

# **Non-retention in HIV care – how many and who?**

**Alison Brown**

Consultant Scientist, UK Health Security Agency



## Policy paper

# Towards Zero - An action plan towards ending HIV transmission, AIDS and HIV-related deaths in England - 2022 to 2025

Updated 21 December 2021

Applies to England

## Contents

[Ministerial foreword](#)

[Executive summary](#)

[1. Introduction](#)

## Ministerial foreword

I'm so proud of how far we've come as a country on HIV. It's a consequence of some incredible work across our health and care system, local government, the voluntary and

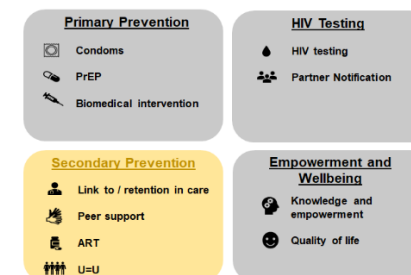
- Objective 1: ensure equitable access and uptake of HIV prevention programmes
- Objective 2: scale up HIV testing in line with national guidelines
- Objective 3: optimise rapid access to treatment and retention in care
- Objective 4: improving the quality of life for people living with HIV and addressing stigma
- Independent HIV Commission recommendations mapped to HIV Action Plan

[Print this page](#)

for HIV infections. On 10 will share details of recent relevant research and good practice.

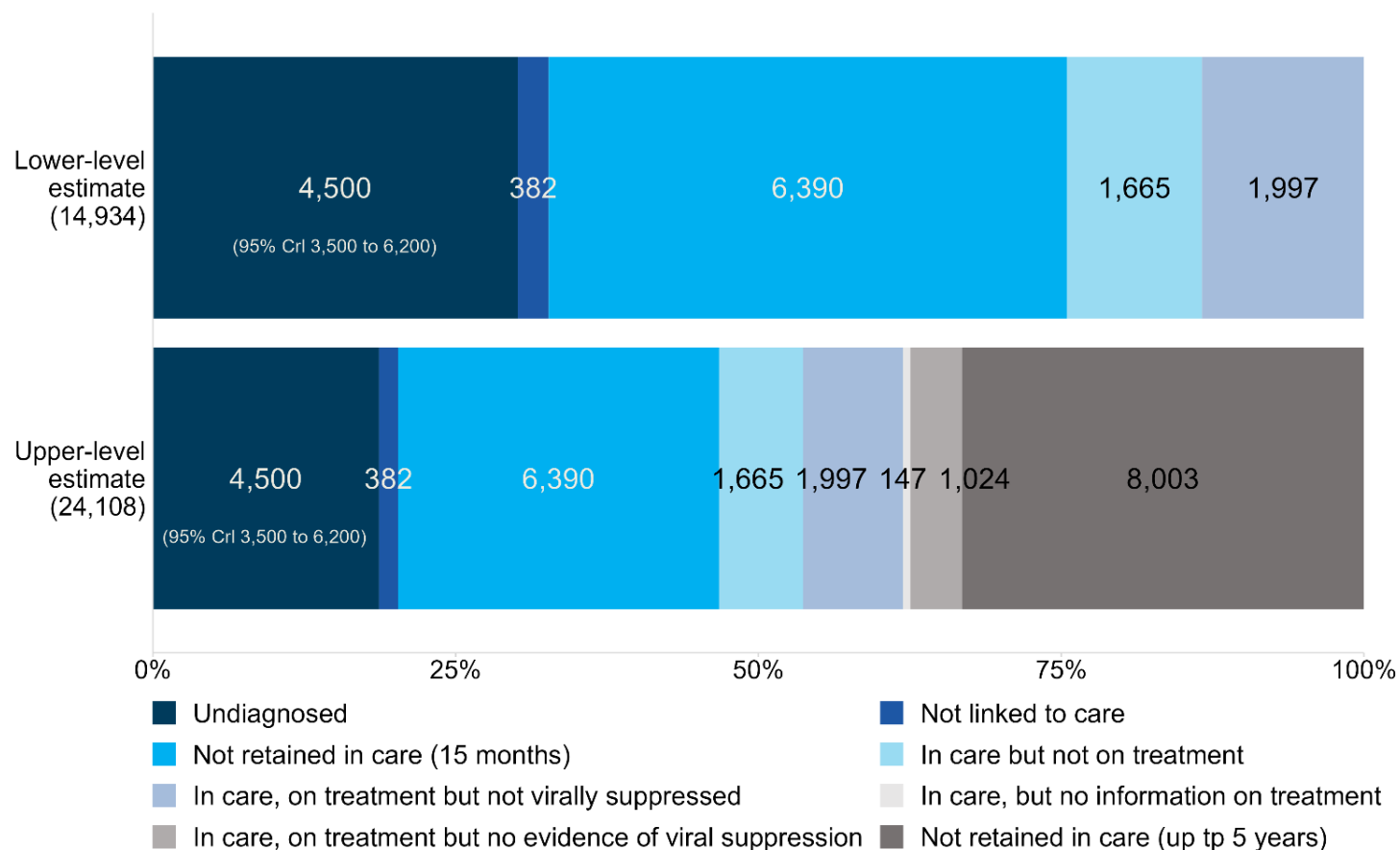
- Providers of sexual health services should evaluate alternative methods of partner notification, including both digital tools and outreach/non-digital approaches for the digitally excluded, and incorporate them into policy and practice as appropriate.

## 4. Objective 3: optimise rapid access to treatment and retention in care



**“Action 7: we will boost support to people living with HIV to increase the number of people retained in care and receiving effective treatment”**

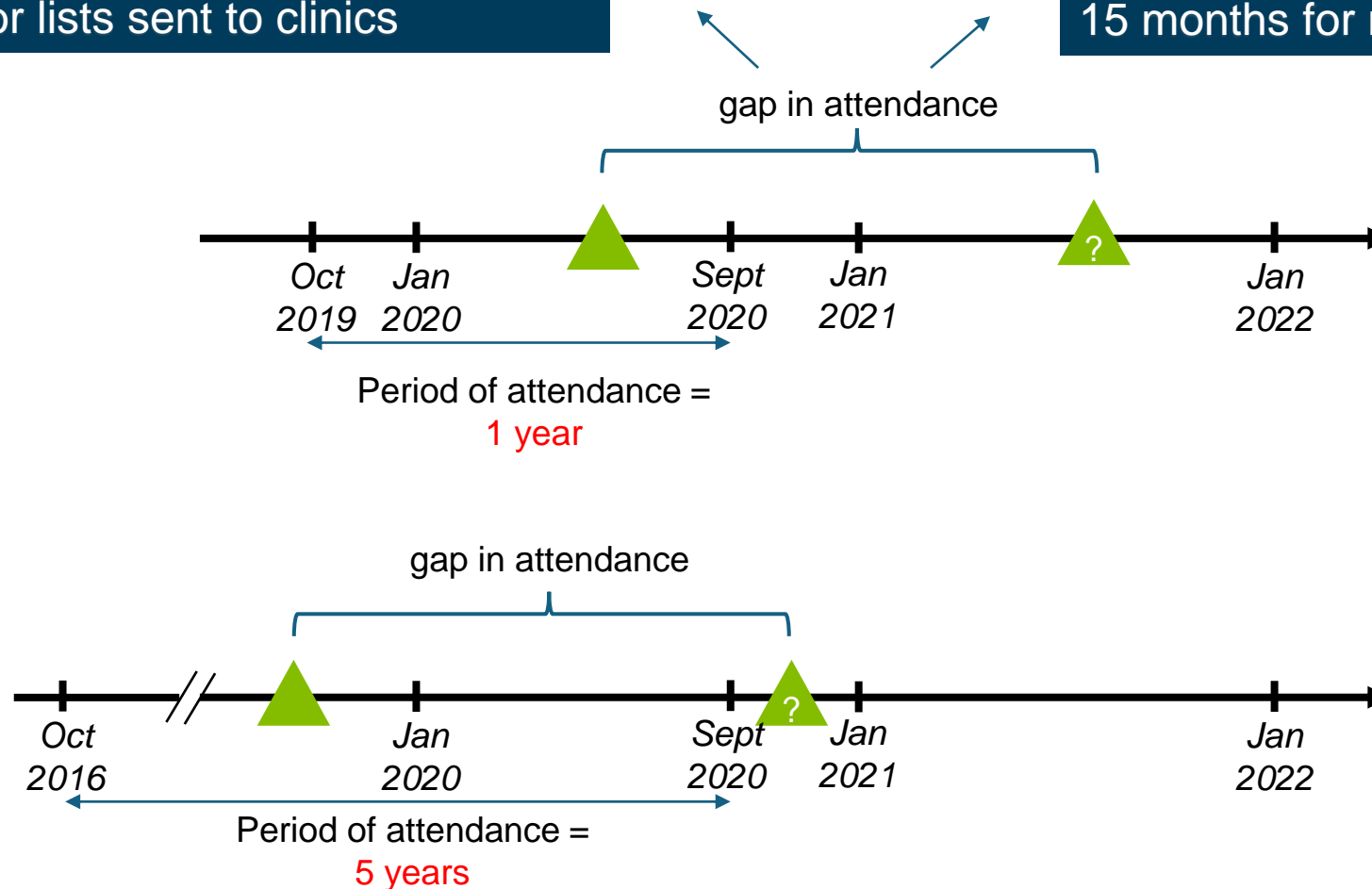
# Estimated number of adults living with transmissible levels of virus: England, 2022



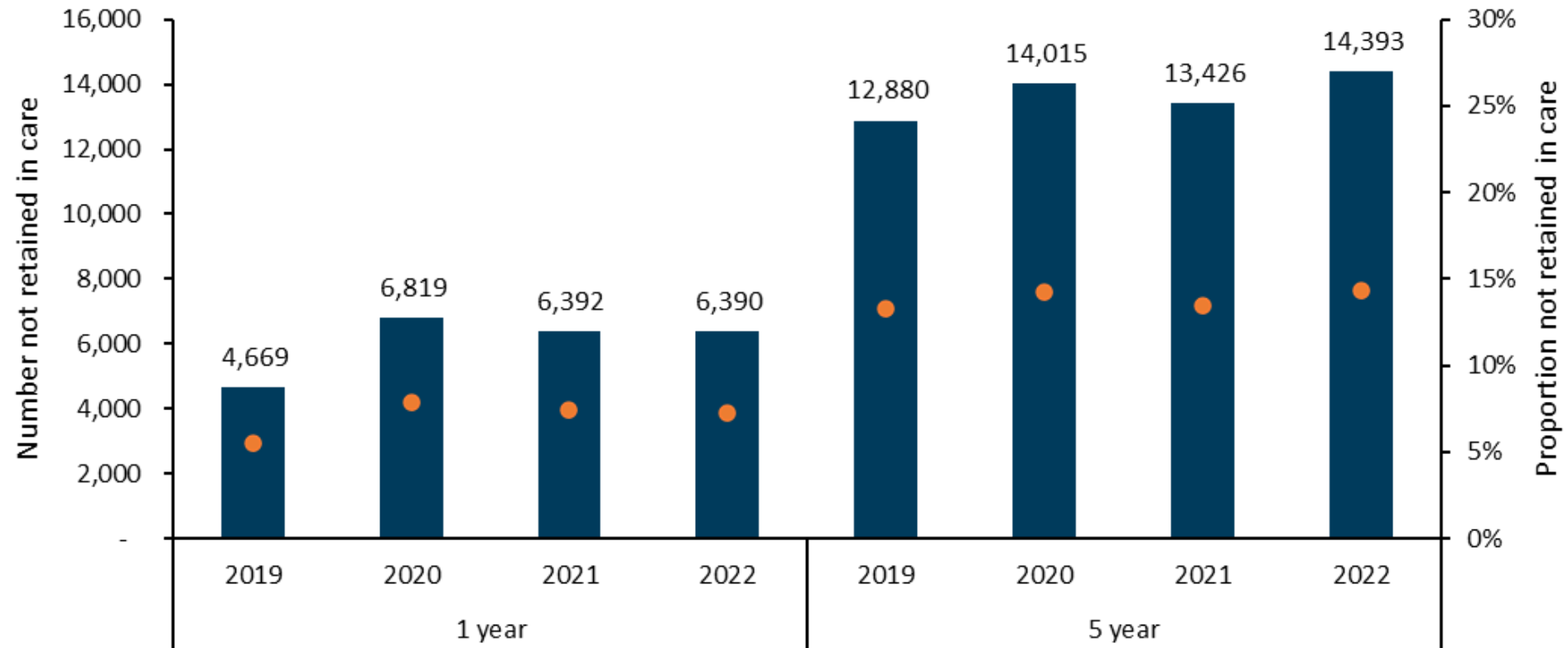
# Engagement in care indicators

12 months for lists sent to clinics

15 months for monitoring indicator

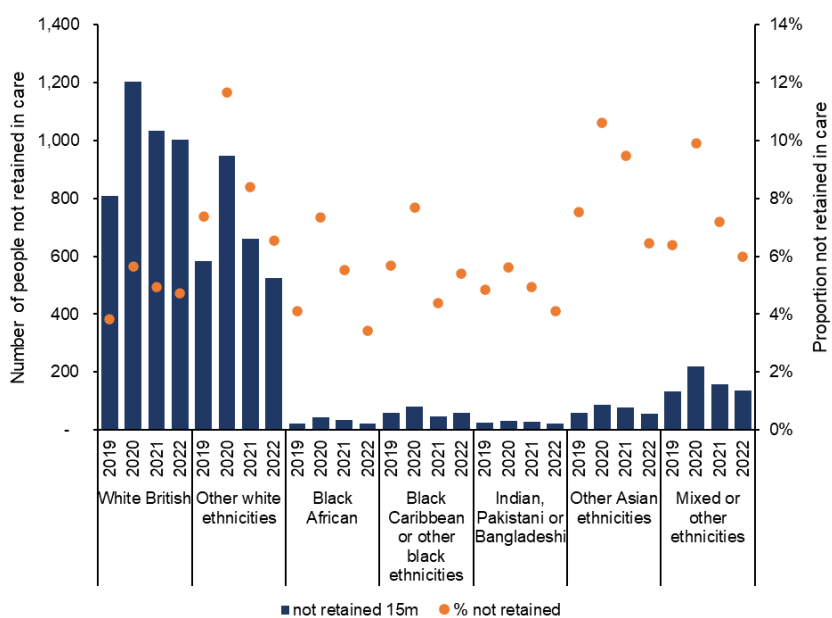


# People with a care gap of 15 months by 1-year and 5-year period of first attendance, England, 2019 to 2022

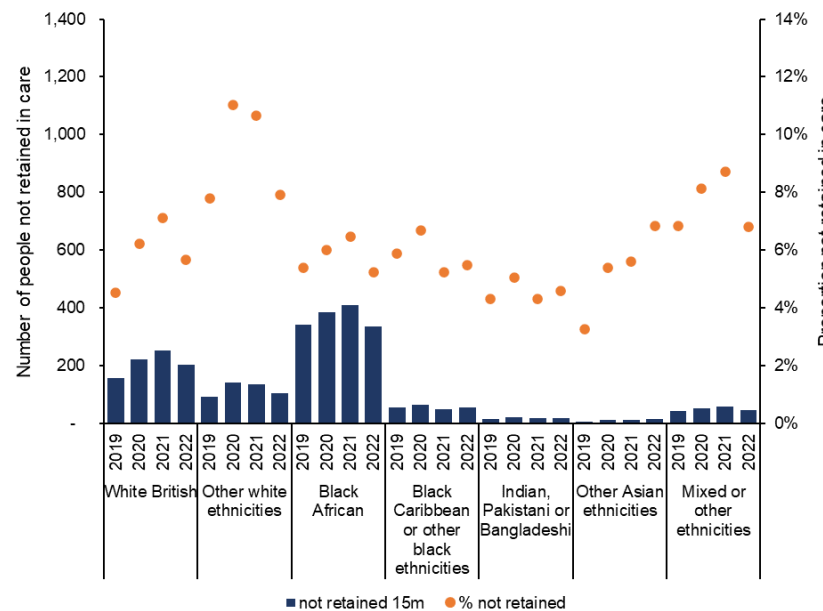


# Inequalities in HIV care gaps by gender, probable route of exposure and ethnicity: England, 2019-2022

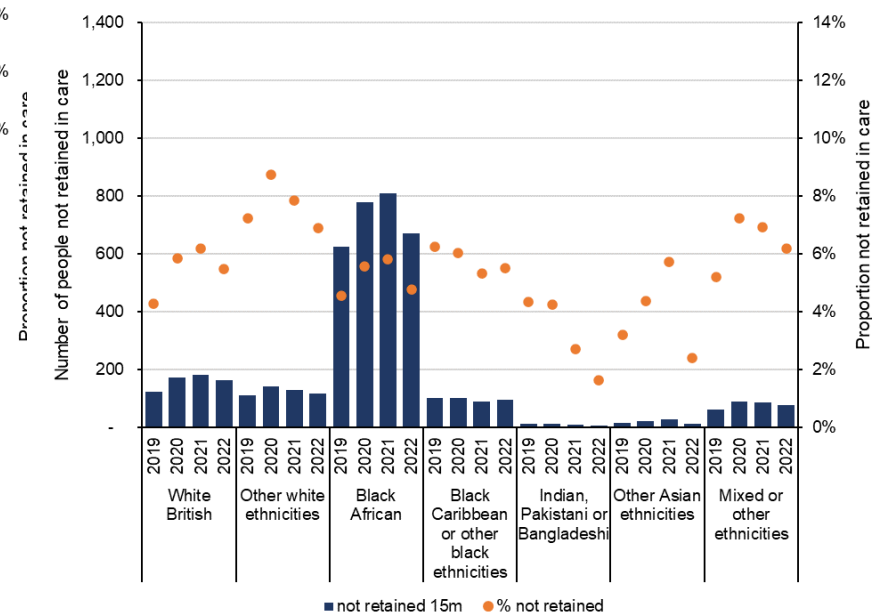
Gay, bisexual and other men who have sex with men



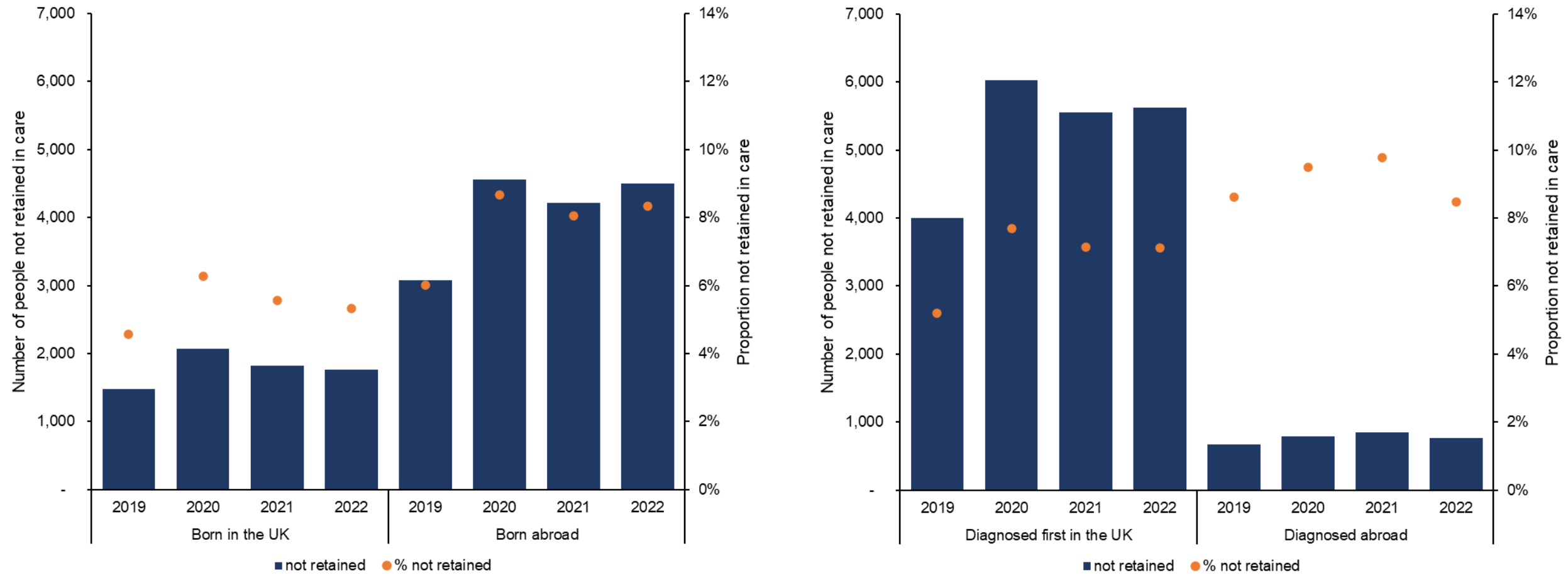
Men exposed through sex with women



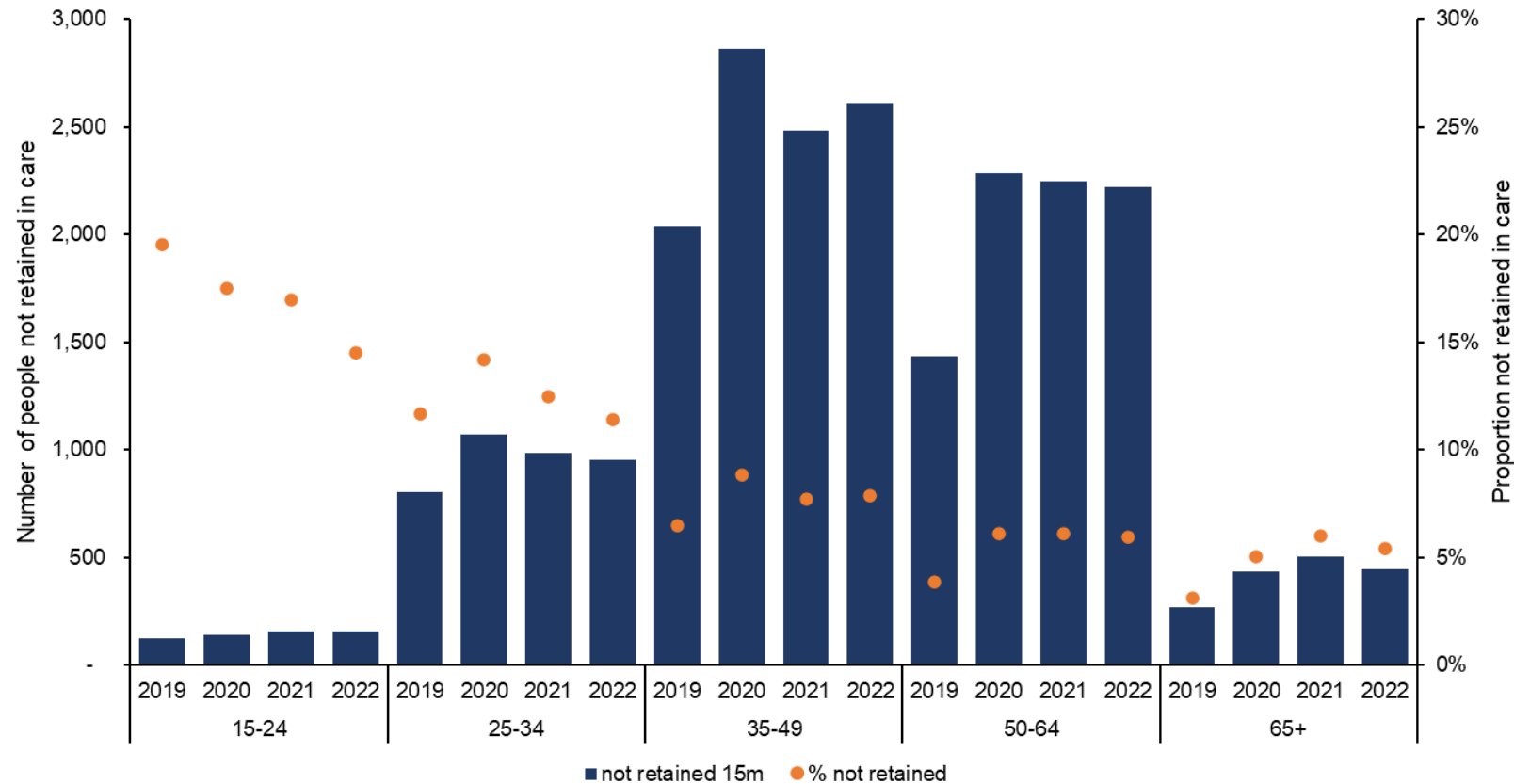
Women exposed through sex with men



# People not retained in care by country of birth and country of diagnosis, England, 2019 to 2022



# Younger people are more likely to have a 15-month gap in HIV care in England

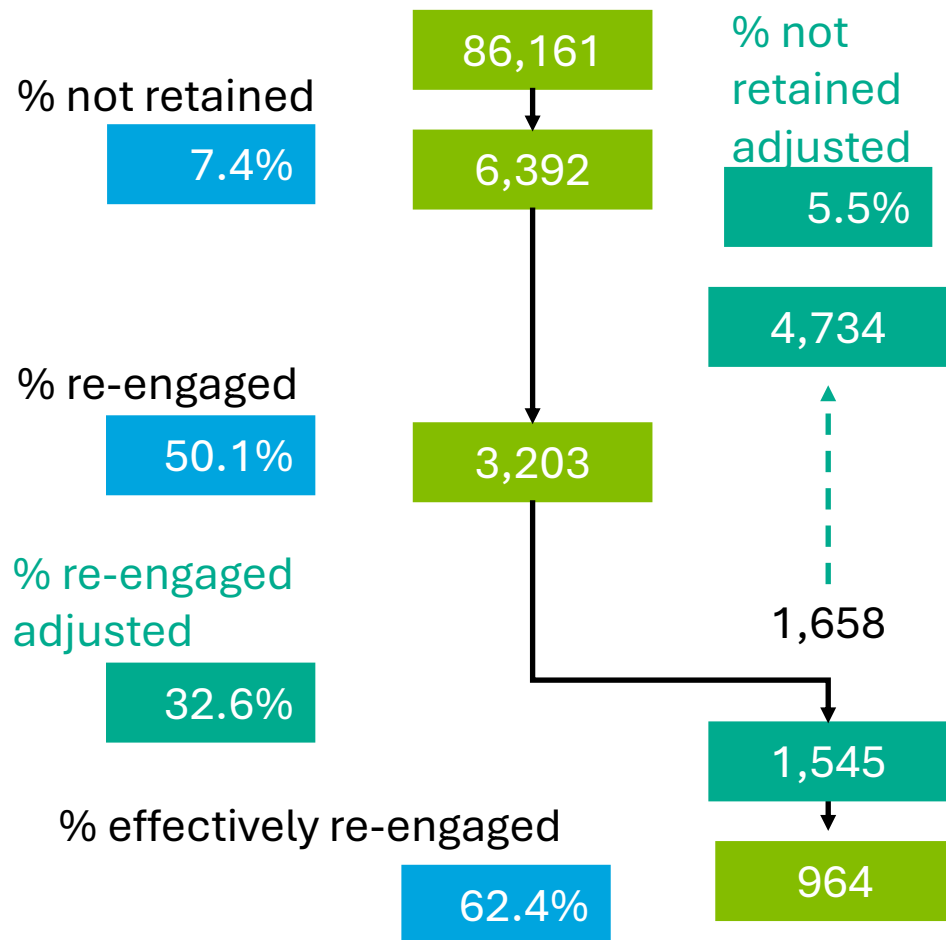




# Supporting clinics with lists of people with a 12-month gap in care

- Surveillance dataset used to identify people not seen for care for 12 months excluding
  - Seen in another clinic
  - Died
- Sending a cleaned list of people with a care gap to prioritise the HIV clinic users to reach out to
- Twice a year

# Re-engagement indicators – proportions re-engaged and effectively re-engaged



Adults seen for care between October 2019 and September 2020

Had a gap of at least 15 month from that last attendance or no further attendance until end of 2021 = **not retained in HIV care**

Not retained in HIV care excluding people already suppressed at re-engagement appointment = **not retained in HIV care adjusted**

Attended HIV care after that 15-month HIV care gap and by end of 2021 = **re-engaged in care**

Already virally suppressed (viral load below or equal to 200 copies per mL) at re-engagement appointment

With a missing viral load or viral load over 200 copies per mL around re-engagement appointment = **re-engaged in care adjusted**

With a viral load <200 copies/mL within 6 months of the re-engagement appointment = **effectively re-engaged in care**

# Conclusions



- Exploring ways to monitor engagement in care and re-engagement in care to support the needs of different groups and to assess impact of interventions - for example:
  - Overall numbers not retained increased in 2020 due to COVID impact and although dropped since, in most groups, these numbers (and %) are not back to pre-COVID levels.
  - Young people and people born abroad are more likely to not be retained in care – explore further and potential impact on policy/interventions



- Supporting clinics with lists of people not seen for care for >12 months (HIV Action Plan Action 7b)
  - Sent twice a year



- Supporting regional and local teams with data (HIV Action Plan Action 7d)
  - HIV Care Pathway workshops



- Data quality
  - Missing data for one clinic/NHS Trust can affect estimated number of people not retained in care for the neighbouring clinics and beyond