



# HIV-associated stigma within healthcare settings. Findings from Positive Voices 2022

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### INTRODUCTION

- Stigma negatively impacts the health and wellbeing of people with HIV and is a barrier to accessing care<sup>[1]</sup>
- The first round of the Positive Voices survey, in 2017 (PV017), reported high levels of stigma experienced by people with HIV in the UK: 10% avoided going to healthcare services when they needed to in the last year, because of their HIV

### METHODS

- Dataset: Positive Voices 2022 (PV2022) cross-sectional survey (first set of data entry)<sup>[2]</sup>
- All data presented are weighted to be representative of the population with HIV in the UK
- Participants were asked what NHS, social care and support services they had contact with in the last year, and the number of contacts
- Participants were asked if various forms of stigma had been experienced in healthcare settings **because of their HIV status**. Data are presented for those who selected 'yes, in the last year' (e.g. 'Avoided going to healthcare services when you needed to')
- Enacted stigma:** Those who felt not treated well in a healthcare setting, refused healthcare or delayed treatment or a medical procedure, or heard healthcare staff gossiping about them in the last year were defined as having experienced enacted stigma
- Met/unmet need:** Participants selected for a range of services (1) I have received this (2) I needed this but could not get it (3) I needed this but did not try to get it (4) I needed this but did not know about it (5) I did not need this. Answer(s) 1=met need, 2-4=unmet need

### PARTICIPANT CHARACTERISTICS

- 4,540 participants from England, Scotland, and Wales participated in PV2022 and 4,422 in 2017 (and provided enough information to be weighted), this represents 1 in 20 people living with HIV in the UK in both years (Figure 1)
- Participants were older in 2022 vs 2017 (median age 48 vs 50 years), other demographic profile are comparable

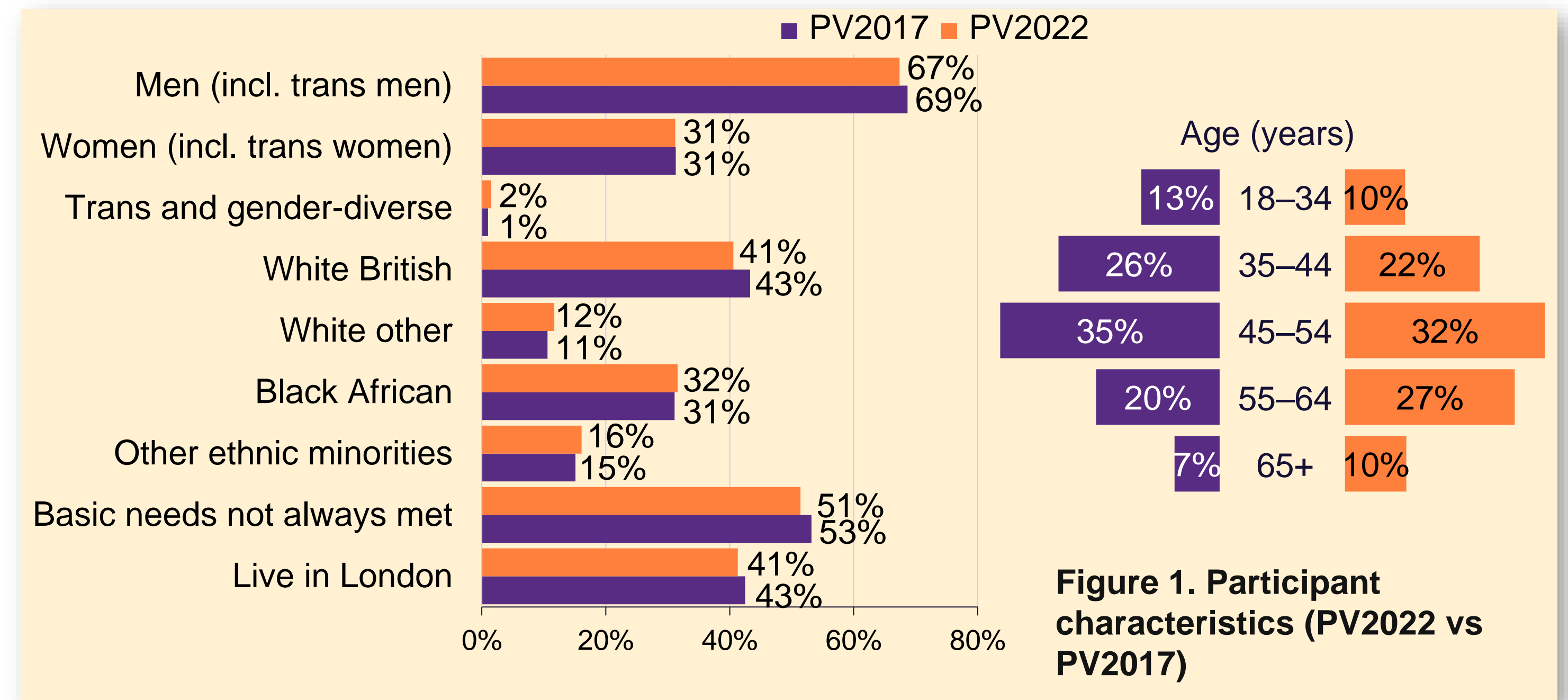


Figure 1. Participant characteristics (PV2022 vs PV2017)

### RESULTS

#### Experiences of stigma in healthcare settings

- In 2022, 7.2% of people avoided going to healthcare services because someone may learn their HIV status versus 9.8% in 2017
- In 2022, 8.5% experienced enacted stigma in the last year
- In 2022, an additional 12.8% had experienced enacted stigma, but more than a year ago
- Levels of enacted HIV-related stigma were lower in 2022 than in 2017 (Figure 2)

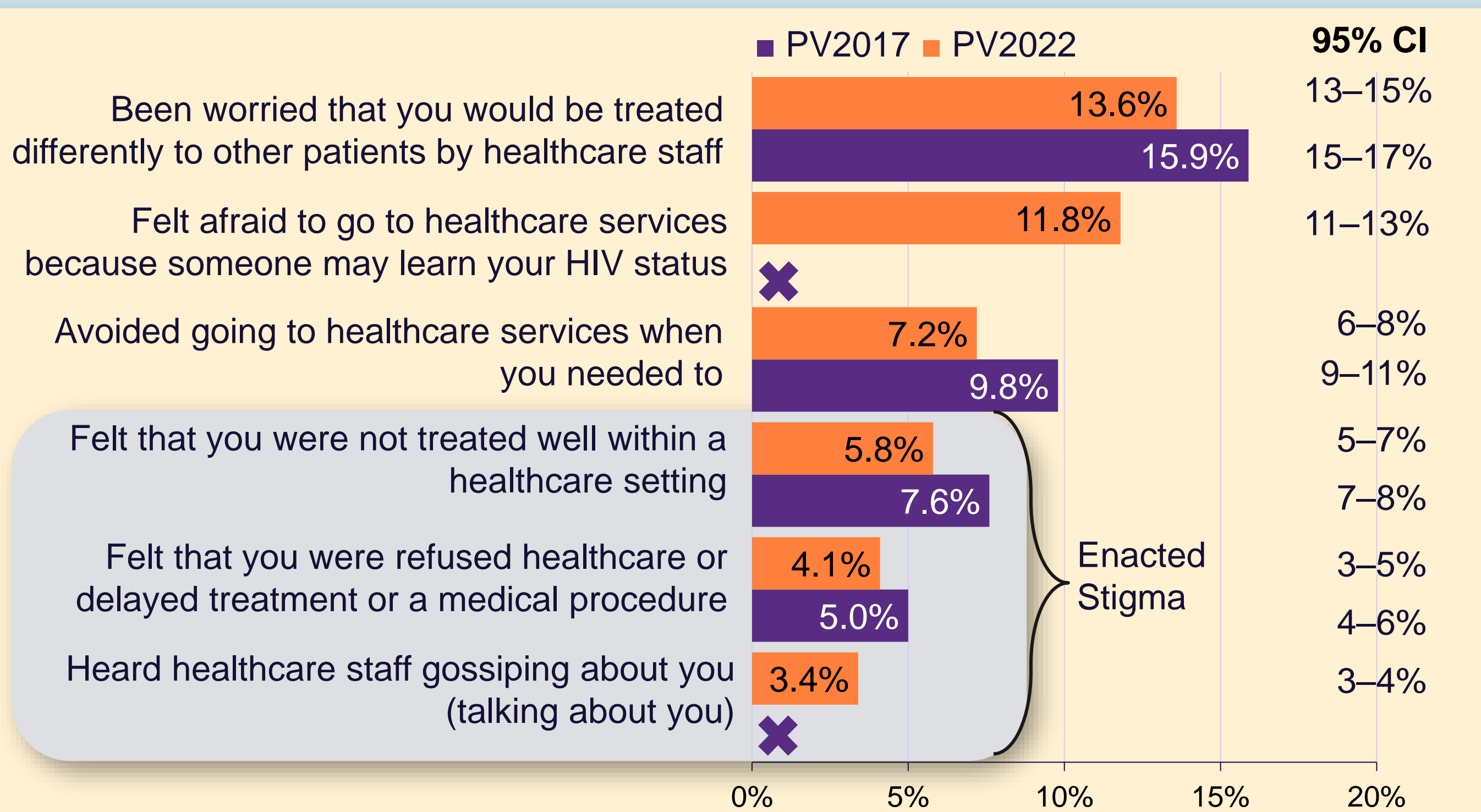


Figure 2. Prevalence of HIV-related stigma experienced in a healthcare setting (2022 vs 2017). X indicates questions not asked in 2017

#### Where are people likely experiencing enacted stigma?

- Although we did not ask where patients experienced enacted stigma, those who attended substance misuse services, inpatient care and mental health services were more likely to report experiencing enacted stigma in the last year than those who did not use these services in the past year (Figure 4)

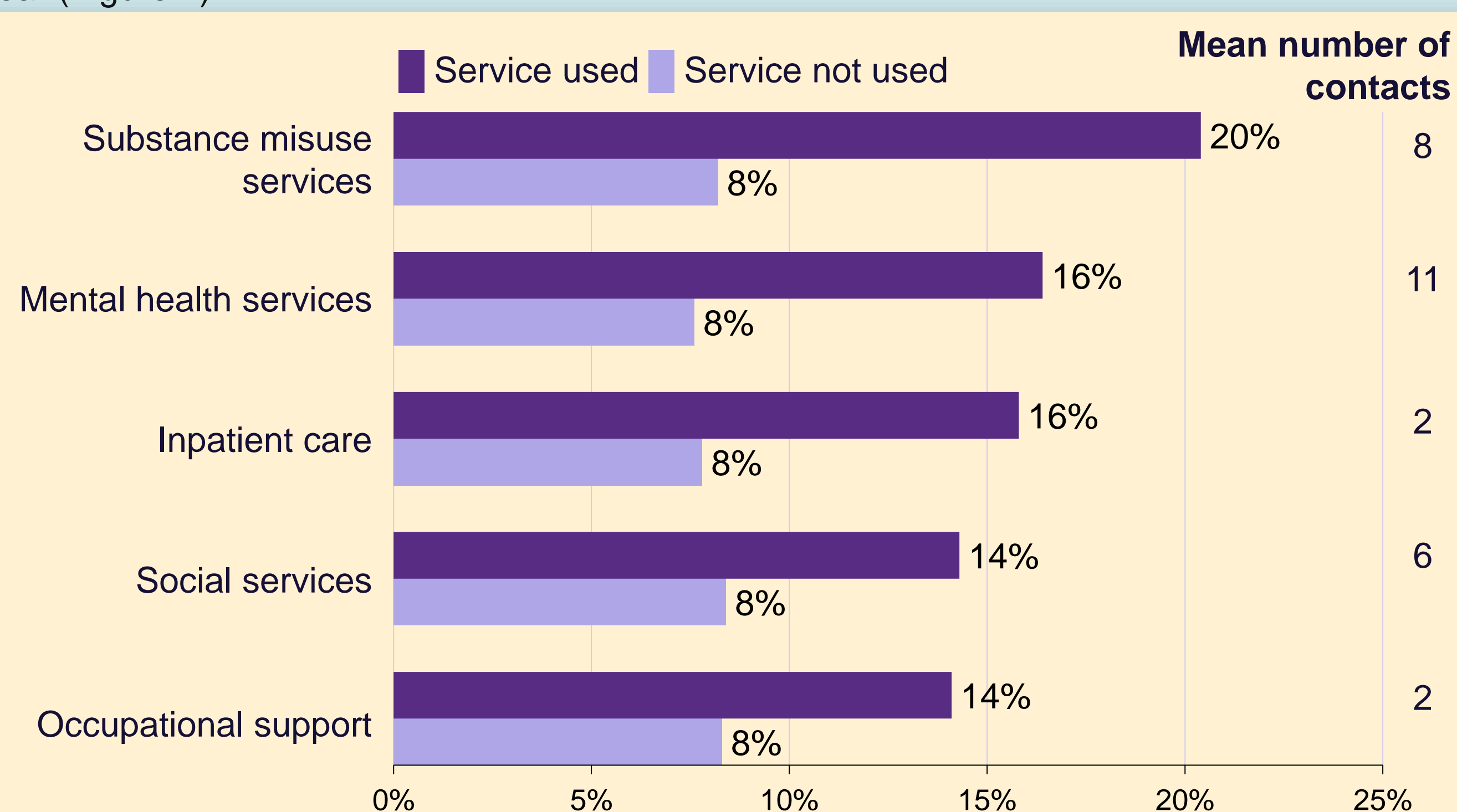


Figure 4. Proportion of people who experienced stigma in the last year, by use of services in the last year, and mean number of contacts

"Despite the U=U program hospitals are still treating HIV Patients with a massive yellow sticker on medical documents as a warning of contagion – so much for the medical world understanding HIV" – White British man, aged 45-54 years

"I have had a nurse assuming I was promiscuous and I was humiliated for that [...] I have had doctors delaying clinical treatment because they were reluctant to make clinical decisions as if my undetectable HIV completely changed how a chest infection or other chronic conditions should be managed" – Other white man, aged 18-34 years

"When going for my COVID19 booster, the staff asked me to wear a sticker that had my status written on it. That made me feel uncomfortable and ashamed" – White British man, aged 35-44 years

#### Who is more likely to experience enacted stigma?

- Enacted stigma was reported more frequently among certain groups: trans and gender diverse people, those living in the north of England, people aged 18 to 34 years, or those who do not always have enough money to meet their basic needs. Enacted stigma was also higher among those who reported unmet needs for HIV services, other health services, and social and welfare services (Figure 3)
- The reported reduction in stigma since 2017 (Figure 2) may be confounded by age: stigma was more common in younger people (Figure 3) and participants were younger in PV2017 than PV2022. There was no reduction from 2017 to 2022 in 18 to 34 years old's who reported not being treated well (9.7% vs 9.8%) and being refused healthcare (6.2% vs 8.3%)

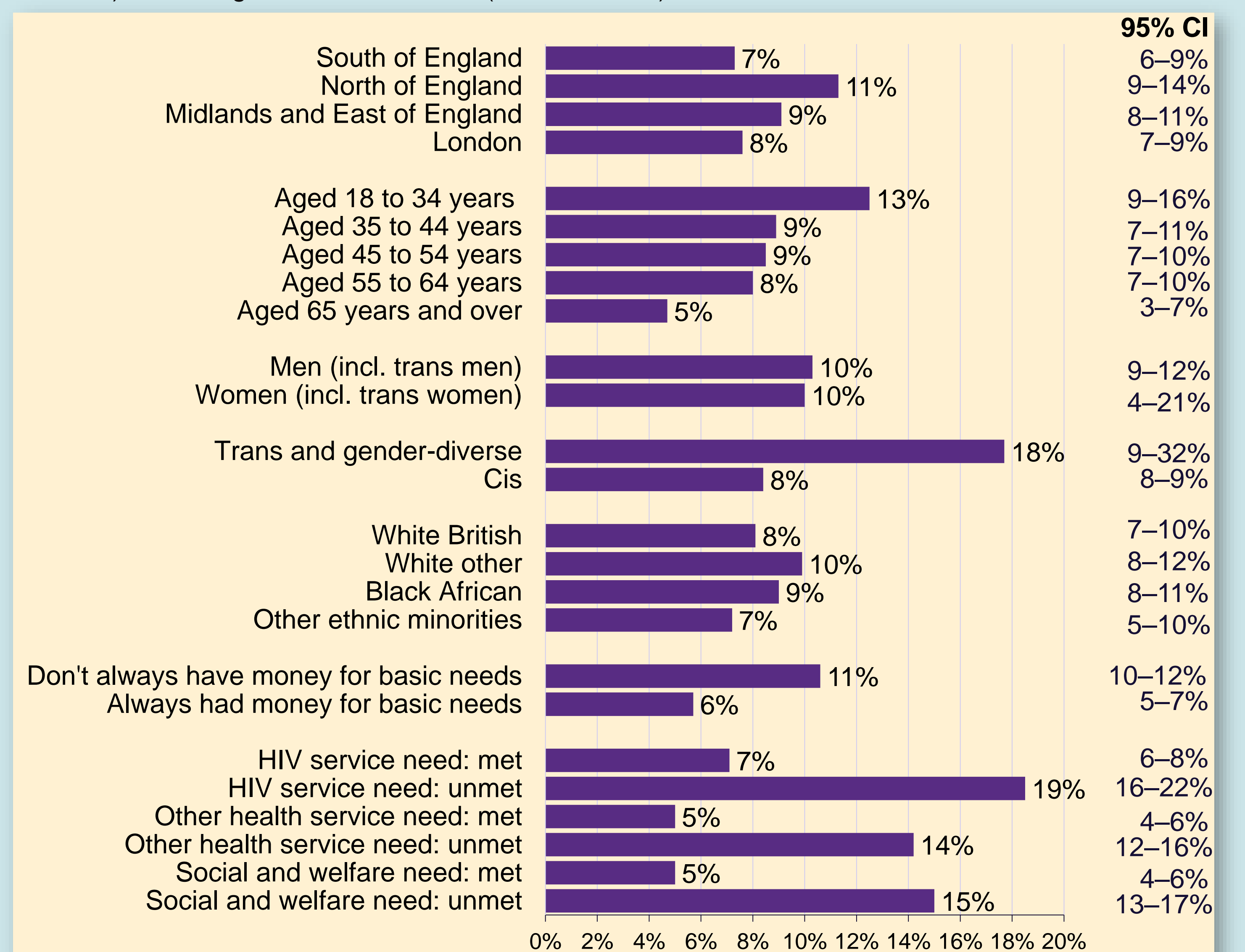


Figure 3. Proportion of people who experienced enacted stigma in healthcare in the last year, by demographic group

### CONCLUSIONS

- Despite improvements since 2017, levels of HIV-related stigma are still unacceptably high
- Some people are more likely to report experiences of enacted stigma in healthcare settings: experiences were more common among trans and gender-diverse people, younger people (aged 18 to 34 years), those living in the north of England, or those who do not always have enough money for their basic needs. Enacted stigma was also higher among those who reported unmet needs for HIV services, other health services, or social and welfare services
- Experiencing stigma is more common among people who accessed substance misuse, mental health, inpatient, social, and occupational services in the last year
- Reducing stigma may decrease levels of need for some services, but more exploration is needed to understand this relationship and to understand where stigma is occurring
- Efforts and investments must be made to ensure adequate training of all healthcare staff in the UK

### REFERENCES AND ACKNOWLEDGEMENTS

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