



Research Paper

Barriers and advocacy needs for hepatitis C services in prisons: Informing the prisons hepatitis C advocacy toolkit

Shelley J Walker^{a,b,c,*}, Lok B Shrestha^{d,e}, Andrew R Lloyd^d, Olivia Dawson^f, Yumi Sheehan^d, Julia Sheehan^g, Nonso B C Maduka^h, Joaquin Cabezas^{i,j}, Matthew J Akiyama^{k,1}, Nadine Kronfli^{l,m,1}, on behalf of INHSU Prisons

^a National Drug Research Institute, Curtin University, Perth, Australia

^b Burnet Institute, Melbourne, Australia

^c Public Health and Preventative Medicine, Monash University, Melbourne, Australia

^d The Kirby Institute, University of New South Wales (UNSW), Sydney, Australia

^e School of Biomedical Sciences, University of New South Wales (UNSW), Sydney, Australia

^f The International Network on Health and Hepatitis in Substance Users (INHSU)

^g The Hepatitis C Trust, London, England, UK

^h Bensther Development Foundation, Enugu, Nigeria

ⁱ Gastroenterology and Hepatology Department, University Hospital Marques de Valdecilla, Santander, Spain

^j Clinical and Translational Research in Digestive Diseases, Valdecilla Research Institute (IDIVAL), Santander, Spain

^k Department of Medicine, Albert Einstein College of Medicine / Montefiore Medical Centre, New York, USA

^l Department of Medicine, Division of Infectious Diseases and Chronic Viral Illness Service, McGill University Health Centre, Montréal, Québec, Canada

^m Centre for Outcomes Research and Evaluation, Research Institute of the McGill University Health Centre, Montréal, Québec, Canada

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ABSTRACT

Background: Carceral settings are a key focus of the 2030 WHO global hepatitis C virus (HCV) elimination goals. Despite this, access to HCV testing and treatment services in prisons remains low globally, limiting opportunities to achieve these goals. Advocacy efforts are needed to address service inequities and mobilise support for enhanced HCV programs in prisons globally. INHSU Prisons, a special interest group of the International Network on Health and Hepatitis in Substance Users (INHSU) is developing a Prisons HCV Advocacy Toolkit to address this need. Here we present findings of a mixed study to inform the development of the Toolkit.

Methods: The aim of this study was to inform the development of the Toolkit, including understanding barriers for scaling up prison-based HCV services globally and advocacy needs to address these. An online survey ($n = 181$) and in-depth interviews ($n = 25$) were conducted with key stakeholders from countries of different economic status globally. Quantitative data were statistically analysed using R Studio and qualitative data were analysed thematically. The data sets were merged using a convergent design.

Results: Key barriers for enhanced prison-based HCV services included lack of political will and action, lack of prison-based healthcare resources, and poor awareness about HCV and the importance of prison-based HCV services. These findings underscore how advocacy efforts are needed to motivate policymakers to prioritise HCV healthcare in prisons and ensure funds are available for services (including diagnostic tools and treatment, healthcare teams to implement services, and systems to measure their success). Advocacy resources to raise the awareness of policy makers, people working in the prison sector, and incarcerated populations were also identified as key to increasing HCV service uptake.

Conclusion: The Toolkit has the potential to support advocacy efforts for reaching HCV elimination targets. By understanding the advocacy needs of potential Toolkit end-users, the findings can inform its development and increase its accessibility, acceptability, and uptake for a globally diverse audience.

* Corresponding author at: National Drug Research Institute, Curtin University, 7 Parker Place, Curtin University Building 609 (Level 2), Bentley, Perth, Western Australia, 6102.

E-mail addresses: shelley.walker@curtin.edu.au, shelley.walker@burnet.edu.au (S.J. Walker).

¹ Both authors contributed equally.

Background

Hepatitis C virus (HCV) infection remains a major public health concern affecting millions of people worldwide (Blach et al., 2022). The most common mode of HCV transmission in high income countries (HICs) is via the sharing of drug injecting equipment, whereas common modes of transmission in low-, and middle-income countries (LMICs) also include exposure to unsterile medical equipment and contaminated blood and blood products (World Health Organization [WHO], 2016). The prevalence of HCV is disproportionately higher amongst people in prison compared with the general population. An estimated 1.5 million incarcerated people globally are living with HCV (Dolan et al., 2016), largely due to the criminalisation of drug use which results in the over-incarceration of people who inject drugs (Altice et al., 2016; Larney et al., 2013). Many people continue to inject drugs while in prison, which increases the risk of acquiring HCV because access to prison-based harm reduction measures such as needle and syringe programs and opioid agonist therapy remains low (Cunningham et al., 2018; Sander et al., 2019). Furthermore, because most people in prison return to their communities, there is an ongoing risk of transmission to the general population from those who are untreated upon release.

Although people who inject drugs experience more complex physical and mental health needs than the general community, their access to and use of health services in the community is poor due to socio-economic factors such as experiences of unstable housing, stigma, poverty and unemployment (Fazel & Baillargeon, 2011; Fazel et al., 2017). Prisons can provide a unique opportunity for the provision of healthcare services because many of the challenges experienced in the community have been removed (Crowley et al., 2019; Lafferty et al., 2018). Furthermore, HCV treatment outcomes in prison have been shown to be equal to, or better than, community-based treatment outcomes (Aspinall et al., 2016).

The WHO has called for a focus on carceral settings to achieve global HCV elimination targets by 2030 (WHO, 2019). However, access to HCV testing and treatment in prisons remains low compared to community settings and varies widely across countries, limiting opportunities to achieve elimination goals (Akiyama et al., 2020; 2021, 2022; Bartlett et al., 2021; Kronfli & Cox, 2018; Kronfli et al., 2018, 2019; 2021; Papaluca et al., 2019; Ruiz et al., 2022; Stone et al., 2023; Winter et al., 2022).

It is estimated that only two thirds ($n = 124$) of countries globally have HCV testing and treatment plans in place, and, of these, less than a quarter (23 %) have dedicated interventions in place for people in prisons (Akiyama et al., 2021; WHO, 2019). Furthermore, most national HCV plans focused on carceral settings are for HICs, highlighting a crucial gap in the prioritisation of prison populations in LMICs for HCV elimination (Akiyama et al., 2022; WHO, 2019). In LMICs, access to HCV services is limited in surrounding communities but is even more scarce in carceral settings (WHO, 2019). Moreover, while many HICs offer universal subsidised access to HCV healthcare in the community, access in carceral settings remains suboptimal (Ocal et al., 2019; Stöver et al., 2019). Several barriers are reported to contribute to these service gaps, including lack of political will, poor awareness of the HCV burden, the prioritisation of security over healthcare needs, limited funding and resources, stigmatisation of people who inject drugs and people living with HCV, lack of HCV knowledge and awareness, prison infrastructure challenges, staff shortages, and the criminalisation of drugs (Akiyama et al., 2022; Akiyama et al., 2021; Nakitanda et al., 2020; Papaluca et al., 2019; WHO, 2021).

It is widely accepted that addressing the barriers described above requires advocacy efforts to motivate action (Akiyama et al., 2021; Kpokiri et al., 2022; Kronfli & Cox, 2018; Kronfli et al., 2018a; Lafferty et al., 2018). At the heart of advocacy is the assumption that change can happen through presenting evidence for the reasons why change should happen, giving voice to those who are affected, and engaging people who have the power to make those changes (Open Society Foundations,

2023). Advocacy efforts rely on awareness-raising via the dissemination of information to inform and educate people about a topic or issue with the intention of influencing their attitudes, behaviours and beliefs towards the achievement of a defined purpose or goal (Cardinal, 2019). Advocacy toolkits are practical resources to encourage and support individuals and organisations to engage in advocacy activities to bring about the change that is desired. Although several advocacy toolkits have been developed to promote and support advocacy efforts to eliminate HCV globally (e.g. *Caring Ambassadors Program*, 2022; *Queensland Health*, 2023; *HepVu*, 2023; *National Alliance of State & Territorial AIDS Directors*, 2011; *World Hepatitis Alliance*, 2018), none focus specifically on prison settings.

INHSU Prisons, a special interest group of the International Network on Health and Hepatitis in Substance Users (INHSU), aims to address this gap via the development of a web-based repository of HCV advocacy resources: the “Prisons HCV Advocacy Toolkit” (hereafter referred to as ‘the Toolkit’). The aim of the Toolkit is to mobilise support for enhanced HCV programs in prisons globally, by equipping individuals and organisations with the advocacy resources needed to champion the cause. The Toolkit aims to target a broad audience, including for example policymakers; civil society advocates; prison health service administrators; prison governors (also known as wardens, superintendents, or directors) and staff; healthcare providers working in prisons; custodial authorities; academic researchers in the field; individuals and organisations who allocate funding; people with lived experience; and peer advocate organisations. To increase the acceptability, accessibility, and uptake of the Toolkit, and ensure it meets the advocacy needs of potential end-users, a needs assessment was conducted to inform its development.

Methods

Human research ethics approval was received from the Institutional Review Board of the Office of Human Research Affairs at Albert Einstein College of Medicine (IRB #: 2023-14716) in March 2023. A project working group provided oversight and input during the study design, data collection, and analysis phases.

A two-phase mixed methods research design was used to conduct the study, followed by a merging of the data sets.

Phase 1: online survey

In Phase 1, a short web-based survey with 18 questions (Survey Monkey Inc., 2023) was developed in English (see Supplementary Material Appendix S1), with the aim of gaining a broad perspective of the availability of prison-based HCV services in countries of different economic status globally, perceived barriers to the scale up of these services, and suggested advocacy resources to address barriers. Two rounds of survey dissemination were conducted, via the INHSU Prisons membership e-mailing list ($n = 470$) and the INHSU monthly e-newsletter ($n = 3293$). We received responses from 181 individuals across 41 countries. The survey response rate was 4.8 %, and responses were received from 38 % of the countries of survey recipients. The names of participants were entered into a draw for free registration to the 2023 INHSU Conference in Geneva. Participation was voluntary and involved implied consent via completion of the survey.

Data were extracted into Microsoft Excel and analysed using R Studio. The association between independent categorical variables was calculated using Chi-square or Fisher exact tests. P values of less than 0.05 were considered statistically significant.

Phase 2: in-depth interviews

To complement Phase 1 survey data and develop more nuanced understandings, in-depth interviews were conducted with 25 key stakeholders. The survey respondent sample was used to recruit

participants in the first instance, followed by snowball sampling. To ensure a diversity of views and experiences from countries of different economic strata were captured, we targeted survey respondents in diverse professional roles (including policymakers, health program implementers and funders) from countries of different economic status. We aimed to recruit ten participants from each stratum divided as equally as possible between the ten included countries. Snowball sampling was used if insufficient participants were recruited from a country. Participation was voluntary and involved informed written consent. Interviews were semi-structured and focused on understanding perceived barriers for implementing prison-based HCV services, advocacy needs for their establishment or scale up, and potential resources for the Toolkit. Interviewee survey responses of relevance were imported into the interview guide for each interview, to help guide conversations. The interview schedule was piloted and adapted to address issues identified. Interviews were audio-recorded and transcribed verbatim. Participants were offered an honorarium of \$50USD for their time and expertise.

Transcripts were organised using NVivo data software (QSR International, 2020) and thematically analysed (Clarke & Braun, 2017). Transcripts were read to develop in-depth understandings of unique narratives and over-arching themes. Key deductive codes were developed in NVivo based on broad-level understandings of the data and investigation topics. Data extracts were assigned to deductive codes, and as patterns, inconsistencies and new insights were identified, new codes and sub-codes were inductively established, refined, collapsed, or expanded to represent emerging themes. Next, coded data were exported into Word documents, and descriptions of segments of coded data were synthesized to represent themes and sub-themes. All identifiable information was removed from participant quotes.

Phase 3: merging the data sets

After the quantitative and qualitative data sets were analysed separately, we used a convergent mixed methods design to integrate the data, which involved bringing the two sets of results together through a combined analysis (Fetters et al., 2013; Guetterman et al., 2015). The interpretative process involved merging the data sets to assess how the results about barriers to enhancing hepatitis C health services in prisons and advocacy needs for addressing these barriers converged and diverged. Finally, we drew conclusions and inferences that reflected what was learned from the combination of results from each study. Final themes were agreed upon by all authors.

Results

Participant characteristics, and their country contexts are provided below; followed by integrated quantitative and qualitative data on barriers to prison-based HCV services and advocacy needs to address barriers.

Participant characteristics and country contexts

Phase 1: online survey

The online survey was completed by 181 individuals from 41 countries, including 18 low-income countries (LICs), 6 middle-income countries (MICs), and 17 HICs (Table 1).² Most respondents were from HICs ($n = 110$; 61 %), almost one-third were from LICs ($n = 55$; 30 %), and 16 (9 %) were from MICs. Nineteen (10 %) participants identified as policymakers and 85 (47 %) as implementers of health programs in

Table 1
Survey respondent countries by income level.

Country income level	Countries of survey respondents ($n = 41$)	Total participants $n = 181$ (%)
Low-income countries ($n = 18$)	Burundi ($n = 2$), Cameroon ($n = 1$), Democratic Republic of Congo ($n = 2$), Ghana ($n = 2$), India ($n = 4$), Indonesia ($n = 14$), Kenya ($n = 7$) Malawi ($n = 1$), Mongolia ($n = 1$), Nepal ($n = 2$), Niger ($n = 1$), Nigeria ($n = 7$), Pakistan ($n = 5$), Sierra Leone ($n = 1$), Tanzania ($n = 1$), Ukraine ($n = 1$), Yemen ($n = 1$), Zambia ($n = 2$)	$n = 55$ (30 %)
Middle-income countries ($n = 6$)	Brazil ($n = 1$), Mauritius ($n = 1$), Republic of Moldova ($n = 3$), Russia ($n = 1$), South Africa ($n = 6$), Thailand ($n = 4$)	$n = 16$ (9 %)
High-income countries ($n = 17$)	Australia ($n = 29$), Austria ($n = 1$), Belgium ($n = 1$), Canada ($n = 13$), England ($n = 6$), France ($n = 2$), Greece ($n = 4$), Ireland ($n = 4$), Italy ($n = 1$), Portugal ($n = 1$), Puerto Rico ($n = 1$), Saudi Arabia ($n = 1$), Scotland ($n = 1$), Sultan of Oman ($n = 1$), Sweden ($n = 1$), Switzerland ($n = 1$), United Kingdom ($n = 28$), United States ($n = 14$).	$n = 110$ (61 %)

prisons. Ten participants (6 %) reported being involved in the provision of funding for health and/or prison sector programs, and 67 (37 %) held other professional roles such as advocates, academics, harm reduction workers, peer workers, or implementers of health services in the community.

All HCV services offered in prisons differed significantly across each economic stratum (Table 2). Notably, the availability of venepuncture-based HCV RNA testing in prisons was reported by 85 % of survey respondents in HICs but only 33 % in LICs, and genotyping was reported by 78 % in HICs and only 24 % in LICs. Similarly, transient elastography (58% vs. 13 %), direct-acting antivirals (DAAs) (76% vs. 38 %) and post-treatment follow-up care (76% vs. 27 %) in prisons were more likely to be available in HICs compared to LICs.

There was no significant inter-country variability for low-income countries and the only factor that was statistically different in middle-

Table 2
Prison-based HCV services available by country income level (survey responses).

HCV services available in prisons	Low-income countries $n = 55^1$	Middle-income countries $n = 16^1$	High-income countries $n = 110^1$	p -value ²
HCV assessment & treatment services	41 (75 %)	14 (88 %)	101 (92 %)	0.010
Venipuncture-based HCV antibody testing	21 (38 %)	14 (88 %)	97 (88 %)	<0.001
Venipuncture-based HCV RNA testing	18 (33 %)	9 (56 %)	93 (85 %)	<0.001
Point-of-care HCV antibody testing	19 (35 %)	7 (44 %)	65 (59 %)	0.010
Point-of-care RNA testing	12 (22 %)	3 (19 %)	59 (54 %)	<0.001
Genotyping	13 (24 %)	10 (63 %)	86 (78 %)	<0.001
Fibroscan/transient elastography	7 (13 %)	5 (31 %)	64 (58 %)	<0.001
Ultrasound imaging	8 (15 %)	10 (63 %)	59 (54 %)	<0.001
Non-invasive fibrosis staging	13 (24 %)	7 (44 %)	68 (62 %)	<0.001
Direct-acting antivirals	21 (38 %)	11 (69 %)	97 (88 %)	<0.001
Post-treatment follow-up	15 (27 %)	9 (56 %)	84 (76 %)	<0.001

¹ n (%).

² Fisher's exact test, Pearson's Chi-squared test.

² World Bank Group income level country classifications are used for Jul 2023 - Jun 2024. For study purposes 'LICs' include low-income and lower middle-income countries; and 'MICs' include upper-middle income countries only. <https://blogs.worldbank.org/opendata/new-world-bank-country-classifications-income-level-2022-2023>

income countries was point-of-care HCV Antibody screening (Supplementary Table S1 and S2). In high-income strata, there was a statistically significant variability on prison-related hepatitis assessment and treatment services, point of care (POC) RNA testing, POC antibody screening, genotyping, non-invasive fibrosis staging, fibroscan/transient elastography, DAA for HCV, post-treatment follow-up and linkage care (Supplementary Table S3).

Phase 2: in-depth interviews

Interviews were conducted in English language via Zoom video conference by SW between June–September 2023 and ranged from 39 to 61 min duration (average 47 min) (Table 3).

Nine (36 %) participants were from LICs including Indonesia, Kenya, Nigeria and Pakistan; eight (32 %) were from MICs including Moldova, Thailand and South Africa; and eight (32 %) were from HICs including Greece, the United Kingdom and the United States (Table 4). The types of prison-based HCV services varied widely across participants' countries. Government-funded universal access to testing and treatment in prisons was available in only two HICs and one MIC, and in other countries, limited or no access to HCV services in prisons was commonplace. Most interviewees identified themselves as "policy-makers" ($n = 9$; 36 %) or "implementers" of healthcare programs ($n = 9$; 36 %) including general practitioners, infectious disease physicians, hepatologists, nurses, and other prison staff. Four participants identified as "advocates" (including two who were peer advocates) and three identified as "academics".

Barriers to prison-based HCV services and advocacy needs to address barriers

Integrated quantitative and qualitative data on barriers preventing the scale up of HCV services in prisons and the advocacy needs to address these barriers are presented below via three key themes: 'political will and action', 'availability and funding of prison-based HCV healthcare resources' and 'awareness raising about HCV and prison settings'.

Political will and action

A lack of political will and action by those with the power to make a difference was considered a key barrier for enhancing HCV services in prisons by survey respondents and interviewees across countries of all economic strata. In LMICs, approximately two-thirds ($n = 35$; 67 %) of survey respondents indicated that "limited motivation by policymakers, funders or implementers of prison services" was a key barrier, compared to just over one third ($n = 39$; 35 %) in HICs. Similarly, interviewees across all countries raised lack of political will and action as hindering efforts for scaling up HCV services in prisons.

Local data on HCV prevalence and incidence in prisons was consistently described as needed to increase the political will of policymakers and funders to prioritise HCV services in prisons. Some participants reported having "good data" about the prevalence and economic benefits of testing and treating HCV in the community, but not having this data for prison settings. In LICs, many spoke with frustration of knowing that data was one of the most important advocacy tools for gaining political buy-in, but that gathering this data could only be possible if funding was made available to screen for HCV in prisons.

Table 3
Interview participant countries.

Country income level	Country of participants ($n = 25$)
Low-income	Indonesia ($n = 1$); Kenya ($n = 3$); Nigeria ($n = 3$); Pakistan ($n = 2$)
Middle-income	Moldova ($n = 2$); South Africa ($n = 3$); Thailand ($n = 3$)
High-income	Greece ($n = 2$); United Kingdom ($n = 3$); United States ($n = 3$)

Table 4

Perceived key barriers to the scale up of prison-based HCV services (survey responses).

Barriers to scale up of prison-based HCV services	Low-income countries $n = 55^1$	Middle-income countries $n = 16^1$	High-income countries $n = 110^1$	p-value ²
Limited motivation by policymakers, funders or implementers of prison services	35 (64 %)	11 (69 %)	39 (35 %)	<0.001
Limited availability of prison healthcare resources	40 (73 %)	10 (63 %)	72 (65 %)	0.6
Low screening rates	25 (45 %)	8 (50 %)	36 (33 %)	0.2
High price of direct-acting antivirals	24 (44 %)	4 (25 %)	15 (14 %)	<0.001
Lack of knowledge/awareness of HCV	39 (71 %)	10 (63 %)	45 (41 %)	<0.001
Stigma and discrimination	23 (42 %)	5 (31 %)	55 (50 %)	0.3

¹ n (%).

² Fisher's exact test, Pearson's Chi-squared test.

One of the major things we need to enhance our advocacy efforts is data. The only thing they want to see is data. Because always, when you go with data, the conversation shifts. But right now, we do not have data about hepatitis in the prison, so we cannot say to the decision-makers "this is how many people need to be treated". And the problem is you can only have data if you are able to test, and you can only test when you have the resources [...] So that is the dilemma for us – we can only get the buy in of the policymakers if we have the available data. (P2, Policymaker, LIC)

Some interviewees described how at the very least, having access to prevalence and/or economic modelling data from neighbouring countries or countries with similar income levels could be used to advocate to policy makers, when their own data was unavailable.

You need to be able to say that this is the status quo and if you don't treat people, this is the number who experience morbidity and mortality and this is the cost you have to bear for treating them for liver cirrhosis, liver transplantation, stuff like that. Because the government - they really only care about the budget, you know – they will say, "If we're going to invest this amount of money, how much are we going to save in the future?" [...] And so, for us, if it is data from countries in our own region it could be used to lobby government. (P6, Advocate, LIC)

Templates of policy briefs for political stakeholders and decision makers that include simple messaging and infographics to enhance HCV services in prisons and accompanying data about cost-effectiveness of HCV care provision, were described as needed resources by some participants in LMICs.

If we're talking about advocacy, first, we need a policy brief. For the politician to understand the issues in one page, what's the problem. In simple words, maybe a few graphs, a few numbers, and the message needs to be that if you spend the money here, you will save money there – in the long term. Yes, we are looking for a win-win situation when we are talking about advocacy. (P9, Academic, MIC)

Consensus existed among interviewees that HCV services in prisons are often not prioritised because incarcerated people are considered less "deserving" of healthcare than those in the community and because prison security takes precedence over the healthcare needs of people in prison. Advocacy resources to change this mindset among decision makers (including governments, policy makers and governors of prisons) were described as needed to address this issue.

We need tools to educate the Governor General of Corrections - he's the head of the prisons. We need to get his buy-in, and to do that, we need to make him understand that [the] inmates are vulnerable to hepatitis C,

because the health of the inmate is really neglected. (P19, Implementer, LIC)

To gain the commitment of decision makers with the power to enact change—to enhance and increase HCV testing and treatment in prisons—participants across all countries believed access to case studies “about interventions that had worked [and] success stories” would be useful for garnering their commitment and buy-in.

For the purpose of advocacy, we need success stories from around the world to share with our decision makers. And the lessons that have been learned must also be shared with the policymakers and the political leaders, so that they will make this disease, this public health issue, a priority for their agenda. (P21, Policymaker, LIC)

Availability and funding of prison-based HCV healthcare resources

The limited availability of prison-based HCV healthcare resources was identified as a key barrier for scaling up prison-based HCV services in the interviews and in the surveys ($n = 122$; 67 %), including being amongst one of the top three barriers identified by survey respondents across countries of all economic status (see Table 4). Interviewees described how if they were to reach HCV elimination targets in prisons, advocacy efforts were needed to garner funding for healthcare resources to implement services and monitor their success.

In HICs, participants described requiring additional funds to sustain existing programs; some shared their frustration at knowing HCV elimination could be achieved in prisons in their country, but only if more funding was made available.

We all believe it's achievable within [our country], that it can be done and dusted, because we really are a relatively small place [...] and we all work together and share information and best practice. It's just really frustrating that we don't have resources and funding to fully support it. (P5, Policymaker, HIC)

According to interviewees, lack of funding in LMICs was found to contribute to “low screening rates” in LMICs ($n = 33$, 46 %), underscoring recognition that advocacy resources were needed to convince decision-makers to bargain down prices of diagnostic tools.

The cost of diagnostics is really one of our biggest barriers [...] One can always negotiate how to get DAAs but unless you have the diagnostic tools - we got on top of HIV because we were able to bargain and drive costs down and I think that's really something that needs to be looked at for [our] region [...] You know, if you can't get diagnosed, you can't even begin to talk to tell your government that this is a problem and this is what we need. (P14, Policymaker, MIC)

The “high price of DAAs” was a reported barrier to enhancing prison-based HCV services among 44 % ($n = 24$) of survey respondents in LICs and 25 % ($n = 4$) in MICs. Furthermore, some interviewees in LMICs described how DAAs were still not on their essential medicines list, and that old treatments (such as ribavirin) were still being used to treat people. Others in LMICs described how DAA “stock-outs” (DAAs unavailable) were common, which was frustrating if people were diagnosed with chronic HCV but could not access medication. Some interview participants suggested advocacy resources about how to access additional funding (including potential funding sources) could help address this issue.

Although all interviewees recognised the importance of monitoring and evaluating the success of HCV programs—to convince governments and decision makers of the need for more funding—in LMICs, many described how, although effective systems were in place for collecting and reporting HIV data, this was not the case for HCV. Some interview participants suggested that resources about how “hepatitis C programming can be integrated into HIV and TB programming should be a key focus of the Toolkit”.

Lack of data and systems to collect it is an issue for [us]. For HIV we have the data - real time data - and a well-coordinated system to collect and report this data. But we do not have the same mechanism for hepatitis C. Our reporting mechanism for hepatitis C is very weak, and so this is something we need (P8, Implementer, LIC)

Prison healthcare staff shortages (including nurses, general doctors, and specialist clinicians) was considered a significant barrier across all countries of interviewees, which was considered frustrating if HCV testing and treatment services were available but there were insufficient healthcare staff to deliver them. In LMICs, healthcare staff shortages meant people sat on long waiting lists and were often released into the community before they could be tested and/or treated, and in HICs where universal testing on entry was the stated policy, this limited their capacity to implement these services.

We've got very clear screening and treatment pathways but unfortunately, because of capacity, it's all on hold. Yes, recruitment and retention of nursing staff is a real problem [...] and if a prison doesn't have a full-time doctor or nurse, you can forget about [HCV] testing at entry. (P23, Policymaker, HIC)

In LMICs, staff shortages meant doctors and nurses were often “burnt out” because they were required to carry such large patient loads, which also made it difficult to retain staff.

We have a challenge in terms of the number of healthcare workers within the prisons. They are overwhelmed and burnt out. We have only a small number of clinicians serving a population of 2000 inmates, so all they can do is just the basic routine tests. (P3, Policymaker, LIC)

Gaining “a commitment of funding” from governments to address staff shortages was considered paramount across all country settings. As one participant in a MIC said, “you cannot expect an overwhelmed health system to provide HCV services if the government doesn't make healthcare staff a priority”.

Awareness raising about HCV and prisons

Raising the awareness of key stakeholders at every level (including those in government and policy roles through to individuals working in prisons and incarcerated people impacted by HCV) was evidenced as needed to create an enabling environment for the scale-up of HCV prison services.

More than half of survey respondents ($n = 94$; 52 %) identified “lack of knowledge and awareness of HCV in the prison system” as a barrier in their country, which was reportedly higher in LMICs ($n = 49$). Similarly, interviewees across countries of all economic strata agreed that awareness raising about HCV was needed (at the levels of policy maker all the way through to incarcerated populations) to bring about the changes needed to enhance HCV testing and treatment in prisons.

In LMICs, where access to HCV diagnosis and treatment services in prisons was generally poor, interviewees were unanimous that advocacy resources were needed to raise awareness of the disease burden in prisons caused by HCV among decision-makers including prison governors and political leaders. This included information presented as factsheets to highlight the health costs on individuals and communities and governments when not providing HCV treatment and care to people in prisons.

Before we even consider allocating resources for testing and treatment, the first step must be to create awareness with the policymakers at the leadership levels - about hepatitis C and why it's important to screen people and treat [...] When it's understood at that high level, as opposed to just going directly to the prisons without backing from the prison leadership, it does not work. So, the awareness raising we need is putting senior leadership first, and then you can cascade down to the prisoners. (P3, Policymaker, LIC)

Several interviewees in LMICs described how it was common for

healthcare providers in prisons (including doctors and nurses) to lack formal HCV clinical training, and that basic Toolkit resources (which are often available in HICs), were needed to build their skills and confidence to deliver HCV services. Resources to promote and advocate for the adoption of better models of care, such as up-to-date clinical guidelines and best practice procedures related to HCV screening and treatment were suggested for addressing this service delivery barrier.

For HIV, we have standard operating procedures for testing and treatment - the protocol is there, the providers are well informed, and the resources are well cascaded and clear [...] But for hepatitis you are not even sure if you are supposed to be testing, and what the proper protocols are [...] What are the new evidence-based guidelines and interventions? We need this information - just the way we did for HIV, for malaria, and for TB. For hepatitis C - we should be able to do the same. (P8, Implementer, LIC)

The stigmatising attitudes and behaviours of prison guards and security personnel, who are often relied upon to escort people to health services or to find space to deliver programs, were perceived by interviewees as logistical obstacles for the delivery of HCV services. Interviewees also spoke about people in prison choosing not to get tested and treated for fear of discrimination (due to perceived association with injecting drug use and HCV) and hence “poorer treatment by guards”. To combat these issues, interviewees suggested that awareness raising resources were needed to challenge commonly held misconceptions. By “changing their mindset” from one of discrimination to one of understanding, participants believed their support could be garnered to motivate people in prison to get tested and treated and to help address issues that prevent timely access to HCV care services. For example, as one interview participant in a HIC stated, raising the HCV awareness of prison staff had proved successful for gaining their support and enthusiasm, which worked to enhance testing and treatment uptake in prisons.

The prison officers were so misinformed, they had no idea. They wanted to put spit hoods on people to protect themselves from hep C and HIV, and it was like, “you cannot get hep C through spit, you cannot use this as a reason”. So, we trained the prison staff and security staff, and that was so important for getting them on side – because once they understood, they were so much more enthusiastic to support the programs. (P18, Advocate, HIC)

Interviewees agreed that myths and misconceptions about HCV among people in prison was also a key barrier that prevented individuals from getting testing and treated. To motivate people to get tested and treated, interview participants believed resources were needed to raise their awareness about HCV transmission and disease, the benefits of getting tested and treated, and what testing and treatment involves.

Stigma is a big issue among the inmates because there is so much misinformation about hepatitis C [...] We have witnessed people getting the positive test and then they were kicked out of their cell because the inmates did not want them there [...] and so there is a huge need for the inmates to get proper information, to be better informed, to understand that this is a health issue and how easy it is to get tested and treated. But also, so they know what the risk behaviours are so [they can] avoid exposure in the first place. (P7, Advocate, HIC)

The above findings suggest that creating an environment more conducive to the scale up of HCV services in prisons requires advocacy efforts to raise the HCV base-level knowledge and awareness of those in policy roles, people working in prisons, and people in prison living with or at risk of HCV.

Discussion

This global study supports and extends evidence of the multiple barriers that exist for enhancing HCV programs in carceral settings (Akiyama et al., 2022; Akiyama et al., 2021; Kronfli et al., 2018; Lafferty

et al., 2018; WHO, 2021). Although simple diagnostic tools are available to test people for HCV and simple, highly effective therapies are available to treat people living with HCV, findings confirm that significant gaps remain in the availability of HCV services in prisons across countries of all economic strata (Akiyama et al., 2021). Our findings emphasise how global inequities between and within countries persist, and that incarcerated people living with or at risk of HCV in LMICs are less likely to receive HCV testing and treatment (Akiyama et al., 2022).

Our study demonstrates how a lack of awareness about HCV and the importance of prioritising testing and treatment in prisons, is contributing to an environment that is not primed for the scale-up of HCV services in prisons. Current data on HCV prevalence in local prison settings was described as a critical advocacy resource for addressing this issue, however, as highlighted by interviewees, this data could only be gathered if funding was made available for diagnostic tools and resources to screen and test and evaluation systems to measure their success. Findings stress how leveraging the political will and action of policy makers and governments is therefore needed to address this funding gap, to ensure diagnostic tools and DAAs are available in prisons, and that skilled and confident healthcare workforces are employed to administer HCV programs. Furthermore, results highlight how advocacy efforts are needed to address basic HCV knowledge gaps and stigmatising attitudes among people in prison (including those living with or at risk of HCV, and those working in prisons) to ensure people in prison are motivated to get tested and treated.

While this study provides evidence of the many obstacles and challenges that remain for scaling up HCV services in prisons globally (Akiyama et al., 2021, 2022; Kronfli et al., 2019, 2021; Nakitanda et al., 2020; Papaluca et al., 2019; WHO, 2021), our findings also demonstrate that high levels of enthusiasm and commitment exist—from individuals in diverse professional roles and from across countries of all economic strata—to advance advocacy efforts in the pursuit of increasing the availability of HCV testing and treatment in prisons globally. Findings provide evidence that if HCV elimination is to be achieved, advocacy efforts are required to convince policymakers, prison administrators and healthcare implementers that action is indeed needed to achieve this. Nonetheless, the findings also suggest a gap exists in terms of equipping and supporting individuals and organisations to engage in advocacy activities.

The Toolkit, which aims to provide key stakeholders with resources intended to mobilise support from those in positions of power and influence to take leadership and action, can address this gap by helping amplify advocacy efforts to ensure HCV programs in prisons are prioritised. Moreover, by examining the views and perspectives of potential end-users of the Toolkit, and using these findings to inform its development, the effectiveness of the Toolkit as an advocacy resource for a global diverse audience of key stakeholders will likely be enhanced.

While many people in prison living with or at risk of HCV do not have access to timely testing and treatment, myriads of successful prison-based HCV projects and initiatives have emerged (Akiyama et al., 2019; Chan et al., 2020; Eisen et al., 2023; Kronfli et al., 2018; Lafferty et al., 2023; Lloyd et al., 2013; Papaluca et al., 2019; Sheehan et al., 2023; Werling et al., 2022). These successes provide evidence of what can be achieved to make elimination a reality in carceral settings (Brunner & Bruggmann, 2021; Lancaster & Rhodes, 2022; World Hepatitis Alliance, 2018); however, they also provide important learnings that can be capitalised upon and shared as advocacy resources in the Toolkit. Going one step further, this study has helped provide an understanding of the distinct advocacy needs of potential end-users, to ensure the forthcoming Toolkit resources are developed and disseminated in ways that meet their expressed needs. For example, our findings underscore how Toolkit resources must be tailored and context-specific to respond to the diverse roles of key stakeholders involved in advocacy efforts, and the diverse political, cultural, and economic status of countries globally. Furthermore, the results highlight how development of the Toolkit must consider the varied needs of individual carceral

settings, including the ways they are governed and by whom, what healthcare resources are available and how they are administered, and the distinct characteristics of each prison population across and within countries (Coffman & Beer, 2015). In doing so, the Toolkit has the potential to influence and mobilise support and action for enhanced HCV services globally and progress the WHO elimination goals.

Findings will inform the creation of practical resources and tools for inclusion in the Toolkit, that address the identified barriers and advocacy needs presented here. Tools and resources will be designed to match the needs of users according to their advocacy role, country context, and the audiences the advocacy efforts are targeting. Examples of tools and resources include advocacy how-to-guides; policy brief templates; facts about HCV; HCV prevalence and modelling data; evidence-based HCV models of care; and case studies of successful HCV services implemented in prisons.

Limitations

The relatively small sample size of the survey means quantitative findings cannot necessarily be generalised across all countries. Furthermore, we acknowledge that the overrepresentation of survey respondents from HICs (in particular, from Australia and the UK) and the under-representation of respondents from LMICs is a limitation, as is the lack of experiences and perspectives of individuals who could not write or speak in English (given participation in the survey and in-depth interviews required English language proficiency). While a breadth of countries across all economic strata are represented, many countries are not represented, and some countries have too few responses to make meaningful conclusions about barriers to HCV programs in prisons and advocacy needs to address these. We recommend future research is therefore needed that targets key stakeholders in non-English speaking countries to ensure a more representative understanding of these issues.

In addition, social desirability bias was possible because the survey distribution and interview participant selection occurred primarily via INHSU mailing lists and networks.

Finally, as described above, successful advocacy efforts to enhance HCV services in prisons should involve those most affected by the issue (i.e., people living with or at risk of HCV), and thus we recognise a limitation of this study is their non-participation. Nonetheless, 17 survey respondents and two interviewees identified as peer workers (including some who were working in HCV services in prison settings), which allowed us to capture at least some of their views and understandings. We recommend more research is needed to capture the experiences and views of people in prison living with or at risk of HCV to determine how their role in advocacy efforts can also be increased.

Conclusion

Examining the views and perspectives of potential end-users of The Prisons HCV Advocacy Toolkit and using these findings to inform its development has the potential to increase its accessibility, acceptability, and inclusivity for a global diverse audience of key stakeholders. It is our aim, that in doing so, individuals and organisations will be motivated and resourced to advocate for the increased implementation of HCV services within prison settings globally, as we strive for HCV elimination.

CRediT authorship contribution statement

Shelley J Walker: Writing – original draft, Methodology, Investigation, Formal analysis. **Lok B Shrestha:** Writing – review & editing, Formal analysis. **Andrew R Lloyd:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Olivia Dawson:** Project administration, Methodology. **Yumi Sheehan:** Writing – review & editing, Methodology, Funding acquisition, Conceptualization. **Julia Sheehan:** Conceptualization, Methodology, Writing – review & editing.

Nonso B C Maduka: Conceptualization, Methodology, Writing – review & editing. **Joaquin Cabezas:** Conceptualization, Methodology, Writing – review & editing. **Matthew J Akiyama:** Writing – review & editing, Methodology, Conceptualization. **Nadine Kronfli:** Writing – review & editing, Methodology, Conceptualization.

Declaration of competing interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

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Ethics approval

The authors declare that they have obtained ethics approval from an appropriately constituted ethics committee/institutional review board where the research entailed animal or human participation.

Human research ethics approval was received from the Institutional Review Board of the Office of Human Research Affairs at Albert Einstein College of Medicine (IRB #: 2023-14716) in March 2023.

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Supplementary materials

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