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Inside Out Health Project: How do people experience HIV healthcare in English prisons? An exploration of patient's experiences and opinions

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Inside Out Health Project:

how is HIV healthcare experienced in prison?

An exploration of patients' and professionals'

experiences and opinions

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Conflict of Interest

I was a recipient of 2019 NHIVNA Research Fellowship

I have participated in a Nurse Advisory Group and have received honorarium from ViiV

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Background

- People living with HIV should receive high-quality, safe, and effective patient-centred care, and should have the opportunity to be involved in the development and delivery of services (BHIVA, 2018)
- People in prison entitled to the full range of NHS services
- Anecdotally there is a negative impact on the delivery of HIV care
- Understanding how people experience HIV healthcare whilst in prison and incorporating these opinions and views into all stages of care provision will contribute to quality care

Methodology

Aims

- Exploration of patient's experience through first-hand testimony, and through that of professional or personal advocates.
- To contribute to improving care through understanding the experience of HIV healthcare in prison.
- To make recommendations for best practice for providing HIV healthcare to people in prison.

• Participants

- People living with HIV who have experienced prison
- Healthcare professionals who have provided HIV care to people in prison
- Other advocates

• Data Gathering

• Data Analysis

• Recommendations

Initial Themes

- Access to antiretroviral therapy
- Quality of HIV healthcare
- Continuity of healthcare
- HIV-related stigma

Access to antiretroviral therapy

- *“...they decided to their infinite wisdom that it was better to keep me waiting for three week, to have no medicine for three weeks...”* **Patient 01**
- *“I took medication with me...but then they take it off you when you get there and then that ran out, and then I think I waited a few weeks for a fresh lot of supplies to come in. But there, there's lots of periods where I didn't have my medication.”* **Patient 07**
- *“and you know I was so cross about that poor lady...who missed her medication, and just the additional fact that she was pregnant, and there just seemed to be so many failings in that which the prison were trying to blame me for and I was like “I'm not, I don't agree with that”.* **HIV Doctor 04**
- *“So we've had a couple of episodes, really, of people being allowed to run out of antiretroviral therapy in [name of prison]. And then the pharmacy there contact us three months later to say he needs more medicine”.* **Nurse 03**

Quality of HIV healthcare

“Healthcare for people with HIV doesn't really exist” Patient 07

“I think the healthcare that I received varied from prison to prison...I felt that the nursing staff at [name of prison] were far less knowledgeable, they were far less caring, and, and, and almost sort of nonchalant about it, and there really wasn't very much attention in what they were doing, even it was very robotic in terms of just handing out medication”. Patient 01

“I have had to fight to get annual bloods done...I felt I had no choice but to write to my [NHS] HIV consultant...begging them to intervene as I wasn't getting the basic level of care required. They were angered to hear about the cancelled prescription, missed meds...they demanded my bloods be redone to check if the missed doses had had any detrimental affect on my VL...”. Patient 20

Continuity of healthcare

“Once they are arrested and kept in prison on remand, they may come with nothing really. So the frustration starts there really, because you're trying to get in touch with the clinic of origin”. Nurse 07

“...and yeah I mean this was all from the very beginning, pretty much from day one, which made a massive difference. So that sharing of information was there although I am aware of just from conversations that I've had with others that isn't always the case”. Patient 01

“And it's a hit and miss. And again, that's a complex problem as well, because the main problem is that they will leave the prison either with no medication in hand or no follow-up appointments in the community”. Nurse 02

HIV-related stigma

“...allowed to share a cell as two gay men who were partners. But the HIV was a complete secret that they were terribly anxious to not disclose...” **Nurse 03**

“I would tell them to keep your mouth shut for HIV because it's a stigma. It's not very nice. As soon as they find out about your HIV, you might get shipped out of that one, because you'll get beat up, your cell will get ransacked and you'll lose all your possessions, everything so you know. I saw it happen, it's not nice”. **Patient 07**

“...there is a lot of stigma I'm sure, and that's the feeling I get is that people just want to be under the radar. They don't want people knowing that they've got HIV, they don't want people knowing they're on HIV meds...” **Prison Doctor 05**

“My experience so far has shown that there is a lot of stigma around HIV and sexual health generally. So people are not openly discussing their diagnosis and not openly engaging with the service”. **Nurse 02**

(Very) Early Summary

- Patients and professionals are providing clear evidence of difficulties.
- NHS and prison systems and practices interfere with the quality of care and the continuity of care.
- HIV healthcare in prison requires commitment to collaborative working between all stakeholders.
- HIV remains highly stigmatised in prison.

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