EXPERIENCES OF STIGMA AMONG PEOPLE WHO INJECT DRUGS IN ENGLAND, WALES & NORTHERN IRELAND

Dr Sara Croxford – BSc MSc PhD MFPH
Public Health Registrar
Health Equity and Inclusion Health Division
UK Health Security Agency
sara.croxford@ukhsa.gov.uk

BACKGROUND

What is stigma?

- Complex concept – "*a social process characterised by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group" (Scambler, 2009)*

Why is stigma among people who inject drugs important?

- Injecting drug use is associated with widespread, multi-faceted stigma that is intensified by criminalisation and intersecting forms of prejudice related to ethnicity, socioeconomic deprivation, homelessness, etc.
- Previous experiences of stigma can lead to avoidance or delay in accessing healthcare and increase engagement in risk behaviours, resulting in poorer physical and mental health.

What do we know about stigma experienced by people who inject drugs in the UK?

- Limited data – no recent quantitative estimates of stigma from the UK
- Questions on stigma in Needle Exchange Survey Initiative (NESI) in Scotland but not yet published

Objective: To explore stigma among people who inject drugs in England, Wales & Northern Ireland using bio-behavioural surveillance data

Scambler, G. (2009). Health-related stigma. Sociology of Health & Illness, 31(3), 441–455.

METHODS

Data source: Unlinked Anonymous Monitoring (UAM) Survey of People Who Inject Drugs

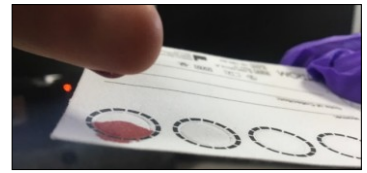
- Frequency: annual since 1990 in England & Wales and since 2002 in Northern Ireland
- Sample: people who have ever injected psychoactive drugs
- Recruitment: drug services (needle exchange, outreach, drug treatment, etc.)
- Bio-behavioural design: dried blood spot (DBS) (tested for HIV, hepatitis B (HBV) and hepatitis C (HCV)) + questionnaire (demographics, risk/protective behaviours, uptake of interventions)

New questions added in 2024 to capture recent experiences of stigma and discrimination (Likert scale responses)

HepHIV 2026
by EuroTEST
2-3 NOVEMBER · DUBLIN



UAM Survey of PWID



SECTION 10: Disclosure, Stigma and Discrimination

27 Thinking about your experience in the **last year**, how often have you…

a Experienced stigma or discrimination because of your drug use?
(e.g. being stereotyped, refused services, or treated negatively?)

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐ Not applicable

b Avoided being open about your drug use when using health services for fear of a negative reaction from others?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐ Not applicable

c Avoided being open about your hepatitis C status when using health services for fear of a negative reaction from others?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐ Not applicable

d Avoided being open about your HIV status when using health services for fear of a negative reaction from others?

☐ Never ☐ Rarely ☐ Sometimes ☐ Often ☐ Always ☐ Not applicable

METHODS

Inclusion criteria

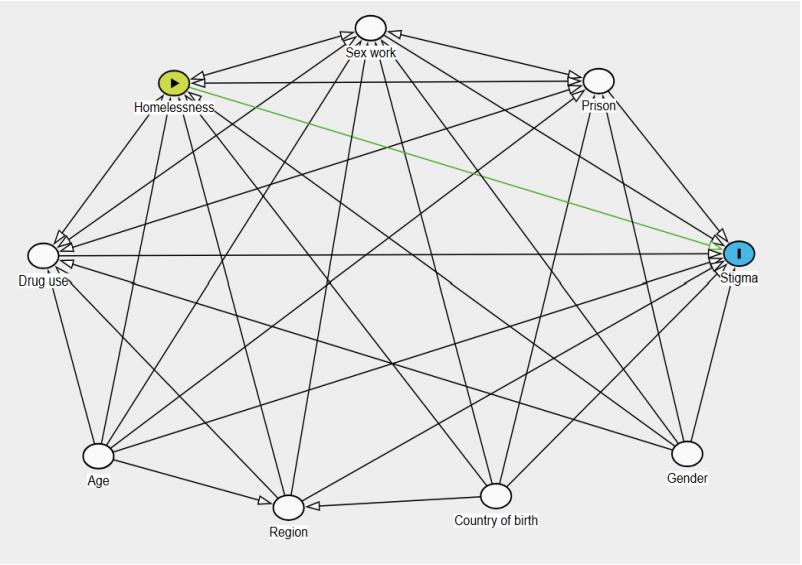
- Took part in the UAM Survey in 2024
- Reported injecting drugs in the past year (12 months)

Outcomes (in the past year)

1) Experienced drug-related stigma - being stereotyped, refused services or treated negatively
2) Anticipated stigma - avoidance of being open about drug use, HIV or hepatitis C when using health services for fear of a negative reaction from others

Statistical analysis (Stata v18)

- Descriptive analyses – prevalence and frequency of the 4 stigma outcomes overall and by participant characteristics
  - Any stigma vs high-frequency stigma (“often” or “always”)
- Ordinal logistic regression to investigate factors associated with an increasing frequency of drug-related experienced and anticipated stigma - direct acyclic graphs (DAGs) to identify minimal adjustment sets

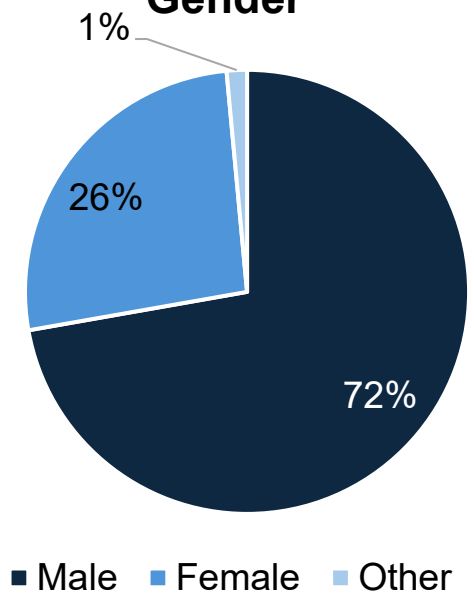


RESULTS

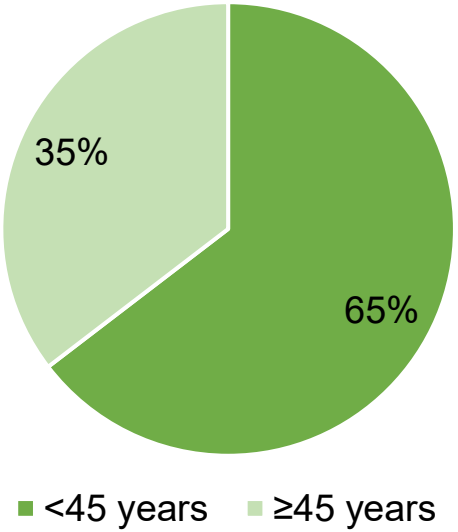
Participant characteristics

- 1,634 participants injecting in the past year
- Mostly men, aged <45 years, born in the UK and recruited in England, outside of London
- HIV prevalence: 1.6%
- HCV prevalence (current infection): 9.2%

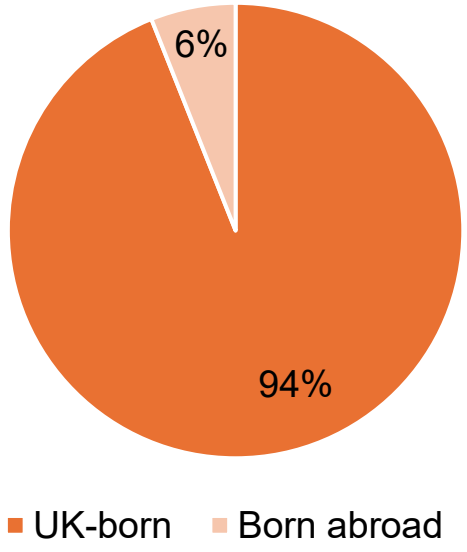
Gender



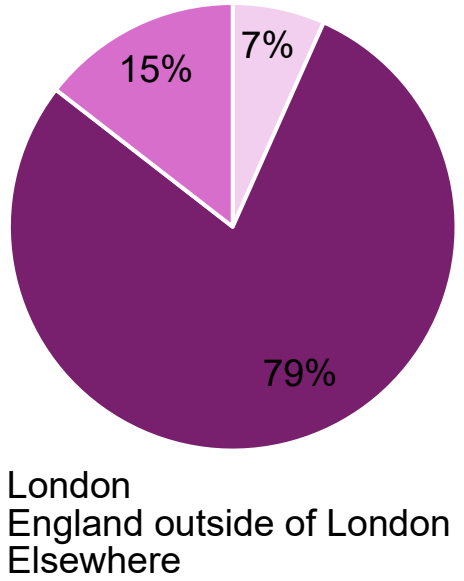
Age at participation



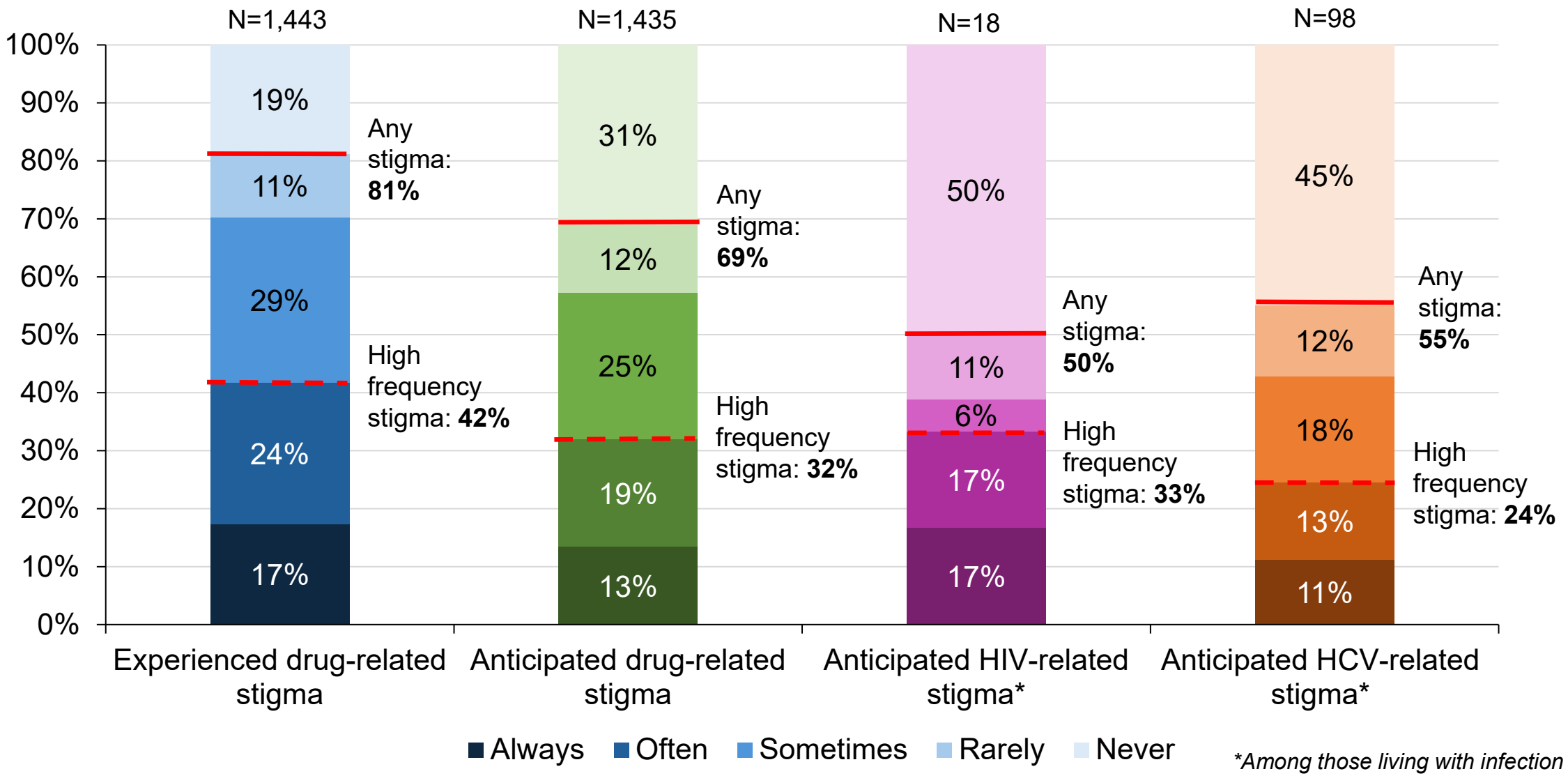
Country of birth



Region of recruitment

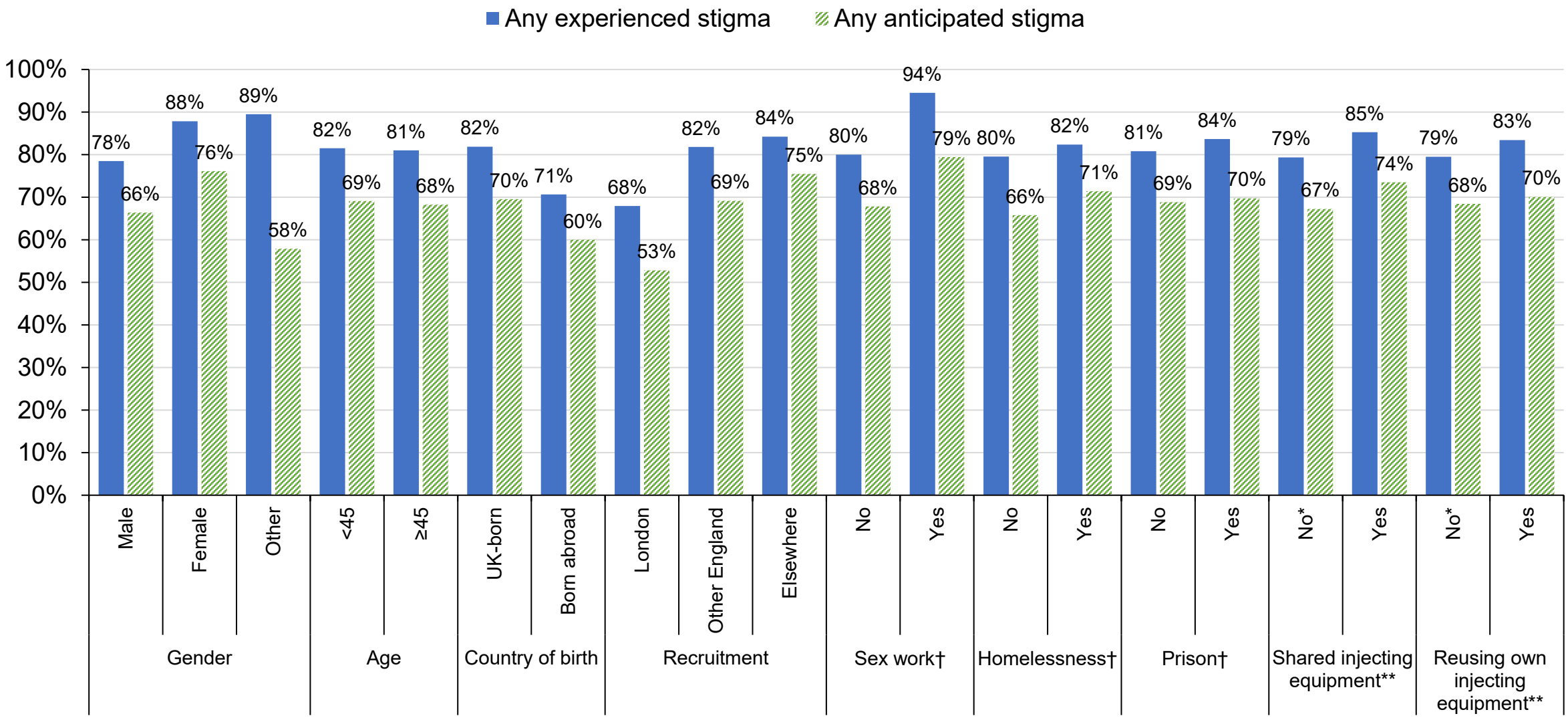


Prevalence and frequency of stigma among people who inject drugs: England, Wales & Northern Ireland, 2024



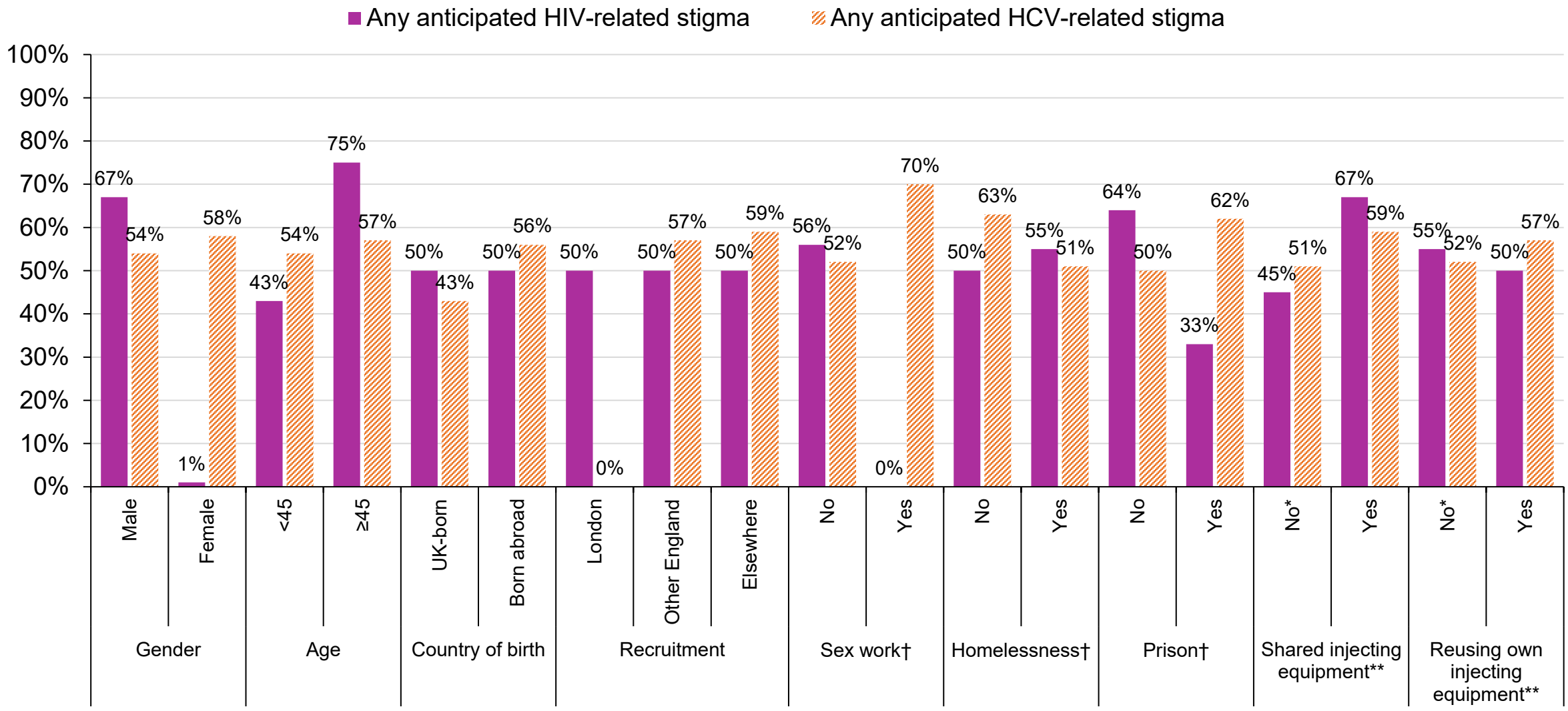
*Among those living with infection

Prevalence of any experienced and/or anticipated drug-related stigma among people who inject drugs: England, Wales & Northern Ireland, 2024



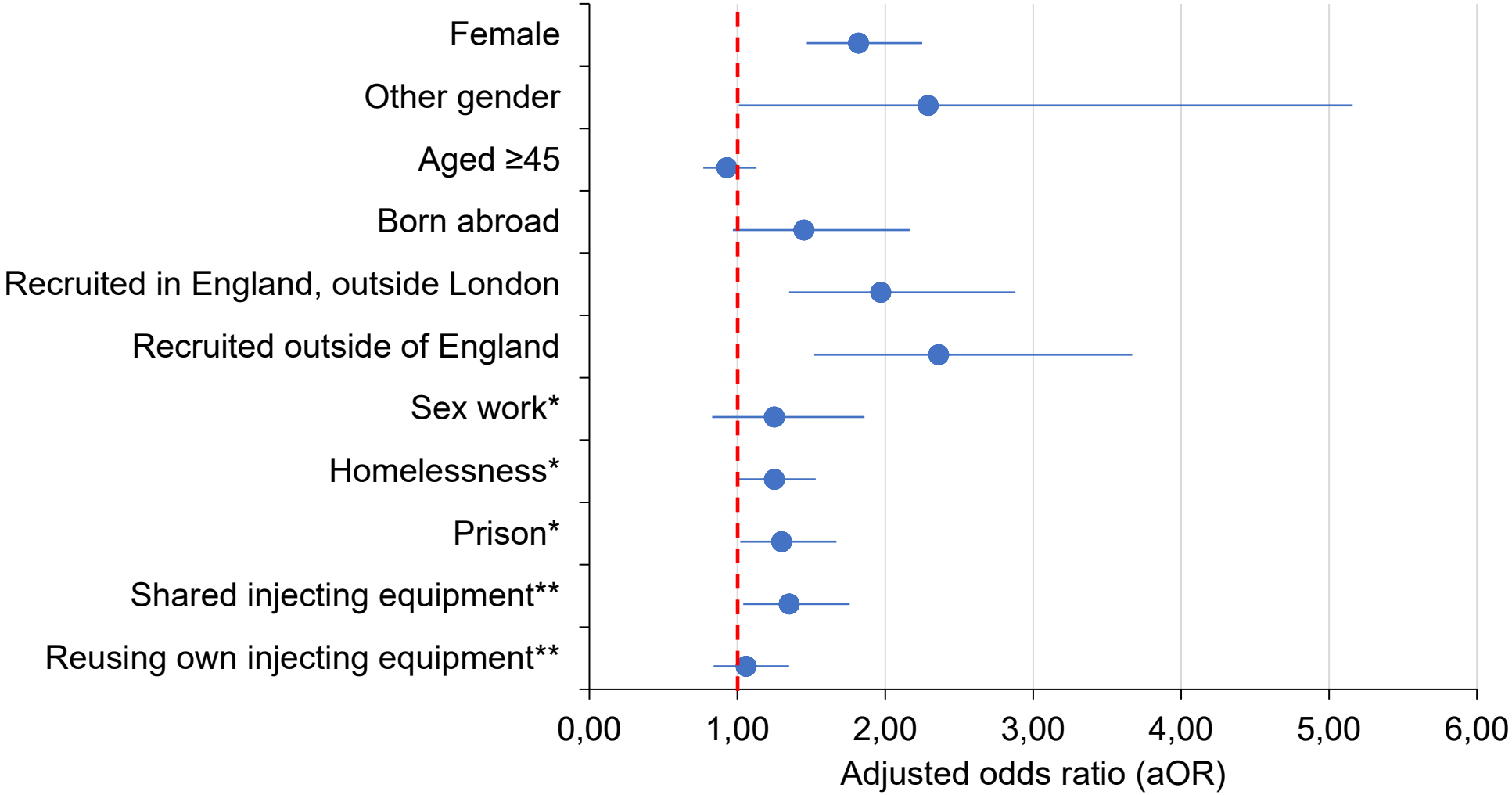
*Including those who had not injected in the past month; **In the past month; † In the past year

Prevalence of any anticipated stigma related to HIV & HCV among people who inject drugs living with these infections: England, Wales & Northern Ireland, 2024



*Including those who had not injected in the past month; **In the past month; † In the past year

Factors associated with more frequent experienced drug-related stigma: England, Wales & Northern Ireland, 2024

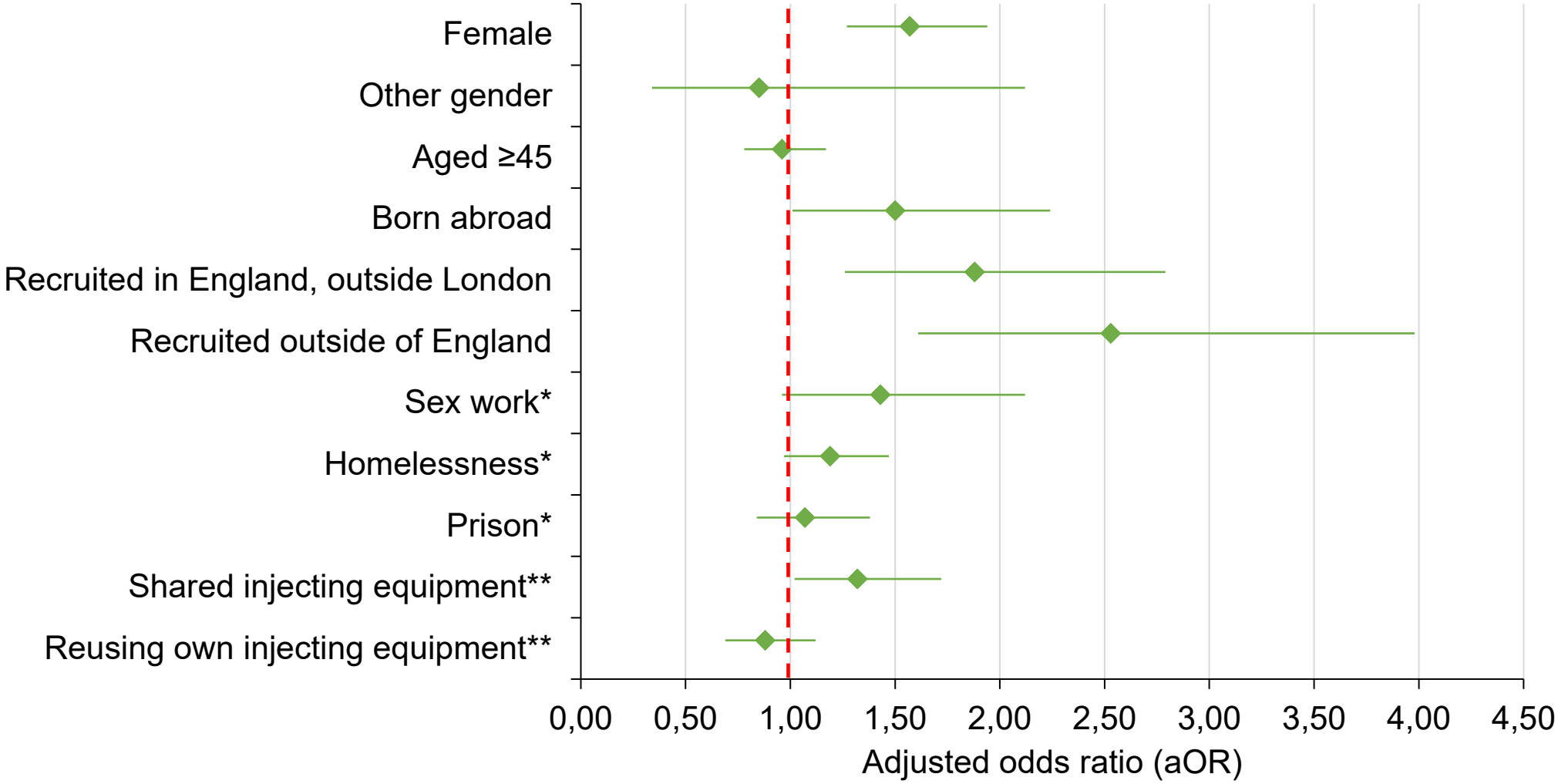


aOR (95%CI)
1.82 (1.47-2.25)
2.29 (1.01-5.16)
0.93 (0.77-1.13)
1.45 (0.97-2.17)
1.97 (1.35-2.88)
2.36 (1.52-3.67)
1.25 (0.83-1.86)
1.25 (1.01-1.53)
1.30 (1.02-1.67)
1.35 (1.04-1.76)
1.06 (0.84-1.35)

Baseline groups: *men, aged <45, born in the UK, recruited in London, no sex work, no homelessness, no prison, no sharing or reusing of injecting equipment*

**In the past year; **In the past month*

Factors associated with more frequent anticipated drug-related stigma: England, Wales & Northern Ireland, 2024



aOR (95%CI)
1.57 (1.27-1.94)
0.85 (0.34-2.12)
0.96 (0.78-1.17)
1.50 (1.01-2.24)
1.88 (1.26-2.79)
2.53 (1.61-3.98)
1.43 (0.96-2.12)
1.19 (0.97-1.47)
1.07 (0.87-1.38)
1.32 (1.02-1.72)
0.88 (0.69-1.12)

Baseline groups: *men, aged <45, born in the UK, recruited in London, no sex work, no homelessness, no prison, no sharing or reusing of injecting equipment*

**In the past year; ** In the past month*

STRENGTHS & LIMITATIONS

Strengths

- National survey of people who inject drugs
- First estimates of different types of stigma among people who inject drugs in the UK
- Study provides a baseline for monitoring progress towards HIV and viral hepatitis elimination goals
- Definition of stigma consistent with other studies

Limitations

- Only those in contact with drug services - may be missing those more likely to report stigma
- Recall and social desirability bias of self-reported risk behaviours – minimised through self completed questionnaire and anonymity
- No data on the sources of reported stigma
- No data on the ethnicity or socio-economic status, known predictors of stigma (ethnicity added in 2026)
- Small numbers make some findings difficult to interpret:
  - Differences in anticipated HIV- and HCV-related stigma across groups
  - Differences in stigma by country of birth (few people born abroad)

CONCLUSIONS

- The levels of stigma reported by people who inject drugs in England, Wales & Northern Ireland are unacceptably high.
  - Reflective of the substantial social marginalisation and isolation as a result of restrictive policies, criminalisation, negative attitudes from health care providers, societal perceptions, etc.
- Certain subgroups are more likely to experience drug-related stigma compounded by discrimination related to marginalised identities to create cumulative disadvantage.
  - Women, recruited outside of London, sharing injecting equipment in the past month, homeless in the past year (experienced stigma), in prison in the last year (experienced stigma)
- The observed high rates of anticipated stigma and resulting non-disclosure of drug-use, HIV and hepatitis when using health services are particularly concerning.
  - Limits the ability of health professionals to provide the appropriate care
- Future work to explore the relationship between stigma and service use in the UK (e.g. uptake of HIV and HCV testing, access to primary care, pharmacy, harm reduction interventions, etc.)

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