

CARE BEYOND THE VIRUS: ENGAGING THE MOST MARGINALISED IN HEPATITIS C CARE

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Overview

- Elimination strategy predicated on reaching the most marginalized
- Treatment as prevention: engage with PWID frequently & less safely.
- Not necessarily in touch with services, stably housed or regular OST
- A population not well represented in research studies
- Care & Prevent study: working with the most marginalized



transferable insights for HCV engagement



Care & Prevent study (2017-2020)

Dual foci: Prevention & care for skin and soft tissue infections (SSTI) among PWID
: Screening & referral for AA amyloidosis kidney disease among PWID

Mixed methods: Risk factor survey & urinalysis with PWID in London (~ 400)
Qualitative in-depth interviews with PWID with & without SSTI (~45)

Positive deviance: Risk but also protection - learning from the experts

To date: Survey & urinalysis data: 259 PWID, qualitative data: 30 PWID

Funded by the National Institute for Health Research (NIHR)



Rationale: skin & soft tissue infections

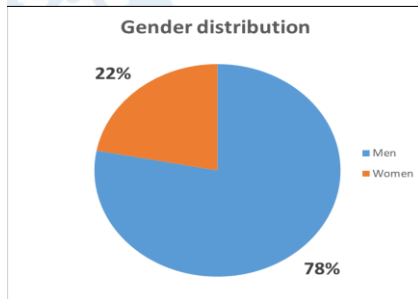
"I know quite a few people around here just lose their legs ..They're not really cleaning their wounds or whatever." (Sammy, LSHTM Staying Safe study)

- HCV prevention study: SSTI a pressing priority among London PWID
- Injecting related injury: a 'hidden epidemic of suffering' ¹
- Impacting the most marginalised PWID – women, homeless, multi-morbidities
- Exacerbates & entrenches social exclusion: stigma, shame, pain, odour, mobility
- Significant barriers to care (~10% UK PWID (20,000) hospitalised p/a for SSTI)
- Delayed care = serious complications (sepsis, gangrene → amputation)

1. Ciccarone. D, et al., *Community Epidemiology Working Group Meeting, National Institutes on Drug Abuse*. 2000



Participant characteristics (n=259)

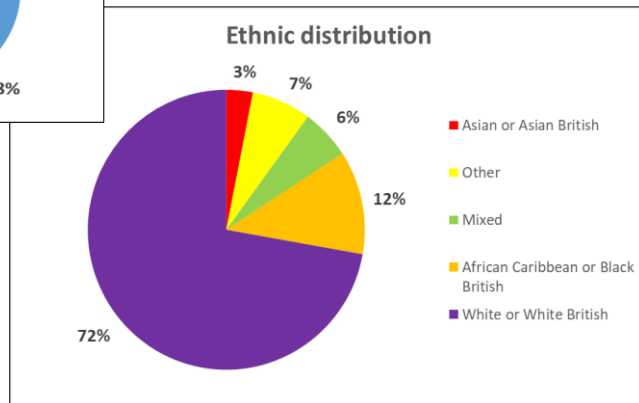


Age range: From 21 to 67 years

Mean age: Total sample - 45 yrs

Males - 45.5 yrs

Females - 42.5 yrs

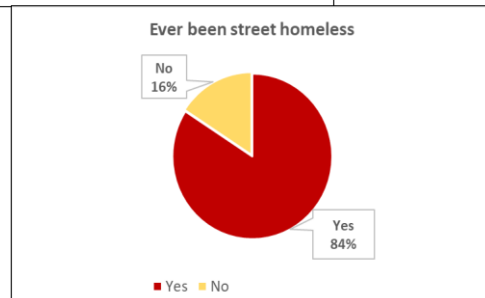


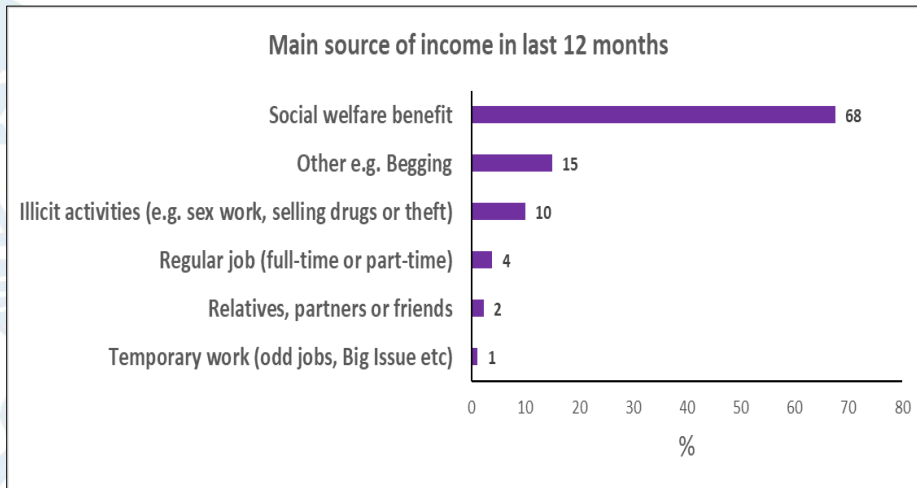
Main place of residence in last 12 months

56% in homeless hostel or rough sleeping



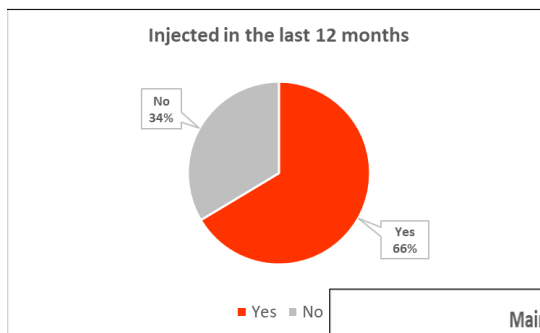
84% ever been street homeless
 Total duration: 1 week to 52 years
 Median duration of homelessness: **2 years**





96% not in any regular legal employment
> 15% main income street begging

- Note – those choosing social welfare benefit, likely to be supplanting income from other sources also. Possible under-reporting of some other categories

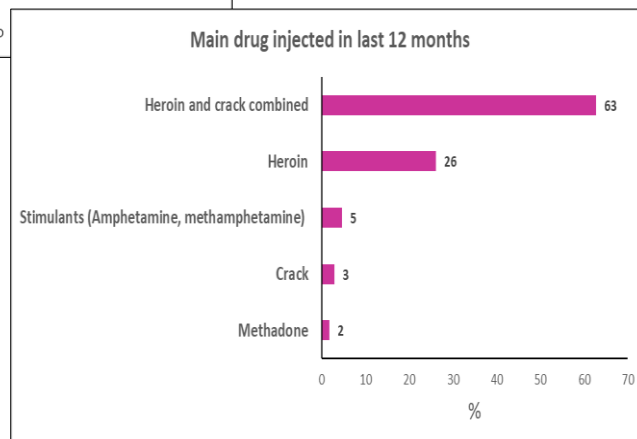


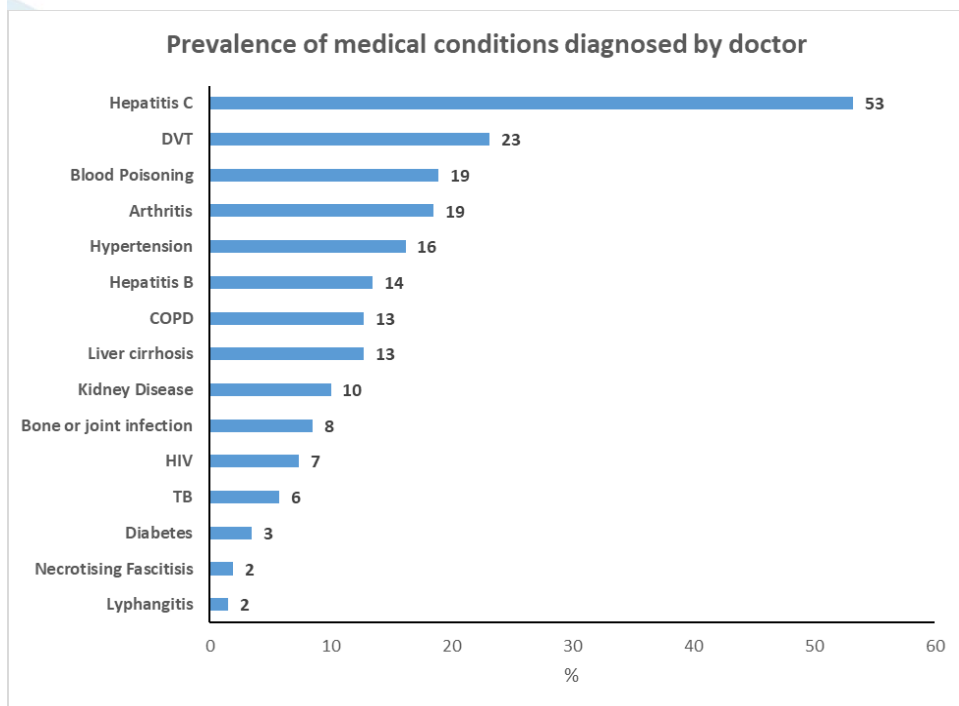
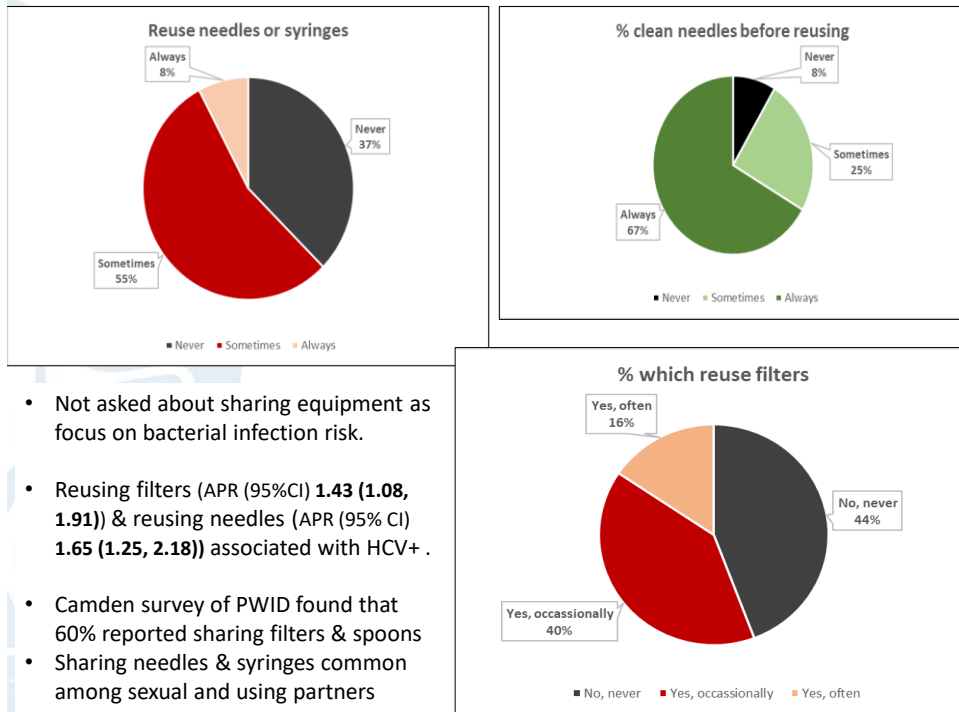
66% injected in past 12 months.

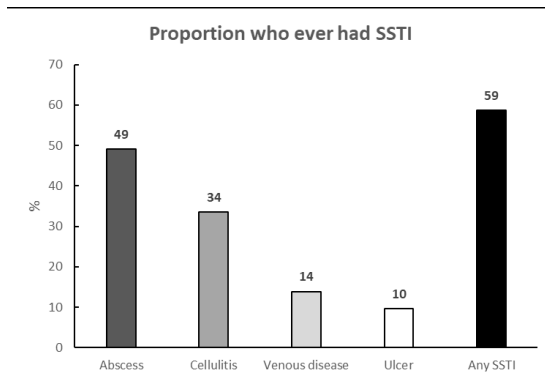
Of these:

- 65% injected once a day or more
- 24% four or more times a day

- 63% inject heroin & crack
- 73% report crack smoking
- Many who just inject heroin also smoke crack



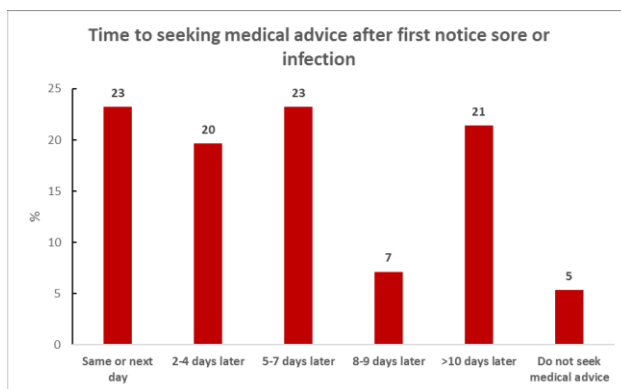
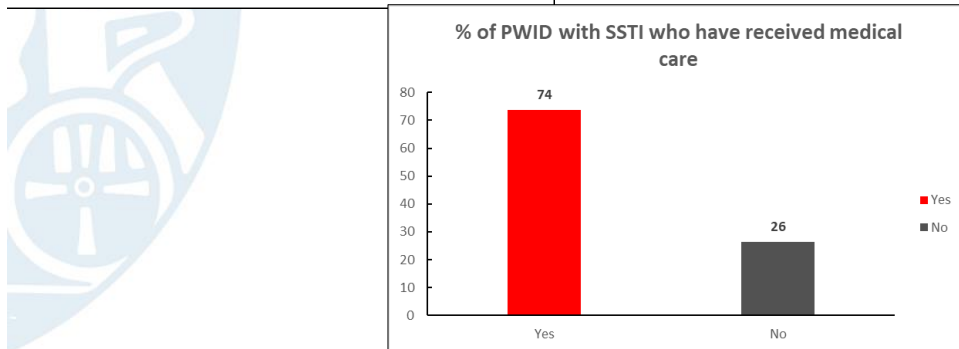




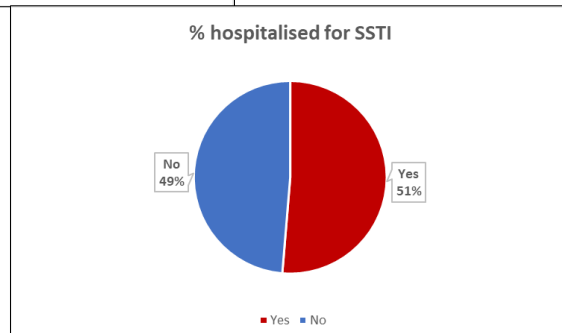
59% (152) had an SSTI, of these 69.1% had HCV.

53% (138) had HCV, of these 76.1% had an SSTI

HCV status significantly associated with having an SSTI: PR 1.89 (1.48, 2.41)



- 59% ever had SSTI. Of these:
- 74% received medical care
- **51% hospitalised**
- 51% wait 5 or more days before seeking advice
- 5% don't seek advice





Qualitative data

- So – what is going on here – why are people not seeking care for injecting injuries that impact their day to day?
- Injuries that are experienced as disfiguring, painful, mobility restricting, odoriferous and shameful.
- What are the conditions that produce SSTI risk and prohibit care?
- Do they have purchase when considering hepatitis C engagement?

Qualitative data provides insight:

- To date, 30 in-depth interviews (22 men, 8 women, 21 – 60 yrs old)
- ~70% hostel or homeless for majority of past year
- Majority lifetime experience of homelessness

‘tell me about a typical day living on the street’

The street injecting risk environment

SITUATIONAL OPPORTUNITY and **URGENCY**

"Anywhere, on the street, anywhere, cook up upstairs of a bus at times, when I was able to get around, in seconds, yeah." (Dan)

"sit on the pavement between 2 cars, put the spoon in an exhaust so it holds it have a hit there and then ...(Ben)

"rushing, you know I'll just bang in there [toilet] you could think it's the cops behind that door any second". (Gary)

"get in and get it out of the way quickly, if the spoon's still unclean from the last 5, 10 hits, bloody all the better". (Sam)

The street injecting risk environment

ENVIRONMENTAL CONSTRAINTS & CONTAMINATION

We were on the streets ... it was a red hot day, there was no water anywhere and I was dehydrating, dehydrating plus there's no toilet, no taps anywhere around, no rain, no nothing, I was proper sick for a hit, in the end because I couldn't find no water and my spit wouldn't work ... I had to do it with a puddle of water and then like filter the water through the serits ... just to get the dirt of the water. (James)

Diluents used: puddle water, surface water on cars, water from toilet cistern, whisky, beer, cider, Coca-Cola, lemon juice, saliva.

There was no water actually and I had to use a bit of saliva ... it worked, I still got my hit but also I got the worst infection of my life, I nearly died ... I was in hospital for nearly 3 months. (Eddy)

The production & normalisation of harm

URGENCY + CONSTRAINT + CONTAMINATION

→ VENOUS DAMAGE, FEMORAL & SUBCUTANEOUS INJECTING = HEALTH HARMS

GARY (30s) AND EMMA (50s)

"I can't go in the groin anymore, like the groin's gone, it's fucked ... I was homeless and the right side was just randomly, out of nowhere, it would just burst with blood, like blood everywhere! ... Within ten seconds my entire trousers would be covered in blood ... it would happen maybe three or four times in a day ... a whole kitchen roll would be covered [in blood]." (Gary)

"After begging for money every day ... every time I tried getting a vein couldn't get the vein, I had to take it out and skin pop it, so I kept doing that and I got one abscess after the other, that led to dirty needles or just dirty hits or whatever ... that caused one infection after the other, after the other." (Emma)

The production & normalisation of harm

PHYSICAL VIOLENCE

I've been set alight sleeping bags, I've been battered, nearly kicked to death, I've had it all. (Sid)

STRUCTURAL VIOLENCE

Because I'm on the streets they're saying oh well you just stick there, basically ... since I come out of the coma I've had no housing, they just kicked me out of the hospital ...no psychiatric help like for my mental health, nothing really, no support what so ever. I'd go anywhere, anywhere at all [for housing]. I'm trying, trying, but no, no one's catching me, no one's holding me no life-line. (Lenny)

DESPERATION & SELF ANNIHALATION

I've had big hits ... like some fucking convulsions with it... it was like you were riding a surf board to death ... fucking scary ... because you're so close, mate, you can feel it, feel death looking down right at me, poking in your back. (Ivor)

I'd just had enough, I wanted to give up, I slit my own throat September gone. (EJ)

Normalised harm: precludes care

GARY

This dealer that I was going to meet ... he was like, what the fuck man, what's going on! And I said, oh nothing-nothing. He was like, come on, get in, I'm taking you to hospital. Even the dealer was worried about it. But I was like no-no... No! I was like, no, it's okay, it'll be alright. And that lasted about a week and a bit...

EMMA

So when did you first seek medical help?

*Probably **about three years** or something after, because I was still sitting on the street begging ... I was sitting on cold, I was sat there for 12, 14 hours a day. So basically all that pressure on the sores ... It was just abscess after abscess ...and it started getting worse and it started building up and going down, and eventually I had no bum ... **there wasn't time**, I just thought *what's the point, what's the point, you know, there wasn't any point.**



Implications for HCV: closing thoughts

"Hepatologists don't understand this client group ... they don't understand the social pressures ... they don't understand why they won't turn up for an HCV appointment [at the drug treatment service]" (nurse)

- How aware are we of the daily harms & pressures facing the most marginalised?
- Is it ethical to compartmentalise HCV & its treatment in isolation from the vulnerabilities that produce risk?
- What might this mean for reinfection potentials?
- What might reinfection mean for people given hope through clearing HCV?
- What can you do in your daily life to advocate for broader change?

*[I'd like] somewhere safe to inject, clean pins, clean, and **just somewhere safe** and you can get like **tea and hot soup** in the winter ... Yeah, it would be good if there was places that'd be open to do that. (Sally)*

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