Corben 2014), compared with 3% of the NSW Aboriginal and Torres Strait Islander population (Australian Bureau of Statistics 2012). In a recent survey of women in prison, one quarter were born outside Australia and more than 20% spoke a language other than English at home (Indig *et al.* 2010).

The Justice Health and Forensic Mental Health Network (JH & FMHN) is the public Board-governed Speciality Network responsible for prison health care in NSW (NSW Government

2014). Health care is delivered primarily by nurses, with a ratio of 4 nurses and 0.2 medical practitioners per 100 people in prison (Australian Institute of Health and Welfare 2013). Further background information relevant to primary health service delivery within NSW correctional centres is provided in Box 1.

This study aimed to examine the health care provided to women in prison and women's health needs as documented in their medical records, and to identify areas for improvement in the delivery and integration of care both while women are in prison and after release. Medical record reviews are a common method for investigating healthcare delivery and patient outcomes, and provide a platform for quality improvement (Coory *et al.* 2009; Wai *et al.* 2012); however, they have been infrequently conducted in prison health services in Australia.

### Methods

#### Ethics approval

A retrospective review was undertaken of JH & FMHN medical records. Ethics approval was obtained from the ethics committees of JH & FMHN (G31-13), the University of Western Sydney (H10322), Corrective Services NSW (13/259026) and the

**What is known about the topic?**

- Women in prison exhibit high health needs, social disadvantage and risk of poor health and wellbeing outcomes after release.

**What does this paper add?**

- Women in prison see multiple healthcare providers. Improved access to and integration with health services in the community and during incarceration will facilitate completion of intended in-prison health management plans.

Aboriginal Health and Medical Research Council of NSW (910–13).

*Setting and population*

The study population constituted women released from a minimum 6-week period of incarceration in NSW correctional centres between May 2013 and January 2014. The sample frame was derived from the JH & FMHN record database and, subsequently, a list supplied by Corrective Services NSW (CSNSW). A single period of incarceration was considered an episode of health care ending at release from prison.

Periods of 3 weeks' duration were selected in 6 of the months within the review time range (May, July, August, September and November 2013 and January 2014). Each period was expanded to 4 weeks for rural correctional centres in an oversampling strategy designed to increase information from smaller sites.

*Data collection*

At the time of the study, all JH & FMHN medical records were paper-based. Data collection was undertaken at the Joint Records Centre in Sydney, where records are stored when women are not in prison. Records were not available for review if the woman was serving another prison sentence at the time of data collection. All available medical records of women who were released during the data sampling periods were reviewed, using repeated data collection visits over 6 months to increase obtainability of records. Data was collected by one researcher (PA), who is also a visiting general practitioner with JH & FMHN. Files were excluded if the individual had received clinical care from PA.

All aspects of the record were reviewed, including clinical notes and correspondence. Quantitative data were collected in predefined categories onto a paper-based tool, which was piloted before data collection. Qualitative data was also collected comprising descriptive summaries and de-identified verbatim quotes relevant to the themes of successful and unsuccessful delivery of health care in prison and to the interface between prison and community health care.

For data pertaining to reception into prison, documentation from the first week in prison was reviewed. For women who were in prison for 6 months or less, the entire medical record was reviewed. For others, only information from the first week and the last 6 months was reviewed because the research focus was on health care for women entering and leaving prison.

*Variables*

Information collected comprised demographics, custodial details and variables relating to:

- (a) the initial nursing assessments – active health problems and referrals to JH & FMHN healthcare providers (HCPs)
- (b) the whole or last 6 months of custody – number of clinical contacts (JH & FMHN HCPs seen; external healthcare provision; health issues requiring ongoing management at release; and medications at release).

Active health problems and referrals related to the initial nursing assessment were determined from review of (1) the standard health history obtained by JH & FMHN reception nurses, which incorporated the Kessler Psychological Distress Scale, K10 (Kessler *et al.* 2002), and (2) the specialist nursing and physician assessments that occurred in the first week of imprisonment. Past history of resolved health issues was excluded.

Clinical contacts included face-to-face, health-related contacts and excluded administrative entries. External care provision comprised hospital emergency department or outpatient services, excluding external radiology services. The categorisation of health issues into physical health, substance misuse and mental health was informed by previous research in a prisoner population (Mallik-Kane and Visher 2008). Conditions were judged as requiring ongoing management if further health care would be needed, including whether a renewed prescription for medications was required. Medications were classified according to the prescription indication. Medications for any mental health condition, including agitation, mood disorders and psychotic disorders, were classified as psychotropic medications.

Culturally and linguistically diverse (CALD) status was informed by the Australian Bureau of Statistics definition of

**Box 1. Healthcare delivery in NSW correctional centres**

Women are housed in six state-owned correctional centres and often move between centres during their custodies. Delivery of health care by Justice Health and Forensic Mental Health Network (JH & FMHN) requires close collaboration with Corrective Services NSW, a separate government agency with responsibility for custodial care. Corrective Services NSW facilitates JH & FMHN clinics within centres and provides custodial escorts to external medical appointments. In addition, they provide limited health-related services, primarily psychology and relapse-prevention programs.

When women come into prison, primary care reception nurses perform standardised health assessments, and arrange follow-up by JH & FMHN healthcare providers, including specialist nurses. The main areas of nursing specialisation are substance misuse, mental health, public health and women's health. Medical practitioners – primarily GPs, psychiatrists, and drug and alcohol physicians – provide sessional clinics. While in prison, people lose access to the universal healthcare system, Medicare, and rely on local public hospitals for services not available through JH & FMHN.

all people speaking a language other than English at home (Australian Institute of Health and Welfare 2014). CALD or Aboriginal and Torres Strait Islander status was initially determined by the reception nurse's classification, with adjustment if later records demonstrated an unequivocal status.

#### Data analysis

Quantitative analysis was descriptive (counts and percentages) and handled using IBM Statistics SPSS Version 22 (IBM Corp., Armonk, NY, USA). Qualitative data were analysed for content pertaining to the planning and completion of health management plans; common themes and patterns were identified.

#### Results

A total of 328 releases of women in prison met the selection criteria. Of these, 68 records were unobtainable for administrative reasons (mostly the woman being in prison again) and 29 were records of women treated by the reviewer. Thus, records of 231 periods of incarceration were reviewed. Quantitative data was collected from all records and qualitative data from 111 records. Records of 6 women were reviewed twice, representing release from two periods of incarceration. Nineteen records related to women who were serving sanctions under Drug Court, a substance misuse diversionary program. The majority of records (74%) were for sentences of less than 6 months. Other characteristics of the women are presented in Table 1.

#### Health issues and referrals on reception into prison

Health issues identified and documented during the reception nursing assessment are summarised in Table 2. Problematic substance misuse (63%) and anxiety and/or depression (52%) were identified in the majority of cases, and 15% were stated to have schizophrenia or other psychotic disorders. Hearing problems were not documented for any women. The majority of women (59%) were referred to the mental health nurse after their initial assessment. Women were also commonly referred to other specialist nurses and to GPs (Table 3).

#### Health care provision

Most women had multiple clinical contacts while in prison: 49% had more than 20, 24% had 10–20, 20% had 5–9 and 7%

had less than 5. The clinicians who provided care are presented in Table 4. Most women saw the primary care nurse, mental health nurse and GP, including beyond the initial reception process. Other specialist medical care was common: 35% of records included an entry from a psychiatrist, and 24% from a drug and alcohol physician. During their incarceration, 7% of women attended a hospital emergency department and 16% attended at least one external specialist or allied health appointment. Of the 59 women who were in custody longer than 6 months, and for whom the clinical contacts include only 1 week of the initial assessment period, most had contact with a GP (71%), mental health nurse (63%) and women's health nurse (56%).

The qualitative data indicated that systematic nursing assessment was occurring, particularly in mental health. Clinical contacts by women's health and public health nurses related predominantly to cervical screening, sexual health and blood-borne viral disease screening and immunisation. Contacts with the drug and alcohol nurse and physician were usually related to opiate substitution therapy. Most referrals to internal and external HCPs occurred soon after women entered gaol. Waiting times for hospital-based medical appointments, at times lengthened by custodial imperatives including attendance at court and movement between correctional centres, decreased the timeliness of care. Some management plans initiated through the reception assessment or subsequently were not completed before the period of incarceration was completed (Box 2). External specialist appointments or medical investigations were pending in 7% at release.

#### Health care needs at release

At release, nearly half of women were on psychotropic medication, namely antidepressants, mood stabilisers or antipsychotic medications. None were prescribed benzodiazepines. Most records contained evidence of a need for ongoing health management post-release (Table 5).

#### Discussion

This study provides valuable information on healthcare provision in Australian prisons, and the health of women in custody. Incarceration may be a sentinel event, creating both

**Table 1. Characteristics and demographics pertaining to records reviewed**

		Number (n = 231)	Percentage
Age (years)	Less than 25	26	11
	25–39	133	58
	40–59	69	30
	60+	3	1
Aboriginal and Torres Strait Islander background		81	35
	Culturally and linguistically diverse background	27	12
Length of custody	Interpreter required	4	2
	6 weeks–3 months	93	40
	3 months–6 months	79	34
	6 months–12 months	32	14
	12 months +	27	12
Correctional centre of release	Metropolitan	198	86
	Rural	33	14



**Table 2. Health issues identified during initial nursing assessment**

	Number ( <i>n</i> = 230, missing = 1)	Percentage
<i>Problematic substance misuse</i>	144	63
<i>Mental health issue</i>		
Depression, anxiety	120	52
Schizophrenia, psychosis	35	15
<i>Chronic physical health issue</i>		
Asthma, chronic airways disease	55	24
Hepatitis C	42	18
Chronic musculoskeletal disorder (back, shoulder, knee, carpal tunnel syndrome)	32	13
Epilepsy	18	8
Genitourinary (including urinary tract infection ( <i>n</i> = 5), stress incontinence, sexually transmissible infection, vulvovaginitis)	11	5
Cardiovascular disease (including hypertension)	8	4
Diabetes mellitus	6	3
Cognitive disability (including acquired brain injury)	5	2
Chronic gastrointestinal (including gastro-oesophageal reflux disease, chronic diarrhoea)	4	2
Dermatitis	3	1
Chronic hepatitis B	3	1
<i>Other health issue</i>		
Cervical screening needed	25	11
Skin or soft tissue (including infection ( <i>n</i> = 8) and acute injury ( <i>n</i> = 6))	14	6
Dental pain	12	5
Pregnancy	9	4
Breast lump	3	1
Respiratory tract infection (including pneumonia, acute bronchitis, coryza)	3	1
Needs glasses	2	1
Headaches	2	1
Umbilical hernia	2	1
Other (1 of each): anaemia, attention deficit hyperactivity disorder, hay fever, haemochromatosis, hyperlipidaemia, recurrent pulmonary embolism, menorrhagia, menopausal symptoms, Raynaud's disease, renal disease, sleep apnoea, sore ear, sore eyes, swelling feet, thyroid disease, wax in ears.		

**Table 3. Referral after initial health assessment to healthcare providers in Justice Health and Forensic Mental Health Network**

	Number ( <i>n</i> = 229, missing = 2)	Percentage
Mental healthcare nurse	136	59
Primary healthcare nurse	123	54
Drug and alcohol nurse	93	41
GP	88	38
Public health nurse	81	35
Women's health nurse	80	35
Nurse attached to Aboriginal chronic care program <sup>A</sup>	29	13
Optometrist	2	1

<sup>A</sup>Enhanced health check comprising cardiovascular, diabetes and respiratory health screening for Aboriginal and Torres Strait Islander women over 35 years of age.

the motivation and the opportunity for healthcare access for a population with high unmet health needs. This opportunity must be harnessed. Mental health problems, substance misuse and physical health problems have all been associated with an increased likelihood of poorer outcomes on returning to the community from prison, including ongoing ill health, social disadvantage and recidivism (Mallik-Kane and Visser 2008);

further, the risk of suicide and death is heightened after release from prison (Kariminia *et al.* 2007; Kinner *et al.* 2011).

The research methods most commonly used in Australian prisons are inmate surveys and cross-sectional health assessments. Previous medical record reviews of women in Australian prisons have focused on public health and risk-factor screening, and have involved small sample sizes (Miller *et al.* 2006; Gilles M *et al.* 2008). Record reviews can complement self-report survey and interview data (Bai *et al.* 2014) and provide distinct data on healthcare delivery (Coory *et al.* 2009). This research complements survey data on care delivered to women in NSW prisons (Australian Institute of Health and Welfare 2013).

#### *Mental health*

The high proportion of women seen by mental health clinicians and released from prison on psychotropic medication is in keeping with the known high prevalence of mental health disorders in women in prison (Hockings *et al.* 2002; Butler *et al.* 2007). Although stressors around the time of incarceration are likely to have contributed to the anxiety and depression identified at reception in the majority of women, 49% were on a psychotropic medication at release – a larger proportion than seen in previous surveys (Indig *et al.* 2010; Australian Institute of Health and Welfare 2013). It is unclear whether this

**Table 4. Number of women seen by healthcare providers in the 6 months before release**

	Number ( <i>n</i> = 231)	Percentage
<i>Healthcare provider in Justice Health and Forensic Mental Health Network</i>		
Primary healthcare nurse	224	97
Mental healthcare nurse	152	66
GP	150	65
Women's health nurse	121	52
Drug and alcohol nurse	88	38
Psychiatrist	75	35
Public health nurse	71	31
Drug and alcohol medical officer	55	24
Nurse attached to the Aboriginal chronic care program	13	6
Midwife	8	4
Optometrist	7	3
<i>Accessed health care external to Justice Health and Forensic Mental Health Network</i>		
Hospital outpatient appointment (1–5 occasions)	38	16
Hospital emergency department (1–2 occasions)	17	7

**Box 2. Challenges in timely healthcare delivery in prison**

- A woman in her twenties had a 16-month sentence. She was seen by a GP 5 months into her sentence and stated that she experienced palpitations and had previously been told she had a 'dilated heart'. The GP diagnosed anxiety but also requested an urgent echocardiogram. Within the next 6 months, the woman was transferred to and from court four times, which required movement between correctional centres. The echocardiogram was documented to be cancelled and rebooked on one occasion. One week before her release date, she was called for transport to her appointment. However, she declined to attend, stating it was too close to her release.
- A woman in her forties was comprehensively assessed by specialist nurses and a GP during the first month of her 5.5-month custody, informed by a health summary requested from her community GP. Plans were made for assessment of a periumbilical hernia, chronic back pain and a breast lump that required progress imaging. Referrals for breast and spinal imaging and surgical opinion were generated. Screening was conducted for blood-borne viral disease and she was commenced on the three-dose hepatitis B course. At the time of her release, all external appointments were pending. Her final vaccine dose was due after release. She was unexpectedly released from court with no health information transferred.

**Table 5. Women's healthcare needs and medication at release**

	Number ( <i>n</i> = 231)	Percentage
<i>Health issue requiring ongoing management at release</i>		
Mental health	163	71
Substance misuse	150	65
Physical health	140	61
<i>On medication at release</i>		
Psychotropic	113	49
Analgesia	52	23
Opiate substitution therapy	49	21
Respiratory	30	13
Vitamin/nutritional supplement	22	10
Cardiovascular, including hypertension ( <i>n</i> = 8)	18	8
Chronic gastrointestinal (including gastro oesophageal reflux disease)	16	7
Topical skin medication	11	5
Other medications recorded for more than 1 person on release, for treatment of: allergy, epilepsy, diabetes, thyroid disease, hyperlipidaemia, migraine (prevention)		

indicates higher medication prescription during the period of this review or relates to the methodology. It seems likely that this finding may reflect treatment commenced in prison as women serving sentences less than 6 weeks were excluded from review. Our methodology cannot establish the appropriateness of medication prescription. However, the number of women released on psychotropic medication has implications for

integrated health care between prison and the community, emphasising the need for continuity of care across this interface. Psychology services were not captured in this review, as they are delivered by CSNSW. However, it seems likely that access to psychology services pre- and post-release may assist to alleviate the burden of mental health distress for these women.

### Hearing health

Hearing health was not a screening item at reception and it is likely that hearing problems were undetected. Hearing impairment is associated with disadvantage, including increased risk of criminality and poorer progress within the criminal justice system (Senate Community Affairs References Committee 2010; Vanderpoll and Howard 2011). In the Northern Territory, testing of Aboriginal and Torres Strait Islander men and women in custody demonstrated that 90% had significant hearing impairment. The majority had not informed the prison health services of their impairment, although they believed it caused problems for them during their incarceration (Vanderpoll and Howard 2011). This prevalence reflects the higher risk of complicated otitis media in remote communities, however audiological screening of people in Victorian prisons identified that 12% of Aboriginal and Torres Strait Islander people had significant hearing loss and 20% self-reported disability. This is significantly higher than the 5% expected in an age-matched non-Indigenous Australian population (Quinn and Rance 2006). A recent Senate enquiry recommended that hearing screening occur in all correctional facilities where more than 10% of the prison population are Aboriginal and Torres Strait Islander people (Senate Community Affairs References Committee 2010).

### Healthcare delivery

Almost all women had multiple clinical contacts while in prison, highlighting the opportunity to detect and address health problems. However, people in prison surveyed in 2009 believed that they did not access the care that they needed, either in the community or in prison (Australian Institute of Health and Welfare 2013). Reasons given for poor access in the community included lack of motivation, cost and being affected by drugs or alcohol; in custody, poor access was most likely due to long waiting times or health care not being available when needed.

There are unique barriers to healthcare access in prison. Half of the men and women in NSW prisons are either awaiting sentencing or are serving sentences less than 1 year (Corben 2014). Delivering health care within short or uncertain periods of incarceration is challenging. Barriers include waiting lists for JH & FMHN providers, particularly medical practitioners, and for public hospital investigations and specialist assessments. Evidence from this review suggests that delays in access to external investigations and specialist reviews are strong contributors to management plans not being enacted pre-release. Although people in prison are eligible to use hospital services, and hospital outpatient services are the most common referral points for female prisoners needing investigations or specialist care, hospitals can rely on community HCPs and Medicare to provide a full range of timely services, which further decreases the pool available to those in prison. Waiting times for external appointments are exacerbated by the need for correctional staff escorts. This can lead to unpredictable cancellation of appointments (often on the day of the appointment) in the event of understaffing or competing priorities. Additionally, people frequently move between gaols throughout their custody, requiring appointment rescheduling.

The universal reception health assessment and number of contacts with in-prison HCPs suggest that a significant amount

of healthcare activity is occurring. Preventative health screening is a strength of JH & FMHN, and this deserves ongoing emphasis, with the addition of hearing health. However, barriers to health service delivery and to timely care must be overcome if we are to provide effective health care to people in prison beyond screening and the commencement of health management plans. Our findings suggest that increased access to a wide range of health services is needed, including psychology services, and allied health and specialist medical services. Rather than attempts to deliver the whole gamut of services in prison, integration of healthcare delivery between JH & FMHN and hospital and community services is needed, both during prisoners' incarceration and on release. To enable CSNSW to support such integrated health care, improved resourcing and systems are required. It is also important to ensure adequate communication and continuity of care across the interface between prison and community HCPs, given that most women leaving prison require ongoing health management.

### Strengths and limitations

Record review can provide a fuller understanding of health needs and actual healthcare delivery compared with the snapshot in time provided by other methodologies. However, limitations include incomplete records and missing data, leading to underestimates of the outcome variables of interest (Bai *et al.* 2014). In a further limitation, medical record reviews alone cannot prove whether the medical care delivered is appropriate to the needs of the population.

Medical record reviews rely on the judgement of the reviewer. In this study, there was one GP reviewer, creating consistency but also risk of bias. Familiarity with the complexities of the JH & FMHN system and primary care may have increased the yield of record information. The risk of bias was mitigated by prospectively defining variables and drawing on variable definitions used in other large studies (Mallik-Kane and Visser 2008). A further limitation related to the difficulties in accessing patient files in a complex, highly fluid system. Some eligible records may not have been reviewed and some records were excluded due to the dual roles of the reviewer. A significant number of eligible files were not available for review; as this was largely due to women having returned to prison, there is potential for confounding. For example, if these women have more mental health and substance use problems, our high prevalence rate may be an underestimate.

### Competing interests

The author PA is also a part-time visiting GP employed by JH & FMHN.

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## **Chapter 3: Continuity of care between prison and the community**

This publication reports on findings of the record review related to continuity of care and health information transfer for women coming in to prison and on their release.

- ***Abbott P, Magin P, Lujic S, & Hu W. Supporting continuity of care between prison and the community for women in prison: A medical record review. Australian Health Review. 2017;41(3):268-276.***

## Supporting continuity of care between prison and the community for women in prison: a medical record review

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### Abstract

**Objectives.** The aim of the present study was to examine health information transfer and continuity of care arrangements between prison and community health care providers (HCPs) for women in prison.

**Methods.** Medical records of women released from New South Wales prisons in 2013–14 were reviewed. Variables included health status, health care in prison and documented continuity of care arrangements, including information transfer between prison and community. Associations were measured by adjusted odds ratios (AORs) using a logistic regression model. Text from the records was collected as qualitative data and analysed to provide explanatory detail.

**Results.** In all, 212 medical records were systematically sampled and reviewed. On prison entry, information was requested from community HCPs in 53% of cases, mainly from general practitioners (GPs, 39%), and was more likely to have occurred for those on medication (AOR 7.08; 95% confidence interval (CI) 3.71, 13.50) or with schizophrenia or other psychotic disorders (AOR 4.20; 95% CI 1.46, 12.11). At release, continuity of care arrangements and health information transfer to GPs were usually linked to formal pre-release healthcare linkage programs. Outside these programs, only 20% of records had evidence of such continuity of care at release, with the odds higher for those on medication (AOR 8.28; 95% CI 1.85, 37.04) and lower for women with problematic substance misuse (AOR 0.32; 95% CI 0.14, 0.72). Few requests for information were received after individuals had been released from custody (5/212; two from GPs).

**Conclusion.** Increased health information transfer to community HCPs is needed to improve continuity of care between prison and community.

**What is known about the topic?** Many women in prison have high health needs. Health and well being are at further risk at the time of transition between prison and community.

**What does this paper add?** This study provides evidence that outside formal programs, which are currently available only for a minority of women, continuity of care arrangements and transfer of health information do not usually occur when women leave prison. Pragmatic choices about continuity of care at the interface between prison and community may have been made, particularly focusing on medication continuity. Barriers to continuity of care and ways forward are suggested.

**What are the implications for practitioners?** Siloing of health care delivered within prison health services through lack of continuity of care at release is wasteful, both in terms of healthcare costs and lost opportunities to achieve health outcomes in a vulnerable population with high health needs. There is need for an increased focus on continuity of care between prison and community health services, HCP support and training and expansion of pre-release planning and healthcare linkage programs to assist larger numbers of women in prison.

**Additional keywords:** delivery of health care, general practitioners, patient discharge, primary care, prisoners.

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## Introduction

Many women in prison have high health needs and particularly high levels of social disadvantage and experience of life trauma. In Australian surveys performed in 2002 and 2009, 24–33% of women in prison rated their health as fair or poor and 34–55% reported a long-term condition that limited them physically or emotionally.<sup>1,2</sup> Incarceration, although often a time of acute distress, can also be a crisis that prompts decisions to seek health care. It is an opportunity to provide preventive care and medical services that may not be accessed in the community,<sup>3</sup> thus decreasing the risk of post-release morbidity and mortality<sup>4,5</sup> and decreasing ongoing dysfunction and reincarceration risk.<sup>6</sup>

Use of primary care services can be high when people are in prison<sup>7,8</sup>. Conversely, some people in prison are less likely to access and receive the health care they need. Reasons for this include distrust of prison health services,<sup>9,10</sup> long waiting lists<sup>3</sup> and custodial barriers to care.<sup>11</sup> Both those who use prison health services and those who do not get their health needs met would benefit from links to community health care providers (HCPs) and services on release. The transition between prison and living in the community is often a difficult one and a time when health and well being are at further risk, with ex-prisoners often facing health deterioration,<sup>4,5</sup> homelessness,<sup>12</sup> disconnection from family and community<sup>13</sup> and poverty.<sup>14</sup> Yet, continuity of care between prison and community health services is recognised to be sub-optimal and challenging.<sup>15,16</sup>

In the New South Wales (NSW) prison health system, Justice Health and Forensic Mental Health Network (JH&FMHN), there are some programs providing holistic, proactive release planning and prison–community linkage and support. The Connections program provides pre-release planning and short-term case management in a linkage model that aims to assertively connect clients with problematic drug use with relevant health and welfare providers after release.<sup>17</sup> At the time of the present study, the Care Navigation Support Program (CNSP) was focused on release planning for people with chronic physical health needs, and is currently widening its scope in ongoing pilot work.<sup>18</sup>

Health service delivery and primary care services within prison are under-researched.<sup>19</sup> There has been very little research on continuity of care arrangements between prison and community health services in Australia, particularly general practice. In the present study we examined the level of health information transfer and continuity of care arrangements between JH&FMHN and community HCPs for women entering or leaving prison.

## Methods

The present study was a retrospective review of a systematic sample of medical records of women who were released from NSW correctional centres during selected time periods between May 2013 and January 2014. At the time of the review, the health record was paper based. The methodology has been described previously.<sup>8</sup> Records were reviewed at the JH&FMHN central record repository by a single researcher (PA), who was also a visiting general practitioner (GP) with JH&FMHN. Records that included health services delivered by PA were excluded in order to avoid potential bias.

Only records of women who had been in prison 6 weeks or more were included in the study. For women who were in prison

for 6 months or less, the entire medical record was reviewed. For others, the first week and the last 6 months were reviewed. Correspondence or post-release medical notes that related to the period of incarceration were included.

Quantitative data were collected for predefined variables, comprising demographics, custodial details and variables related to health care delivery in prison, health information transfer and post-release health care (Table 1). Administrative communication with HCPs to ensure continuation of opioid substitution therapy (OST) was not considered health information transfer for the purposes of this review. Crude and adjusted odds ratios (ORs) of documented health information transfer and other continuity of care arrangements were estimated using logistic regression analysis, and adjusted for age and current prescribed medication, either medication at reception or at release according to the outcome being studied. Analyses were performed using SPSS for Windows Version 22.0 (IBM Corp.).

Qualitative data comprised a descriptive summary and excerpts from the record, including de-identified communications with community providers, the content of discharge summaries and release planning record entries. Qualitative data were analysed for content pertaining to the interface between prison and community health care; common themes and patterns were identified.

Ethics approval was obtained from the ethics committees of JH&FMHN (G31–13), Western Sydney University (H10322), Corrective Services NSW (13/259026) and the Aboriginal Health and Medical Research Council of NSW (910–13).

## Results

Of 328 eligible records, 68 were unobtainable (predominantly due to the woman being in prison again), 29 were records of women treated by the reviewer and 19 related to custodial sanctions under the diversionary drug dependence program Drug Court. These latter records were not included because qualitative review identified that clinicians within the Drug Court program delivered pre- and post-release health care, creating a different type of continuity of care to the usual care provided to other women. Thus, data from records related to 212 periods of incarceration were included in the study. Quantitative data were collected from all records and qualitative data were collected from 111 records.

Most records (73%) were for sentences less than 6 months, thus the entire record was reviewed. Eleven per cent (24/212) pertained to women from culturally and linguistically diverse (CALD) backgrounds, and 36% (76/212) were of Aboriginal and Torres Strait Islander women, consistent with the proportion of women of CALD or Aboriginal and Torres Strait Islander background in prison in NSW.<sup>2,20</sup> Most women were aged 25–39 (56%) or 40–59 (32%) years, and 84% were released from a metropolitan correctional centre.

Some details of health care delivery relevant to the interface between prison and community HCPs are given in Table 2. A community GP was documented in 61% of records. A lesser proportion of women from CALD backgrounds had a GP documented (8/24; 33%), with no difference by Aboriginal and Torres Strait Islander status.

**Table 1. Predefined descriptors of quantitative data categories used in data collection**

CALD, culturally and linguistically diverse; GP, general practitioner; JH&FMHN, Justice Health and Forensic Mental Health Network; HCP, health care providers; CNSP, Care Navigation Support Program; OST, opioid substitution therapy

Demographics	
CALD status	All people speaking a language other than English at home. <sup>30</sup> CALD status was initially determined by the reception nurse's classification, with adjustment if later records demonstrated an unequivocal status.
Aboriginal and Torres Strait Islander status	Aboriginal and Torres Strait Islander status was initially determined by the reception nurse's classification, with adjustment if later records demonstrated an unequivocal status.
Variables relating to health on reception into prison	
Active health conditions	Documented current or active health conditions or diagnoses; excludes resolved health conditions, such as previous surgery or episodes of illness with no ongoing care needs. Active health conditions were determined from review of: (1) the standard health history obtained by reception nurses, which incorporated the Kessler Psychological Distress Scale; <sup>31</sup> and (2) the specialist nursing and physician assessments that occurred in the first week of imprisonment.
Medication on reception	Self-reported or otherwise documented regular, prescribed medications on reception into prison, excluding simple analgesics.
Variables relating to health care during the period of incarceration and to release from prison	
Community GP	Recorded community GP providing previous or planned health care, including GPs who were nominated during in-custody pre-release planning.
Request for health information sent to community HCPs from JH&FMHN	Any request for transfer of health information sent to HCPs or services external to JH&FMHN, including but not limited to requests sent in the first week of incarceration.
Clinical contacts	Clinical contacts included face-to-face, health-related contacts and excluded administrative entries. The total number of contacts was derived from a review of records from the first week and last 6 months of the period of incarceration and was not adjusted for the length of the sentence.
Health conditions receiving care in prison	Any health condition for which health care was provided within prison, excluding minor episodic illness such as minor trauma or infections. The division into physical health, substance misuse and mental health conditions follows previous research categorisation. <sup>6</sup>
Health care delivery from an external HCP while in custody	Health care that was delivered by HCPs or health services external to JH&FMHN, primarily hospital emergency department or out-patient services. Radiology services were excluded, given these were sometimes provided in prison and sometimes in hospital radiology departments depending on the location of the correctional centre.
Health conditions requiring ongoing management at release	Health conditions were judged as requiring follow-up after release if ongoing care would be needed, including if medication prescription would require renewal.
Medication at release	Regular, prescribed medications on release from prison, excluding simple analgesics. OST at release was noted but classified separately.
Formal JH&FMHN transitional support program	Participation in Connections or CNSP programs.
Correctional centre at release	Although women frequently moved between prisons, the prison from which they were released is noted in this category. Five prisons were included in the review, with the two rural centres considered together. One metropolitan and both rural centres were reception centres for women coming into prison and women could be released from any of the five correctional centres.
Post-release appointments	Any appointment organised by JH&FMHN with HCPs or health services after release.
Health information transfer to a community HCP on release from prison	Documentation in the record that health information transfer had occurred, including the presence of a discharge summary, a release care plan or clinical notes stating health information had been transferred verbally or in a written form to a community health service, GP or other HCP. Evidence of verbal discussions pertaining to release between a JH&FMHN HCP and a woman about to leave prison was not included if there was no evidence that written health information had been provided, or of other communication with community HCPs. Communication solely to ensure continuation of OST on coming into or leaving prison was considered administrative and excluded.
Community HCP requests for medical information after release.	Any request for health information transfer from a community HCP or health service related to the reviewed period of incarceration that was received after release.

### Health information transfer for women entering prison

Patient information was requested of community HCPs in 53% of records, mainly from GPs and hospitals. Very few requests for information were sent to other HCPs (Table 3). All requests resulted in information being returned. The odds of information requests were higher for women who were on medication on prison entry (adjusted OR (AOR) 7.08; 95% confidence interval

(CI) 3.71, 13.50) or who had schizophrenia or other psychotic disorders (AOR 4.20; 95% CI 1.46, 12.11) and lower for women of CALD background (AOR; 0.14; 95% CI 0.04, 0.49).

### Continuity of care and health information transfer at release

Most women were on medication at release (72%) and had medical conditions that would require follow-up after release.



**Table 2. Health care at the interface between prison and community health care providers (*n* = 212)**

Data are given as *n* (%). GP, general practitioner; JH&FMHN, Justice Health and Forensic Mental Health Network; HCP, health care provider; CNSP, Care Navigation Support Program; OST, opioid substitution therapy

Reception into prison	
Details of community GP in file	
Yes	128 (61)
No	82 (39)
Missing data	2 (1)
Request for health information sent from JH&FMHN to community HCP	
To any HCP	111 (52)
To GP	82 (39)
To hospital	35 (17)
To community mental health team	11 (5)
To non-GP medical specialist	6 (3)
Psychologist	1 (<1)
Optometrist	1 (<1)
Residential rehabilitation facility	1 (<1)
Pre-release health care	
Health management before release	
Health conditions receiving care in custody	
Mental health	151 (71)
Substance misuse	133 (63)
Physical health (excluding minor episodic care)	131 (62)
Accessed healthcare services external to JH&MHN during incarceration	44 (21)
Release from prison	
Medications on release	
On OST at release	41 (19)
On medication at release (excluding OST)	154 (73)
Release destination	
Community	200 (94)
Residential rehabilitation or other transitional placement	8 (4)
Immigration centre or deportation	4 (2)
Hospital	2 (<1)
Formal JH&MHN transitional support programs	
Connections	30 (14)
CNSP	13 (6)
Information exchange	
Evidence of information transfer at release <sup>A</sup>	
Any evidence of transitional care or information transfer	77 (36)
Documentation of information prepared for GP	43 (20)
Any individuals who had appointments made with any HCP after release <sup>A</sup>	19 (9)
Request for health information received from health care provider after release	
GP (one private GP, one GP within Aboriginal Medical Service)	2 (<1)
Community mental health team	1 (<1)
Immigration detention centre	1 (<1)
Residential rehabilitation centre	1 (<1)

<sup>A</sup>Excluding administrative arrangements or appointments for continuation of OST.

However, less communication occurred between prison and community HCPs at release (36%) compared with prison entry (52%; Table 2). Arrangements for post-release health care or transfer of health information were usually related to a formal pre-release program: all 43 of these records demonstrated planning for continuity of care as would be expected, although a minority evidenced a pre-release plan that included GPs (19/43). Excluding administrative arrangements for OST, only 20% of records of women outside the formal programs (34/169) had evidence of information transfer to any community HCP, and 14% to GPs (24/169).

Excluding those engaged in a formal program, the only factor that predicted health information transfer or continuity of care

arrangements between prison and community HCPs at release was being on medication (AOR 8.28; 95% CI 1.85, 37.04; Table 4). The odds of documented continuity of care arrangements were significantly lower in those women with problematic substance misuse (AOR 0.32; 95% CI 0.14, 0.72).

Information transfer to community GPs was associated with being on medication at release (AOR 7.51; 95% CI 2.15, 26.17) and being in a pre-release program, particularly CNSP (AOR 11.83; 95% CI 3.17, 44.08). One metropolitan correctional centre was more likely to transfer information to GPs than other centres (AOR 4.54; 95% CI 1.72, 11.98). Variables that would indicate higher levels of health care in prison, such as accessing health services external to JH&FMHN while in prison and longer

**Table 3. Factors predicting a request for health information being sent to community health care providers on reception into prison (n = 210; missing data = 2)**

OR, odds ratio; CI, confidence interval; CALD, culturally and linguistically diverse

	No. subjects	% With outcome	Crude OR (95% CI)	Adjusted OR <sup>A</sup> (95% CI)	Adjusted OR <sup>B</sup> (95%CI)
Age (years)					
<29	54	38.9	1		1 <sup>C</sup>
30–49	137	55.5	1.96 (1.03, 3.72)		1.46 (0.70, 3.03) <sup>C</sup>
≥50	19	78.9	5.89 (1.72, 20.19)		4.47 (1.16, 17.25) <sup>C</sup>
Aboriginal and Torres Strait Islander					
No	134	55.2	1	1	1
Yes	76	50.0	0.81 (0.46, 1.42)	0.91 (0.51, 1.63)	0.83 (0.43, 1.59)
CALD					
No	186	58.06	1	1	1
Yes	24	16.7	0.14 (0.05, 0.44)	0.12 (0.04, 0.40)	0.14 (0.04, 0.49)
On medication at reception into prison					
No	83	25.3	1	1	1 <sup>D</sup>
Yes	125	72.0	7.59 (4.04, 14.26)	7.08 (3.71, 13.50) <sup>D</sup>	7.08 (3.71, 13.50) <sup>D</sup>
Active health conditions					
Substance misuse	128	57.8	1.59 (0.91, 2.77)	1.54 (0.87, 2.74)	1.52 (0.80, 2.88)
Schizophrenia or psychotic disorder	33	84.8	6.20 (2.29, 16.79)	6.42 (2.34, 17.59)	4.20 (1.46, 12.11)
Anxiety or depression	112	60.7	1.90 (1.10, 3.29)	1.88 (1.07, 3.30)	1.27 (0.67, 2.40)
Chronic physical disorder	71	67.6	2.45 (1.34, 4.45)	2.17 (1.17, 4.01)	1.43 (0.72, 2.83)

<sup>A</sup>Adjusted for age.<sup>B</sup>Adjusted for age and medication at the time of reception.<sup>C</sup>Adjusted for medication only.<sup>D</sup>Adjusted for age only.

periods of being in prison, also increased the odds of information transfer (Table 5). Very few requests for health information were sent to JH&FMHN by community providers after individuals had been released from custody (five of 212, of which two came from GPs; Table 2).

Some women (19/212) had documented appointment arrangements made with HCPs after release (excluding OST), the majority of whom (12/19) were with Connections or CNSP (Table 2). Post-release appointments were more likely for women with physical health conditions requiring follow-up after release ( $\chi^2=7.92$ , d.f. 1,  $P=0.004$ ) but were not associated with diagnoses of mental health conditions ( $\chi^2=2.20$ , d.f. 1,  $P=0.20$ ) or substance misuse ( $\chi^2=0.24$ , d.f. 1,  $P=0.63$ ).

#### Features of record entries and discharge communication relating to the prison–community interface

Analysis of the qualitative data showed that release of information requests sent to GPs when women came into prison often focused on confirmation of current medications, and sometimes this was the only information requested and received. Release information was generally written by nurses, although occasionally prepared by others (psychiatrist, 1; GPs, 3). The information provided on the JH&FMHN handwritten release summaries in use at the time of the review was usually brief, with a contact number for further information. At times comprehensive information was provided, for example when women had substantial health needs and had received significant changes to their health management. Mental health assessments that occurred in prison were usually not communicated, even if multiple assessments had been done or if prescribed release medication required specific indications

for subsidised community prescription. The exception to this was when women were being referred to community mental health teams on release. There was very little transfer of information related to preventive health or chronic disease management.

Sometimes prison HCPs conducted release planning consultations with women in which it could be decided no transfer of information was desired or required or a decision was made that medical appointments that had not been attended by the release date were no longer needed. However, some pending medical appointments and investigations did not appear to be discussed or communicated to external HCPs at release. Unpredictable timing of release from custody and movement between correctional centres appeared to affect transfer of information at release.

## Discussion

### Main findings

The present study provides evidence of underdeveloped continuity of care processes between prison and community health services, particularly at the time of release. When people leave prison they have an increased risk of hospitalisation and death,<sup>4,21</sup> suboptimal continuity of care may exacerbate their health vulnerability. If relevant health information is not passed on between providers, health costs can be increased by investigations being unnecessarily repeated in the community or unmanaged conditions worsening and requiring more intensive and costly care. Poor links with GPs may feasibly increase the burden on hospital emergency departments.

On prison entry, transfer of information requests appeared to be often driven by a need to ensure medication continuation and

**Table 4. Factors predicting any continuity of health care arrangements between prison and community health care providers (HCPs) at release from prison for those not on a formal transitional program (n = 169; excluding administrative information transfer relating to opioid substitution therapy (OST))**

OR, odds ratio; CI, confidence interval; CALD, culturally and linguistically diverse

	No. subjects	% With continuity arrangements	Crude OR (95% CI)	Adjusted OR <sup>A</sup> (95% CI)	Adjusted OR <sup>B</sup> (95% CI)
Age (years)					
<29	44	13.6	1		1 <sup>C</sup>
30–49	107	22.4	1.83 (0.69, 4.85)		1.18 (0.42, 3.31) <sup>C</sup>
≥50	18	22.2	1.81 (0.44, 7.38)		1.00 (0.23, 4.33) <sup>C</sup>
Aboriginal and Torres Strait Islander	58	17.2	0.75 (0.33, 1.71)	0.76 (0.33, 1.76)	0.86 (0.36, 2.02)
CALD	21	19.0	0.93 (0.29, 2.95)	1.00 (0.31, 3.23)	1.48 (0.42, 5.21)
Correctional centre of release					
Metropolitan centre 1	58	19.0	1	1	1
Metropolitan centre 2	46	23.9	1.34 (0.52, 3.45)	1.26 (0.49, 3.29)	1.53 (0.57, 4.15)
Metropolitan centre 3	36	19.4	1.03 (0.36, 2.96)	0.98 (0.34, 2.85)	1.00 (0.34, 2.97)
Rural centres 1 and 2	29	17.2	0.89 (0.28, 2.86)	0.84 (0.26, 2.73)	0.97 (0.29, 3.29)
Date of release					
13 May	28	14.3	1	1	1
13 July	31	35.5	3.30 (0.91, 11.98)	3.24 (0.89, 11.82)	3.43 (0.91, 12.95)
13 August	30	16.7	1.20 (0.29, 5.01)	1.20 (0.28, 5.03)	1.42 (0.32, 6.18)
13 September	24	20.8	1.58 (0.37, 6.70)	1.70 (0.39, 7.39)	1.70 (0.37, 7.49)
13 November	27	18.5	1.36 (0.32, 5.73)	1.32 (0.31, 5.62)	1.28 (0.29, 5.61)
14 January	29	13.8	0.96 (0.21, 4.28)	0.93 (0.21, 4.22)	1.10 (0.24, 5.18)
Length of custody					
6 weeks to <3 months	68	14.7	1	1	1
3 months to <6 months	62	17.7	1.25 (0.49, 3.19)	1.22 (0.47, 3.12)	1.19 (0.45, 3.13)
6 months to <12 months	23	39.1	3.73 (1.27, 10.90)	3.87 (1.30, 11.49)	2.80 (0.92, 8.56)
≥12 months	16	25.0	1.93 (0.52, 7.21)	1.91 (0.50, 7.35)	1.61 (0.41, 6.34)
No. health care contacts during sentence					
<5	13	7.7	1	1	1
5–9	37	10.8	1.46 (0.15, 14.35)	1.46 (0.15, 14.47)	0.53 (0.04, 6.39)
10–19	41	9.8	1.30 (0.13, 12.76)	1.30 (0.13, 12.82)	0.46 (0.04, 5.56)
≥20	78	32.1	5.66 (0.70, 45.98)	5.49 (0.67, 44.81)	1.78 (0.17, 18.15)
Health care delivery from an external HCP while in custody	29	34.5	2.54 (1.05, 6.15)	2.49 (1.02, 6.04)	1.97 (0.79, 4.87)
On any medication at release (excluding OST)	120	26.7	8.54 (1.96, 37.23)	8.28 (1.85, 37.04)	8.28 (1.85, 37.04) <sup>D</sup>
On OST at release	17	17.6	0.84 (0.23, 3.09)	0.79 (0.21, 2.98)	0.84 (0.21, 3.31)
Health issue requiring ongoing management after release					
Problematic substance misuse	101	12.9	0.33 (0.15, 0.72)	0.31 (0.14, 0.68)	0.32 (0.14, 0.72)
Mental health	118	25.4	4.01 (1.33, 12.05)	4.09 (1.35, 12.38)	3.09 (0.99, 9.69)
Physical health	102	25.5	2.52 (1.06, 5.98)	2.38 (0.99, 5.75)	1.53 (0.61, 3.85)

<sup>A</sup>Adjusted for age.<sup>B</sup>Adjusted for age and medication at the time of release.<sup>C</sup>Adjusted for medication only.<sup>D</sup>Adjusted for age only.

care for more severe psychiatric conditions. At release, continuity of care arrangements were also associated with prescribed medication, as well as with more health care in prison. However, such arrangements were documented for less than one-third of women on medications or with ongoing health needs.

GPs are a common healthcare access point for people who have been in prison.<sup>2,22</sup> However, the present study suggests discharge information was not routinely provided to GPs, despite a majority of women having an identifiable GP in their records. Although discontinuation of some pre-incarceration relationships with GPs is inevitable, including due to moving to a new area after release,<sup>23</sup> provision of health information assists in establishing care with new providers and re-establishing care with previous providers. Previous research with former prisoners identified that

lack of pre-release planning and discharge summaries causes avoidable difficulties on exiting prison.<sup>16</sup> Although community HCPs are able to request information about health care provided in prison, there appeared to be minimal demand for this, with very few post-release requests recorded, none of which came from hospitals and only two from GPs.

#### Barriers to communication

Continuity of care and communication between different providers is a well-recognised challenge in all health settings, but there are distinct challenges in the prison setting. Contextual factors affecting discharge planning include unpredictable timing of release, frequent moves between prisons because of custodial

**Table 5. Factors predicting transfer of health information to a community general practitioner (GP) at the time of release from prison (n = 212)**  
OR, odds ratio; CI, confidence interval; CALD, culturally and linguistically diverse; CNSP, Care Navigation Support Program; JH&FMHN, Justice Health and Forensic Mental Health Network; OST, opioid substitution therapy

	No. subjects	% With information transfer to GP	Crude OR (95% CI)	Adjusted OR <sup>A</sup> (95% CI)	Adjusted OR <sup>B</sup> (95% CI)
Age (years)					
<29	54	20.4	1		1 <sup>C</sup>
30–49	138	21.0	1.04 (0.48, 2.27)		0.69 (0.30, 1.58) <sup>C</sup>
≥50	20	15.0	0.69 (0.17, 2.78)		0.39 (0.09, 1.64) <sup>C</sup>
Aboriginal and Torres Strait Islander	76	21.1	1.08 (0.54, 2.16)	1.05 (0.52, 2.11)	1.17 (0.56, 2.42)
CALD	24	16.7	0.76 (0.25, 2.37)	0.78 (0.25, 2.41)	1.05 (0.32, 3.43)
Transition support					
None	169	14.2	1	1	1
CNSP	13	69.2	13.59 (3.88, 47.66)	14.09 (3.97, 50.03)	11.83 (3.17, 44.08)
Connections	30	33.3	3.02 (1.26, 7.24)	2.88 (1.19, 6.98)	3.01 (1.20, 7.55)
Correctional centre of release					
Metropolitan centre 1	63	11.1	1	1	1
Metropolitan centre 2	71	32.4	3.83 (1.51, 9.71)	3.92 (1.54, 9.99)	4.54 (1.72, 11.98)
Metropolitan centre 3	45	17.8	1.73 (0.58, 5.18)	1.70 (0.57, 5.11)	1.75 (0.57, 5.39)
Rural centres 1 and 2	33	15.2	1.43 (0.42, 4.91)	1.38 (0.40, 4.77)	1.61 (0.45, 5.76)
Length of custody					
6 weeks to <3 months	79	10.1	1	1	1
3 months to <6 months	76	21.1	2.37 (0.95, 5.91)	2.30 (0.92, 5.77)	2.36 (0.92, 6.04)
6 months to <12 months	31	32.3	4.23 (1.48, 12.07)	4.11 (1.43, 11.78)	3.22 (1.09, 9.47)
≥12 months	26	34.6	4.70 (1.58, 13.97)	4.99 (1.65, 15.06)	4.95 (1.58, 15.50)
No. health care contacts during sentence					
<5	13	7.7	1	1	1
5–9	41	7.3	0.95 (0.09, 9.98)	0.96 (0.09, 10.16)	0.37 (0.03, 4.53)
10–19	51	15.7	2.23 (0.54, 19.65)	2.21 (0.25, 19.48)	0.82 (0.08, 8.42)
≥20	107	29.0	4.90 (0.61, 39.27)	5.03 (0.62, 40.48)	1.67 (0.18, 15.93)
Received health care from non-JH&MHN provider while in custody	44	38.6	3.44 (1.65, 7.19)	3.56 (1.69, 7.50)	3.07 (1.42, 6.61)
On any medication at release (excluding OST)	154	26.0	6.43 (1.91, 21.71)	7.51 (2.15, 26.17)	7.51 (2.15, 26.17) <sup>D</sup>
On OST at release	41	19.5	0.94 (0.40, 2.22)	0.94 (0.40, 2.22)	0.97 (0.40, 2.34)
Health issue requiring ongoing management after release					
Problematic substance misuse	133	15.0	0.43 (0.22, 0.85)	0.42 (0.21, 0.83)	0.45 (0.22, 0.92)
Mental health	151	25.2	3.77 (1.40, 10.1)	3.74 (1.39, 10.03)	2.53 (0.91, 7.06)
Physical health	131	24.4	2.06 (0.97, 4.36)	2.20 (1.02, 4.76)	1.38 (0.61, 3.12)

<sup>A</sup>Adjusted for age.

<sup>B</sup>Adjusted for age and medication at the time of release.

<sup>C</sup>Adjusted for medication only.

<sup>D</sup>Adjusted for age only.

factors, lack of clinical pathways for release arrangements<sup>15</sup> and time pressures within short custodial sentences that limit health care delivery.<sup>8</sup> The paper-based notes in use at JH&FMHN at the time of the present review decreased the efficiency with which information could be generated, creating a further barrier to information exchange.

Information transfer is affected by demand, and this is also complicated by the prison context. Limited health information transfer may reflect low demand from women entering or exiting prison. The stigma of imprisonment is likely to be a barrier to communication with community HCPs.<sup>24</sup> Shame at imprisonment is heightened in some cultural groups<sup>25</sup> and may be an explanation for our finding that women from CALD backgrounds were less likely to have had a request for information sent to GPs on prison entry. Some women may wish to avoid disclosing their incarceration to HCPs by choosing not to pass on discharge

information from prison health services. Needs such as accommodation and re-establishment of family connections may be prioritised over health in the critical post-release period. Poor connections with GPs on leaving prison, exacerbated by lack of awareness by GPs of their patient's recent incarceration or of the health care delivered in prison, may further decrease demand for information sharing.

Prison HCP factors may contribute to a low level of continuity of care arrangements, including beliefs that preparation of discharge information is not needed. For example, HCPs may judge that a woman had no significant health problems or that she is unlikely to pass on discharge health information. Prioritising information sharing for more urgent, ongoing health conditions, such as being on medication and receiving more care in prison, may be a pragmatic response within a prison environment to limited time and resources. There may also be low recognition of

the value to community GPs of certain types of health information generated in prison, such as mental health assessments and preventative health activities, contributing to a less holistic approach to information sharing.

### Solutions

A systems approach to communication and transfer of health information for people moving between different health sectors and providers is needed.<sup>26</sup> Although at the time of the review JH&FMHN records were paper based, change to a partial electronic health record commenced in 2014. Electronic medical records will provide an opportunity to embed information transfer, for example through mandatory data completion fields and automatically generated discharge information. In moving forward with this opportunity, it is essential to reinforce systems to ensure health information is actually transferred on release, and to provide the information that will be most helpful. Adequate clinical handover processes must include support and training of the staff who prepare discharge summaries.<sup>27</sup> Training must be a priority in JH&FMHN given the large numbers of nurses who share responsibility for clinical release arrangements. Facilitating transfer of information beyond medication and pathology results that are easily captured by clinical software is vital. For example, given the pressures on community mental health services, providing information to GPs about mental health assessments women receive in prison would appear valuable and yet infrequently done. In addition, HCP training, including more undergraduate exposure to people in prison or a history of imprisonment, may assist to overcome the stigma faced by ex-prisoners and thus facilitate communication across the prison–community interface.

Continuity of health care was demonstrated for women in formal JH&FMHN programs, which take a more holistic approach to health care than the focus on medications seen in the present study. However, these programs are not universally available to people leaving prison.<sup>17,18</sup> Wider availability of pre-release health planning and case management that promotes links cross the prison–community health care interface is a key way forward.

Stronger links to community health services and HCPs throughout periods of imprisonment may also allow improved continuity of care after release, as well as more comprehensive in-prison care, and decrease the siloing of care, which is a particularly high risk in prisons.<sup>15</sup> For example, prioritised access to specialist and allied health services while women are in prison, such as through shortened hospital waiting lists or in-reach programs in prisons, or continuing Medicare eligibility so women can access community-based services, would allow higher-quality care delivery within the usual short prison sentences and promote health care links that can be maintained after release. Similarly, improved links with Aboriginal community-controlled health services both before and after release can increase the effectiveness of in-prison care and care continuity after release.<sup>16,28</sup>

### Limitations

The present study has several limitations. Challenges in medical record reviews include incomplete data and variable

interpretations of the record when determining outcomes.<sup>29</sup> The medical record only reflects one aspect of communication between HCPs, within a complex system. The value of record reviews depends on the outcome of interest. In the present study, record review was well suited to assessing evidence for health information transfer, but it is possible that records may have been incomplete and information transfer and release arrangements may not have been recorded, leading to underestimation of continuity of care activities. In particular, informal information transfer could have occurred without being documented. Conversely, the presence of a discharge summary in the records does not mean that information was actually transferred. Researcher judgement was required for several variables, including the features of the discharge communication. Potential bias may have been created by the number of eligible files that were not available for review because the women were again in prison. Although the prison health care system within NSW is comparable for men and women, the present study cannot be assumed to be generalisable to all people leaving prison. However, the cultural diversity, age range and sentence length of women included in this review do accord with NSW inmate census data.<sup>20</sup>

### Conclusion

The present study provides evidence that other than through formal pre-release programs, which are currently available for a minority of women, continuity of care arrangements and transfer of health information do not usually occur when women leave prison. Pragmatic choices about health information transfer at the interface between prison and community may be made, resulting in a focus on medication continuity. The prison setting poses unique and difficult challenges to provision of continuity of care that require systematic solutions. These include increased utilisation of the electronic medical record, focus on links between prison and community health services both when delivering health care in prison and on prison exit, support and training for prison- and community-based HCPs to decrease stigma and promote continuity of care and expansion of pre-release and transitional programs for women being released from prison.

### Competing interests

PA was a visiting GP employed with JH&FMHN at the time of the study and is currently a member of the JH&FMHN Board.

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## **Chapter 4: 'If they're your doctor they should care about you': Women on release from prison and general practitioners**

This publication reports on the aspects of the qualitative research related to the expectations and experiences of women leaving prison regarding community-based general practice care.

- *Abbott P, Davison J, Magin P, & Hu W. (2016). 'If they're your doctor they should care about you': Women on release from prison and general practitioners. Australian Family Physician. 2017;45(10):728-731.*

# 'If they're your doctor, they should care about you': Women on release from prison and general practitioners

Penelope Abbott, Joyce Davison, Parker Magin, Wendy Hu

## Background

Nearly half of the people leaving prison see a general practitioner (GP) within a month of release, which provides an opportunity to promote health for this vulnerable group.

## Objective

The objective of this article is to examine the expectations and experiences of GP care of women leaving prison.

## Method

Semi-structured interviews pre-release and post-release from prison were analysed using inductive thematic analysis.

## Results

Sixty-nine interviews were conducted with 40 women while they were still in prison and 29 of these women after they were released. Women perceived GPs as lacking interest in their social support needs and believed GPs needed more skills in substance misuse management. Given the fear of stigma, women may not disclose recent incarceration, affecting the continuity of healthcare initiated in prison.

## Discussion

GPs' acknowledgement of, and assistance with, the broad issues that have an impact on the health and wellbeing of women after release is valued. Whole-person care also requires GP accessibility, management of substance misuse, continuity of care and understanding of the stigma associated with incarceration.

General practice is an important healthcare access point for people who are released from prison. In a recent Australian study of healthcare use by people leaving prison, 46.5% saw a general practitioner (GP) within a month of release.<sup>1</sup> However, there has been little Australian or international research that has examined effective primary healthcare for people leaving prison.

Mental health disorders as well as previous life trauma and high levels of psychological distress are common in people in prison.<sup>2</sup> Substance misuse, bloodborne viral disease, and chronic disease and its risk factors are all more common in people in prison, compared with the general population.<sup>2-4</sup> Health vulnerability is heightened immediately post-release and in the first year after release, including increased risk of hospitalisation and death.<sup>5-8</sup> Most women who are in prison are on medications or have health problems that require follow-up after release.<sup>9</sup> Homelessness,<sup>10</sup> disconnection from family and community,<sup>11</sup> poverty, unemployment,<sup>12,13</sup> and return to a criminogenic environment<sup>14</sup> are all factors that increase health instability. Competing demands, often related to family wellbeing, are particularly important for women leaving prison.<sup>15,16</sup>

Approximately 8% of the prison population in Australia are women.<sup>17</sup> Aboriginal and Torres Strait Islander women are over-represented in prison, making up approximately 30% of those in New South Wales (NSW) prisons,<sup>18</sup> compared with 3% of the NSW population.<sup>19</sup>

This research examined the perceived health needs and plans of women during the period of transition from prison to the community, with a focus on their expectations and experiences of GP care.

## Methods

Women who were within six weeks of release from prison and able to be interviewed in English were invited to take part in semi-structured interviews prior to release and one to six



months after release. Recruitment took place in three metropolitan correctional centres in Sydney. The first author, who undertook all interviews, was a visiting GP in one of the correctional centres. Women who had received substantial medical care from the first author prior to the interview were excluded from the study. Participants were selected using purposive sampling for age, ethnicity, custodial history, health status, health service use and engagement in transitional support programs.

Pre-release interviews were conducted face to face in private rooms and post-release interviews were conducted by phone. Participants were offered a payment of \$10 into their in-prison account or a \$50 supermarket voucher if they were in the community. Interview questions covered health needs and expectations or experiences of accessing healthcare after release, including GP care. Interviews were audiotaped and transcribed verbatim and inductive thematic analysis<sup>20,21</sup> was undertaken. The first author coded transcripts concurrently with data collection; sampling continued until saturation for key themes was reached. The second and fourth authors undertook parallel coding on one-third of the interviews. The second author acted as an Aboriginal cultural mentor throughout analysis. Themes were finalised in an iterative process through research team discussions.

Ethics approval was obtained from the ethics committees of Justice Health and Forensic Mental Health Network (G31-13), Western Sydney University (H10322), Corrective Services NSW (13/259026), and the Aboriginal Health and Medical Research Council of NSW (910-13).

## Results

Sixty-nine interviews were undertaken with 40 women pre-release and 29 of these women post-release. The women's ages were 19–59 years and length of incarceration was two months to two years. Five women identified as

coming from a culturally and linguistically diverse (CALD) background, defined as speaking a language other than English at home. Sixteen participants identified as Aboriginal women and one as a Torres Strait Islander woman.

Nine women were released from prison with the support of formal prison–community linkage programs,<sup>22,23</sup> two to residential rehabilitation and two to transitional release accommodation. Of the 29 post-release interviews, seven were with women who were back in prison. The pre-release interview duration averaged 28 minutes and the post-release interview averaged 22 minutes.

Pre-release and post-release interviews were analysed together, given many women reflected on their experiences of multiple incarcerations. The major themes are presented below.

### Needs and vulnerability immediately after release

The enormity of the life challenges faced by women after their release from prison often overpowered their need to access healthcare. These challenges included finding housing, employment, transport, finances and reintegration into families. Accessing services could require considerable resourcefulness, such as determinedly seeking out charities that would provide practical support.

Women who had little or no support from family or friends faced the most difficulties and, often, had worse linkages to health services. Women vividly recalled the overwhelming impact of social isolation on their wellbeing after release, reporting they felt vulnerable and alone.

*Someone just to talk to, you know what I mean, [be]cause it's depressing. It is depressing like having no-one. You're around so many girls here, you know, you've got so many people that talk to you and that here. Getting out there it's like, you know, no-one. – Participant 16*

Some women contrasted their hopes for successful integration into the community with previous bad experiences and what they had observed in other women.

Several expressed fearfulness for their future, particularly those who had poor health prior to incarceration, usually because of substance misuse or mental health problems. This battle with addiction and life stressors came to a head in the immediate post-release period, and vulnerability after release was a common theme.

*What they don't understand is there's only, like, even though I've been off it for so long now, anything could trigger it again and I could start up.*

– Participant 38

However, this period was also identified as a time of increased motivation to maintain health. Some women saw the first few days or weeks after their release from prison as a time-limited window of opportunity to link with services to assist with their health and social support needs, and prevent relapse and recidivism. This was also a perceived advantage of transitional programs because they linked the women to healthcare when they were most receptive.

*A plan, an appointment, set for a week after you're out ... I think if you make that appointment quickly, you've got that little bit of time where you can get them in. – Participant 35*

### Post-release continuity of healthcare

Continuity of care on leaving prison was seen as desirable, but the fear of differential treatment resulting from disclosure of incarceration led some to avoid GP follow-up of previously managed conditions. Some withheld their prison discharge summaries because of previous negative experiences.

*I had to go to that doctor to get medication for when I got released, and I only had the release paper with me and it was just awkward ... The conversation just went dead real quick. You know what I mean. Then it wasn't about again what I needed, it was about, you know, just come out of jail and what are you trying to get.*

– Participant 6

Geographical dislocation, due to a need to avoid previous associates through choice or as part of parole conditions, could mean women had to seek GPs and health agencies in unfamiliar areas. Women reported particular difficulties in rural locations where GPs had longer waiting lists. Delays in seeing a GP caused stress and resulted in discontinuing medication.

There were also facilitators of continuity of care. Aboriginal health services and sexual health services were considered to be more accessible and less likely to stigmatise ex-prisoners. The national network of Aboriginal medical services (AMSs) increased women's confidence that care would be available in the event of release to an unfamiliar location, although getting appointments could still be difficult. Pre-release and post-release programs that linked women with health services in the community were valued.

*They [transitional case managers] help you, any help you need, they'll sometimes take you there and meet you there. If you're unsure and if you're not very good at speaking or whatever, to go to the doctors or communicating – or anywhere that you need to go, they'll help you with that. – Participant 21*

Other individuals and services that supported healthcare access were parole officers, churches and charities. Continuity of care was easier for women with priority health conditions, such as human immunodeficiency virus (HIV) and schizophrenia. Those with priority health conditions reported they received more supportive and accessible care to ensure adequate management.

*Because of my status, I'm more of a risk to the community ... so, they put me straight in. – Participant 37*

Pre-existing relationships with GPs or other health services were helpful at release. Some women reported that, after release, their strong existing relationships with GPs would help to prevent relapse to substance misuse and previous behaviours that had led to their incarceration. However, themes in post-release interviews suggested that

this perception was sometimes idealised or impractical, and several women did not access care as planned.

*I'm hoping that Dr X [however Dr X had retired] is gonna be sort of like a home base, you know, and once this healthcare plan is drawn up I just follow that guidance sort of thing. In here, where you're given directions every day, you know you get up at this time, you do this, you do that. So if I just take it like that ... it's got to be a day-to-day part of my routine to do whatever's on this healthcare plan then I'll be right.*

– Participant 34

### GP services: Expectations and experiences

Study participants expected their GP to have good communication skills, interest in the whole person and a non-judgemental and empathic approach; to be thorough, accessible and flexible with appointments; and to provide adequate consultation time. Many women reported that prior GP consultations did not adequately explore or address problems related to their incarceration and life challenges. Instead, they focused solely on their physical health, although they would have preferred a more holistic approach.

*I've known him [my GP] for years, sometimes it's ... just like, yeah, I had the golden staph and then he'd obviously realised [my injecting drug use] by looking through the notes but it was never talked about. It was never like, 'Are you okay?', you know, like counsellors do. – Participant 9*

*If they're your doctor, they should care about you and not only your physical health, but your mental [health] as well.*

– Participant 7

Several women had experienced being blocked from GP services and were anxious that this would happen again after release. At the most extreme level, some women had been previously barred from local GP surgeries because of their behaviours prior to incarceration and were not sure if there were any local practices where they would be welcome.

*A professional approach, yep. Instead of judging you because you're a criminal or a drug-user ... With my track record, from when I used to be on the [oxycodone], I'm barred from a lot of doctors' surgeries. As soon as they type in my name, I'm asked to leave. That's also hard too, even though I'm not the same person anymore. – Participant 8*

For some women, accessing GP care after release could be compromised by negative attitudes from GPs and practice staff.

*My GP on the outside ... was quite discriminative towards the fact that I was in custody and I had my daughter in custody. It's like he looked down on me ... pretty much saying that I had to get my act together and that, even though I had my act together – I had my own house – I was always, like, my daughter was always well looked after. I was there getting an immunisation needle for her. – Participant 19*

The stigma of imprisonment was seen as being linked with that of substance misuse, and poor interactions with GPs often revolved around this. In particular, prescription of medication that had potential for misuse could cause concern or conflict, either because they were being prescribed too freely by some GPs or because they were seen as being unfairly denied. Some GPs who did not ask about substance misuse or mental health were seen to lack skills or lack care, and thought to be ignoring what mattered the most. Other GPs were commended for their skills in managing prescription medicine abuse or for linking women to relevant services.

*He's not really that good of a doctor anyway, because I'll go there and he makes me feel like he just wants me to leave. So I'll go there and he doesn't sit down and talk to me properly. He just gets it over and done with. Because I've got a drug problem, he thinks I'm there to look for drugs. But I'm not ... I just – sometimes I just want to talk.*

– Participant 7

*When I tried to get [alprazolam] from [my GP], he was, like, no chance. He's good. He cares about people ... I used*

*to just go from doctor to doctor and get them. And they would mess me up.*

– Participant 23

## Discussion

There has been little research into the role of GPs working with people leaving prison, despite people commonly seeking consultations with GPs after release,<sup>1</sup> and mental, physical or substance misuse problems at release increasing the risk of recidivism.<sup>24</sup> Women in this study believed that having a GP was important when leaving prison and GPs should be non-judgemental, skilled and good communicators, consistent with known expectations of high-quality healthcare.<sup>25</sup>

In a large study of people leaving prison in the US, one of the main facilitators for engagement in community primary care was that 'health providers be pleasant'.<sup>26</sup> However, the challenges of providing effective healthcare for people leaving prison can extend beyond patient-centred consultations, given the complex disadvantage that often precedes incarceration, and the high health and social support needs at release.<sup>10,12,17</sup>

Engagement in healthcare by women after their release from prison can be difficult, particularly when there are other priority needs such as accommodation. Yet, the participants in this study considered such engagement to be urgent to harness motivation and prevent relapse, which is consistent with previous research.<sup>27</sup> Furthermore, continuity of care can be poor when people leave prison because of a lack of release planning and discharge communications being provided to GPs.<sup>28</sup> Notably in this study, poor continuity of care on leaving prison appeared to be further exacerbated by women not disclosing their incarceration or in-prison healthcare to GPs because they feared differential treatment and stereotyping.

In the view of the women who took part in this research, care is more effective when, as part of whole-person care, GPs acknowledge and actively consider the broad difficulties that these women face. However, this did not usually occur in the

GP consultations they had experienced. Some participants perceived this to be because of stigma and a lack of empathy or skills on the part of the GPs. However, this perception may also arise because GPs themselves want to avoid differential treatment and stereotyping. Fear of appearing judgemental or of making inaccurate assumptions when consulting with patients from diverse backgrounds can inhibit healthcare providers from acknowledging difference, which can be perceived as ignoring important aspects of a patient's life.<sup>29</sup> The evidence from our study suggests women leaving prison value enquiry about the antecedents to their incarceration to facilitate access to care they needed. Examples of potential care include GP prescription of opioid substitution therapy or referral to psychologists, domestic violence or gambling services.

Skilled GP management can greatly assist people leaving prison who have a history of substance misuse. Prescription drug misuse is an important clinical problem that may cause relapse or death for those leaving prison. There is particular danger immediately after release, as medications perceived to be misused are commonly ceased in prison. Consequently, women are at greater risk of overdose because of lowered tolerance. Additionally, other medications with potential for adverse events may have been prescribed in prison, including psychotropic medication.<sup>9</sup>

In this study, women reported being permanently barred from GP practices because of behaviours linked to prescription drug misuse, exacerbating their lack of access to care on release. Such behaviours are challenging symptoms of addiction. One management approach may be to put a time limit on decisions to discontinue care because of unacceptable patient behaviour, thus allowing potential resumption of future care within agreed boundaries. Practice protocols for the management of people requesting drugs of addiction are available to assist the safe management of people with substance

misuse<sup>30</sup> and encourage the therapeutic relationships that the women reported as important.

This study has limitations. The primary researcher was known to some participants to be a GP who worked in both community and prison settings. This may have decreased the participants' confidence in expressing critical views about GPs. While participants were purposefully sampled to explore the views of women with a variety of backgrounds, our findings are not necessarily transferrable to other women leaving prison.

## Conclusion

Women who are transitioning from prison to the community often have multiple health and social support needs. GPs' acknowledgement of, and assistance with, the broad issues that have an impact on the health and wellbeing after release are important. Skills in the management of substance misuse, promotion of continuity of care on exiting prison, good accessibility to GP care and understanding of the stigma of incarceration may assist women leaving prison to maintain and improve their health and wellbeing.

## Implications for general practice

- Active consideration by GPs of the life challenges facing many women leaving prison, such as homelessness, poverty, social isolation, family disruption and risk of relapse to substance misuse, is valued by women leaving prison.
- The early post-release period is a time of increased vulnerability for many women, and healthcare and added support through the GP may assist at this crucial time.
- Holistic care for people on release from prison may require facilitation of links to relevant community social support and health services.
- Confidence in the management of substance misuse and mental health problems by GPs is needed, including good management of prescription drug misuse.

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**RESEARCH WOMEN ON RELEASE FROM PRISON**


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- Continuity of care across the prison
  - GP interface can be disrupted by women choosing not to disclose healthcare given in prison through fear of differential treatment.

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## **Chapter 5: Medical homelessness and candidacy: women transiting between prison and community health care**

This article presents a qualitative analysis using the theoretical lens of candidacy to examine healthcare access for women in contact with the criminal justice system.

- ***Abbott P, Magin P, Davison J, & Hu W. Medical homelessness and candidacy: women transiting between prison and community health care. International Journal for Equity in Health. 2017;16(1):130.***

## RESEARCH

## Open Access



# Medical homelessness and candidacy: women transiting between prison and community health care

Penelope Abbott<sup>1\*</sup> , Parker Magin<sup>2</sup>, Joyce Davison<sup>1</sup> and Wendy Hu<sup>3</sup>

## Abstract

**Background:** Women in contact with the prison system have high health needs. Short periods in prison and serial incarcerations are common. Examination of their experiences of health care both in prison and in the community may assist in better supporting their wellbeing and, ultimately, decrease their risk of returning to prison.

**Methods:** We interviewed women in prisons in Sydney, Australia, using pre-release and post-release interviews. We undertook thematic analysis of the combined interviews, considering them as continuing narratives of their healthcare experiences. We further reviewed the findings using the theoretical lens of candidacy to generate additional insights on healthcare access.

**Results:** Sixty-nine interviews were conducted with 40 women pre-release and 29 of these post-release. Most had histories of substance misuse. Women saw prison as an opportunity to address neglected health problems, but long waiting lists impeded healthcare delivery. Both in prison and in the community, the dual stigmas of substance misuse and being a prisoner could lead to provider judgements that their claims to care were not legitimate. They feared they would be blocked from care even if seriously ill. Family support, self-efficacy, assertiveness, overcoming substance misuse, compliance with health system rules and transitional care programs increased their personal capacity to access health care.

**Conclusions:** For women in transition between prison and community, healthcare access could be experienced as 'medical homelessness' in which women felt caught in a perpetual state of waiting and exclusion during cycles of prison- and community-based care. Their healthcare experiences were characterized by ineffectual attempts to access care, transient relationships with healthcare providers, disrupted medical management and a fear that stigma would prevent candidacy to health care even in the event of serious illness. Consideration of the vulnerabilities and likely points of exclusion for women in contact with the criminal justice system will assist in increasing healthcare access for this marginalised population.

**Keywords:** Prisoner, Health care access, Health services accessibility, Substance misuse, Primary health care, Stigma, Candidacy, Prescription drug misuse, Qualitative research (3–10 keywords)

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## Background

Women in prison have poor self-reported health and high levels of social disadvantage, experience of trauma and mental health problems [1–4]. In Australia, women are usually in prison for less than 6 months, re-incarceration is common and the majority report problematic substance misuse [3–6].

Approximately 8% of people in prison in Australia are women and the imprisonment rate for women is increasing, currently standing at 33 prisoners per 100,000 female adult population [7]. Aboriginal and Torres Strait Islander women are over represented in prison, related to historical and systemic disadvantage, and these women are even more likely to experience serial incarcerations with short sentences or on remand [5].

Poor access to health care is common for women in contact with the criminal justice system. Substance misuse and struggles related to accommodation, socioeconomic disadvantage and family needs can mean health is neglected in the community [8, 9]. In a national survey of people in prison in Australia in 2015 [10], 48% of women reported they did not access the health care they needed when they were in the community. Additionally 15% said they did not access needed care in prison. The main reason reported for men and women not accessing care in either setting were reported to relate to choosing not to and lacking motivation to seek care. Additional barriers in the community were reported to be cost, substance misuse and competing priorities, while in prison, waiting times and health care not being available when needed were the other major barriers.

Although prison is often a time of compromised well-being due to the deprivation and loss of choice and control inherent to incarceration [11], it can also be a window of opportunity to improve health through access to overdue health care [12, 13]. Furthermore, the importance of managing health well across the interface of prison and community is clear. Leaving prison is a time of vulnerability, associated with high morbidity and mortality [14–16]. Health problems at release decrease the likelihood of successful community re-entry [15]. However, the ideal of post-release continuity of care can be disrupted by complex health and social support needs, relapse to substance misuse, poor health information transfer and difficulty in establishing connections with community healthcare providers [17–19].

In this study, we examined the ways in which women in contact with the prison system experience access to health care, particularly those with histories of problematic substance misuse. We focused on women who were exiting prison and aiming to re-establish their lives in the community, and explored their experiences of both prison and community health systems. Through understanding their experiences of healthcare access, healthcare providers and

health services may be better enabled to provide equitable care for this marginalised group.

## Theoretical framework

We used the conceptual framework of candidacy as described by Dixon-Woods and colleagues [20] to examine the women's healthcare access. The framework was first developed to examine equity of access to the United Kingdom National Health Service, thus providing a useful lens on how access is determined and enabled for people in disadvantaged situations. It emphasizes that healthcare access is contingent and subject to constant negotiation. Candidacy has been applied to healthcare access in diverse situations including people with intellectual disability [21], mental health problems [22], multiple sclerosis [23], young people seeking sexual health care [24], women who were sex workers needing primary care [25] and children with asthma [26]. It has not yet been applied to people in contact with the criminal justice system and people with histories of substance misuse in the research literature.

As explained by the candidacy framework, potential service users identify a health need and seek care (labelled '*identifying*' and '*appearing*'). After care has been requested, providers are seen as '*adjudicating*' the claims, deciding whether and in what way care will be delivered. Providers' judgements can be based on how deserving potential service users are and how well they will do if given treatment, which can disadvantage those in more deprived circumstances [20]. Limited resources, such as in prisons and hospitals, may increase adjudications of ineligibility by raising thresholds for what is thought to be a legitimate need. The candidacy framework also considers the '*navigation*' and '*permeability*' of services. To navigate services, potential users must be aware of them and have adequate resources such as transport and time. Permeability refers to the ease with which people can use services, including through feeling comfortable and having the capabilities to access the service. For example, services which align with user cultural values are more permeable and services with complex or rigid referral and appointment systems are less permeable.

## Methods

Given the ethical and practical challenges of recruiting people in prison as research participants, we report our methods in detail according to the Standards of Reporting Qualitative Research guidelines [27]. The principal researcher (PA), who undertook all interviews, was employed as a part-time general practitioner (GP) in the prison health service and also worked as a GP in the community.

## Setting

This study took place in 3 women-only correctional centres in New South Wales (NSW) Australia. Health care for

women in NSW prisons is delivered predominantly in state-owned correctional centres through a Board-governed network under the NSW Ministry of Health [28]. Health care is primarily delivered by general and specialist nurses [6, 29]. Women see GPs and other medical practitioners after being triaged by nurses to waiting lists. This differs from the community model, where GPs provide most primary health care and are directly accessible under universal health insurance.

### Sampling and data collection

We invited women who were within 6 weeks of release to participate in two interviews, firstly in prison and then 1–6 months after release. Women were eligible if they had been in prison at least 1 month, could be interviewed in English without an interpreter and if they had not received health care from PA beyond treatment for minor self-limited problems.

We identified potential participants through self-response to flyers, custodial lists and nursing and correctional staff knowledge of pending release dates. Women were invited by staff to meet with the researcher. Initially all eligible participants who responded to flyers were recruited. To ensure maximum variation, nursing staff subsequently identified participants who varied in age, ethnicity, custodial history, health status, healthcare utilisation and engagement in transitional support programs [30]. PA undertook the consent process with all participants, emphasising the voluntary and confidential nature of the research and that decisions to participate would have no effect on their health care or relationships with healthcare providers.

Interviews in prison were conducted in prison health clinics or general visitor areas under general surveillance of correctional officers outside the interview rooms. Post-release interviews in the community were by telephone. Participants received a payment of \$10 AUD into their in-prison account consistent with usual research practice in NSW prisons, or a \$50 AUD supermarket voucher, if in the community.

Interviews were semi-structured and questions explored needs, expectations and experiences of health care with participant-led content encouraged. Focused questions were added to explore themes identified in the emerging analysis [31]. Interviews were audiotaped and transcribed verbatim.

### Data analysis

Given that many participants spoke of experiences in multiple incarcerations, we analyzed women's pre and post-release interviews together as continuing narratives of their experiences of health care. We used inductive thematic analysis informed by constructivist grounded theory [31]. The constructivist approach was considered appropriate for this research as it encourages recognition

of, and ongoing reflection on, how researcher perspectives, position and privilege influence the analysis. PA undertook open coding on all transcripts concurrently with data collection. WH and JD independently coded a third of selected information-rich transcripts to enhance rigor and JD also provided interpretations arising from her Aboriginal cultural expertise. Focused coding and analysis proceeded with repeated reference back to the data, memo-writing, checking of the emerging analysis in new interviews with participants and research team discussions. We further reviewed the findings using the theoretical lens of candidacy to generate additional insights on healthcare access.

### Results

We interviewed 40 women prior to release and 29 of these women in a second interview. Their characteristics are described in Table 1. The majority of women had problematic substance misuse (35/40). The average duration of pre-release interviews was 28 min and second interviews, 22 min. The location of interviews and reasons for not participating in a second interview are shown in Fig. 1. Seven women returned to prison within 6 months of release. One woman died of an overdose.

Due to commonality of experiences across prison and in the community, findings from both settings are presented together. Women's experiences pertained largely to primary health care delivered by prison-based nurses and doctors and by community GPs, but also to hospital-based providers including Emergency Departments. The major themes related to the opportunity to access health care in prison and the constraints in that environment; being seen as legitimate seekers of care; the experience and fear of being blocked from care; and the services and personal capabilities which promoted access to care. These are explored below with illustrative quotes.

#### Prison as a health care opportunity

Despite the many disadvantages of being in prison, women also believed it to be an opportunity to seek overdue care for preventive health and neglected health problems. Although good health was seen as desirable in the community, it could be difficult to achieve. Increased focus on health in prison was possible because of decreased substance misuse, mental health treatment, time on their hands, fewer competing priorities and a desire to make positive life changes.

*When you come in here, is when you really are straight and you really want to know if you've got anything ... your head becomes clearer and then you do think about your health as you're getting older.*  
(Participant 4).



**Table 1** Description of participants (n = 40)

Characteristics	n
Age	
19–24	6
25–30	11
31–40	13
41–50	6
51–59	4
Background	
Aboriginal	16
Torres Strait Islander	1
Culturally and linguistically diverse <sup>a</sup>	6
Self-identified health issue of concern	
Substance misuse	35
Mental health	31
Physical health	25
Nil	2
Affiliated with formal release support program	
Transitional support by prison-based health linkage programs <sup>b</sup>	7
Residential transitional program	2
Residential drug rehabilitation	2
Community-based case management program	2
Custodial details	
Previous incarceration	
Yes	25
No	15
Incarceration duration	
Less than 3 months	4
3 < 6 months	6
6 < 12 months	21
12–24 months	9

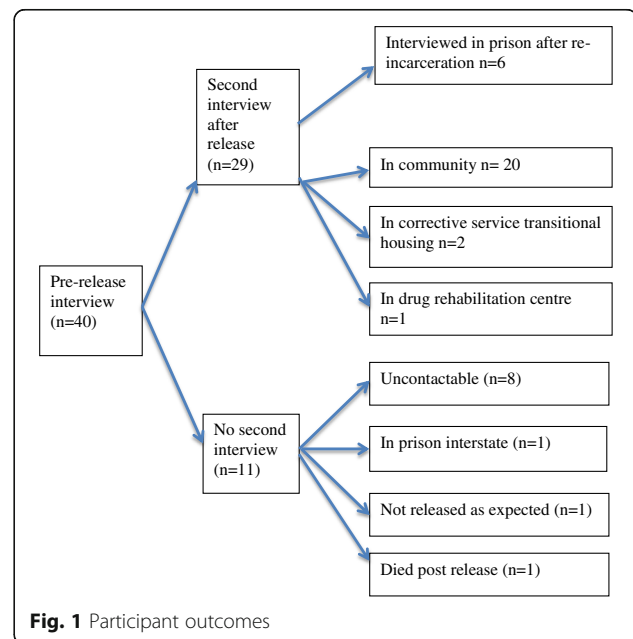
<sup>a</sup>Defined as speaking a language other than English at home

<sup>b</sup>Prison-community linkage programs in place prior to release. For 5 of 7 women case management continued for 1 month after release

Some women moved in and out of prison so frequently that they saw prison health services as their main provider.

*The only time I – I literally see doctors and that is in gaol... I'm not out long enough to get that appointment. (Participant 30).*

For some, health care in prison was better aligned with their needs than care they had experienced in the community due to prison clinicians' understanding of addiction and its comorbidities. Women believed community GPs lacked interest and skills in substance misuse management and therefore women were more likely to disclose and seek care for this in prison. Hepatitis C treatment in prison was

**Fig. 1** Participant outcomes

often mentioned as a healthcare opportunity and one which could create personal meaning out of being in prison.

*I wanted to take something positive out of this experience, 'cause it's been an ordeal - ... to address whatever I could to make the most of this time rather than to have it dead time. (Participant17).*

#### Constraints in prison care - 'the waiting game'

However, prison could also be experienced as a missed opportunity. The key systemic constraint was long and unpredictable waits for care. Several women referred to this as 'the waiting game'. Preventive health care delivered by nurses was effective and valued, but if women required access to a GP, secondary care or specialized investigations, waiting times could be substantial. Some women saw the waits as acceptable because care was ultimately delivered, particularly during longer sentences. Other women strongly felt waiting put them at risk of health complications, and waiting could be interpreted as a judgement that their problems weren't important, or as withholding of care. Their frustration was magnified by wanting to have care completed while in prison, as they believed they would not follow up in the community. Women with shorter sentences reported deflection of health care requests because investigations or specialist care could not realistically be achieved before release. Some women did not seek care while in prison because of previous experiences of waiting.

*I'm like, "Well I'm going home soon. Within a week or two I'm going home and now you see me." ... It would*

*have been so much easier than out there. Like, my life's full-on out there. (Participant 8).*

Another constraint was the limited range of care compared to the community. Usual medications, alternative therapies, dietary preferences and preferred healthcare options were not always available.

*You've got more options out there. You've got counsellors, um, you've got groups that you can go to. (Participant 32).*

### **Legitimacy and stigma in prison and the community**

Women perceived they were frequently judged not to have health problems worthy of receiving care and were denied health care both in prison and in the community. They described this as a battle to be seen as legitimate patients and experienced this as personal rejection, linked to the dual stigmas of substance misuse and imprisonment.

*The drug user could be having a leg hanging off and [the community GP thinks]'Oh well. She just got released from gaol. She's – she looks like a user, so couldn't harm her to wait another 10 min, 5 minutes, whatever. I'll just see this family'. (Participant 30).*

*You're not trying to get pills, you know, because you want them. It's when you're a genuine person and, you know, you - you think there is something wrong with you, you'd like to feel safe and feel like [prison healthcare providers] are there for you, and I just don't think they have been. (Participant 9).*

Being refused care at GP practices in the community could be experienced as a profound and traumatizing rejection. This could occur because of past behaviours leading to permanent barring from practices, or when GPs suspected prescription drug misuse. Some women believed that their requests for mental health care were misinterpreted by community GPs as drug seeking due to stigma and lack of GP skills. Waiting room signs aimed at deterring prescription drug misuse could reinforce perceptions of lower status and women reported a heightened sensitivity to the inclusion of past medical opinions in their health records.

*[Community GPs] treat you like, you know, you're nobody really... It has to be something in my file that someone's put in there that, straightaway, discriminating against me. (Participant 13).*

Participants who did not have a history of substance misuse perceived prison healthcare providers to be accustomed to managing women with addictions, and the

system to be set up accordingly, such that they also experienced lack of credibility in their claims to care. While their access to community providers was satisfactory, in prison they felt a need to differentiate themselves from other prisoners with substance misuse histories. At times this appeared to relate to their own negative attitudes to addiction. They reported that women with substance misuse problems took excessive healthcare provider attention, with providers disbelieving their own, more legitimate claims to care.

*The ones that are not druggies, they're the ones that really need help. (Participant 39).*

Some women felt that healthcare providers both in and outside the prison didn't believe them when they discussed their medical histories, and particularly their reported medications, requiring 'proof' before instituting treatment. They considered this to be emblematic of their ongoing struggle to be seen as 'legit'. One participant expected community GPs to be suspicious of any information she gave them, even official paper-based test results which needed follow up.

*Maybe they'll think [the test result] it's not legit or something... They would think it was fake... because it's got to do with prisons and criminals. (Participant 7).*

With such experiences over time, some women chose not to seek care in prison or the community because they assumed providers would not be receptive, or the care they would receive would be substandard. In the community, women could choose not to disclose their incarceration to avoid differential treatment.

*The doctors outside don't know that you've been to gaol. You don't have to tell them anything, you know what I mean. So there's no real stigma when you're out. (Participant 11).*

Conversely, access was facilitated by having a health condition which was prioritized by healthcare providers, such as HIV or schizophrenia. When seeking healthcare access these otherwise stigmatising conditions could reinforce women's status as legitimate patients both in prison and the community, increasing their ability to access services and receive continuity of care.

Some health services were considered inclusive of people with histories of substance misuse or incarceration, such as sexual health services and services which catered for marginalised members of the community. In Aboriginal Medical Services, women reported there was usually no stigma related to their status as ex-prisoners, however substance misuse could still be a source of stigma.

*[I go to] Aboriginal medical centres 'cause not many discriminate I don't think. I don't know. Well there's some do I reckon and some don't really. When you say you're a drug user and they blurt "huh," you know what I mean? (Participant 33).*

Despite anger at not being seen as legitimate when they believed care was needed, some women also acknowledged the complexity of prescription drug misuse, the danger this posed to them, and the prescriber's role in accurately judging the legitimacy of requests for medications.

*You get the doctor to write it for you anyway, which is not the doctor's fault. It's the person's fault for lying. (Participant 4).*

### **Being let down and blocked from care**

Women related experiences of feeling uncared for and let down by providers in prison and in the community. Women commonly reported not being called up to the prison clinic or contacted by community providers despite their attempts to seek care, interpreting this as withholding of care and a judgement they were not important.

*I want to be treated like a normal patient, you know, that wants to get something done... It's just gaol, it makes you feel like a number, you know. But, um, yeah, I guess, when you get out, you just, yeah, no-one really – no-one cares for when you get out. (Participant 7).*

Differential treatment was seen to have serious implications. Women feared the possibility of being blocked from care despite a serious health problem, fearing misdiagnosis, uncontrolled pain or life threatening illness. This was seen as a risk both when in prison, for accessing hospital emergency departments whilst a prisoner, and when accessing GPs and hospitals in the community.

*I said, "Oh, no I don't use drugs anymore," but what [the community GP] wrote was reflecting on me as a drug-user, and I was treated differently. Yeah. Especially when I went to hospital for my gallstones, one time, they wouldn't medicate me because they thought I was a morphine seeker... I wouldn't even know how to seek morphine. (Participant 8).*

### **Capabilities, self-efficacy and supporting access**

Capabilities for accessing both prison and community-based health systems related to family support, self-efficacy, assertiveness and knowledge of and compliance with the rules of different systems. Those who did not successfully meet formal requirements, for example by carrying their medical benefits cards or attending appointments, were

likely to conflict with providers. Some women described being vocal and determined in seeking care, changing providers when necessary until they received the care they needed.

*I had to change doctors because I was refused by two doctors in [name of town] when I got out of custody the last time... I have an alcohol problem - and I missed appointments... I think [the barring doctor] must've thought I was looking for drugs, pain medication or, you know, making it up. But I most certainly wasn't making it up. (Participant 3).*

Women who lacked confidence in their ability to manage their health often invoked their previous lack of success. Mental health problems, addiction, social isolation and poor life experiences and circumstances decreased their sense of self-efficacy. Self-efficacy was reported to be increased by existing personality traits and resilience, personal growth and overcoming addiction.

*If I can't look after myself, who's going to look after me? ... I've always known how to get help. (Participant 2).*

Some believed the passive role they assumed in prison decreased their confidence in accessing care after release. Others reported increased self-confidence at release related to overcoming pre-incarceration health problems or to positive healthcare experiences while in prison. Healthcare providers could be important in supporting women's self-confidence.

*I've addressed more issues since coming to gaol than I ever did ... I've taken a good look at all that has affected me in my life so it's been quite a positive experience coming to gaol... I can identify what's going on and I can get myself help. (Participant 40).*

*When you hear a good thing said about you by a doctor or a nurse ... it really means a lot, like, you know that it's true and, like, if they think that, then – you know what I mean? And it gives you a bit of confidence and a bit of strength. (Participant 21).*

Transitional programs, care coordinators or mentors were seen to be effective facilitators to care on leaving prison. They were valued for practical and emotional support particularly for women who had little family support. Linkages with community healthcare providers were also enhanced by transitional case managers who also acted as advocates and communication brokers.

*If you're unsure, and if you're not very good at speaking or whatever, like, to go to the doctors or communicating - or anywhere that you need to go, [the care coordinators], you know, they'll help you with that. (Participant 22).*

## Discussion

Women in our study experienced significant barriers to healthcare access both in prison and in the community, particularly related to their histories of substance misuse. Many sensed that they were not perceived to be legitimate patients with legitimate healthcare needs, which created a fear of being blocked from care when it was urgently needed.

### Candidacy for health care

The candidacy framework can be used to uncover vulnerabilities in access [20]. In our study of women in contact with the criminal justice system, concepts related to making claims to care (*identifying* and *appearing*) and judging of eligibility by providers (*adjudication*) were illuminating.

### Claims to care

Dixon-Woods and colleagues note that marginalised groups may be more likely to identify themselves as candidates for care through a series of crises rather than planned health care, resulting in high uptake of emergency care compared to preventive care [20]. This accords with findings from a large survey of Australian prisoners in 2009, who reported high uptake of hospital emergency department care in the community [3, 4].

The increased help-seeking behaviour seen in prison [10] has been suggested as linked to increased distress caused by incarceration [32]. However, in our study, the main motivator for seeking care was greater self-identification of candidacy due to decreased substance misuse, fewer competing priorities and a desire for positive life change. Women wanted to address overdue healthcare needs. Prison was seen as a healthcare opportunity, however one which could be missed due to system constraints.

In our research, prison health services were seen to perform well in providing preventive health care but were less able to deliver complete investigation or management of more complex health needs within the confines of a prison sentence. In prison, care is delivered within a correctional system which is ill-designed for healthcare delivery. There are time-limited windows of access within a regulated daily schedule, and a transient prison population serving sentences which may be short or include frequent movements between prisons [6]. After women *identified* a healthcare need and *appeared* to the prison health service, the rest of the prison sentence could be spent waiting for the health management plans made in those consultations to be implemented.

Waiting had a negative effect on relationships with prison healthcare providers and could be interpreted as providers withholding care or judging women's claims as unimportant.

### Relationships with healthcare providers

Women describe a struggle to establish their legitimate access to care both in prison and in the community because of negative provider *adjudications*. Prescription drug misuse affects therapeutic relationships both in prison and the community. Prison doctors perceive one of their key tasks is judging patient credibility [32] and the challenge in being considered a legitimate patient in prison has been described [33, 34]. In the community, stigma is compounded by healthcare provider discomfort and lack of skills in managing ex-prisoners or substance misuse problems [18, 35], which the women in our study readily identified.

Mental illness is a known source of stigma within primary care which can hinder help seeking [36]. In our study, the stigma of mental illness was not seen to impede healthcare access. Rather, women perceived their mental health care was suboptimal because they were not taken seriously by providers who suspected exaggeration related to their addictions.

Provider adjudication had a profound emotional meaning for many women in this study, imbued with expectations and experiences of rejection and withholding of care. In other studies of access using candidacy theory, service users could feel devalued by negative interactions with providers [23] and frustrated by delays in diagnoses [26] or ineligibility for programs [21]. However the fear of being denied future care for serious illness illustrates the heightened significance of provider adjudications to women with substance misuse and in contact with the criminal justice system.

Overcoming stigma may require women to be articulate and persistent both in and out of prison, consistent with the candidacy concept that negotiation between providers and users is a key factor in accessing care. The power imbalance between providers and patients can make negotiations challenging for patients in many healthcare situations, but even more so for prisoners, who have controls and limits on their choices in prison. Although prisons may aim to release more empowered individuals with control over their lives, agency may decrease in prison and persist after release, as part of the institutionalization that can be fostered by serial incarcerations [37].

### Experiencing 'medical homelessness'

A key aim of primary care is to reduce health inequalities by providing coordinated whole-person care, also an underlying principle behind the recent emergence of patient-

centered medical homes [38]. However, in the same way that women's lives are destabilized by lack of accommodation on leaving prison [39], our research also shows that they are destabilized by a lack of access to trusted and reliable medical care. Furthermore, women can be caught in an ongoing state of waiting and exclusion during cycles of prison and community-based health care, leading to a persistent state of transition and 'medical homelessness'.

Their medical homelessness is characterized by ineffectual attempts to access care, transient relationships with healthcare providers, disrupted medical management and a profound sense of exclusion from health care. Health system constraints, provider judgements that their claims to care are not legitimate and experiences of poor provider skills in managing addiction and its comorbidities contribute to a sense that they have no place in either prison or community-based health care. Experiences of rejection contributed to an ongoing state of inadequate care by engendering avoidance and helplessness in our participants.

At a practical level, women in contact with the prison system are a transient population. Women may frequently move between prison and community on multiple short sentences, a particular problem for Aboriginal and Torres Strait Islander women. Custodial decisions may lead to them being placed in different prisons or in unfamiliar community locations on release. Developing trusting therapeutic relationships with providers when displaced from familiar settings is difficult, and even more so if the basis for trust is eroded by providers who assume drug seeking, regardless of the presenting health problem.

Although control in the prison environment led to some women being more able to seek care, their custodial situation also created barriers which meant women could leave prison feeling their needs were not met. Women on remand are not eligible for all prison-based health programs and not all services available in the community are accessible in prison. If health care is not completed prior to release, initial efforts may be wasted by failures of continuity due to disconnected systems of care [9, 19] or by choices to not to disclose incarceration after release [18].

Women who have been in contact with the criminal justice system have often had poor life experiences including trauma, abuse and violence. Our participants' sense of personal rejection and of falling between the cracks of health care are likely to be based both on experienced events as well as on psychological vulnerability related to life trauma and experiences of being let down throughout their lives. Their deep and often lifelong disadvantage is perpetuated in the personal and structural barriers they face in accessing health care both in prison and the community.

#### **Overcoming barriers to care**

Skilled and empathic healthcare providers assist in overcoming barriers to care. Women in contact with

the prison system value community GP acknowledgement of, and assistance with, the broad issues that have an impact on their wellbeing, as well as skilled management of substance misuse and a non-judgemental patient-centred approach [18]. Exposure of students and trainees to people in prison or with substance misuse problems may decrease stigma and promote more effective health care for these people [40, 41]. This should include training in trauma-informed health care so that healthcare providers are aware of the psychological dynamics that may impact on the development of therapeutic relationships with people in contact with the custodial system [42]. This may assist providers to avoid re-traumatizing vulnerable patients, for example through words and actions which reinforce the sense of withholding care.

Family and other advocates can greatly assist access to care [21]. However, women leaving prison often lack social connectedness and support in the community [43]. Access may be facilitated by prison and community providers working together prior to women leaving prison to plan for care following release [44]. Care navigation through re-entry programs can provide instrumental and relational support to promote health care access [9, 30, 45]. Given the risk of medical homelessness, our study reinforces the importance of resourcing transitional programs to assist women to link with skilled, non-judgmental community care on release.

#### **Limitations**

The participants in this study had high reported health problems and needs particularly related to substance misuse. Although our participants also reported mental and physical health problems, their primary focus when reporting barriers to healthcare access revolved around current or past histories of substance misuse. Our findings are likely to be more transferable to other people who struggle with substance misuse, both inside and outside prisons. Although our participants were reflecting on their experiences as women within the Australian prison and community health system, the applicability of candidacy concepts suggests wider relevance for marginalised groups, particularly those caught in a pattern of serial incarcerations or of substance misuse.

The roles of the primary researcher and interviewer as a visiting GP within the prison health service and as a community GP were made known to the participants. Although this may have enhanced the research through shared understandings of complex health systems, it may also have inhibited participants from expressing their views completely, and led to lack of identification of findings which may be novel to an outsider. However, the fact that the women freely shared in their experiences of suboptimal care suggests that they did not feel constrained by a fear of further impacting on their access to care. The inclusion of researchers who are not involved in delivery of prison

health services and a cultural adviser assisted in ensuring the analysis was comprehensive and inclusive of multiple perspectives and interpretations.

## Conclusion

Women in contact with the criminal justice system, and particularly those with histories of substance misuse, can face difficulties in accessing health care both in prison and in the community. For those women who cycle in and out of prison, healthcare access can be conceived as an ongoing state of 'medical homelessness'. Their experiences of poor community provider skills in managing addiction and provider judgements, both in prison and in the community, that their claims to care are not credible may contribute to a persistent state of waiting and exclusion during cycles of prison and community-based care. Consideration of the vulnerabilities and points of exclusion for women caught in this cycle will assist in determining how to ensure healthcare access for this marginalised population.

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## Availability of data and materials

Data from this project will not be shared. Consent from participants was not sought to share the data more widely than for the purposes of this study.

## Authors' contributions

PA led study conceptualization and design, data acquisition and analysis and drafting the manuscript. JD contributed to data analysis and cultural mentorship. PM contributed to study conceptualization, data analysis, and manuscript revision. WH contributed to study conceptualization and design, data analysis and manuscript development. All authors read and approved the final manuscript.

## Ethics approval and consent to participate

Approval was obtained from the ethics committees of Justice Health & Forensic Mental Health Network (G31-13), University of Western Sydney (H10322), Corrective Services NSW (13/259026) and the Aboriginal Health and Medical Research Council of NSW (910-13). Each participant gave written, informed consent to take part in an interview and for the interview transcript to be used in this research.

## Consent for publication

Not applicable.

## Competing interests

PA is a visiting general practitioner and member of the Board of Justice Health & Forensic Mental Health Network.

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## **Chapter 6: Methods for conducting qualitative research with people in prison: a scoping review**

This manuscript is under review, having been resubmitted with recommended minor revisions. It is a scoping review of the literature on qualitative research with prisoners, with a focus on reported recruitment and data collection processes and the challenges of qualitative research in the prison context.

- ***Abbott P, DiGiacomo M, Magin P, Hu W. Methods for conducting qualitative research with people in prison: a scoping review. Submitted to International Journal of Qualitative Methods, 7.10.17 and minor revision resubmitted 14.2.18.***

### **Abstract**

Researchers undertaking qualitative interview and focus group research with prisoners must give specific consideration to the research methods they use due to the ethical and practical complexities affecting the conduct of research in prisons. In particular, there is explicit and implicit coercion risk and barriers to access, privacy and confidentiality. To examine how the challenges of conducting rigorous qualitative research with prisoners were handled, we undertook a scoping review of recruitment and data collection processes reported in qualitative research with prisoners. We searched for peer reviewed articles of qualitative interview and focus group research with adult prisoners, published in the English language from 2005 – 2017, using Medline, Embase, PsycInfo and CINAHL databases. There were 142 articles reporting on 126 studies which met the review inclusion criteria. Although not comprehensively reported in all articles, some authors detailed strategies for managing coercion risk, informed consent, participant recruitment, sampling, confidentiality and privacy, and working with prison-based intermediaries. Our findings highlight contextualised strategies for recruitment



and data collection and key considerations for researchers who seek to conduct rigorous and ethical qualitative research with prisoners.

### **What is already known?**

Undertaking qualitative research with prisoners is complicated by the nature of incarceration and the inherent control and power imbalance in this setting. The prison context increases risk both of coercive and of impeded research participation. The closed nature of prison and custodial processes affects the confidentiality and privacy of participants and limits on access to participants can make research challenging.

### **What this paper adds?**

Through scoping review methodology, we detail recruitment, sampling and data collection processes reported by researchers undertaking qualitative interviews and focus groups with prisoners, emphasising research published in the health literature. This provides insight into the challenges and the ways to undertake ethical, rigorous and successful qualitative research with participants who are in prison. Our review also highlights the importance of providing adequate methodological information when reporting such research and considering the effect of custodial surveillance, prison based intermediaries, and recruitment and sampling methods to allow understanding of how the prison context may have affected the research.

### **Introduction**

There are a number of choices and dilemmas in research when participants are prisoners, particularly when qualitative researchers seek to understand their perspectives and experiences through in-depth interview and focus group research. Limits on access, privacy and confidentiality, as well as implicit and explicit coercion risks, are commonly encountered during recruitment and data collection and can affect the ethics, rigour and success of the research.

Throughout history, prisoners have been at risk of abuse through research which was disproportionately high risk and utilised unethical study designs (Byrne, 2005; Coughlin, Lewis, & Smith, 2016; National Commission for the Protection of Human Subjects of Biomedical or Behavioral Research, 1976). Research with prisoners requires careful ethical consideration before proceeding. Nevertheless, prisoners have the right to participate in research that might benefit them and others, and qualitative research with prisoners can have substantial value. For example, there is a call for more health services research in prisons (Kouyoumdjian, Schuler, Hwang, & Matheson, 2015) and prisoner perspectives on their health needs and health care is vital to such research. Therefore, a balance between safeguarding prisoners and enabling research participation is necessary (Coughlin et al., 2016).

Coercion risk is clearly heightened in prisoner research given that prisons are research environments where the personal autonomy of prisoners is limited. A well-defined power imbalance exists between people in prison and those who may prevent or facilitate their access to research participation, namely prison authorities, prison healthcare providers and correctional staff. These authorities and the prison system itself exert power over all aspects of prisoner life, and prisons can be seen as agencies of disempowerment (de Viggiani, 2007). Prisoners may not feel they are in a position to refuse research requests and choices to participate may be influenced by their relative deprivation (Hanson et al., 2015).

There has been little systematic review of qualitative research methods undertaken in prison-based research. One review, which aimed to inform standardised data collection procedures for cross-study comparisons, found low reporting of data collection processes in research with violent offenders (Daniels, Angleman, & Grinnan, 2015). We were prompted to undertake this review by our own research with women's experiences of health care in prison (removed for blinded review), during which we reflected on the challenges of conducting rigorous qualitative research with prisoners, particularly related to recruiting participants and collecting data. We saw the need for guidance as to the ways qualitative researchers undertake research in prisons within the constraints and opportunities provided by that setting and the problematic history of health research with prisoners.

We followed the methodological framework of Arksey and O'Malley (Arksey & O'Malley, 2005) to undertake a scoping review of the extent and nature of participant identification, sampling, recruitment and data collection processes reported within qualitative interviews or focus group research with prisoners. We further sought to examine how such processes can be understood in the context of the challenges of undertaking qualitative research in prison, including coercion risk and barriers to privacy and confidentiality.

## **Method**

The review was guided by the following research questions: what research processes are reported in qualitative interview and focus group research in prisoners, in particular relating to ethical approval, participant sampling, participant recruitment and data collection? How can reported processes inform the planning and conduct of future research with prisoners? We approached these questions from our perspective as a research team comprising an academic general practitioner experienced in prison-based health care and research, and three university-based researchers with backgrounds in psychology and general practice and experience in qualitative methods.

*Eligibility criteria:* We included studies in which the primary research approach was qualitative wherein prisoners participated in interviews or focus groups. Peer reviewed articles in the English language published after 2005 were eligible for inclusion. This time period was chosen to allow scoping of an adequate sample of recent health literature. An initial search was conducted on 10/9/2015. A subsequent search, using the same protocol, was done on 15/6/2017 to capture recently published articles and the results were merged in the final sample of scoped articles.

We included research which was driven by qualitative inquiry, but excluded research in which qualitative data was collected through structured interviews, open ended survey items, or interviews and focus groups done solely for program evaluation. This distinction was made because such data is more distanced from the participant's perspective and subsequently, issues of confidentiality and coercion and the effect of the interviewers and researchers on the data are less marked. Other exclusion criteria

were determined according to participants, type of article and research methods (Table 1).

**Table 1. Criteria for exclusion of articles**

Excluded participants	<ul style="list-style-type: none"> <li>• non-prisoners (staff, ex-prisoners and family members)</li> <li>• young offenders (under 18 years)</li> <li>• other detainees (police custody, mandated substance misuse programs, military or immigration detainees)</li> <li>• prisoners interviewed in psychiatric or external health services</li> </ul>
Excluded articles	<ul style="list-style-type: none"> <li>• non-primary research</li> <li>• program evaluations in which qualitative inquiry did not extend beyond the program</li> <li>• not full research reports.</li> </ul>
Excluded methods	<ul style="list-style-type: none"> <li>• verbally administered structured questionnaires</li> <li>• interviews analysed quantitatively</li> <li>• clinical interviews</li> <li>• text analysis</li> <li>• studies in which methods pertaining to prisoners was not presented separately to that of other research participants</li> </ul>

*Information sources and searching:* We searched Medline, Embase, PsycInfo and CINAHL databases using the search terms ‘prisoner’ (detainee; inmate; offender; incarcerat\*), ‘prison’ (gaol; jail; penitentiary; custody; detention; correctional settings/ facilities/health services) and ‘qualitative research’ (qualitative studies; interviews in qualitative research; interviews as topic; focus group; focus groups as qualitative research). The terms were searched as key words, topics, MeSH terms and subject headings. Hand searching references for information-rich or linked research articles was done to maximise the yield of relevant papers. The search protocol was developed with a health librarian and tested against pre-selected articles. We made these database choices to focus our review on research published in the health literature given our interest in health research, however all articles elicited by the search protocol were considered in our review, including those which did not relate to health care, and the research topics were then tabulated for clarity.

*Study selection:* One reviewer (XX) screened titles and abstracts according to the inclusion and exclusion criteria. A second reviewer (YY) undertook a verification check on one third of randomly selected articles and a third researcher (ZZ) adjudicated contested articles. Multiple articles from the same study were reviewed together as they

often provided complementary detail on research methods, and the first published article from the series from the one study was cited for the purposes of this review (all included articles are reported in Appendix 1).

*Data extraction and analysis:* Two authors (XX and YY) extracted data into a spreadsheet using categories related to recruitment and data collection, informed by the Standards for Reporting Qualitative Research (SRQR) critical appraisal checklist (O'Brien, Harris, Beckman, Reed, & Cook, 2014). This checklist was developed by medical educators, but seeks to apply to both healthcare and non-healthcare related qualitative research. It was not used to critically appraise the included articles, rather to determine the data to extract from the articles, given the checklist comprised key components of methods which should be reported. An additional focus of our review was whether interviews were undertaken in conditions where privacy can be provided, as this is a particular issue in prison research. We tabulated study characteristics and extracted descriptions of methods, including excerpts of article text, into categories and undertook content analysis on the extracted data (Hsieh & Shannon, 2005). We defined prison staff as correctional officers, prison employees who were not involved in health care or those who were identified only as staff by authors.

## **Results**

Our first search generated 626 articles after duplicates were removed and our second search a further 167 articles. After screening abstracts, we undertook full text review of 474 articles, determining 142 articles reporting on 126 studies to be eligible for inclusion (Figure 1). Articles were mainly excluded because participants were not prisoners (primarily ex-prisoners, prison staff and family members) or methods were quantitative or open-ended surveys.

A summary of the characteristics of the included studies is shown in Table 2. In keeping with the databases searched, most articles reported on findings related to health and wellbeing and to health services. Most articles originated from the United States and United Kingdom and reported on interview studies.

There were a significant number in which methods were not reported in the detail recommended by the SRQR checklist (Tables 2-4). Approximately a third of studies had no information about approval by ethics committees or appropriate authorities or on recruitment procedures. In some studies, the limited reporting precluded clear understanding of how participants were identified or sampled. Statements on privacy during data collection or on researcher background were not usually included in published articles.

**Table 2. Study characteristics**

Characteristic		Number of studies
Geographic location	Africa	5
	Australia	9
	Canada	3
	China / Taiwan	3
	Europe (continental)	17
	India	1
	Iran	1
	Ireland	1
	Israel	5
	Jamaica	1
	New Zealand	1
	Southeast Asia	2
	South America	2
	United Kingdom	34
	United States	41
Data collection method	Individual interviews	87
	Focus groups, group interviews	26
	Both	13
Participant gender	Male	64
	Female	44
	Both male and female	15
	Transgender	1
	Not stated	2
Number of study participants	3- 20	46
	21-40	46
	41-100	25
	101-250	9
Topic	Health and social and emotional wellbeing (communicable disease, self-harm, parenthood, tobacco, substance misuse, mental health, health profile, social antecedents to incarceration, impact of prison on wellbeing, sexuality, health behaviours, bereavement, financial difficulties, resilience, identity, contraception)	62

	Health services, treatment programs and therapies ( <i>health services- general; programs -substance misuse, mental health, palliative care, sexual offending, HIV, reading</i> )	39
	Custodial issues and programs ( <i>Offending behaviours, violence, radicalisation, rioting, food, custodial programs e.g. cooking, animal visits, conjugal visits</i> )	22
	Education ( <i>health, higher education, reading</i> )	2
	Prison-based research	1
Ethics approval processes	Institutional review board, formal research committee	80
	Authorities ( <i>including prison boards and administrators</i> )	10
	Not stated	36

### *Participant identification, sampling & recruitment*

Findings related to recruiting research participants are presented in Table 3, including identification of participants, recruitment processes and sampling methods. Articles that are illustrative examples are cited. Where researchers have used multiple strategies, the studies have been charted in more than one category. Sampling strategies were determined by our review of the study methods as a whole.

**Table 3 Participant identification, sampling and recruitment**

Methods	Number of studies	Examples
<b>Strategies to identify potential participants</b>		
Custodial database or records	16	Bennett & Brookman, 2009; Chambers, Ward, Eccleston, & Brown, 2009; Fogel et al., 2014; Howerton et al., 2007; Plugge, Douglas, & Fitzpatrick, 2008; Shen, 2016; Smirnova & Owens, 2017
Health database or records	8	Chambers, 2009; Hassan, Edge, Senior, & Shaw, 2013; Khaw, Stobbart, & Murtagh, 2007; Newman, Cashin, & Waters, 2015; Topp et al., 2016
Program participation	19	Boothby, 2011; Bourke, Ward, & Rose, 2012; Carlin, 2005; Drapeau, Korner, Granger, & Brunet, 2005; Mahoney, Chouliara, & Karatzias, 2015
Linked research, researcher contacts	11	Alves, Maia, & Teixeira, 2016; Copes, Hochstetler, & Brown, 2013; Haley et al., 2014; Harawa, Sweat, George, & Sylla, 2010; Loeb & Steffensmeier, 2011; Plugge et al., 2008; Treloar, McCredie, & Lloyd, 2015; Wainwright, McDonnell, Lennox, Shaw, & Senior, 2017
Resident in certain prison section	6	Bennett, 2014; de Viggiani, 2007; Gilham, 2012; Harner & Riley, 2013; Kenning et al., 2010; Ralphs, Williams, Askew, & Norton, 2017

Response to flyers, posters	21	Blagden, Winder, & Hames, 2014; Cobb & Farrants, 2014; Condon et al., 2007; Dinkel & Schmidt, 2014; Easterling & Feldmeyer, 2017; Enders, Paterniti, & Meyers, 2005; Harner, Hentz, & Evangelista, 2011; Oliver & Hairston, 2008; Pritchard, Jordan, & Jones, 2014
Healthcare provider	20	Baker, Wright, & Hansen, 2013; Carlson, Sexton, Hammar, & Reese, 2011; Feron, Tan, Pestiaux, & Lorant, 2008; Guin, 2009; Hassan et al., 2013; Mangnall & Yurkovich, 2010; Soffer & Ajzenstadt, 2010; Yap et al., 2014
Prison staff	10	Hefler, Hopkins, & Thomas, 2016; Pinheiro, de Araujo, de Vasconcelos, & do Nascimento, 2015; Ralphs et al., 2017; Todrys & Amon, 2011; Weldon & Gilchrist, 2012
Prison manager / administration	3	de Guzman, Imperial, Javier, & Kawasaki, 2017; Loeb et al., 2013; Machado & Silva, 2012
Other prisoners	2	Andrinopoulos, Figueroa, Kerrigan, & Ellen, 2011; Magee, Hult, Turalba, & McMillan, 2005
Fieldwork contacts	5	de Viggiani, 2007; Earle, 2011; Kjaer Minke, 2014; Liebling & Arnold, 2012; Mjaland, 2015
Health screening	2	Chang, Huang, & Chen, 2010; Sondhi, Birch, Lynch, Holloway, & Newbury-Birch, 2016
Random selection	8	Cobb & Farrants, 2014; DeHart, 2008; Earle, 2011; Einat, 2009; Fogel et al., 2014; Rahmah, Blogg, Silitonga, Aman, & Michael Power, 2014; Smirnova & Owens, 2017; Topp et al., 2016
Attendees at non-affiliated meeting/event	3	Hefler et al., 2016; Schonberg, Bennett, Sufrin, Karasz, & Gold, 2015; Woodall, Dixey, Green, & Newell, 2009
External records	1	Schneider & Feltey, 2009
Not stated	14	
<b>Sampling methods</b>		
Convenience	59	Saraiva, Pereira, & Zamith-Cruz, 2011; Carlson et al., 2011; Easterling & Feldmeyer, 2017; Haley et al., 2014; Hatton, Kleffer, & Fisher, 2006; Machado & Silva, 2012; Mercer, Gibson, & Clayton, 2015; Schonberg et al., 2015; Soffer & Ajzenstadt, 2010; Weldon & Gilchrist, 2012
All participants in a program	9	Akerman & Geraghty, 2016; Billington, Longden, & Robinson, 2016; Boothby, 2011; Drapeau et al., 2005; Mahoney et al., 2015; Miller, Tillyer, & Miller, 2012; O'Grady, Rolvsjord, & McFerran, 2015; Walton & Duff, 2017
Purposive for selected characteristic(s)	15	Baker et al., 2013; Borrill, Snow, Medlicott, Teers, & Paton, 2005; de Guzman et al., 2017; Fogel et al., 2014; Garrett, 2010; Howerton et al., 2007; Kennedy, 2014; Marzano, Ciclitira, & Adler, 2012; Newman et al., 2015; Ralphs et al., 2017; Schneider & Feltey, 2009; Sondhi et al., 2016
Purposive for variation of characteristics or views	20	Alves et al., 2016; Andrinopoulos et al., 2011; Bowen, Rogers, & Shaw, 2009; Dinkel & Schmidt, 2014; Feron et al., 2008; Hefler et al., 2016; Machado & Silva, 2012; Plugge et al., 2008; Rocheleau, 2015; Smirnova & Owens, 2017; Wainwright et al., 2017
Snowball	4	Blagden et al., 2014; Carlin, 2005; Fogel et al., 2014; Magee et al., 2005
Sub-study of	4	Kenning et al., 2010; Loeb & Steffensmeier, 2011; Rocheleau,



larger research		2015; Wainwright et al., 2017
Theoretical	2	Djachenko, St John, & Mitchell, 2016; Harawa et al., 2010
Purposive at level of prison / prison section	9	Bennett & Brookman, 2009; Blagden et al., 2014; Condon et al., 2007; Decorte, 2007; Giertsen, Nylander, Frank, Kolind, & Tourunen, 2015; Kenning et al., 2010; Topp et al., 2016; Tzvetkova et al., 2016; Woodall, 2010
Random or quasi-random	6	Cobb & Farrants, 2014; DeHart, 2008; Einat, 2009; Fogel et al., 2014; Rahmah et al., 2014; Topp et al., 2016
Unclear	7	
<b>Recruitment strategies (excluding self-response to advertisement)</b>		
Researcher presented to group (including meetings for other purposes)	8	Aday, Krabill, & Deaton-Owens, 2014; Saraiva et al., 2011; Harawa et al., 2010; Harner & Riley, 2013; Lewin & Farkas, 2012; Staton-Tindall et al., 2007; Woodall et al., 2009
Individual invitation by researchers (including researchers in dual roles)	22	Alves et al., 2016; A. N. Chambers, 2009; Earle, 2011; Fogel et al., 2014; Gilham, 2012; Haley et al., 2014; Howerton A et al., 2007; Kennedy, 2014; Khaw et al., 2007; Mjaland, 2015; Pedlar, Yuen, & Fortune, 2008; Plugge et al., 2008; Reading & Bowen, 2014; Schneider & Feltey, 2009; Treloar, McCredie, & Lloyd, 2016
Healthcare provider invitation or facilitation	16	Baker et al., 2013; Carlson et al., 2011; Castro Madariaga, Gómez Garcés, Carrasco Parra, & Foster, 2017; Einat & Rabinovitz, 2013; Elisha, Idisis, & Ronel, 2012; Guin, 2009; Hassan et al., 2013; Havnes, Clausen, & Middelthon, 2014; Lee, Fu, & Fleming, 2006; Mangnall & Yurkovich, 2010; Ritter & Elger, 2013; Soffer & Ajzenstadt, 2010; Yap et al., 2014
Prison program leader/worker invitation	7	Billington et al., 2016; Borrill et al., 2005; Kerley & Copes, 2009; O'Grady et al., 2015; Sondhi et al., 2016
Prison staff invitation /facilitation	11	Decorte, 2007; Harner & Riley, 2013; Havnes et al., 2014; Muessig et al., 2016; Oliver & Hairston, 2008; Ralphs et al., 2017; Todrys & Amon, 2011; Tzvetkova et al., 2016; Yap et al., 2014; Zamani et al., 2010
Inmate peer invitation	2	Andrinopoulos et al., 2011; Enders et al., 2005
Unclear	43	
<b>Participant incentives</b>		
Monetary or equivalent	13	Ahmed, Angel, Martell, Pyne, & Keenan, 2016; Hatton et al., 2006; Howerton et al., 2007; Lewin & Farkas, 2012; Smirnova & Owens, 2017
Refreshments, cosmetics, clothes	5	Fogel et al., 2014; Oliver & Hairston, 2008; Plugge et al., 2008; Schonberg et al., 2015; Zamani et al., 2010
Group donation	1	Andrinopoulos et al., 2011
No	23	Akerman & Geraghty, 2016; Alves et al., 2016; Enders et al., 2005; Facchin & Margola, 2016; Harner et al., 2011
Not stated	84	

Participants were commonly identified via self-response to advertisement.

Advertisements could target all or selected prisoners using flyers, posters and letters instructing interested individuals to contact staff, researchers or to demonstrate interest by choosing to attend focus groups. A potential advantage of this method was that it avoided screening of participants by researchers or prison administrators, within the limits of institutional access (Moe & Ferraro, 2006).

In many studies, prison staff and healthcare providers advertised the research or identified potential participants through their own knowledge of eligible prisoners. At times they had dual roles as researchers (Kennedy, 2014; O'Grady et al., 2015; Treloar et al., 2015). Occasionally prison staff or healthcare providers undertook recruitment and consent on behalf of the researchers, including due to prison regulations (Borrill et al., 2005; Einat & Rabinovitz, 2013; Soffer & Ajzenstadt, 2010; Tzvetkova et al., 2016).

Inviting all the participants in a particular prison-based program was common. This could be a purposive sampling strategy because the research topic related to the program or its participants, but could also be a convenient means of access and opportunistic recruitment.

Researcher presentations to group meetings or direct researcher approach to prisoners, including by letter, occurred in some studies after gaining the permission of authorities. Ethnographic researchers who were embedded in prisons described recruiting prisoners by seeking volunteers, selecting from custodial records and convenience sampling (de Viggiani, 2007; Earle, 2011; Kjaer Minke, 2014; Liebling & Arnold, 2012; Mjaland, 2015).

Researchers could consult with prison staff or healthcare providers after identifying potential participants but before recruitment. This was done as part of purposive sampling (Dinkel & Schmidt, 2014; Howerton et al., 2007) or to exclude those with impaired capacity to consent or whose health may be put at risk by participation (Condon et al., 2007; Earle, 2011; Fogel et al., 2014; Mercer et al., 2015) or who presented a risk to researchers (Condon et al., 2007).

The most common sampling method was convenience sampling or sampling of a group sharing common characteristics of interest, such as all people taking part in a program. Custodial or health records or previous research records could be used to select

participants with certain characteristics, such as health conditions or offending behaviours, or for convenience and random sampling.

Purposive sampling for variation of selected characteristics or for information-rich cases was most commonly achieved through the assistance of prison staff and healthcare providers. Another strategy allowing sampling for variation was to undertake an initial survey, and subsequently determine who to invite to the qualitative study (Smirnova & Owens, 2017; Wainwright et al., 2017). Purposive sampling could also occur at the level of the prison or prison unit, such as through choosing prisons or units with different security classifications or purposes. Snowball and theoretical sampling were uncommon.

Coercion risk at recruitment was explicitly discussed by some authors (Earle, 2011; O'Grady et al., 2015; Woodall et al., 2009), including regarding monetary incentives (Howerton et al., 2007; Moe & Ferraro, 2006) and exclusion of participants with mental health vulnerabilities. Careful informed consent was emphasised by some authors (Guin, 2009; Kuo et al., 2014; Woodall, 2010). A well-articulated strategy used to decrease coercion risk and increase the reliability of informed consent was to require that a period of time, such as a day or a week, should elapse between the researchers providing detailed participant information and actual recruitment (Garrett, 2010; Howerton et al., 2007; Plugge et al., 2008).

#### *Data collection processes, privacy and confidentiality*

Key data collection processes are charted in Table 4. The location of research visits was often not specified, or noted to be 'a private room'. Specified locations varied, including education rooms, common rooms, prison wings or cells, visitor rooms, offices or health clinics. Recruitment by a usual healthcare provider in a usual clinical room, or choosing an accustomed or usually accessed setting for interviews, was reported to increase the confidentiality of research participation (Saraiva et al., 2011; Garrett, 2010; Guin, 2009; Plugge et al., 2008). Such a setting meant participation would not be noticed, which could be important for sensitive research such as related to HIV (Shalihu, Pretorius, van Dyk, Vander Stoep, & Hagopian, 2014). Decreasing staff awareness of the research could

also be achieved through minimising custodial escorts to research-related interactions (Copes et al., 2013).

**Table 4 Data collection processes**

		Number of studies
Interview location	Stated	51
	Not stated (beyond in private room)	75
Privacy during data collection	Yes	51
	No or semi-private	12
	Not stated	63
Interviewer characteristics / role (excluding statement of independence)	Any information	59
	No information	67
Audiotaping	Yes	84
	No	18
	For some participants/ prisons only	5
	Not stated	19

Some articles detailed the custodial involvement with research interactions. Custodial involvement included officer escort to the interview (Einat & Rabinovitz, 2013), unspecified guard supervision (Magee et al., 2005; Weldon & Gilchrist, 2012), video-surveillance (Harner & Riley, 2013; Lee et al., 2006; Supiano, Cloyes, & Berry, 2014; Yap et al., 2014), monitoring through windows (Smirnova & Owens, 2017), and an officer outside the closed room (Chambers, 2009; Dinkel & Schmidt, 2014) or out of ear shot (Condon et al., 2007; Copes et al., 2013; Moe & Ferraro, 2006; Todrys & Amon, 2011). Surveillance could also include officers periodically entering the interview room (Copes et al., 2013; Harner & Riley, 2013; Supiano et al., 2014). Some authors did not provide details but acknowledged the setting was semi-private (Harawa et al., 2010; Harner, Wyant, & Da Silva, 2017).

Some authors acknowledged or discussed the privacy and confidentiality implications of this surveillance. Confidentiality tended to be carefully reported in HIV research (Guin, 2009; Lee et al., 2006; Shalihu et al., 2014). Some authors reflected on how limits on privacy and confidentiality affected research data (Earle, 2011; Giertsen et al., 2015; Kennedy, 2014; Lee et al., 2006; Supiano et al., 2014) and on potential repercussions for

prisoners if data was collected under surveillance of prison staff (Miller et al., 2012; Plugge et al., 2008).

Participant confidentiality and privacy was most commonly reported to have been achieved through prison staff not being present during interviews or focus groups. Additional strategies used included institutional confidentiality agreements (Kjaer Minke, 2014), re-stating the rules of mandatory reporting during interviews (Harner et al., 2011; Mangnall & Yurkovich, 2010), avoiding collecting demographic information (Pedlar et al., 2008; Staton-Tindall et al., 2007) or signed consent forms (Copes et al., 2013) and otherwise maintaining anonymity during recruitment, data collection and dissemination of findings (Guin, 2009; Hatton et al., 2006; Havnes et al., 2014; Lee et al., 2006; Tzvetkova et al., 2016).

Confidentiality was of concern to some authors reporting on focus group research. Some reflected on its limits due to other prisoners participating in the groups (Harner & Riley S, 2013; Hatton et al., 2006; Kuo et al., 2014; Lee et al., 2006; Stöver, Casselman, & Hennebel, 2006). Focus groups were usually on topics which were relatively safe to talk about in front of peers and relevant to discuss in a group, for example program availability or smoking cessation. However, at times, focus groups explored potentially sensitive topics such as HIV, sexuality and intimate partner violence. Strategies to manage this related to informed consent and facilitation of the groups. Authors reported encouraging people to speak generally about sensitive topics in focus groups without personal disclosure (Hatton et al., 2006; Pritchard et al., 2014; Staton-Tindall et al., 2007) and designing study advertisements to allow people to attend groups because of general views on a topic rather than personal experience (Pritchard et al., 2014). Some researchers discussed the need to carefully ensure participant understanding of focus group methods and the limits on privacy and confidentiality in the prison context (Akerman & Geraghty, 2016; Kuo et al., 2014). A useful strategy was to hold meetings ahead of the focus groups to discuss their scope and process so participants were more comfortable and were less likely to disclose any sensitive personal matters (Akerman & Geraghty, 2016).

### *Interviewer and researcher characteristics*

Interviewer and researcher characteristics were usually reported briefly by gender, language or professional roles, such as ‘doctoral student’ or ‘prison nurse’, or in terms of experience in prison-based research (Dinkel & Schmidt, 2014; Harner & Riley, 2013; Hatton et al., 2006). Working in partnership with prisoners was part of some research (Hatton et al., 2006; Torre & Fine, 2005) and some reported on the absence of prior relationships with participants (Copes et al., 2013; Loeb et al., 2013).

It was uncommon for authors to include substantial detail on researcher positioning or the effect of the researcher on the research, though this was included at times (Cloyes, 2007; Moe & Ferraro, 2006). Reflections on the effects of interviewers or researchers on the research or on relationships with participants usually related to independence from the prison (Bourke et al., 2012; Bowen et al., 2009; Giertsen et al., 2015; Plugge et al., 2008). Some authors who were embedded within the prison in ethnographic studies emphasised the ways they were independent from the prison and why that was important (de Viggiani, 2007; Woodall, 2010). Some reflected on how their role as a clinician or program director currently or previously working in the prison system affected the research (Harner & Riley, 2013; Kennedy, 2014; O’Grady et al., 2015; Shalihu et al., 2014).

### **Discussion**

Commonly used qualitative research processes are likely to require adaptation and increased planning when participants are prisoners. In our review, a number of reviewed articles did not provide enough methodological details to meet recommended reporting standards for qualitative recruitment and data collection processes (O’Brien et al., 2014). Clarity on how research data may have been affected by recruitment and data collection processes is needed for understanding the trustworthiness of findings (Kristensen & Ravn, 2015). Adequate detailing of the recruitment and data collection processes is perhaps even more important for understanding the ethical conduct and credibility of the research with prisoners given the challenges to access and rigorous sampling, the explicit and implicit coercion risk and the heightened yet impeded need for privacy and confidentiality.

However a number of articles in our review provided details of and reflections on research processes which highlight some of the important considerations in prison-based qualitative research and could assist other researchers. Given the diverse and highly contextual nature of prison-based research across the world, it is not possible to create universal procedural 'guidelines' for researchers to follow, beyond the broad and frequently stated principles of research with prisoners. However, a detailed examination of procedures used in recruitment and data collection with prisoners will assist researchers to consider a range of options and whether they transferable to their own particular context.

### *Consent and coercion*

There is tension between minimising coercion whilst ensuring inclusion of prisoners in research. Research participation can bring benefits, such as access to treatments through clinical trials (Eldridge, Robinson, Corey, Brems, & Johnson, 2012). Equitable prisoner access to research participation is consistent with the principle of equivalence in prison health care (Charles, Rid, Davies, & Draper, 2016) and some qualitative research indicates that prisoners believe coercion risk is overstated (Copes et al., 2013). However, given the relative deprivation of prisoners and the power differential between prisoners and prison staff and managers, coercion risk goes beyond the explicit loss of choice and control in the prison environment. Decisions whether to participate in research can be affected by subtle incentives of access to services or resources and promotion of positive relationships with prison staff. Even the prospect of visiting researchers may be an attractive opportunity for social support and a break from boredom (Eldridge et al., 2012; Hanson et al., 2015; Johnson, Kondo, Brems, & Eldridge, 2015).

Informed consent is a critical safeguard of ethical research; however, particular care is required to ensure consent really is informed in the prison setting. Literacy, communication skills and cultural or linguistic barriers may limit understanding of participant information (Eldridge et al., 2012; Johnson, Kondo, et al., 2015; Pont, 2008). Limits to confidentiality in the prison setting may need careful emphasis, as highlighted in our review. Participants may conceivably disclose risk of self-harm or danger to

others. Furthermore, the requirement of mandatory reporting to protect the 'public good' must be clear to potential participants. For example, any security risk or disclosure of crimes for which the person has not been charged would be passed on to authorities (Cowburn, 2010; Quraishi, 2008).

A minority of studies in our review reported that monetary or other participant incentives were offered and a comparable number stated they were not given. Usually incentives were not mentioned and it is likely they were not available. Providing incentives to prisoners for research participation is frequently disallowed to avoid inducement (Hek, 2006; Institute of Medicine Committee on Ethical Considerations for Revisions to DHHS Regulations for Protection of Prisoners Involved in Research, 2007) and it is likely different jurisdictions have different rules. Recent arguments have been made that people in prison have the same right to receive recompense for their time and lost wages as other community members and that participant incentives for prisoners is a socially just practice (Matheson, Forrester, Brazil, Doherty, & Affleck, 2012).

#### *Access, sampling and research intermediaries*

In prison, there are time-limited windows of access within a regulated daily schedule and a transient population serving custodial sentences which may be short or include frequent movements between prisons. Custodial imperatives take precedence and participants may be unpredictably unavailable when researchers visit. This may be resource intensive and determine what research designs are feasible in different prison contexts and may lead to a choice to use opportunistic sampling, as was common in our review, instead of more rigorous sampling methods. Focus groups may be chosen to sample more participants quickly (Sondhi et al., 2016). Other mechanisms of promoting rigour in qualitative research may be impeded, such as through limiting opportunities to interview participants more than once or to check findings with participants. Working with prisoners as research partners is challenging and was only reported in a small number of reviewed articles, though collaborative and participatory approaches may be growing more common in prison research (Martin et al., 2016).



Importantly, there is particular reliance on prison-based intermediaries to bring researchers and participants together and multiple stakeholders need to approve the research and work together (Johnson, Kondo, et al., 2015). Researchers cannot usually make direct contact with prisoners, even after self-response to prison-approved advertisements. Use of intermediaries, also known as research mediators or gatekeepers, is common in all research practice and well known to have implications for ethics and rigour (Kristensen & Ravn, 2015). As highlighted in our review, prison authorities, staff or healthcare providers commonly mediate participant identification and recruitment. Recruiting prisoners to qualitative research without any prison-based mediator or researcher involvement would appear unlikely. As well as increasing coercion risk at recruitment, there is also significant risk of privileging certain prisoners to research participation. The risk that 'difficult' voices are silenced is thus high in prison based qualitative research and of added significance given the power differential inherent to incarceration.

The role of prison-based intermediaries and the control exerted on researchers and participants does require reflection when undertaking research in the prison context. In articles in this review, the predominant reflection from authors emphasised their independence from the prison. Researchers are likely to be concerned about research integrity and that their work will be censored by authorities (Byrne, 2005). This is a valid concern as there may be political threat to prisoners and to those working in prisons if research is on a sensitive topic or if they are cast in a negative light (Cowburn, 2010). Nevertheless, as reinforced by our review, when research is undertaken with prisoners, researcher independence is operationalised in a context of permission and facilitation by prison authorities, correctional officers and prison healthcare providers. Prison authorities and staff may be represented as a potentially malevolent force who need to be overcome by researchers (Bladt & Nielsen, 2013; Magee et al., 2005), even though the research has been facilitated by many prison-based mediators. Such reporting may result from qualitative researchers' epistemological standpoints or advocacy aims, but risks stereotyping of prison intermediaries.

### *Confidentiality and privacy*

In the closed system of the prison, confidentiality and privacy can be compromised during recruitment and data collection; a particular consideration in research on prisoners with stigmatising conditions. Researchers were particularly mindful of the effect of custodial surveillance. Correctional officers have a responsibility to be aware of the movements of inmates, staff and visiting researchers, with surveillance being a trade-off between researcher security and participant privacy (Eldridge et al., 2012). In our review, some authors detailed how they decreased the visibility of their research within the prison, such as by undertaking visits in frequently accessed areas where they would be many reasons for prisoners to be present or, alternatively, in areas that were infrequently accessed.

Focus group research in prison raises particular considerations. Focus groups are useful to seek views and experiences in a collective context and may empower people to be more confident in speaking out (Halcomb, Gholizadeh, DiGiacomo, Phillips, & Davidson, 2007). However, participating in groups with other prisoners and then continuing to live with them in the closed prison community may be problematic (Lee et al., 2006). Findings from our review suggest that focus groups in prison are best suited to topics which do not require personal disclosure. Care when informing participants about the proposed research and the limits of confidentiality in this method is needed.

Dissemination of research findings may have significant confidentiality implications, as highlighted by some authors in our review. For example, participants who have committed high profile offences may conceivably be identified if researchers are not diligent. This is a known risk for participants in qualitative research (Wolgemuth et al., 2015), but greater when participants are prisoners.

### *Reflecting on being a qualitative researcher in prison*

It is well recognised that the rigour of qualitative research is enhanced if the researcher's positioning in relation to those being researched is explicitly considered. This is particularly acute in the restrictive setting of the prison and the many possible power differentials between researcher, prisoner, and prison staff. In our review the

majority of articles did not include significant detail about the researchers or interviewers. Reflexive approaches to research undertaken in prison will also allow consideration of philosophical as well as pragmatic methodological challenges (Freshwater, Cahill, Walsh, Muncey, & Esterhuizen, 2012).

Researchers also need background knowledge of local prison systems and research regulations (Johnson, Brems, Bergman, Mills, & Eldridge, 2015; Kondo, Johnson, Ironside, Brems, & Eldridge, 2014), and of the prisoner population so that their research is inclusive of participants with differing perspectives and needs. Participants who are perceived to have vulnerabilities or to be harder to reach may be excluded from research, thus excluding many prisoners, such as those with mental health issues, cognitive disability or with limited proficiency in the local language. Prison-based research which includes Indigenous participants should be planned according to locally defined values, principles and requirements, including those of partnership, consultation and self-determination (Castellano, 2004; Smith, 1999).

### *Limitations*

The databases searched were health-related and literature from the sociology and criminology disciplines was less likely to be included in this review. Health journals are more likely to have a positivistic approach, include more articles which require less reflexive reporting, and have more restrictive word limits and decreased focus on qualitative rigour than the sociological literature. The majority of studies in this review came from Europe and the United States; different prison systems necessitate different approaches.

Finally, we only reviewed selected elements of methodological reporting directly relevant to our focus on coercion risk, access and risks to privacy and confidentiality during data collection. Other components relevant to research rigour were not examined in detail.

## Conclusion

Qualitative interview and focus group research with prisoners requires particular consideration of how participants are recruited and how data is collected within the limits imposed by the prison setting. Considerations include coercion risk, informed consent, participant identification and recruitment, sampling, confidentiality, privacy and working with prison-based intermediaries. Reflections and specific strategies reported by qualitative researchers as they consider and manage these challenges are highlighted. These may assist planning and reporting of qualitative research with people in prison.

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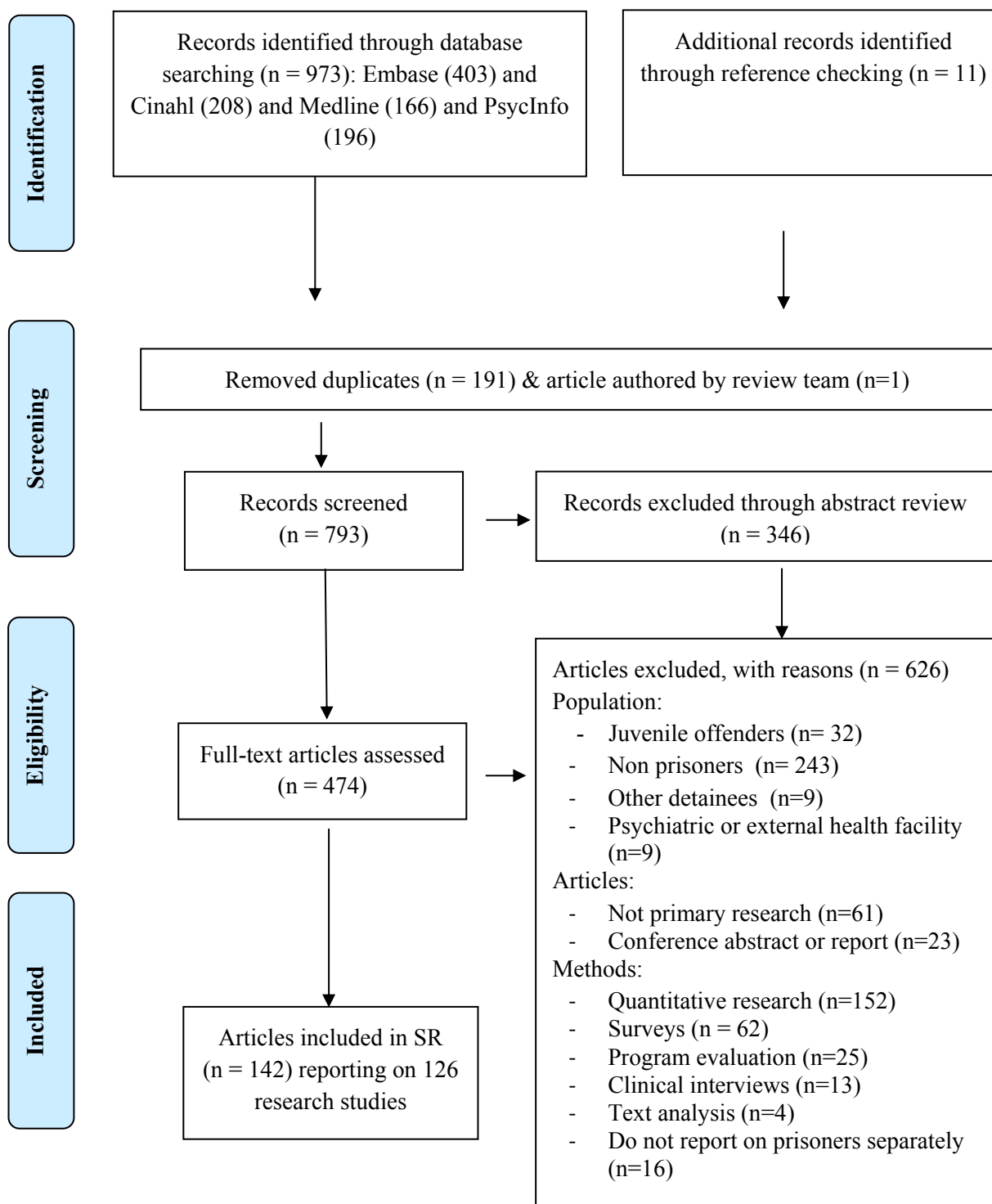
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**Figure 1**

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## **Chapter 7: Undertaking the research**

In this chapter, I return to and reflect on my research journey following the beginnings outlined in Chapter 1. This chapter includes a detailed contextual consideration of the strengths and limitations of the research beyond the specific strengths and limitations of its individual components addressed in the respective papers.

Ongoing reflection on my intersecting roles within the research was an important part of my goal to undertake worthwhile, rigorous and ethical research. In particular, I reflected on my dual identities as a clinician and a researcher and subsequently, the different ways in which I was both an insider and outsider. While my research was informed by being an “insider” clinician, my clinical role was illuminated by the “outsider” information gained from my research as it progressed.

I reconsidered some of my early suppositions as the research proceeded, changing my expectations of the research and of myself.

### **Reflecting on my work identity**

When I initiated this research I had worked as a GP in prison over many years, however I had never presented myself as a ‘prison doctor’, choosing other aspects of my working week to be my primary professional identity. Perhaps this related to my awareness that the professional standards of doctors who worked in prison could be perceived by others as inferior to other doctors(1). I aimed to provide equivalence of health care to my patients, while recognising the challenge of working within the confines of a custodial system which was not well suited to delivery of health care. I had not sought to influence prison healthcare delivery greatly beyond the team-based care we provided in our clinic.

My professional goals and capabilities changed during this candidature as I started to understand the broader picture of healthcare access for people in contact with the criminal justice system. My understanding of my patients deepened, and I increasingly saw my role within the prison health sector as a valuable one, with possibilities beyond that of a clinician.

I became more involved in promoting and investigating learning opportunities for medical students and GPs to interact with people in contact with the criminal justice system. I accepted a role in my professional body, the Royal Australian College of General Practitioners (RACGP), as Chair of the Custodial Health Special Interest Group, of which I had previously been a silent member. I was invited to and accepted a position on the Justice Health & Forensic Mental Health Network Board. Through the broadening of my clinical, academic and professional roles I was able to increase the avenues available to me to promote and improve the health of people in contact with the criminal justice system.

### **Considering the 'Insider-Outsider' Model**

As a practicing clinician, I had inside knowledge of the prison system and community-based general practice. Inside knowledge can increase understanding and the reliability of research(2). During the medical record review, this was quickly advantageous. The clinical and system issues were familiar both in expression and content. I also understood the subtext of the records, including prison or community factors, which were affecting healthcare delivery and continuity of care. This allowed me to not only recognise, but also to reflexively challenge and question the patterns I was seeing in the records, beyond a simple categorisation of health issues and clinical contacts. These patterns informed the qualitative work which followed. For example, I saw the sparseness of the information sent in by community GPs who had been nominated by women on entering prison as the ones who held their health information. It seemed the therapeutic relationships were neither strong nor proportionate to the health needs of the women. I noted the intense period of healthcare activity when people came into prison and the delayed follow up of planned care, such that a substantial number left prison without investigations or referrals having eventuated.

As the qualitative research commenced, my reflections on my insider status became more nuanced. I reflected on how I would position myself within the research. The concept that some researchers are insiders in the settings in which they work, while others are outsiders, has been highly important in ethnographic research, but is also important in other qualitative research. Early conceptualisations of the insider-outsider model presented it as a dichotomy, but more modern understandings acknowledge that the insider or outsider status of researchers is fluid and on a continuum, and that in fact a researcher can be an insider and an outsider at the same time(3, 4). Insider status is commonly sought by researchers in relatively closed settings, such as prisons, to allow greater research access and insights through increased trust and familiarity (5). However, the researcher is generally simply being allowed by prison authorities to share spaces with prisoners under restricted conditions. This immediately sets limits on the interactions which could lead to research findings. Insider perspectives are always relative and only partial(6).

As a GP within the prison system seeking to undertake research with women in prisons, I perceived myself to be an insider and outsider at the same time.

I was an insider within the prison system who had knowledge and connections in order to navigate its systems. I also saw myself as having inside knowledge of the health and social challenges facing women in contact with the criminal justice system after the many years of hearing their stories within consultations.

An outsider perspective was derived from my role as a GP practicing outside the prison. I was aware of what good primary care could look like in the community, and so was able to critically examine prison-based primary care from this perspective.

Despite insights into primary care and prison health, however, I was not a prisoner. I did not have personal experience of addiction and other challenges faced by prisoners, and I come from a relatively privileged background in the dominant cultural group in Australia. I may have had many other characteristics which showed me to the women participating in this study to be an outsider. Several participants told me that people without personal experience of drug addiction couldn't ever fully understand their

situation. At times women appeared to check my understanding of the information they were giving me, particularly related to their substance misuse, perhaps assuming I wouldn't be able to follow their meaning. In one particular interview, my outsider status was clearly stated:

If I was to sit with you on the outside, I probably wouldn't say I've been to jail.

But if I was to sit down with a group of mates and they asked where I'd been, I'd probably tell them, you know what I mean? Yeah. (Participant 15)

My status as a GP and as a prison staff member further increased my outsider status to the women I was interviewing. I was in a position of power in a system where they had little autonomy, and could be perceived as a supporter of a system they were criticising.

Authors of work included in the scoping review in Chapter 6 were qualitative researchers undertaking work with prisoners, and considering the issue of insider-outsider status in the way they presented themselves in their papers was illuminating. Some were in similar positions to myself and acknowledged and tried through their research methods to manage the power differential that existed between them and participants, sometimes reflecting specifically on their insider status(7). One, who was a music director, embraced her insider role as adding richness and intimacy to the research(8), and did not appear to have the same difficulties and apprehension regarding coercion risk as healthcare providers may have. For those who were positioning themselves as external to the prison, statements of independence were not accompanied by reflections on being an outsider. In this group of papers, largely from the health literature, the statements were largely aimed at stating that they were not being controlled or influenced by prison authorities.

At the beginning of the research my dual roles were, at the most basic level, that of a clinician within JH&FMHN and of a researcher at the University. At the midpoint of this research, after the data collection phase was finished but while analysis was continuing, I was invited to the added role of Board member for JH&FMHN, giving me the opportunity to contribute to the management and strategic direction of the organisation. This both resulted from my doctorate work, and affected it.

## **Reconsidering self-presentation and changing focus**

While I commenced the research with the intention of minimising the effect of my role as a GP within the prison sector on the research, I knew that I needed to be reflective as to the effect of that role on the research to maintain rigour and quality. I found this to be an aspect of the research where I had much to learn.

At the outset, I intended to focus only on release planning and post-release community-based care. My rationale was that avoiding discussion of healthcare delivery in prison mitigated the conflict between my research and my clinical role in the prison.

As the research progressed I adopted the constructivist grounded theory method as my approach, informed particularly by the work of Charmaz(9). Constructivist grounded theory draws on the original work of Glaser and Strauss(10). Glaser and Strauss sought to create a method which allows accessible and useful middle-range theories to be derived from qualitative data in an inductive, comparative and open-ended approach. The constructivist approach builds on this and addresses some of the criticisms made of the grounded theory method. It recommends acknowledging and reflecting on the researcher's position, privilege, perspectives and interactions, and rejecting assumptions that researchers can discover an external 'reality' through being a neutral observer(9). Studying this approach allowed me to recognise and accept the strong effect I had on the data. I recognised this effect had commenced at the point of conceiving the research and that I could not control this as much as I had thought.

My initial realisation related to the way I presented myself as an interviewer. Choices are made regarding which part of your identity to present when undertaking qualitative research, including those related to insider-outsider status, and how these choices will affect the research(3, 11). I originally hoped to use my university affiliation alone and not disclose I was a GP or that I was employed by JH&FMHN for fear of affecting the data unduly. I believed at that time it would be possible to present myself as a more neutral, or even supportive, party and hence obtain more authentic data.

Despite the research design, in which women for whom I had previously provided significant health care were deliberately excluded as potential participants, I recognised

that some would nevertheless be aware I was a GP within the prison health system. Furthermore, after the first two interviews with participants who didn't know me, it became clear women were going to want to discuss prison-based health care more broadly than I had anticipated or intended. I paused at this point to consider afresh how I was positioning myself in the research. I reflected on my role in the creation of knowledge, beginning with this early phase of data collection. I recognised that when I was asking participants their views on GPs, data was very likely to be affected by my identification of myself as a GP. Similarly, revealing my insider role in the prison system could decrease their confidence in frankly discussing prison-based release planning, even without discussion of other prison care occurring. Furthermore, they may have perceived their information to be less securely confidential.

I decided that this was an ethical issue, and in respecting the women's autonomy, I needed to advise that I was a GP employed by the prison health service during the informed consent process, thus allowing participants the choice to disclose information differently. Pragmatically, there was a chance that I would meet with them again in my clinical role. The fact that I felt uncomfortable at this thought demonstrated the ethical dimension of the situation and reinforced to me the need to disclose my insider role. Reflexivity is, for the most part, conceived as a mechanism of ensuring research rigour, however reflection on research processes can alert researchers to issues affecting both knowledge creation and ethical research practice(12). Given the power differential between a doctor in prison and women in prison, and the loss of autonomy and threats to confidentiality which are inherent research considerations in the prison system(13), stating my commitment to confidentiality during the consent process was not enough. My thinking about these issues, including the limitations of consent, drove and informed the later development of the scoping review on undertaking qualitative research with prisoners (Chapter 6).

Holstein and Gubrium(14) discuss that qualitative interviewing is an active process where the interviewer is inevitably involved in the construction of the data. They reject the assertion that there is any way that an interviewer can be seen as being outside that process, emphasising that interviewers are always active participants in qualitative interviews. They warn against my initial unrealistic thoughts that I should strive to be neutral and not 'contaminate' interview data by revealing my dual roles. My

understanding of the 'active interview' also freed me in my decision to identify my professional roles as parts of my identity which participants needed to know, while accepting and reflecting on how this subsequently affected the interview data.

My next realisations related to the interview schedule. When I designed the semi-structured interview guide, I intended the initial questions on healthcare delivery in prison to elicit background information to inform more detailed exploration of post-release healthcare needs and release planning (Appendix 2). When conducting the initial pre-release interviews, the veering of the interview to in depth discussion of healthcare delivery in prison nevertheless seemed inevitable. As I tried to limit discussion of prison health care to release planning I suspected that the 'structure' within my semi-structured interview had become a control mechanism which censored the participant from saying what they wanted me to hear.

At first the fact I was reluctantly eliciting extensive data on prison healthcare access and delivery made me uncomfortable, bringing my potential conflict of interest into sharp focus. I wondered if some women perceived me as a potential 'whistleblower,' now that I had clarified I was a prison-based GP, hoping I would use their information to unveil deficiencies at the local health clinic level. This felt like a further responsibility. I also reflected that I had asked them what they thought they needed from their health care, and given they were in prison, prison-based health care was an understandable priority.

Charmaz uses the term 'intensive interviews' to describe individual interviews done by grounded theorists. She notes that an interactional space is opened during such interviews, to which participants and researchers both bring their own priorities and concerns, and these are not always compatible(9). As the research progressed, I accepted that my research was about access to health care in prison as well as in the community. While I continued to use the same interview guide, I recognised that the first question about health care in prison ('Have you had any health problems / been receiving medical treatment in prison?') was an important question. Instead of collecting a list of health conditions and activities as I had envisioned, I probed the women's experiences and expectations of prison-based health care delivery. I also used the second interview with participants to follow up the prison health care themes as they developed.



My initial disquiet was resolved as I came to see that the goals of the participants and my goals as a researcher were aligned. We both wanted to identify ways in which prison health services could better meet the needs of women in prison, including as they were approaching re-entry into the community. Now, I see it is obvious that the effectiveness of healthcare delivery in prison is a strong factor in the care that is needed on release, and on how and why continuity of care occurs.

## **Managing multiple roles and role conflict**

There is little published literature specifically reflecting on the position of researchers who are also clinicians within prisons. In publications, reflective considerations show that researchers are aware of the increased power differential associated with dual roles (Chapter 6), and in particular of the risk of coercion to participate and its effects on the data(7, 15).

Along standard lines, I sought to manage the risk of coercion by recruiting participants indirectly via flyers and intermediaries, including both prison nurses and correctional staff, so that women were not put in the position of being asked to participate or being screened for suitability by me personally. However, I encountered a difficulty in this process which brought home to me how practically challenging it can be to avoid inducement to research and to manage dual roles in the prison setting. Women sometimes sought medical care from me after the conclusion of research interviews. In some cases, such requests were introduced by a complaint that they were on the waiting list to see a doctor and it was taking too long, or they preferred a doctor's opinion to the prison nurse-led care. Although I tried during the consent process to be clear on the separation of my roles, this remained a complication in my research and of my ethical decision to disclose my dual roles. My name was on the flyers and I had been a visiting GP in the prison health service for a number of years and so was clearly identifiable to many women, even before the consent process.

While organising care to be provided by another clinician was not difficult and I was confident that no medical harm occurred by declining such requests, it could be an

uncomfortable experience to do so. It was not easy to see a GP in the prison; women were required to be triaged by a nurse to be accepted onto the GP wait list. Thus, participation in the research could be seen as an opportunity to access care which was otherwise restricted. The relative deprivation of people in prison increases the potential of coercion to participate in research, including through offering an opportunity for relationship building between people in prison and staff(13). These requests from my participants required some sensitivity, and it further brought the potential conflict of my roles into the light.

I reflected on how this may have affected the data and the research findings, such as by attracting women to the research project who already felt they were having trouble accessing health care or women who didn't feel satisfied with the care they were receiving. I further recognised that this situation was particularly poignant as I had just interviewed women on the topic of healthcare access. Although I had been aware there were waiting lists and barriers to care prior to the research, I had not fully recognised the depth of feeling from some women that these were perceived as evidence they were second-class citizens. Furthermore, through the research I increasingly understood how the women's personal stories of neglect and trauma had led them to expect that their needs would not be met and that they would be let down by others.

Practitioner researchers need to reflect on their duty of care as well as consider the ethical questions within their research that derive from their role as providers(16). After women told me within the research space that their requests for health care were blocked because they were not seen as legitimate or important, I could then be asked to move into the healthcare provider space after conclusion of the interview. As a result I could be seen to be blocking their care by failing to provide the health care they requested because they had participated in the research. I handled this as best I could through the protective mechanism of informed consent, specifically discussing in advance the boundaries and purpose of the interview, and through facilitating their health care through other GPs or nursing staff. I justified maintaining my position as a researcher in terms of the value of my insider understanding of context and the value of my access to the means to drive future, longer term solutions through the research. Nevertheless my reflections on this role conflict echoed the warnings of Pillow: that reflexivity within research is not always comfortable(17). It could be said, however, that

my reflections led to my identifying and valuing the women's disclosure as a key finding, which became central to the publication on 'Medical homelessness' (Chapter 5) and its dissemination in other fora.

As I took on the role on the Board, I wondered if I would find a challenge in managing organisational expectations, and whether they would clash with the expectations of my participants. Although I have perceived no threat to research integrity to date, largely because of the clear Board focus on strategy and not operational matters, this is certainly a potential role conflict upon which ongoing reflection is necessary beyond the submission of this thesis.

### **Checking findings back**

Reflexivity allows researchers to monitor tensions between the involvement and detachment of the researcher(18). Assumptions, motivations and constraints were inevitable in each of my various roles requiring specific reflection as data analysis proceeded. Familiarity and assumptions can affect research findings and the quality of research(6). I used a process diary and included a second interview as part of the study design in which I carefully checked emerging themes with participants.

Another main strategy to check assumptions was to seek multiple different perspectives on the analysis(19). The Aboriginal cultural mentorship and the external perspectives of my two supervisors, neither of whom worked in the prison health system, were highly valuable. I also checked results with peers and experts both in prison and outside prison in formal and informal meetings.

I did not have a mentor with lived experience of incarceration, which is something I would plan for in future research. Instead, a few women had said they would be happy to be contacted for a third interview with the purpose of reviewing the more complete analysis, which I thought would increase its trustworthiness. No particular time frame was set, however a further year had passed before I was at that point. However, due to an experience with one participant I decided not to approach any women who had undertaken the research to check the analysis beyond the second interview. I sought a

meeting with this participant in her community health care setting, having selected her as the person who had seemed most interested. I described to her that we would look at the broad themes from the research, in the way we had previously discussed. After initially appearing welcoming, after I described the themes relating to disrupted healthcare access and the stigma of substance misuse, she started to look uncertain. She said she was trying to set aside her past experiences. It appeared this would be a difficult conversation for her, and I reflected on her situation as a woman who had multiple experiences of incarceration and loss and of problematic substance misuse. It seemed that the research did not lend itself to safely engaging with the participants in this way, and even discussing these themes carried a risk of re-traumatising this participant.

### **Including women from culturally and linguistically diverse backgrounds**

In managing the scope of the qualitative research I decided not to include women whose English proficiency was limited to the extent that interpretation would be required for the interview. This made me uncomfortable that I could be excluding some women who may have wanted to participate. I was aware of the multiple layers of cumulative marginalisation that exist for women in prison from a cultural background which differs from the mainstream and who have limited English proficiency.

I was also aware that it was important to understand the experiences and perspectives of women from culturally and linguistically diverse (CALD) backgrounds when examining healthcare delivery for women in prison. Approximately 20% of women in prison in NSW are from a culturally and linguistically diverse background, consistent with the Australian population(20). We defined CALD status according to the Australian Bureau of Statistics definition of people speaking a language other than English at home(21).

CALD women in prison can face isolation, discrimination and impeded access to prison-based service, particularly if they have limited English proficiency(22-24). There has

been limited research on this population of women, who can be seen as having been overlooked and unheard(25).

I intended to seek CALD women who were proficient in English for inclusion in the qualitative study. The importance of this was further heightened after the medical record review, when we identified that CALD women had lower odds of health information being requested from a community GP when coming into prison (Chapter 3). I questioned if this was related to the stigma of incarceration, resulting in women declining to give permission to the prison to contact their previous healthcare providers, and if post-release transition was also affected. At release, women from CALD backgrounds were just as likely to have evidence of information transfer or continuity of care arrangements in their medical records. However this may not have translated to actual continuity of care. Fear of differential treatment can lead women to choose not to disclose incarceration on release (Chapter 4) and this was feasibly a particular problem in some CALD communities given the findings presented in Chapter 3.

I had tried to purposively recruit and interview women from Chinese and Vietnamese backgrounds as these were the largest female CALD populations in my prison research study setting(26). However, I found that most women who responded to initial invitations to discuss the research then declined to participate as they did not want post-release contact, which led me further to believe that this was an important issue to understand. While I stated I did not need to collect post release details or to undertake a second interview in that case, this method was still described on the participant information sheet, and appeared to prevent participation. Ultimately, two young women of Vietnamese background chose to participate, but neither was available for a post-release interview. Four of the five other participants of differing CALD backgrounds described themselves as lacking strong ongoing connection to a CALD community. I didn't feel I had explored the ways in which incarceration and leaving prison were different for women of CALD backgrounds.

I decided an additional research project was needed to address this gap and sought an academic GP Registrar to lead the project. We modified the methods to include interpretation and to include focus groups, and we removed the post-release interview component of the original research. There was no difficulty recruiting to this modified

study, which is ongoing and appeared to allow women to be more empowered and enabled to speak and to increase their perception of confidentiality.

## **Being a Supervisor**

I found being a Supervisor of an academic GP Registrar on a prison-based research project to be a personal learning experience. In particular, it prompted additional reflection on my insider role and how that affected the way I supervised, and its potential impact on the Registrar and our joint research. I had been supervising junior researchers for several years, including the registrar I subsequently approached regarding this research idea, but had not supervised anyone in prison-based research.

There were advantages for the Registrar in that I was able to add her project to my work, and that I was a trusted insider at the prison health service. This meant she could undertake research which would otherwise not have been achievable within her time-limited academic post. On a pragmatic level, my own project had taken 1 year to complete a complex ethical review process through four ethics committees, whereas the process for the new project was comparatively easy. I was also able to advise on the specific context of prison research.

Crucially, I was able to facilitate her access to the prison through the appropriate approaches and endorsements with relevant authorities. A recognised role of a supervisor is to assist in gaining entry into closed communities(27). During the negotiations for the Registrar project, I was told by a supportive manager that while it was an unusual arrangement, I was trusted to provide the required supervision. Although I was familiar with the skills and sensitivity of the Registrar and happy to proceed, the added responsibility of supervision in this context was clear and I wondered if there was a subtext of warning in this compliment. I reflected that, within the prison health service, external researchers were sometimes said to use their facilitated access to 'gain glory' rather than making positive contributions to healthcare standards and work in respectful partnership with the prison.

After undertaking the scoping review of methods in qualitative prisoner research (Chapter 6), I reflected further on the dilemma facing prison health authorities. While seeking to facilitate research for the benefits it brings, including improved quality of care and academic standing(28), prison authorities and staff also must tolerate a risk of stigmatisation and negative publicity regarding prison health services and prison healthcare providers on release of the findings. Authors of papers included in the scoping review commonly identified their independence from the prison, before proceeding to elucidate their research which focused on prison system deficiencies. This is not unexpected, given that critical thinking is an integral part of research and identification of potential improvements is the main reason for undertaking health service research. Qualitative researchers in other settings identify that strong relationships with managers of the research setting may be problematic and a source of bias, and care and consideration is needed(19). In the prison setting, there may be additional sensitivity because prison health services are already stigmatised. People who work in prison settings can be seen as substandard clinicians(1) who support substandard healthcare delivery, and prison health care is a field which still seeks validation(29).

My role as a Supervisor needed to be examined for the disadvantages it could bring to the Registrar and to the research. Firstly, I needed to consider how my dual affiliations may have affected my supervision and the trustworthiness of the research. It was important to ensure I didn't censor my co-researcher's work. Secondly, I reflected on how my insider status in a relatively closed setting could compound the power I already had as a Supervisor and overall research lead, and negatively affect the quality of the research and the Registrar's learning and independence. Familiarity with the research topic can negatively affect research value by leading to more superficial findings and findings which are grounded in assumptions rather than the data itself(18). I found at times in our discussions I would assume the role of a co-researcher with a more privileged understanding. This created a risk that I would dominate our discussions and emerging analysis and undervalue her perspective, thus decreasing the rigour and trustworthiness of the research.

Another important aspect of the supervision is anticipating the secondary trauma that the new researcher is likely to experience when undertaking intensive interviews with

women in prison. I was used to hearing their stories, including of their life trauma, the pain of separation from their children and the challenges of prison life. Managing secondary trauma is an integral part of the work of a qualitative researcher working with people in prison(30). As an insider there is a risk that this will be overlooked due to one's own familiarity and coping strategies, leaving the learner without appropriate supervisory support in this important area. Conversely, the learner may bring revelatory insights which would not have been identified by the seasoned insider. The supervisory relationship can thus become a collaboration that enhances and informs the research, provided the benefit from mutual learnings is acknowledged by the supervisor.

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## **Chapter 8: Discussion and conclusion**

### **Summarising the research findings**

As demonstrated in this research, challenges to health care access and service delivery in both prison and the community contribute to the disadvantage of women in contact with the criminal justice system. In both settings, improvements are needed to improve health and wellbeing for women leaving prison. By considering the commonalities and peculiarities of access barriers in both the prison and the community setting, this research provides a valuable new perspective on these women's healthcare experiences as a whole. This allows broad consideration of multiple opportunities for positive change across the interface between prison and community health services.

### **Improving the health of women in prison**

Although imprisonment can cause further harm to women who are already disproportionately disadvantaged(1), there is also evidence that some women report personal growth from this time(2). Positive identity transformation is possible in a prison setting if appropriate, respectful, capacity building opportunities are in place(3).

This accords with the research findings (Chapter 5) that some women perceived that prison had 'helped them', such as through health gains, overcoming addictions and developing supportive relationships with healthcare providers. Correspondingly, many women had high expectations of the health gains they could make in prison and actively sought care on entry to prison. While incarceration was difficult for most, it was also seen as an opportunity to address health needs which had been unmet in the community, to use their time in prison productively, and to increase their wellbeing in preparation for release. The medical record review supported the qualitative findings, evidencing an intense period of multidisciplinary healthcare activity when women first

came into prison (Chapter 2). However, commonly, not all components of a woman's planned care were able to be completed within the time-span of a prison sentence.

The negative effect of waiting and incomplete care on the women's morale is one focus of the analysis of healthcare access presented in Chapter 5. The 'waiting game' was discussed by the women as a central feature of prison health care. An underpinning ethical principle of prison health care internationally is equivalence of care(4).

However, placing patients with health needs on the same external hospital waiting lists as community members, or on long prison-based waiting lists for care, does not result in receiving equivalent care. The fewer service options for people in prison, the fragmented care caused by repeated incarcerations, and the under-resourced prison and hospital systems may mean that placing prisoners on long waiting lists becomes equivalent to declining to provide the care at all.

Lack of timely health care was one reason that women could perceive they were neglected in prison. Another reason was their past substance misuse, which they felt marked them as not being legitimate patients both in prison and in the community. While the women considered prison health services to be well set up to provide treatment for substance misuse, they also perceived they were not always taken seriously and could experience misdiagnosis and under treatment (Chapter 5).

Review of healthcare delivery in prison through the medical record review suggested another area of concern in healthcare in prison, namely, the lack of screening and history taking regarding ear and hearing health (Chapter 2). This is notable given the link between poor hearing and poor progress in the custodial system, and the high proportion of prisoners who are at high risk of hearing problems related to their Aboriginal and Torres Strait Islander background(5). Failure to consider hearing during health assessments is also outside recommended practice in Australian prisons where there are high numbers of Aboriginal and Torres Strait Islander people(6).

### **Accessing health care in the community**

In Australia, GPs are considered the central agents of healthcare coordination and access within the health system. Therefore situating this research in the Australian

general practice context has highlighted shortcomings of the health system as regards women leaving prison.

A particularly important finding regarding healthcare access after release was the women's perceptions that healthcare providers do not provide equivalent care to people for whom substance use is a current or past health problem (Chapters 4 and 5). Concerns were expressed about stereotyping of people with histories of substance misuse, as well as lack of GP skills and confidence in the management of substance misuse. The dual stigmas of substance misuse and incarceration were strongly linked and could prevent disclosure of incarceration and of health problems which could point to their incarceration or substance misuse. Stigma related to substance misuse was also seen as a barrier in Aboriginal Medical Services.

GPs were not perceived to provide the holistic care or support needed by women leaving prison, rather, their physical ailments were considered to be the main role and interest of GPs (Chapter 4). It can however be argued that the scope of general practice is much broader than physical disease. The current campaign by the Australian professional college for general practitioners, the Royal Australian College of General Practitioners (RACGP), aims to increase awareness of accredited GPs and has the slogan "I am not *just* your GP. I am your specialist in life" (7). Although a somewhat controversial campaign, it is clear that this promotes a view of Australian GPs as providing whole person care. In the case of women leaving prison, it follows that attending to the whole person requires attention to many facets of their life, including their social and emotional wellbeing and supports for their safety, housing and social needs. However, from the perspective of the women who participated in this study, the GPs they are coming into contact with are not sufficiently interested in their lives.

Finally, the research as a whole highlighted that continuity of care at release was essential, though commonly not achieved. The disengagement of women leaving prison with GPs, and the stigma that may accompany the passing of medical information to the GP, further complicates the practicalities of transfer of health information and is discussed in Chapters 3 and 4. As highlighted in Chapter 3, continuity of care arrangements or health information transfer was unlikely on leaving prison if women were not part of a formal transitional program. Advocacy and facilitated linkage at the

interface between prison and the community were found to increase continuity of care at release, as well as increasing the confidence of women leaving prison that their post-release needs would be met (Chapters 4 and 5).

## **Building on the research**

The research findings inform strategies to improve access to health care for women in contact with the criminal justice system and have better health. Firstly, I will consider how we can build on this research to improve prison-based care such that people leave prison with better health and more support. Secondly, I will focus on strategies to build the capacity of the community-based GP sector to better engage with and provide more effective care to women leaving prison.

## **Releasing healthier, well-supported people into the community**

- ***Increasing the timeliness of prison healthcare through telemedicine***

Health services in prisons need to focus on care being timely, not just theoretically available, if we are to overcome the ‘waiting game’ identified by participants as a barrier to care. One avenue is to promote telemedicine, including shared electronic records and increased use of teleconsultations. Telemedicine is being increasingly promoted internationally as a way to increase healthcare access within the cost restrictions of prisons(8, 9). Teleconsultations in prison, both with external providers and with providers within the prison network, have the potential to shorten waiting lists, surmount custodial barriers and increase care provision in prison.

- ***Supporting the prison doctor workforce***

The prison context is a challenging healthcare environment and doctors who work there need specialised skills(10). As found in this research, prison health services and prison healthcare providers are not infrequently criticised, with researchers highlighting the need for high quality provider communication skills and professional systems in prison(11, 12). There is an ongoing clear need for prison health services to consider and

emphasise the human rights of prisoners(13) and be cognisant of the dangers of dual loyalties which could pressure doctors to work in ways that benefit prison authorities rather than patients(14).

The lack of professional status of a career in prison medicine and the constraints of the prison system may make it difficult to attract and maintain a suitable workforce.

Medical school placements in prisons can foster more favourable attitudes to working in prison systems(15), and support the aspirations of those with an interest in prison health(16). Collegial networks, conferences and educational opportunities for doctors who work in prisons are also needed, to validate the value of prison medicine and to maintain a committed workforce(17).

- ***Promoting the health and wellbeing of Aboriginal and Torres Strait Islander people***

The ‘medical homelessness’ experienced by women cycling between prison and community, in which engaging in care is difficult in both settings, may be a particular problem for Aboriginal and Torres Strait Islander women because of their increased likelihood of more frequent short sentences and of being on remand(18). Additional access barriers may exist for Aboriginal and Torres Strait Islander people, including lack of culturally competent care in some health settings(19). Despite the holistic, culturally appropriate care delivery models in Aboriginal Medical Services (AMSs)(20), the stigma of substance misuse persists as a barrier to care in AMSs as identified by our research participants (Chapter 4).

AMSs have called for stronger partnerships with prison health services and increased financial means to assist those in contact with the criminal justice system(21).

Supported links between prison and AMSs may increase continuity of healthcare on leaving prison(22).

It is also notable that Aboriginal and Torres Strait Islander people have a particularly high burden of ear disease and hearing impairment(23), and this can negatively affect their interactions within the criminal justice system(24). The apparent low identification of ear problems on reception into prison (Chapter 2) suggests more attention should be paid to hearing health, which particularly applies to this population of prisoners.

## **Improving community-based primary care for people leaving prison**

- ***Improving substance misuse management in general practice***

Primary care is key to overcoming the increasing burden of substance misuse given the extent of the problem(25) and the evidence from this research that poor GPs skills in substance misuse management are a barrier to care for women leaving prison (Chapters 4 and 5). Better management of substance misuse at the GP level may lessen re-incarceration rates given the links between crime and problematic substance misuse(26) and the risk of prescription medication misuse in ex-prisoners(27).

There are well-evidenced ways to build the capacity of primary care to better manage substance misuse. Clinical strategies include provision of training and up to date guidelines, and promotion of specific treatments within primary care, such as opioid replacement therapy(25). Access to substance misuse treatment in primary care is also promoted by appropriate funding and linkage between GPs and multidisciplinary care providers, such as specialist substance misuse services(25).

- ***Increasing the capabilities of GPs to assist women leaving prison***

The ability of the GP workforce to manage people in contact with the criminal justice system will be enhanced by increasing GP knowledge of the situation of this group of people, as discussed in Chapter 4. Knowing that relevant care has been delivered in the prison, that health information is easily obtainable from prison health services, and about the kinds of health and social needs commonly seen in this population, will assist GPs to provide post-release care.

GPs will also be better able to assist their patients if they recognise the importance of trauma and violence informed care(28) and reflect on the effect of their patients' traumatic life experiences on the doctor-patient interaction. Training in all these aspects of care can be delivered to GPs through their usual educational channels, including medical multimedia, the RACGP and the primary health networks.

Additionally, in the same way that undergraduate experiences in prison can increase understanding of prisons and prisoners, such exposure can assist to overcome stereotypes about people in contact with the criminal justice system whom they



encounter in the community(16). Given that women in this study perceived stigma was a barrier to care, this is an important path forward.

- ***Providing more health linkage support for continuity of care***

Clearly, the often intergenerational and lifelong histories of disadvantage and trauma experienced by many women in prison will not be overcome by their participation in a short-term post-release programs. Rather, wide ranging structural societal change is needed(1). However, participants in this research valued the assistance provided by transitional programs which sought to overcome some of the barriers to their reintegration (Chapters 4 and 5), and the medical records showed evidence that these formal programs did increase continuity of care (Chapter 3).

Despite the effectiveness of transitional programs in supporting the health of people leaving prison(29), there are insufficient such programs to meet the need in Australia(22). How such programs engage with GPs in the community is an underappreciated area for improvement within these programs.

## **Future research directions**

Understandings gained through the literature review of prison health research (Chapter 6) and the research presented in Chapters 2 to 5 has highlighted future directions of research which would inform positive change in healthcare access for women leaving prison.

### **Prison health service research**

Most research in the Australian prison sector focuses on descriptions of the health and social status of people in prison or on population health initiatives such as Hepatitis C. Health service research, particularly relating to primary care, has been understudied, yet its importance for women leaving prison is clear from our research. Such research should include evaluation of interventions which seek to promote quality, timely healthcare interventions and continuity of care for people leaving prison, necessary

interventions as identified in our research. This also accords with findings from Canadian researchers, who have also identified that more prison health service research is needed(30).

### **People in prison as co-researchers**

Participatory research approaches which involve people in prison in co-creation of knowledge are becoming more common(31-33) but have not yet been published from the prison health sector in Australia. Involving ex-prisoners in prison-based research, including as service user consultants and co-researchers, can be challenging but can improve research quality(34). Research which involves people in prison or people with lived experience of prison should be expanded and supported. Involvement of women in prison or women who had recently left prison as co-researchers would have enhanced my research, as discussed in Chapter 7.

### **Access to GPs for people leaving prison**

The interface between community general practice and prison is an important area of future research to build on the work undertaken within this doctorate. In our research we have explored the perspective of women leaving prison regarding GP care. Through this we identified that women perceived negative provider attitudes, practice policies which blocked people suspected of substance misuse and limited GP interest beyond physical health. The next step is to investigate the GP perspective on providing comprehensive care to women leaving prison, including what is needed to make this more feasible, attractive and effective within general practice. This would shed further light on how the link between people leaving prison and general practice can be strengthened.

Further research on how re-entry programs and prison-initiated linkage programs can engage with GPs to facilitate post-prison care would be valuable. Our research identified that GPs have a prominent role in this context, and post release linkage programs do seek to engage women with general practice in the community. However, there is no published evidence as to how successfully this link functions beyond the women's

perceptions and whether therapeutic relationships eventuate. There is also little evidence on how continuity of care and effective patient engagement of people leaving prison can be improved from the perspective of GPs and of staff working within these re-entry programs, and ultimately, the impact of these programs on health outcomes.

Such evidence will fill gaps in our understanding of how continuity of care can be facilitated in a way that is sustainable for both prison health services and general practice services. This information would inform development of integrated pathways for people leaving prison, as well as to provide guidance on how primary care can be supported to provide better access to other vulnerable and marginalised populations.

## **Conclusion**

This thesis has provided evidence about the substantial barriers to healthcare access both in prison and in the community for women leaving prison, and identified where further work is needed to reduce these barriers. The overlapping stigmas of substance misuse and incarceration can mean that healthcare providers may not treat women leaving prison as legitimate patients with credible healthcare needs. A large amount of health care is delivered in prison, however waiting lists and custodial barriers to care can mean that planned care is only partially delivered within the relatively short prison sentences usually served by women. The siloing of health care within the prison walls due to poor continuity of care at release further contributes to women's experiences of 'medical homelessness', such that they are unable to effectively engage in health care in prison or in the community. Opportunities to change the resulting poor healthcare access are evident in both prison health services and community-based general practice and at the interface between these sectors. The findings have highlighted specific areas for improvements in timeliness of care in prison, healthcare provider engagement in managing the complex needs of women leaving prison and support for women transiting between prison and the community. The research has further identified that there is a need to further address the evidence gap in how to improve access to effective general practice care for people leaving prison.

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## Appendices

### Appendix 1: Medical record audit tool

Patient identification code	
Age	
Previous incarcerations	
Length of last incarceration	
Indigenous status	
CALD status	
Interpreter needed	
Health issues	
Medications at reception	
Referral to healthcare provider	
GP contact details	
Release of Information request sent	
Requested information received	
Information provided by GP without being requested	
Correctional centre of release	
Release destination	
Transitional/post release support	
HCP contacts in 6 months prior to release	
Type Health care last 6 months	
HCP seen last 6 months	
Emergency Department visits last 6 months	
Number of external medical appointments last 6 months	
Types of external medical appointments last 6 months	
Pathology taken in last month	
Medication at release (number)	
Medication at release (type)	
Discharge summary in file	
Release planning needs type	
Method of giving release health information	
Appointments pending at release	
Health information request received after release	



## Appendix 2: Semi-structured interview guide

PRE RELEASE	
These questions are about your healthcare needs when you leave prison.	1. Have you had any health problems / been receiving medical treatment in prison?
	2. Do you have health problems that will need attention after you leave? What are they?
	3. What are your plans about accessing health care after release?
	4. Has anything been organised for you at the prison clinic end for after release?
These questions are about how you access health care in the community.	5. Is there a regular place you go to usually if you have a health problem?
	6. Do you have a GP in the community?
	7. Do you see anybody else in the community for health issues usually? How regularly? In what way do they provide health care for you?
These questions are about how easy it is to access the health care you need after release.	8. Do you think it is important to access health care after release?
	9. Do you have confidence you can access the health care you need after release?
	10. In your experience/opinion, what are the biggest issues facing people being released from prison?
POST RELEASE	
These questions are about your health and wellbeing and how the transition back to community health care worked out for you after release.	1. How have things been going for you since you were released?
	2. Did you plan to access health care after your release? How has it been in reality?
	3. Do you think it is important to access health care after release?
	4. Have you had any health problems or treatment since you were released?
	5. What was done at the prison end that helped you get health care in the community? Did it work out?
These questions are more specifically about accessing GPs and general practice.	6. Have you seen a GP in the community? Tell me about that.
	7. Did you let the GP you saw know you have been in custody?
	8. Did you see other people who work in the general practice you attended?
	9. In your experience, are GPs confident in seeing people who have been released from prison?

### Appendix 3: Conference and meeting presentations

Parts of the work presented in this thesis have been presented as follows:

Abbott P, Magin P, Hu W. 'Medical homelessness': health care access and women in contact with the criminal justice system. Asian Conference on Prison Health, Bangkok, November 2017.
Abbott P, Magin P, Davison J, Hu W. 'Medical homelessness' and women in contact with the criminal justice system. GP17 - The RACGP Conference for General Practice. Sydney; October 2017 (Research Awards session)
Abbott P. Women in transition from custody: where does general practice fit in? Correctional Services Healthcare Conference. Melbourne; August 2014.
Abbott P, Magin P, Hu W. Continuity of care for women leaving prison and returning to GP care. GP17 - The RACGP Conference for General Practice. Sydney; October 2017.
Abbott P, Magin P, Davison J, Hu W. 'You need to have a doctor. Someone that you know, someone that you can trust' – GPs and women on release from prison. GP16 - The RACGP Conference. Perth; September 2016.
Abbott P, Magin P, Hu W. Health Care Delivery for Women in Prison in New South Wales, Australia. (Poster). 10th Academic and Health Policy Conference on Correctional Health. Atlanta, US; March 2017.
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