NORTH EAST AND NORTH CUMBRIA HIV CONFERENCE

Zero HIV Transmission and Zero Stigma

NEWCASTLE | 15:07:26

WELCOME: Setting the scene and strategic overview

Lorraine Hughes

Director of Public Health, Darlington Borough Council

Dawn Phillips

Sexual Health Facilitator, UK Health Security Agency

OVERVIEW OF THE DAY

What we will do today

09:45 — Welcome, housekeeping, photos and strategic overview – *National Ambitions*

10:00 — Survey insights; epidemiology; expert reflections

10:50 — Stigma, trauma and the HIV Confident Charter

11:35 — HIV Prevention Activities, HIV testing experience and collaborative discussion panel

13:30 — Opt-out testing; treatment and care; quality of life

14:00 — Thrive: Improving quality of life, with support groups

14:30 — Breakouts to identify regional priorities

15:50 — Closing reflections and next steps

We will hear data, lived experience, practical examples — and leave with priorities for action.

What are HIV and Stigma?

HIV

HIV is a virus that weakens the immune system and increases the risk of serious illness if untreated.

With effective treatment, most people living with HIV can live long, healthy lives. When treatment makes the viral load undetectable, HIV cannot be passed on sexually: U=U.

Stigma

Stigma means negative attitudes, assumptions, prejudice or discrimination linked to HIV.

It is often driven by fear, outdated information, misinformation and judgement. Stigma can stop people testing, talking openly, accessing PrEP or staying in care.

Examples of HIV stigma

Everyday contact

Avoiding touch, food, cups or toilets because someone is living with HIV.

Language and assumptions

Using blame-based language or assuming how someone acquired HIV.

Confidentiality

Sharing someone's HIV status without consent or treating them differently at work or in services.

Key message: HIV has changed. Stigma still needs to change.

SETTING THE SCENE

Why today matters

HIV is not one single story

A story of sadness

Loss, stigma, fear and inequalities have shaped many lives.

A story of hope

Treatment, prevention and community leadership have changed what is possible.

A story of progress

We now have the tools, partnerships and evidence to end new transmissions.

Today is about holding all three truths — and choosing practical action

QUICK PRACTICAL POINTS

Housekeeping

- Please keep to time so every voice and session has space …
- Questions and reflections are welcome
- Respect confidentiality and lived experience: listen with care, avoid assumptions
- Breaks and lunch are opportunities for networking and zero stigma pledges
- Let the team know about access needs or any issues on the day
- No fire alarm test planned
- Toilets are located on every floor near the elevators

Tone for today: respectful, practical, inclusive — focused on zero transmission and zero stigma.

START AS WE MEAN TO GO ON

Your role today

Be curious Ask what the data and lived experience mean for your place.

Be honest Name barriers, gaps and inequalities clearly.

Be practical Focus on actions we can deliver together.

Be ambitious Keep zero transmission and zero stigma in sight.

Thank you — let's make today useful, honest and action-focused.



Strategic Overview

HIV in England – where are we now?

Progress

1. **New HIV diagnoses have begun to fall,** with a reduction from 2023 to 2024
2. The **number of people tested** in sexual health services increased by 3% from 2023 to 2024
3. There was a **7.7% increase in people accessing PrEP**, from 2023 to 2024
4. **Deaths from HIV-related causes decreased by 14%,** from 2023 to 2024
5. The **ED opt-out testing programme contributed to 8%** of all new HIV diagnoses in 2024

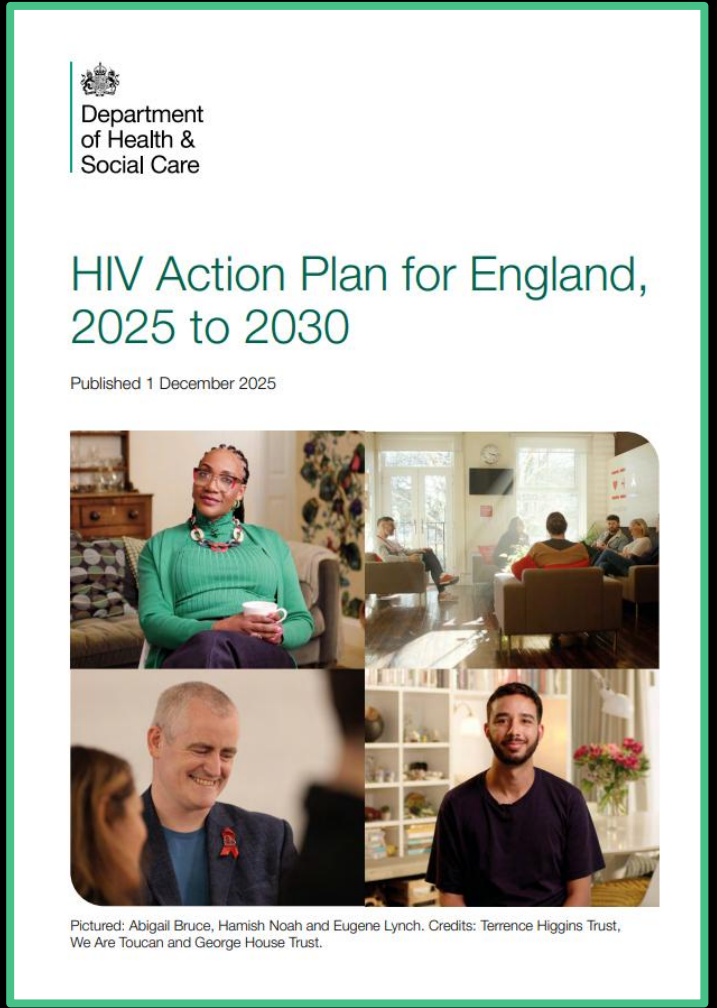
Challenges

- **Uneven progress**: new infections falling overall but rising in high-risk groups
- **Late diagnosis** and **retention in care gaps** remain - around 5,000 people not in care
- **Stigma, discrimination, and structural inequalities** continue to deter testing and treatment
- **PrEP access inequity -** coverage below 40% for Black African communities
- System pressures: **workforce capacity**, funding alignment, and integration across NHS, UKHSA, and local government

Engagement

This plan has been developed by **DHSC** in partnership with **UKHSA and NHS England**, and informed through extensive engagement with **other government departments, local government, voluntary and community sector partners, sexual health stakeholders and people with lived experience**. Our engagement has included:

- **10 roundtable events with over 250 system partners**, from industry and primary care to local government, charities and people living with HIV
- Two engagement sessions with over **60 VCS representatives**
- UKHSA HIV Data Deep Dives
- Extensive engagement with **other governmental departments**
- A series of **1:1 conversations** with key VCS charities, focusing on how to support underserved groups

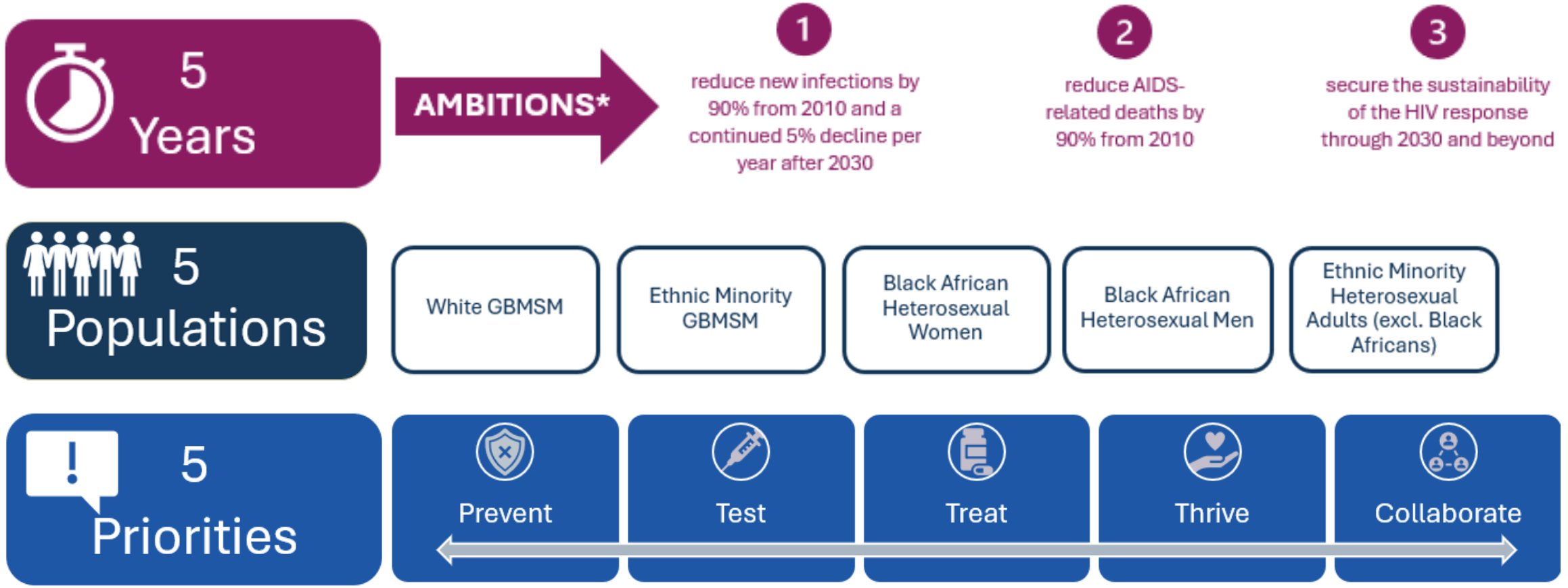


Financial commitments

- £9 million for national HIV retention and re-engagement in care initiative
- £108 million to deliver ED opt-out HIV testing in areas of very high and high HIV diagnosed prevalence inc £9.4m for peer support
- £5 million to pilot HIV testing via the NHS app
- £1.6 million annual investment in new HIV prevention programme
- Funding for formula milk and related sterilising equipment

HIV Action Plan backed by investment of more than £170 million

HIV action plan overview



HIV Action Plan for England

HIV Strategic Priorities



PREVENT

Prevent HIV transmission through equitable access to HIV prevention services



TEST

Scale up HIV testing to find people living with undiagnosed HIV and to reduce HIV transmission



TREAT

Rapidly link and retain people living with HIV in care, ensuring individuals can live healthy lives and to prevent onward transmission



THRIVE

Address stigma and improve the quality of life of people living with HIV



COLLABORATE

Strengthen the healthcare system to improve HIV care and sexual health

Ending new HIV transmissions by 2030

HIV Priority Areas for Regions to Focus On

Regional Priority	Key Actions
1. Increase PrEP Access	Improve offer and uptake among underserved populations
2. Expand Testing	Community testing, partner notification, routine testing and digital pathways
3. Reduce Inequalities	Work with communities and VCSE partners to improve access and engagement
4. Improve Quality of Life	Peer support, stigma reduction and integrated care
5. Strengthen Women's HIV Services	Embed HIV within Women's health Strategies and deliver trauma-informed care
6. Build Local Capacity	Needs assessments, workforce audits and adoption of innovation

Twitter - @ADPHNE

Building on strong foundations

Over the last 18 months we have …
established the infrastructure needed to deliver on national ambitions:

- Regional HIV Steering Group established and providing strategic leadership
- Prevention & Testing, Treatment & Care, and Stigma sub-groups established with agreed work programmes
- North East and North Cumbria HIV Action Plan produced in partnership
- Peer Reference groups established in the North and South of the Region
- Regional support for HIV prevention and awareness campaigns – eg Elephant in the Room / HIV Testing Week / World Aids Day
- ED opt Out Testing now in three hospitals in the region
- Online condom services now in 12/13 areas
- Increased PrEP Provision
- Increased HIV Testing in most areas

World Aids Day 1 DEC

- Raise awareness
- Pause and reflect
- Remember

HIV is now preventable, testable and treatable











ONE DAY, ONE SYSTEM, PRACTICAL ACTION

How today connects



Morning: understand the evidence and experience

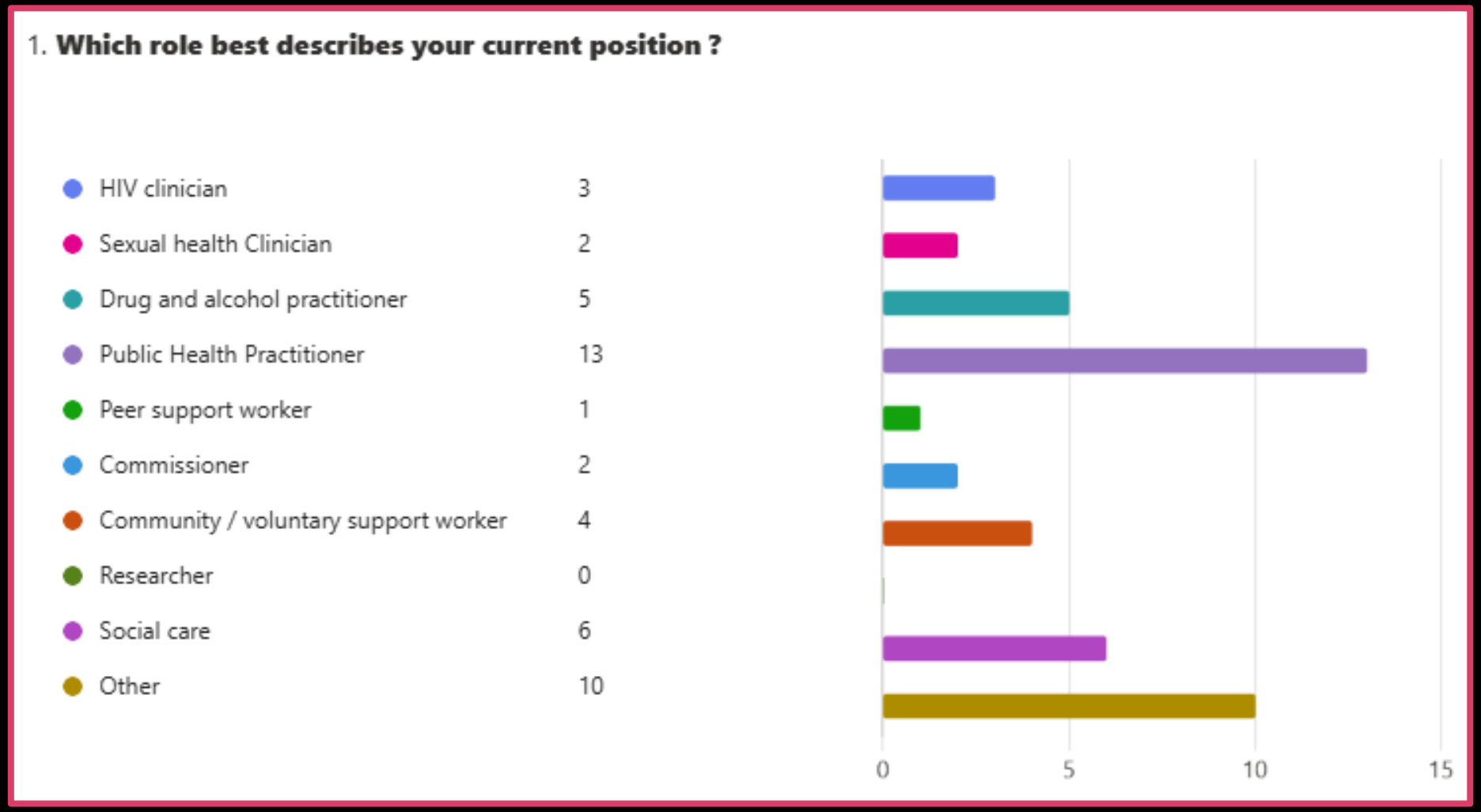
Afternoon: translate it into priorities, pledges and next steps

The output we need: a stronger regional action plan owned by the system

INSIGHTS: Pre-event survey

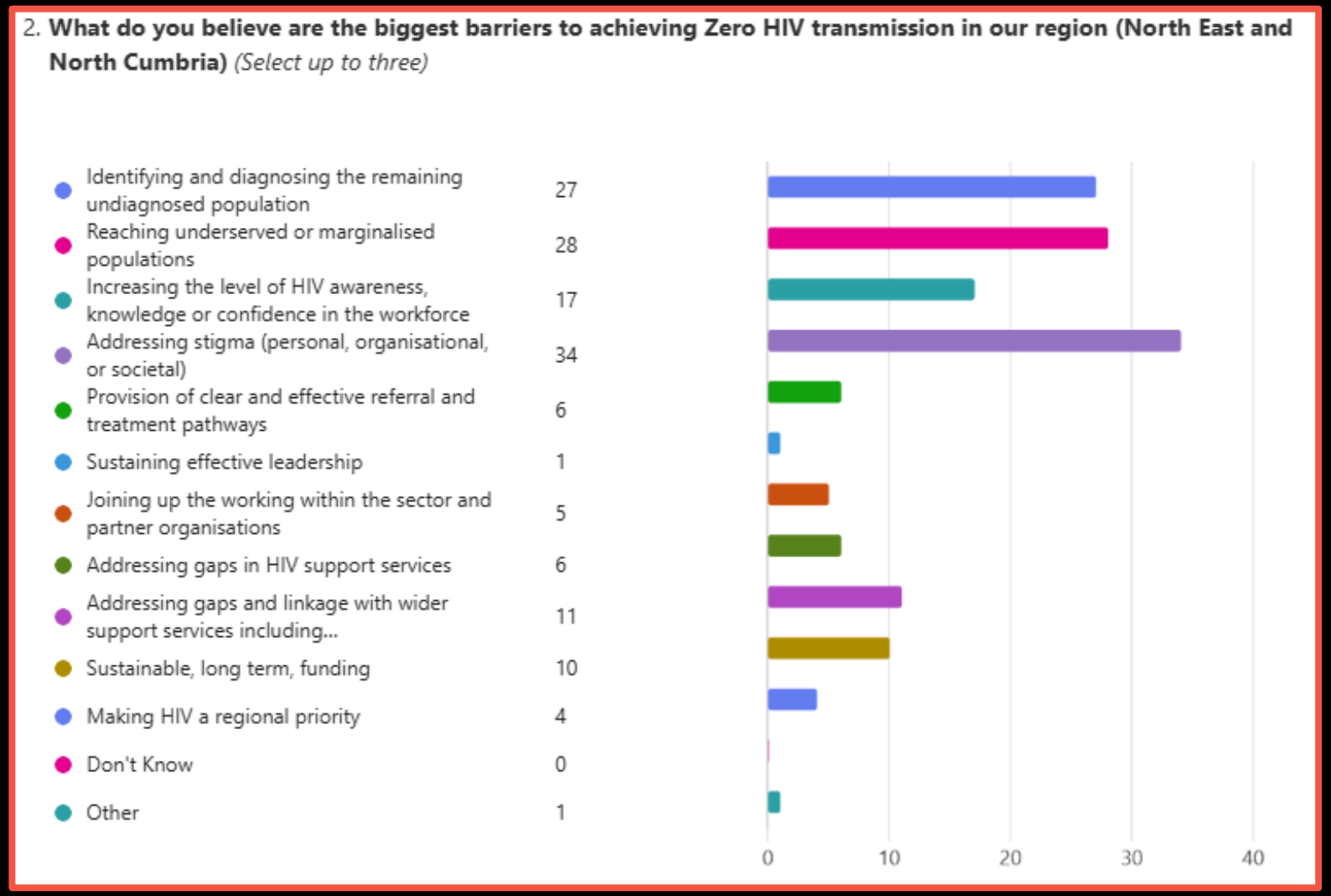


Which role best describes your current position ?



HIV Pre-Event Survey – Collaboration

What do you believe are the biggest barriers to achieving Zero HIV transmission?



HIV Pre-Event Survey – Collaboration

What is the single most important action needed to achieve Zero new HIV transmissions?



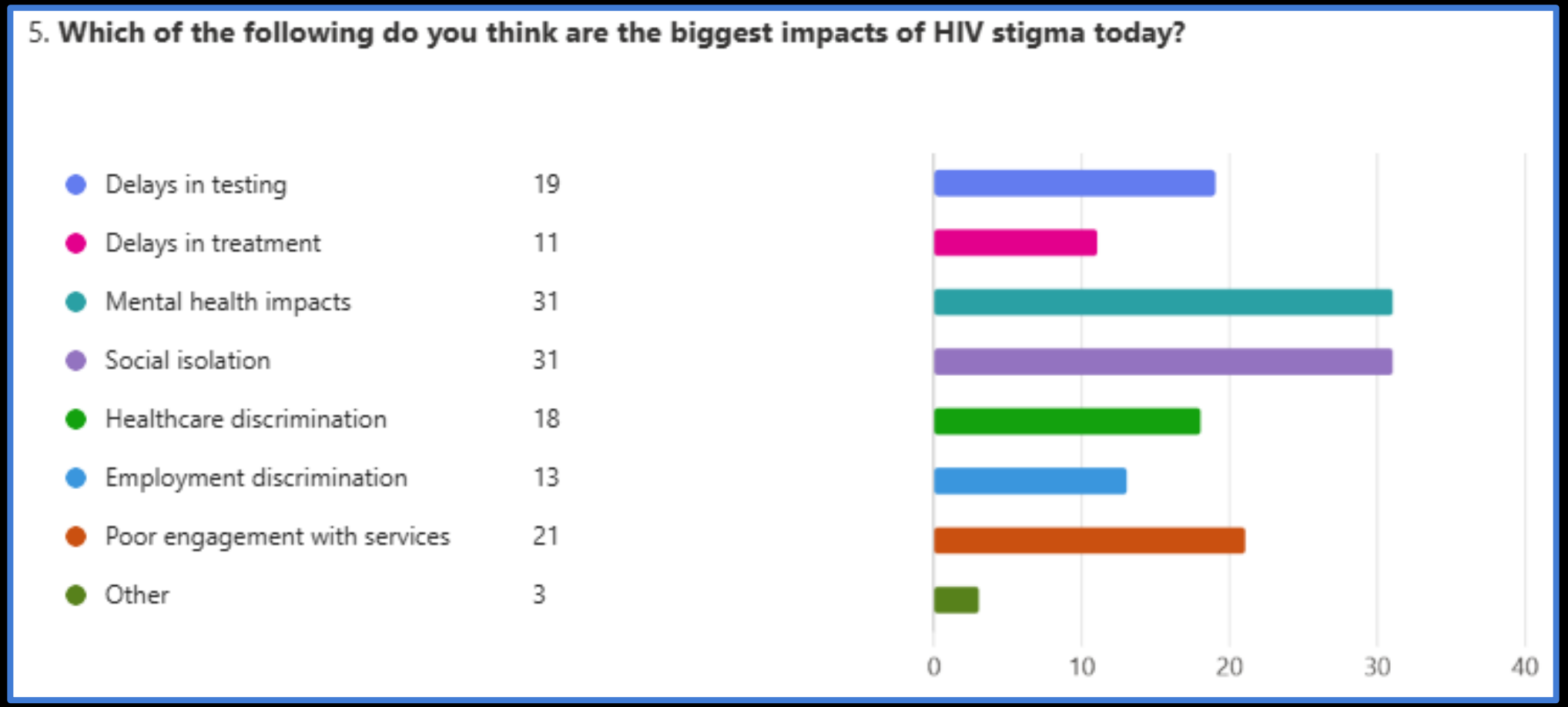
HIV Pre-Event Survey – Collaboration

What one thing could improve COLLABORATION across organisation and systems in our region?



HIV Pre-Event Survey – Collaboration

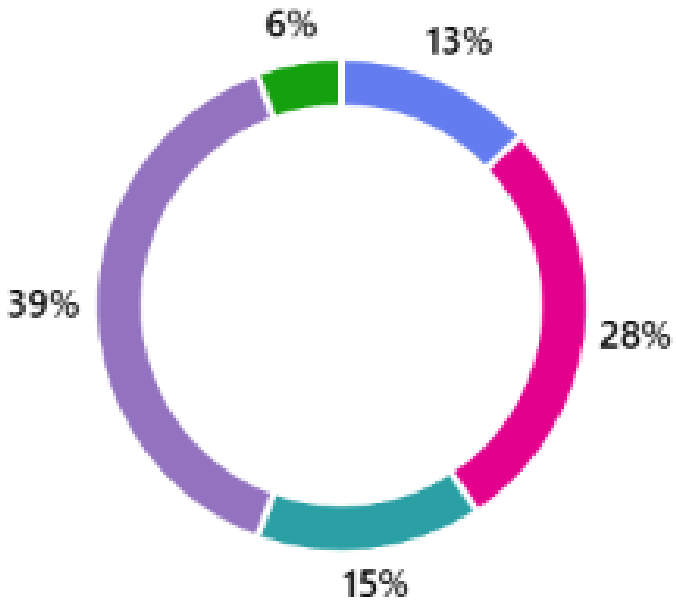
Which of the following do you think are the biggest impacts of HIV stigma today?



HIV Pre-Event Survey – Collaboration

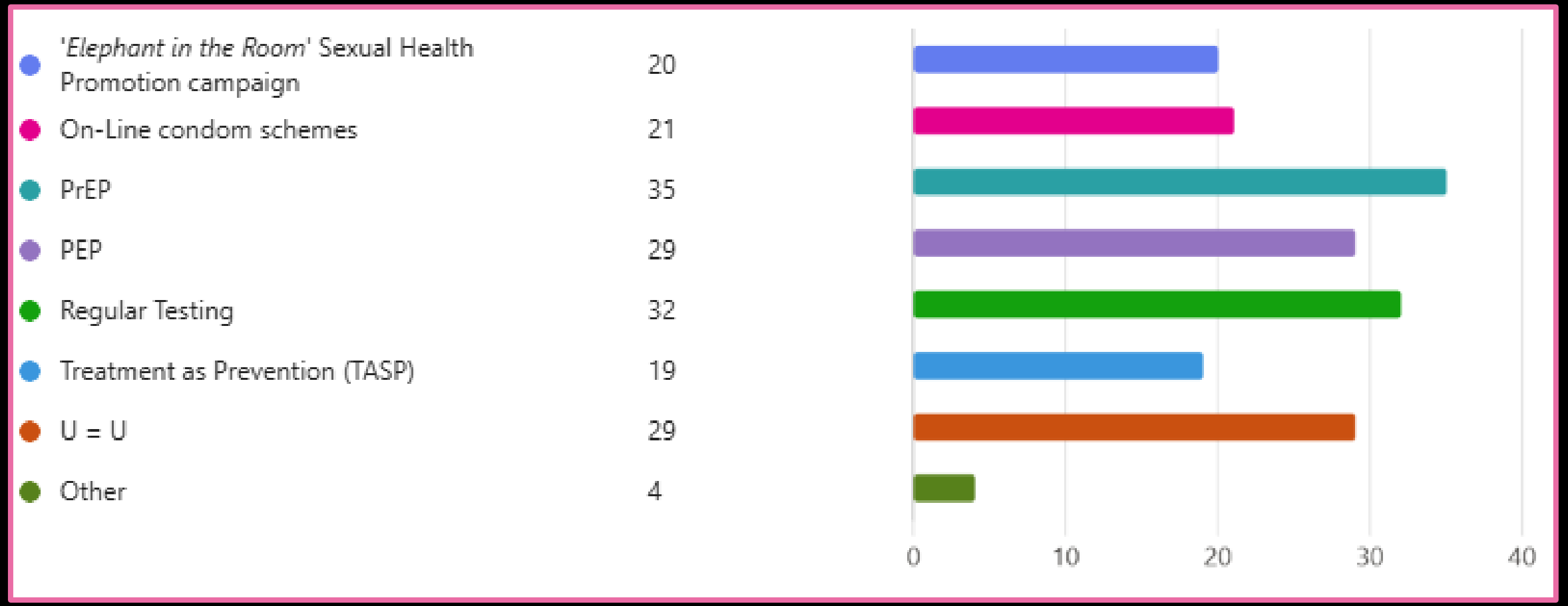
Have you completed any HIV-related training? - select all that apply?

HIV confident training	7
Other HIV related training	15
HIV stigma training	8
No HIV related training	21
Unsure	3



HIV Pre-Event Survey – Collaboration

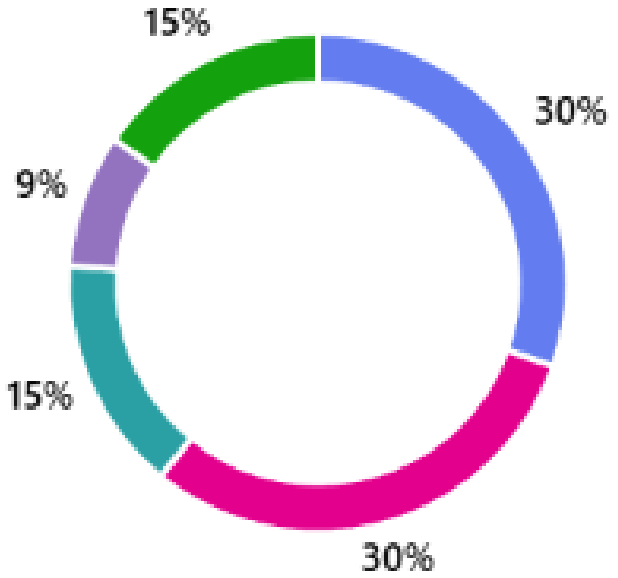
Are you aware of the following HIV prevention strategies, sexual health campaigns & services?



HIV Pre-Event Survey – Collaboration

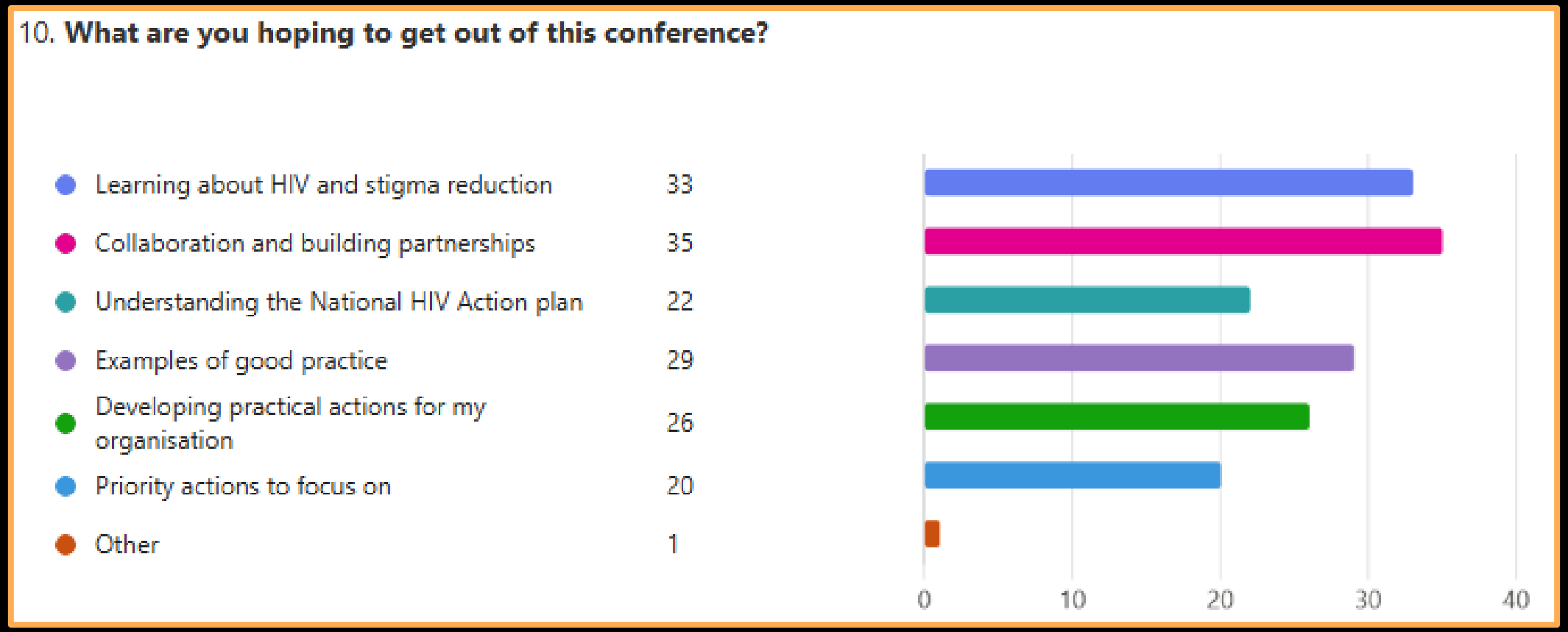
How confident do you feel discussing HIV prevention, testing and treatment?

Very Confident	14
Fairly confident	14
Neutral	7
Slightly confident	4
Not confident	7



HIV Pre-Event Survey – Collaboration

What are you hoping to get out of this conference?



HIV Pre-Event Survey – Collaboration

EPIDEMIOLOGY: National and regional HIV data

Kirsty Foster

Consultant in Health Protection, UK Health Security Agency

UK Health Security Agency

HIV in North East and North Cumbria

Data to end of December 2024

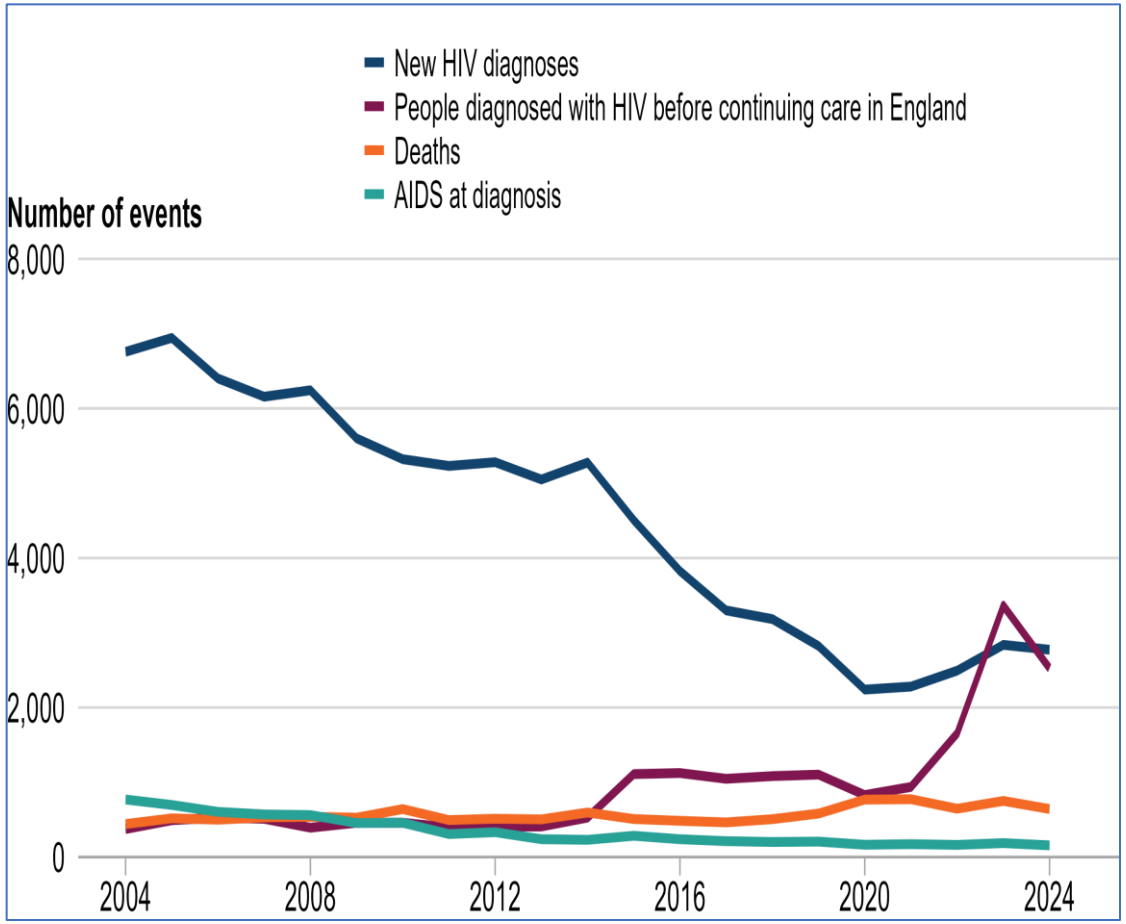
Kirsty Foster, Consultant in Health Protection, UKHSA North East

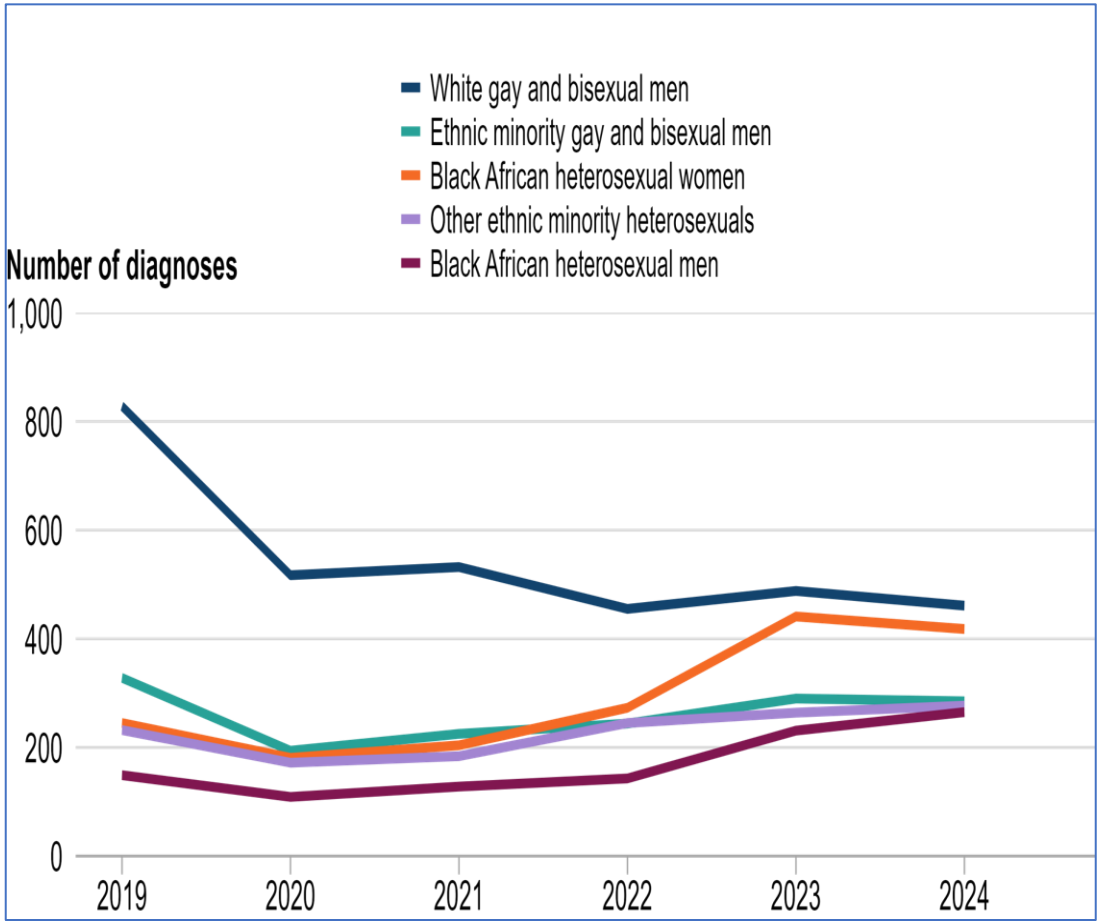
Slides produced by Kate Houseman, Field Services NEY&H Team

Overview

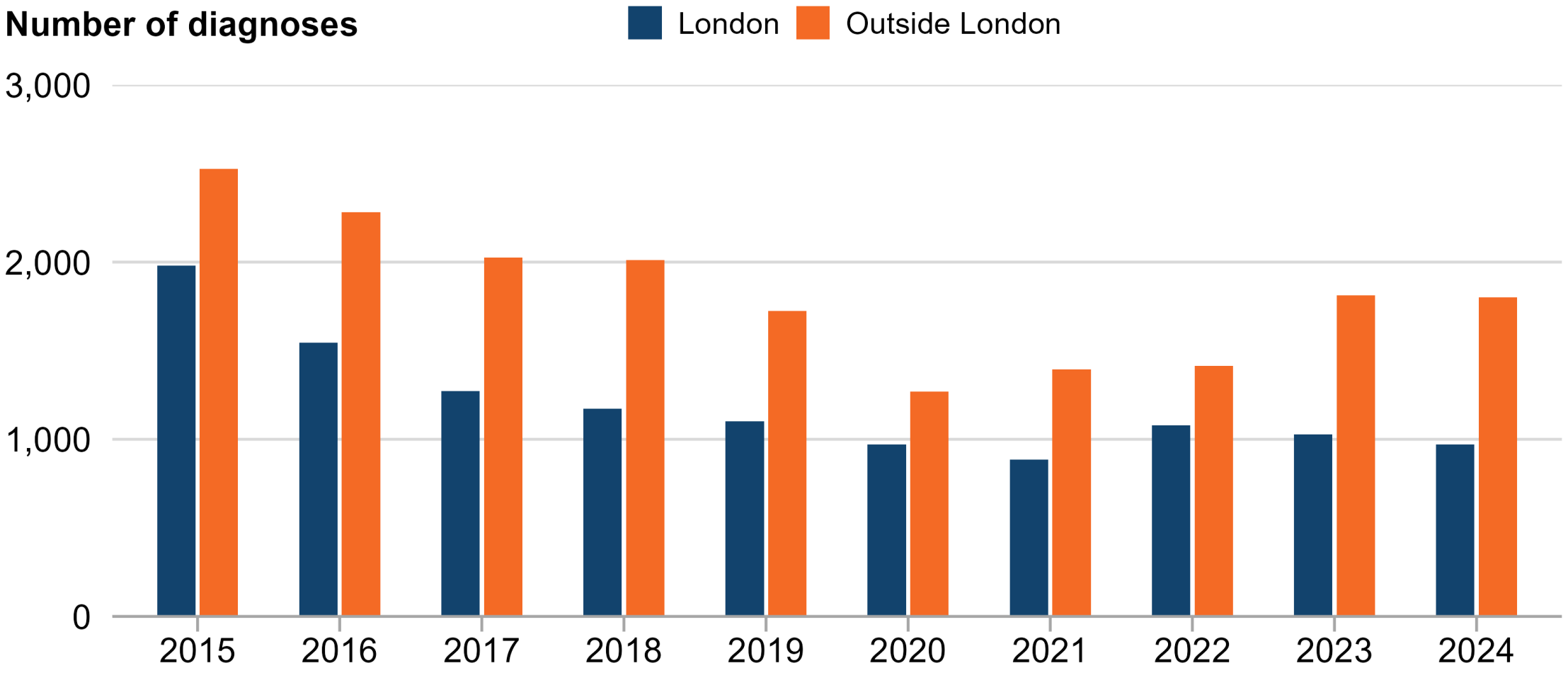
- National data
- People receiving care in North East & North Cumbria
- New diagnoses
  - People diagnosed in North East & North Cumbria
  - People diagnosed elsewhere and continuing care in NENC
- Points to consider

National picture: new diagnoses, people continuing care, AIDS diagnoses and deaths, and breakdown by key groups

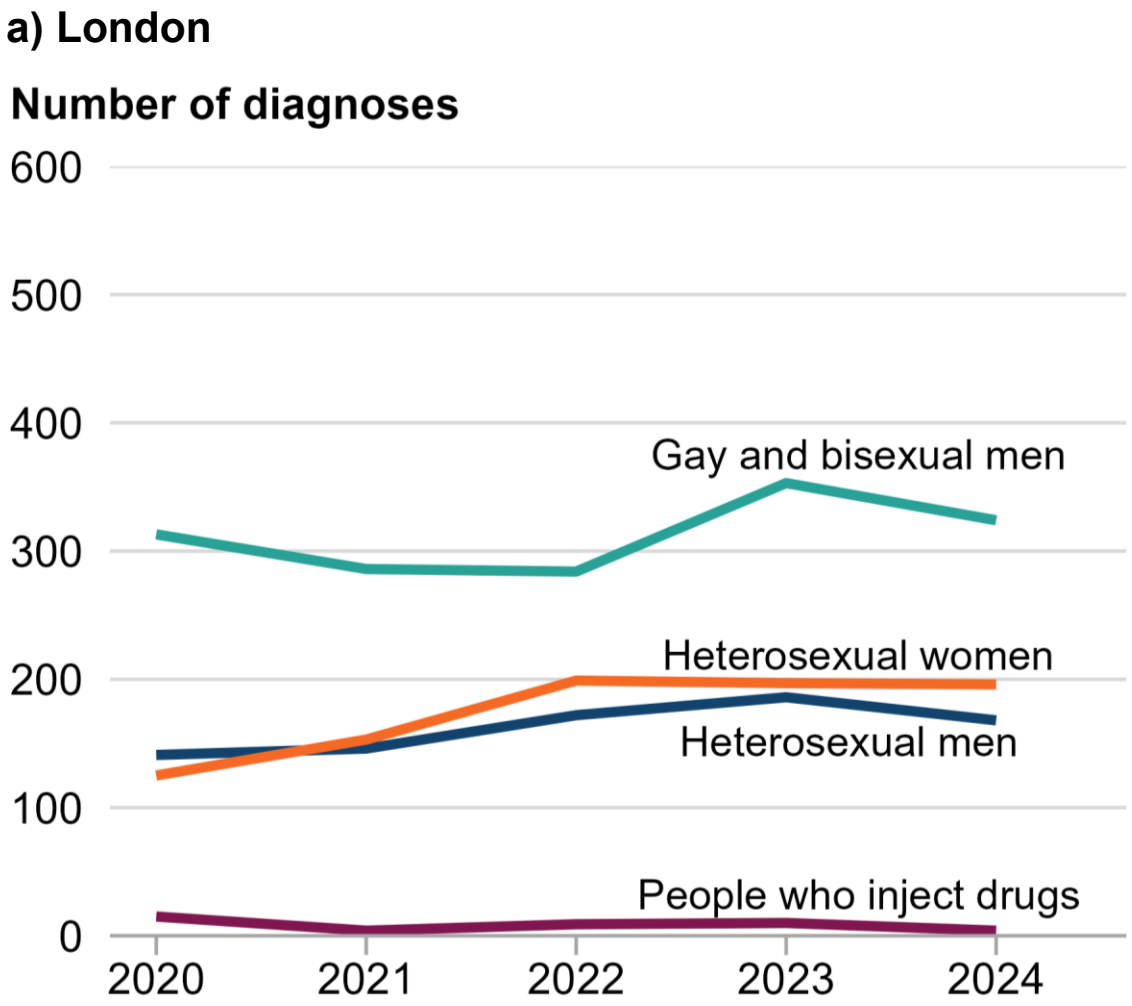


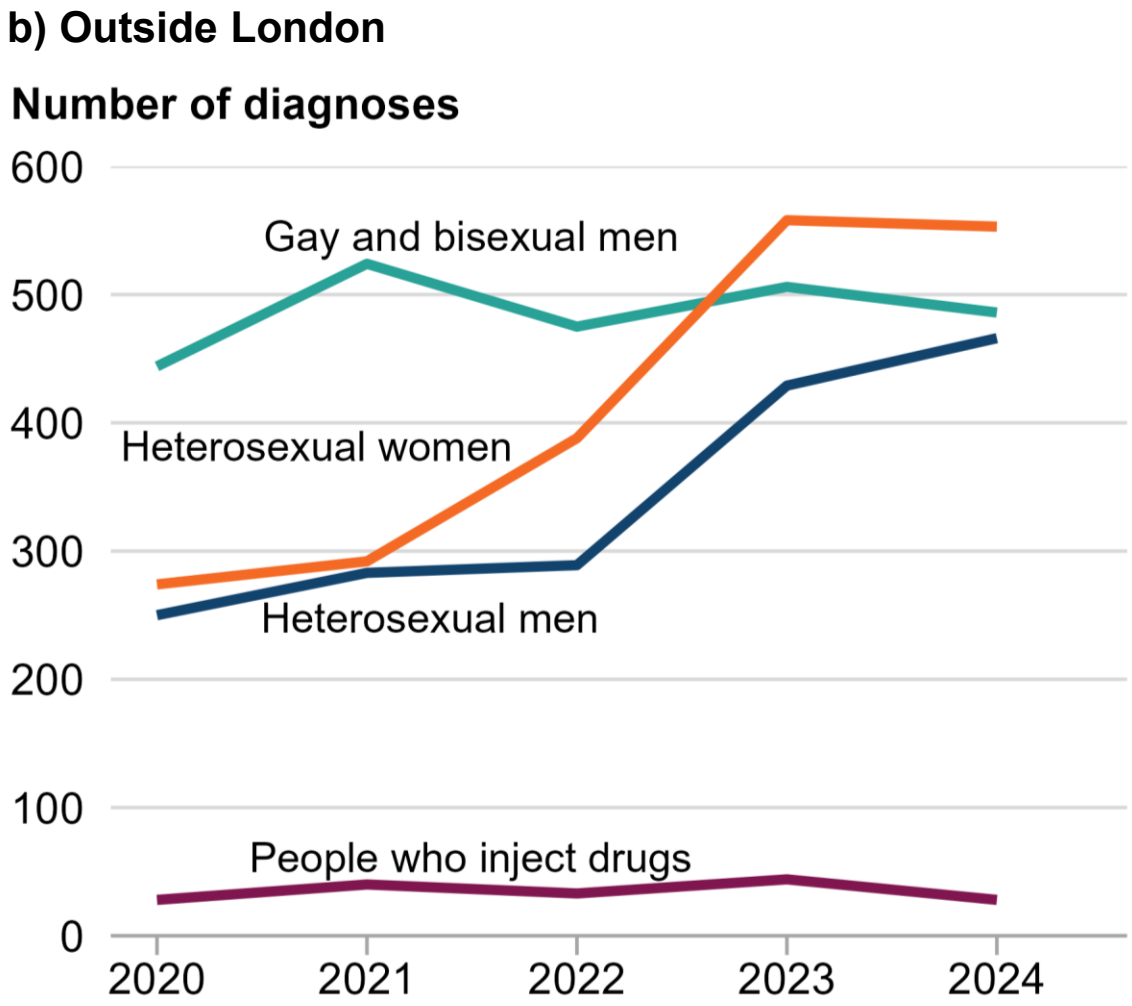


New HIV diagnoses by region of residence: England, 2015 to 2024



New HIV diagnoses by probable route of exposure: England, 2020 to 2024





UK Health Security Agency

People accessing HIV care in North East and North Cumbria

Prevalence by local authority

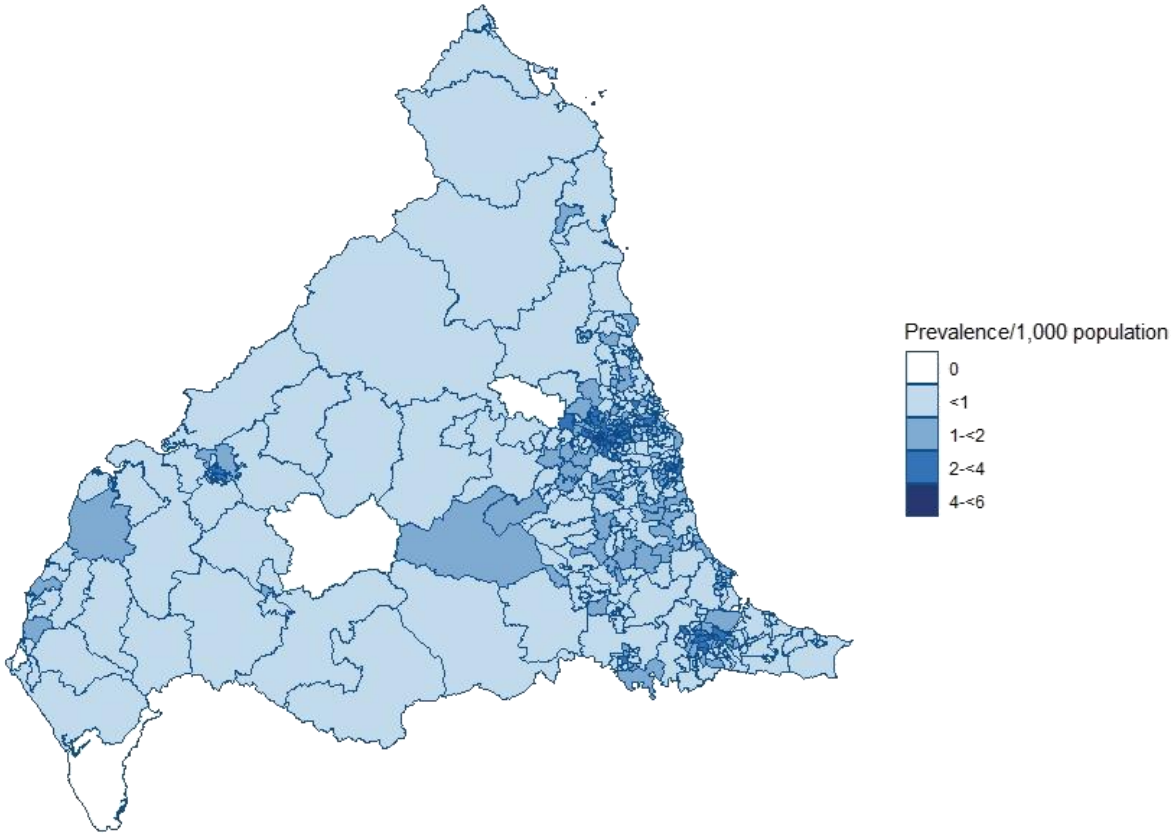
HIV diagnosed prevalence rate per 1,000 aged 15 to 59 years **New data** 2024

Crude rate - per 1,000

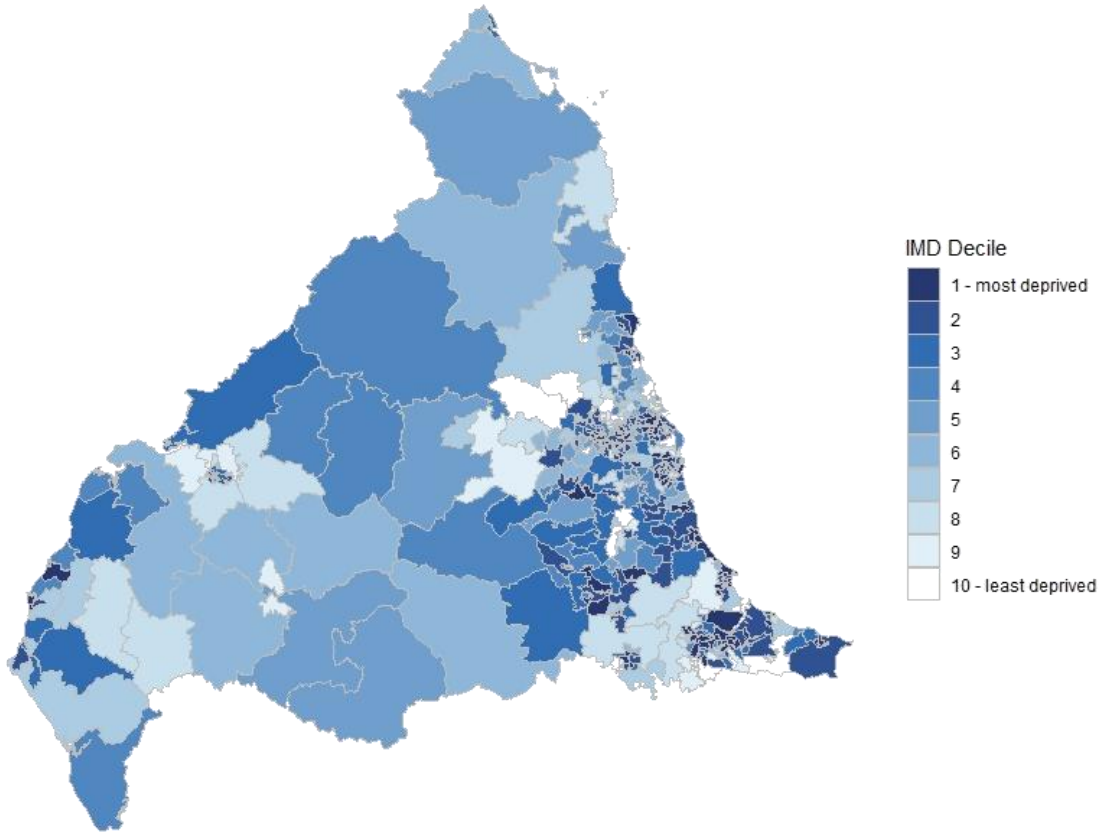
Area	Recent Trend	Count	Value	95% Lower CI	95% Upper CI
England	↑	81,748	2.40	2.39	2.42
North East region (statistical)	↑	2,065	1.33	1.27	1.39
Newcastle upon Tyne	↑	484	2.35	2.15	2.57
Gateshead	→	203	1.76	1.53	2.02
Middlesbrough	→	156	1.71	1.45	2.00
Stockton-on-Tees	→	162	1.40	1.19	1.63
Darlington	→	86	1.38	1.10	1.70
Sunderland	→	203	1.25	1.08	1.43
North Tyneside	→	135	1.12	0.94	1.33
County Durham	↑	319	1.06	0.95	1.19
Hartlepool	→	56	1.03	0.78	1.34
South Tyneside	→	79	0.95	0.76	1.19
Redcar and Cleveland	→	55	0.76	0.57	0.98
Northumberland	→	127	0.75	0.63	0.90

Prevalence of residents accessing HIV care aged 15 and over: 2024

Prevalence by MSOA

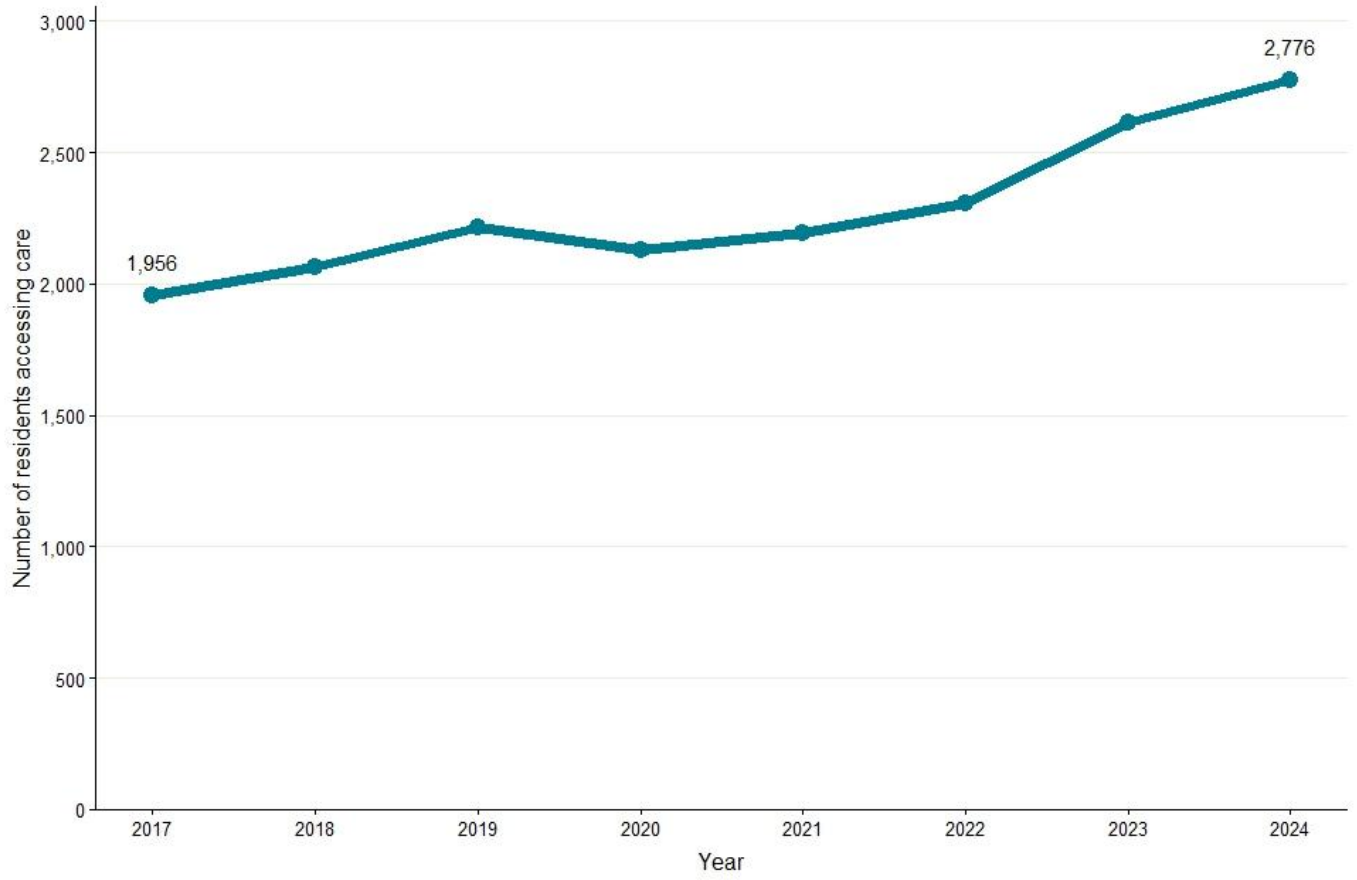


IMD by MSOA



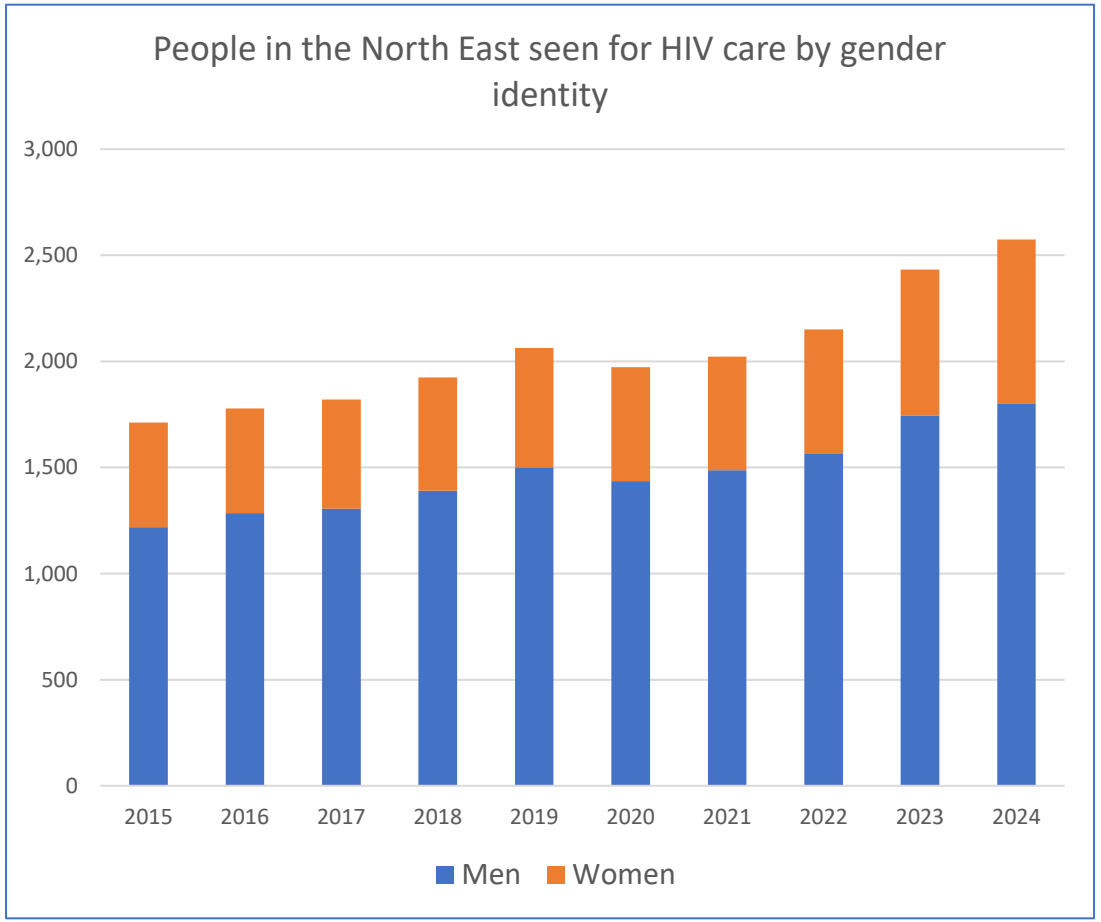
Number of residents accessing HIV care aged 15 and over: 2017 to 2024

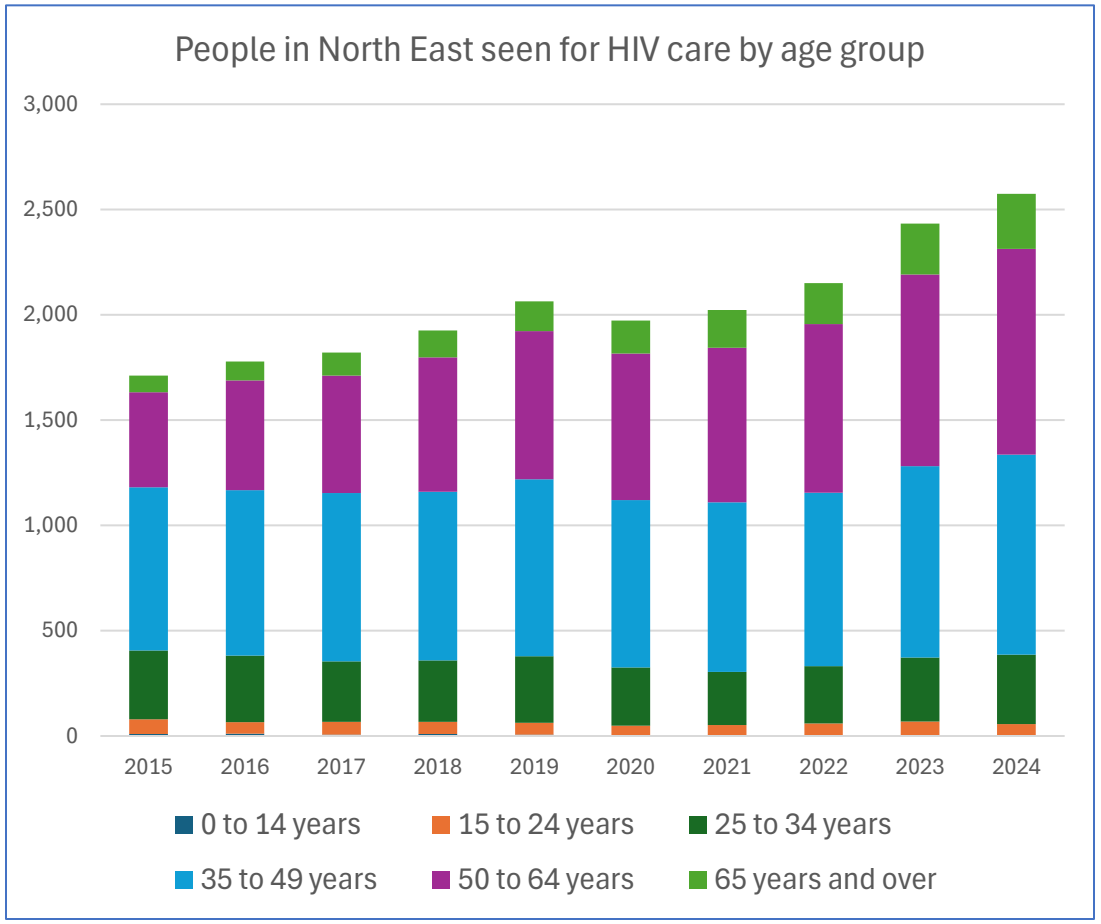
- 42% increase since 2017
- Equates to a rate of 1.0/1,000 population in 2024.



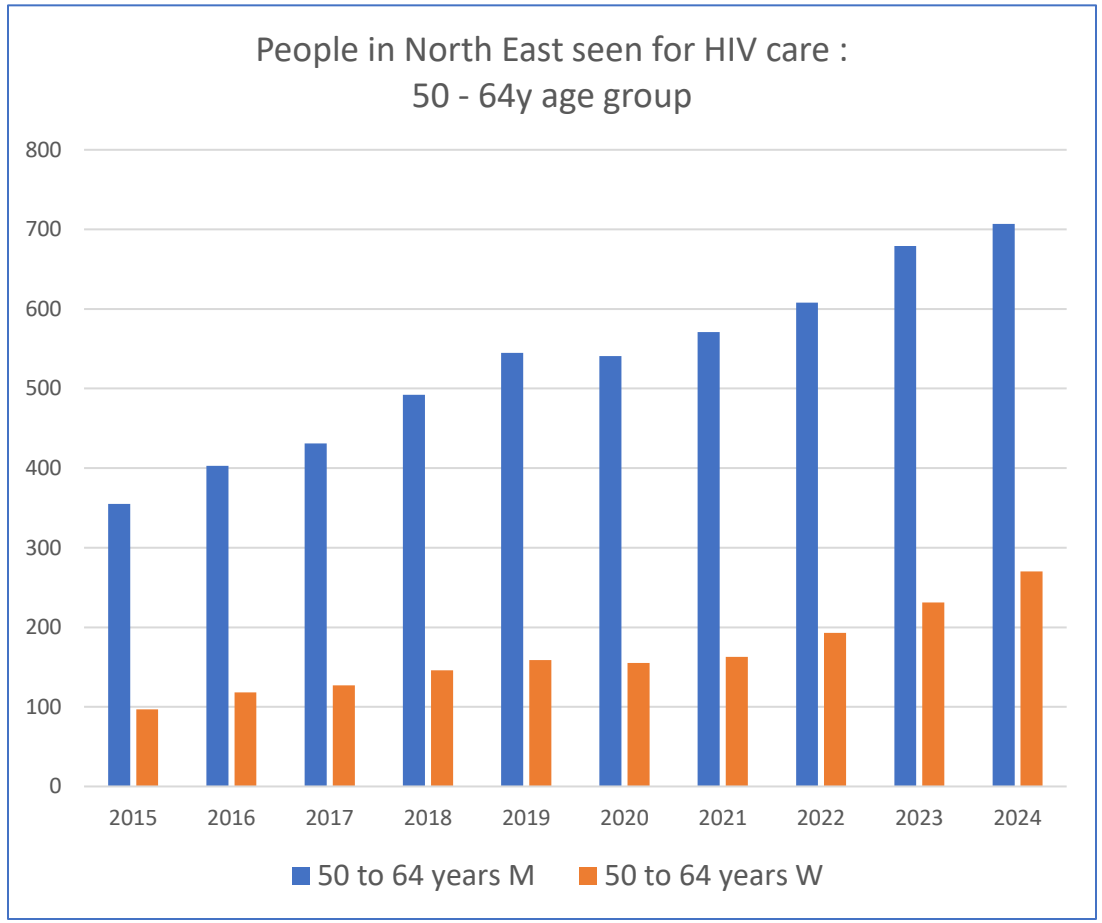
NB: numbers presented here do not match https://fingertips.phe.org.uk/ perfectly as here LSOA of residence in previous attendance (if available) or LSOA of clinic is used as a proxy when current LSOA is not available. This ensures 100% coverage for residence.

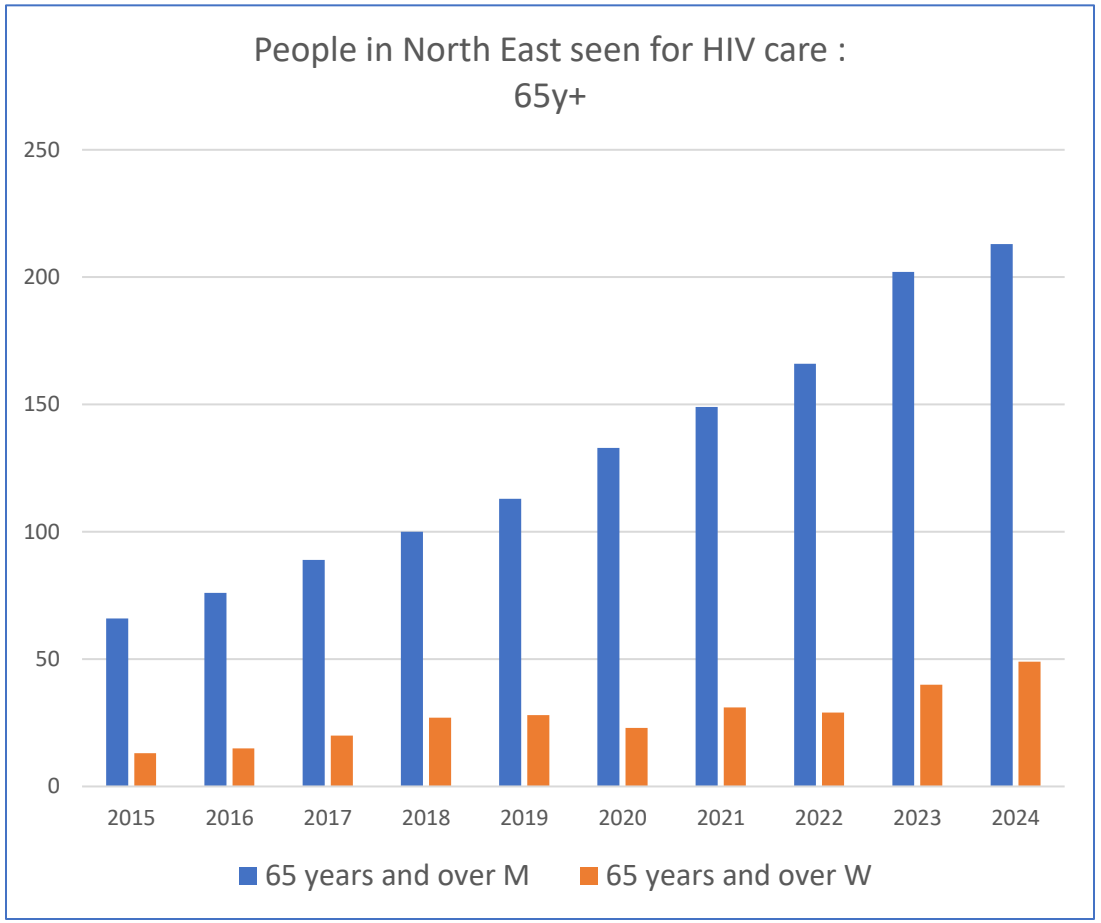
People seen for HIV care (NE)



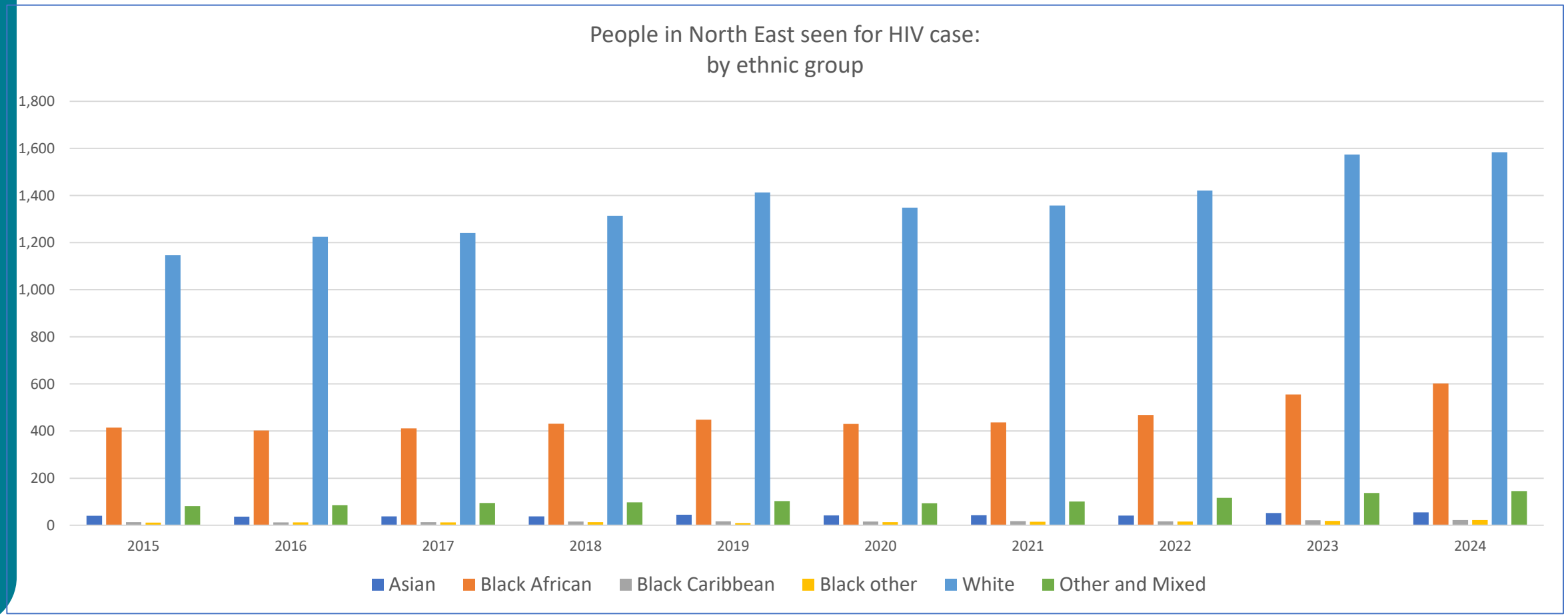


People seen for care (NE) – over 50y olds

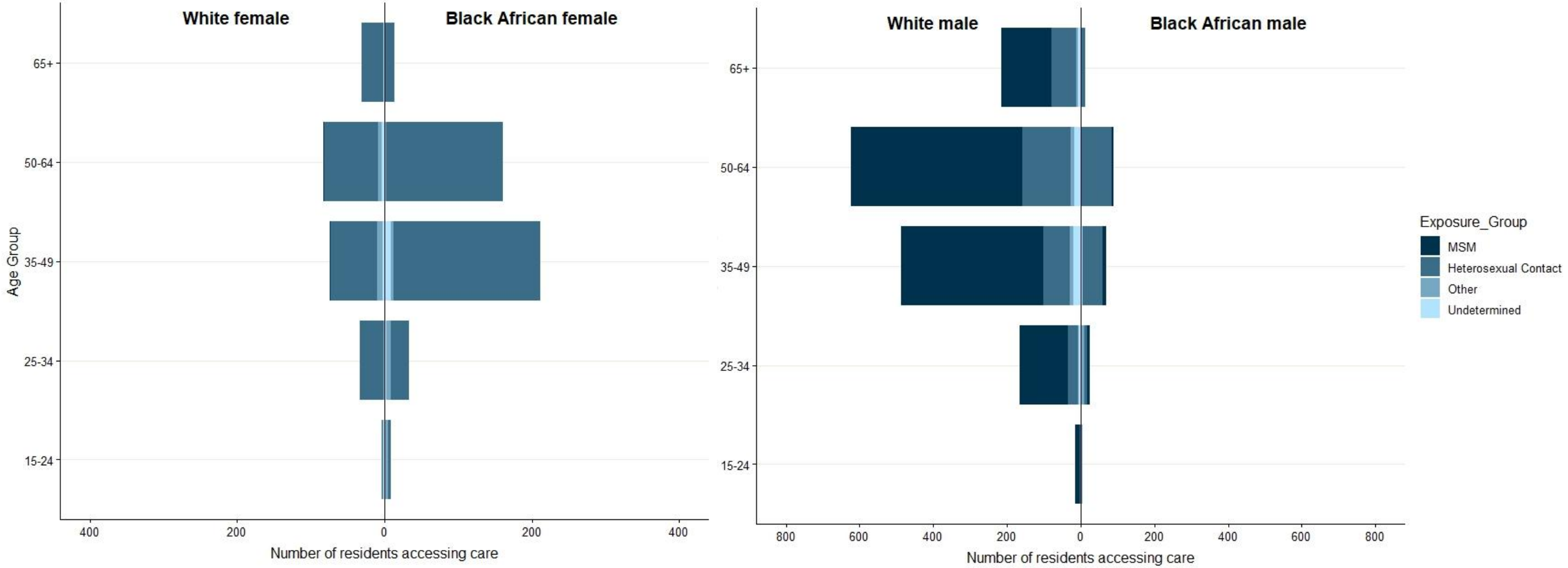




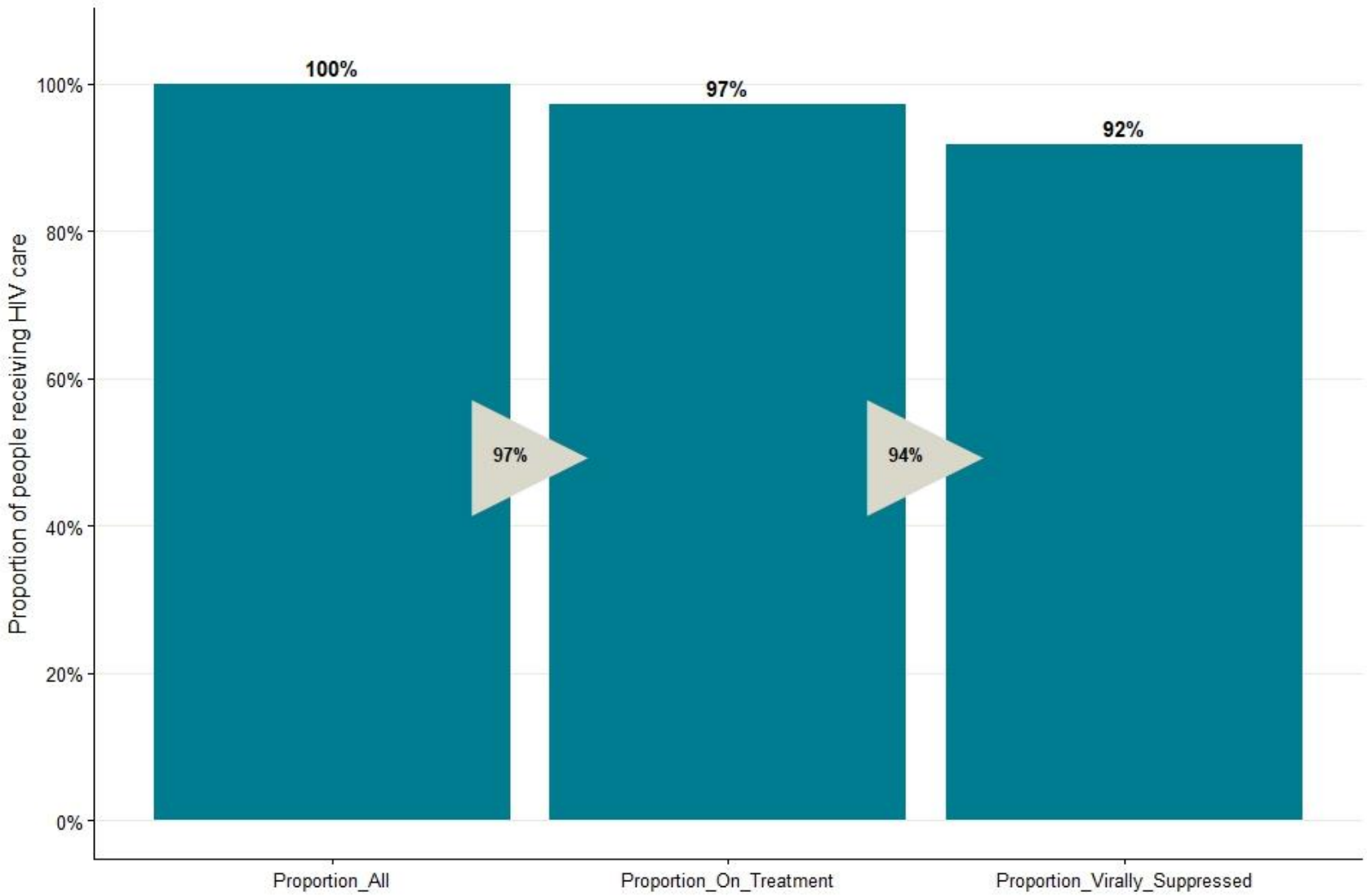
People seen for care by ethnic group (NE)



Number of residents accessing HIV care by gender identity and ethnicity: 2024



Continuum of care in all residents: 2024



Percentage of individuals from the preceding stage of the care continuum

But there is variation…….

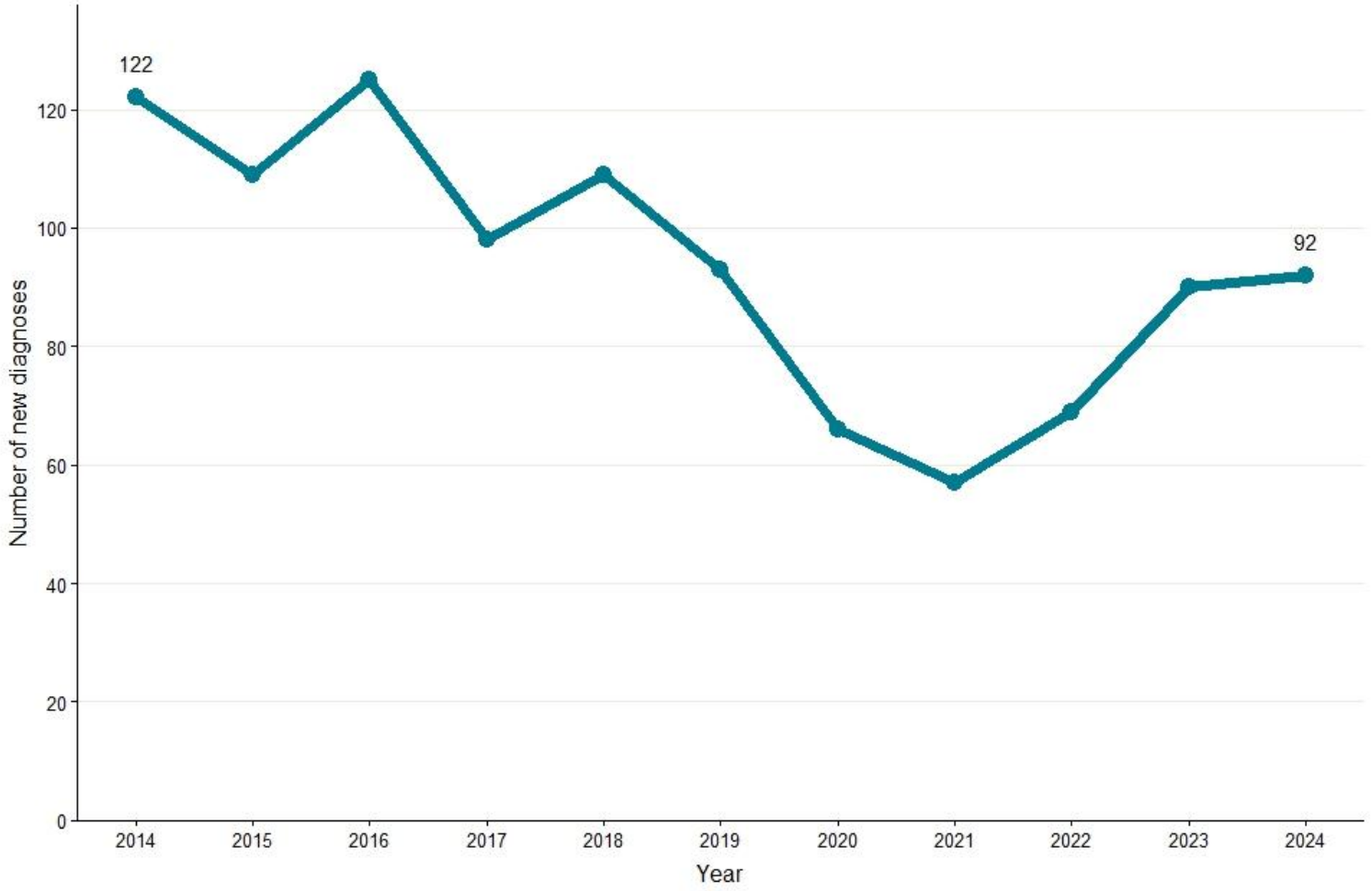
- Young people less likely to be virologically suppressed
  - 81% of 15 – 24 yr olds vs. 91% of 25-34y olds
- Females in white and Black African groups appear to have lower levels of viral suppression than other females and than heterosexual men
- Lower proportion of GBMSM from ethnic minorities are on treatment and virally suppressed
  - 91% viral suppression in Black African GBMSM / 89% in Black other GBMSM vs. 93% in white GBMSM [BUT care re small numbers]

UK Health Security Agency

New diagnoses in North East and North Cumbria residents

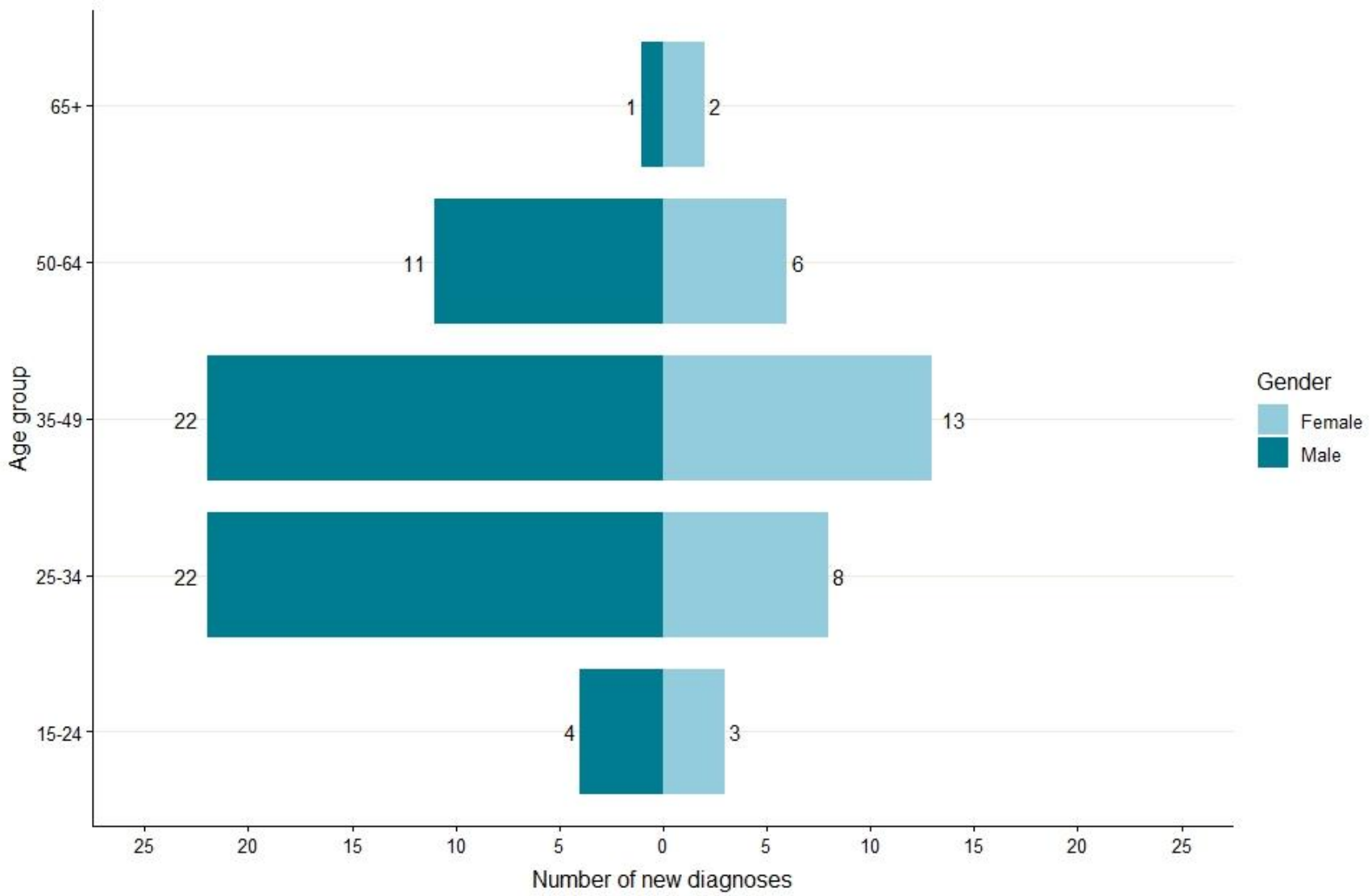
Number of new diagnoses in residents aged 15 and over: 2014 to 2024

- 25% decrease since 2014
- Equates to a rate of 3.4/100,000 population in 2024.

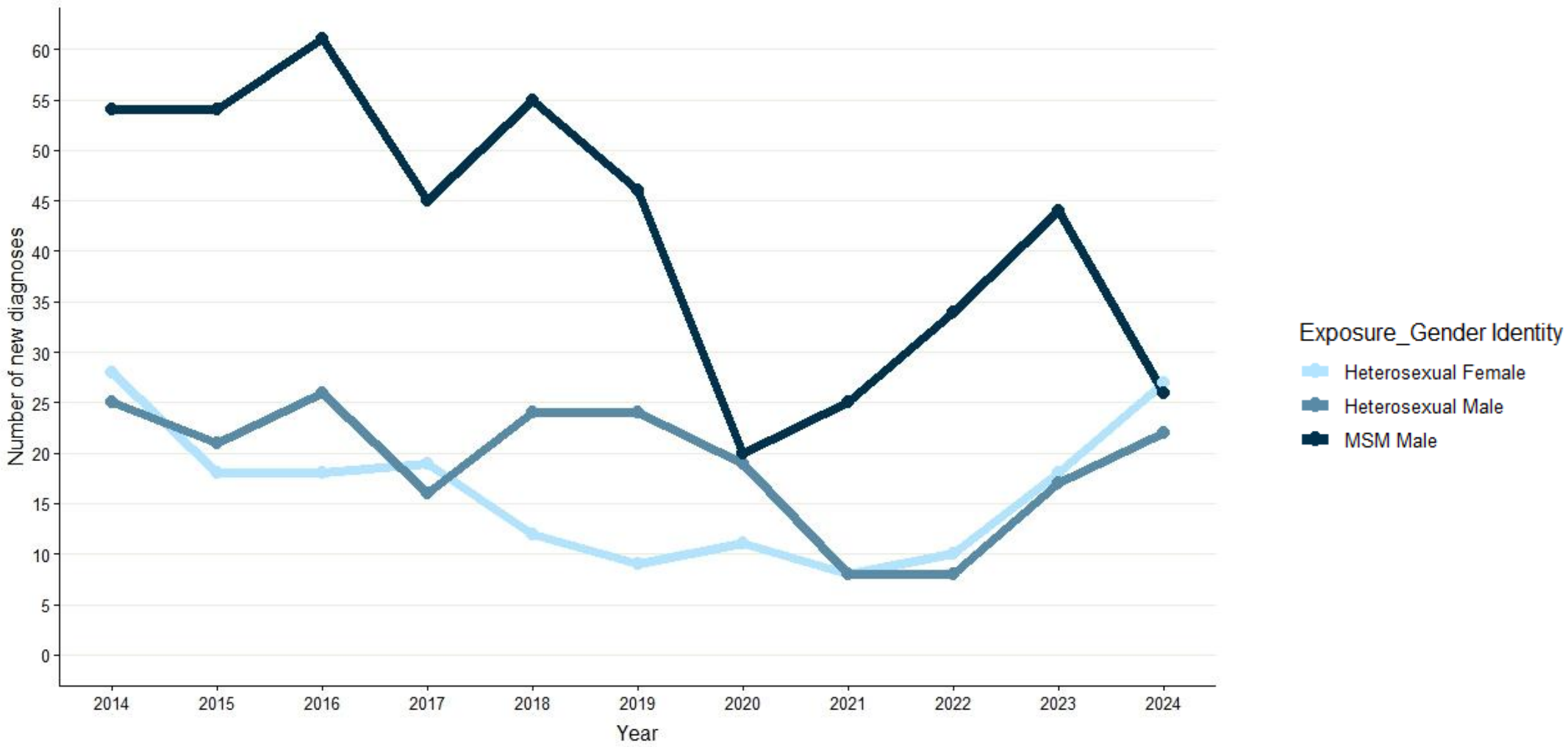


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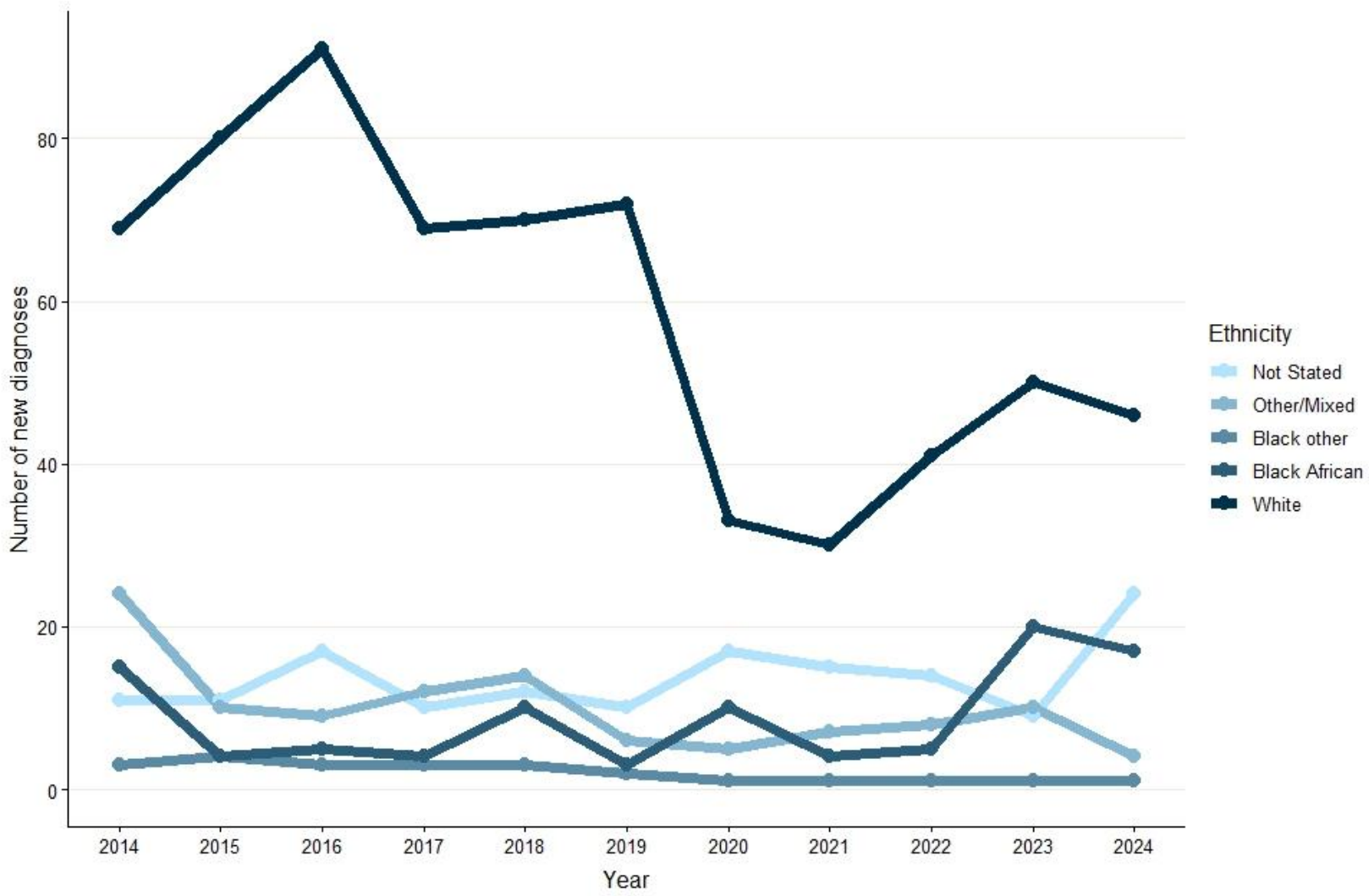
Number of new diagnoses in residents by age group: 2024



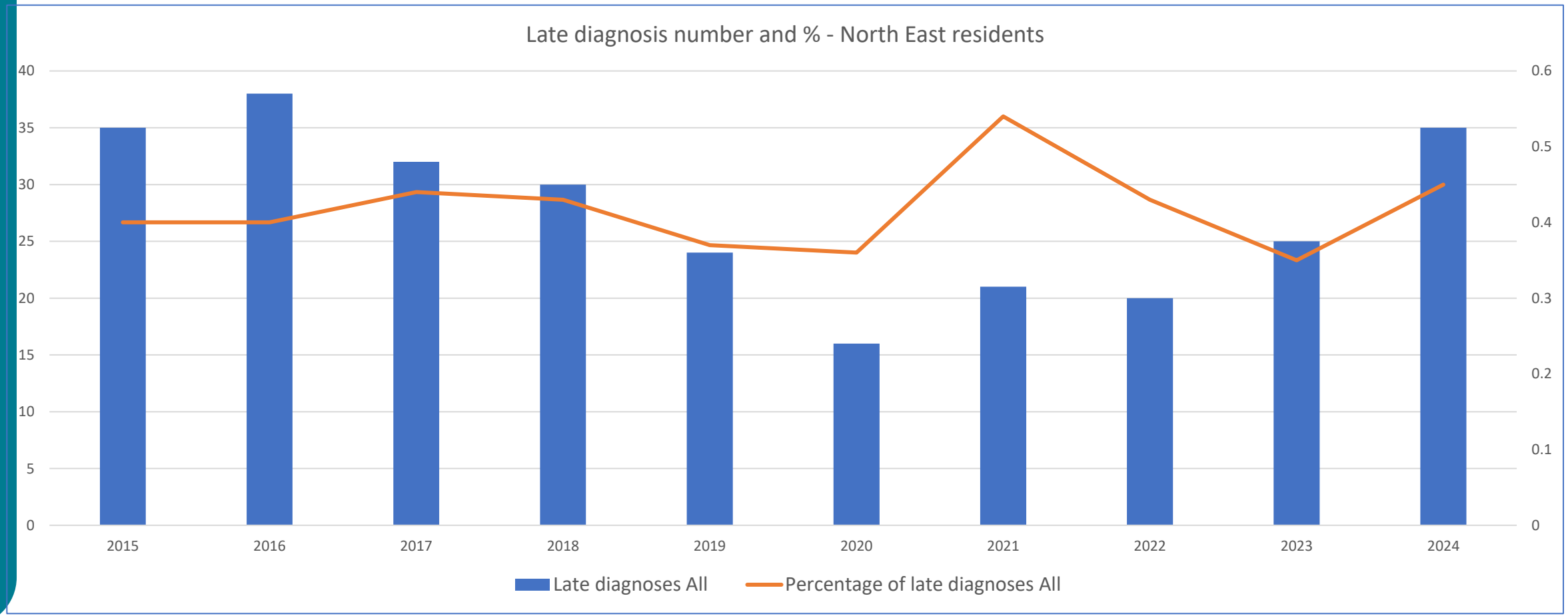
Number of new diagnoses in residents by route of exposure and gender identity: 2014 to 2024



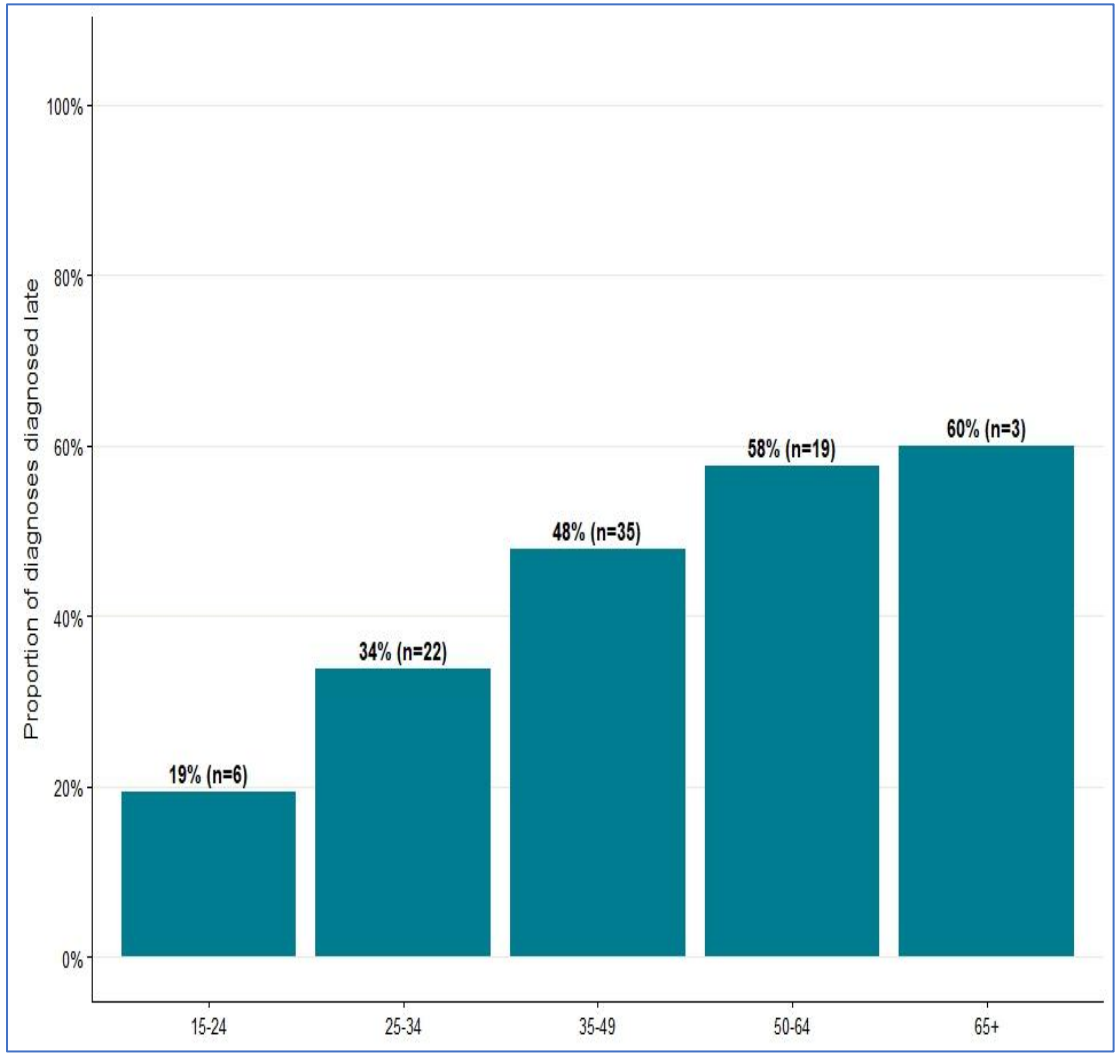
Number of new diagnoses in residents by ethnicity: 2014 to 2024

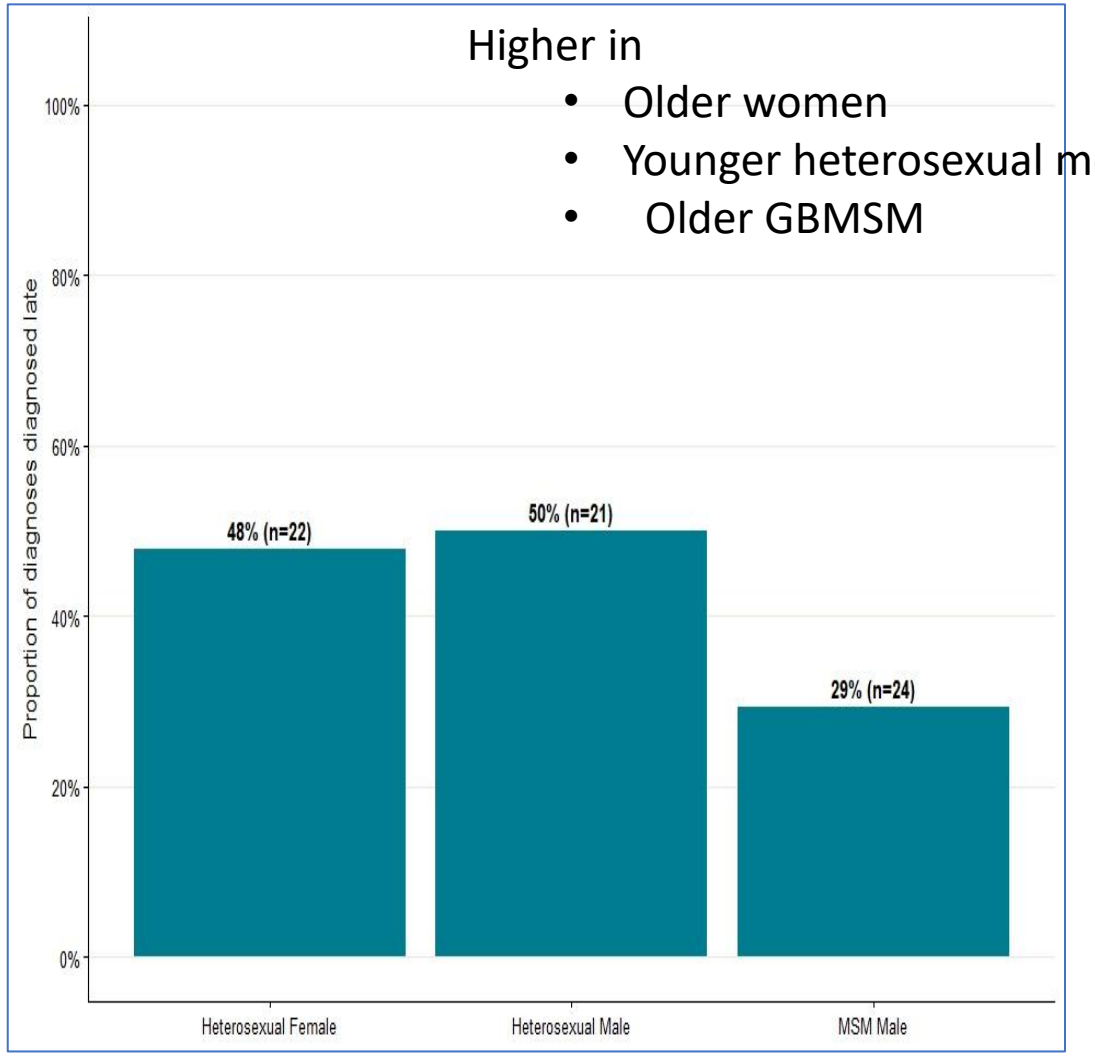


Late diagnosis trend data (NE)

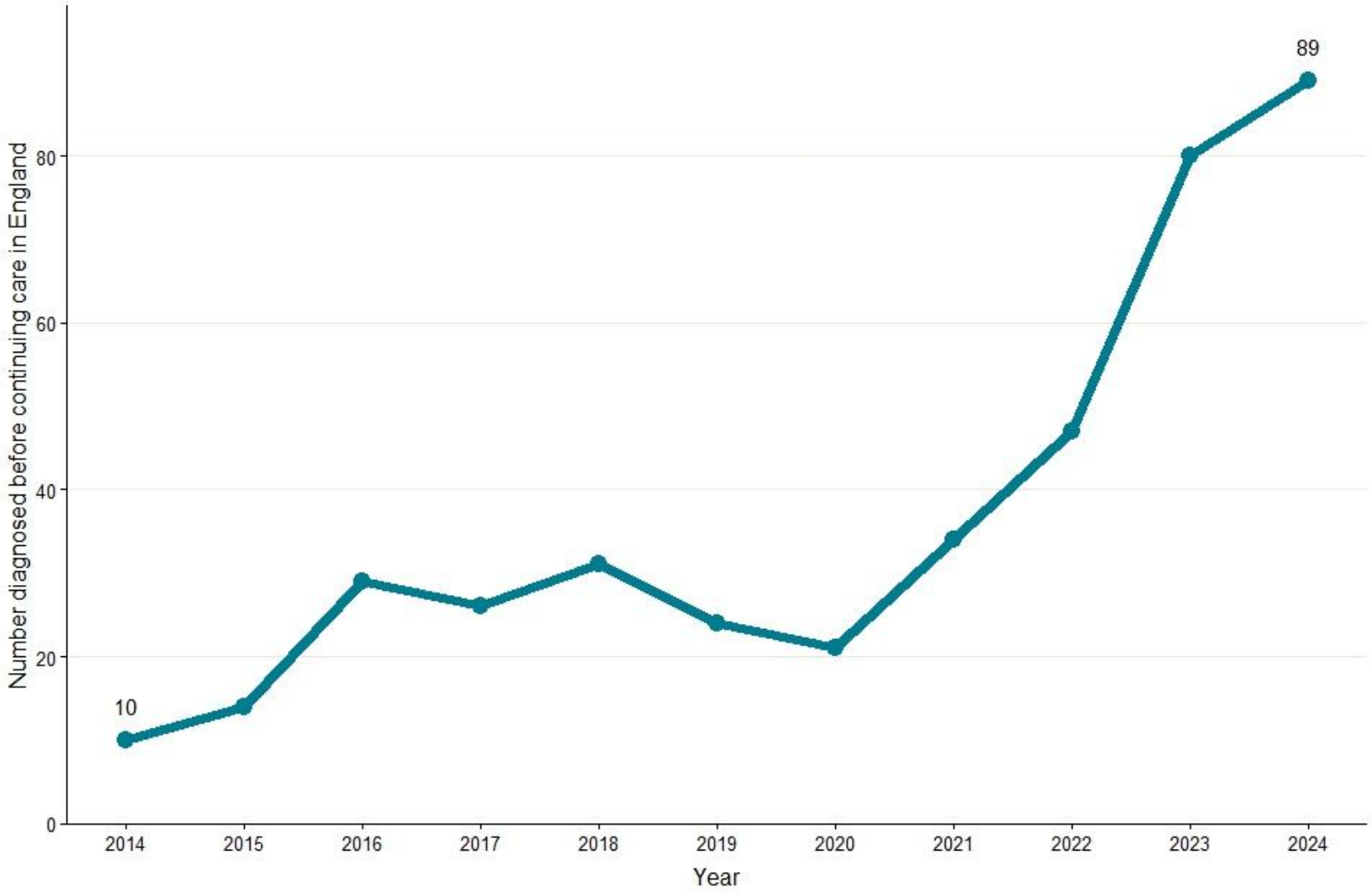


Number of new diagnoses diagnosed late by age group and gender / route of transmission: 2022-2024



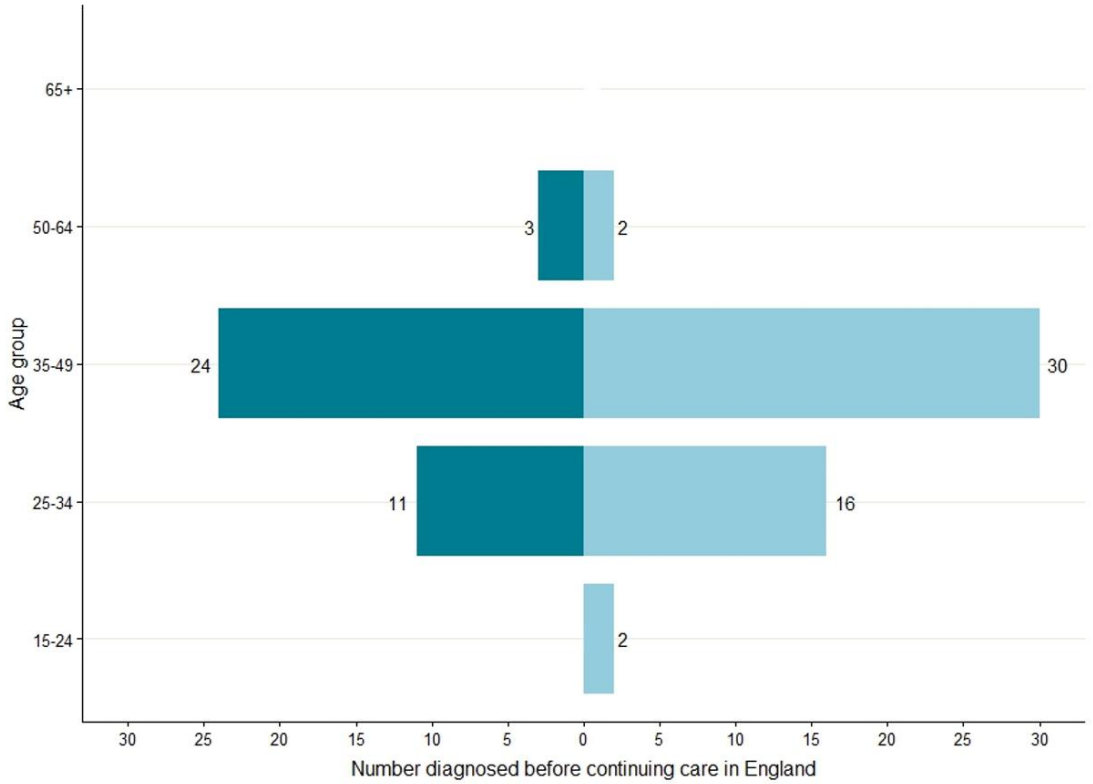


Number previously diagnosed before continuing care in North East & North Cumbria: 2014 to 2024

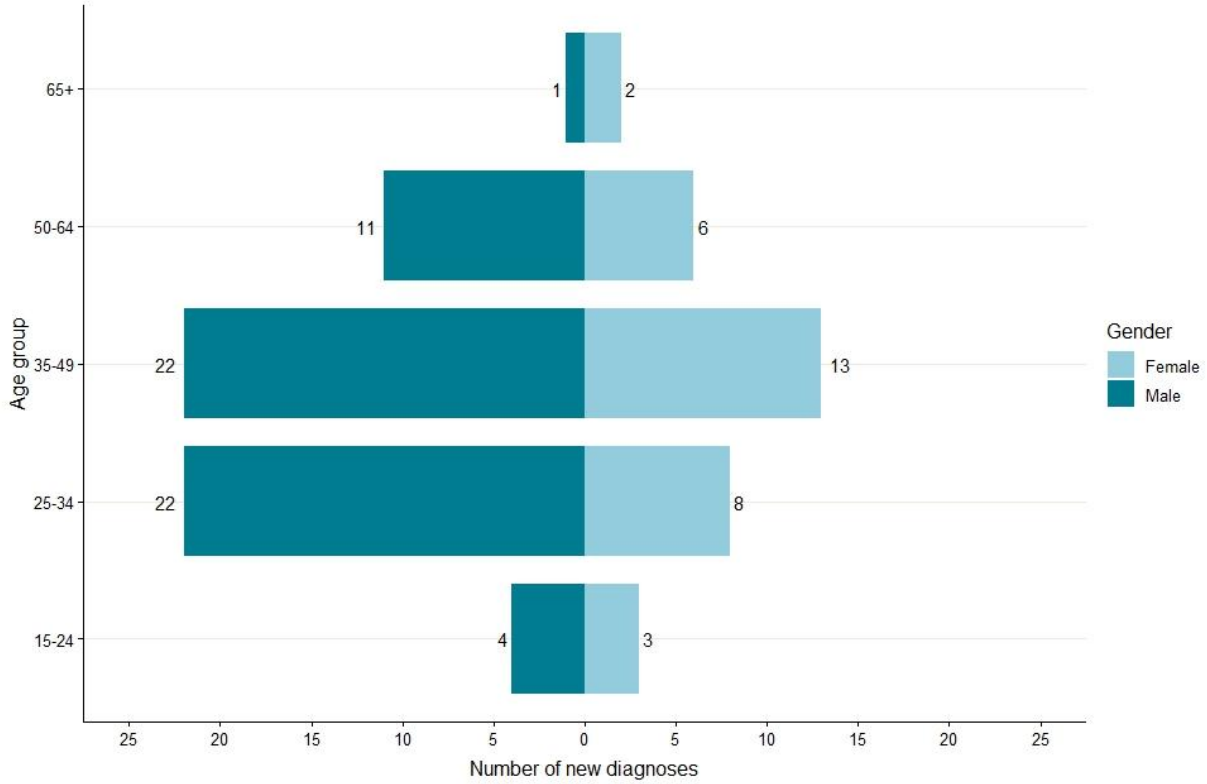


Number of new diagnoses vs previously diagnosed before continuing care in North East & North Cumbria by gender identity and age group: 2024

previously diagnosed before continuing care in England



new diagnoses



Summary

- Low prevalence region (North East) and LA (North Cumbria) but within that there are areas of high prevalence
- Some groups are more affected
- Increasing number of older people living with HIV
- Different health needs of groups of people living with HIV
    - Women
    - Black Africans
    - Other ethnic minority groups
    - Differences within GBMSM

Acknowledgements

We gratefully acknowledge the continuing collaboration of people living with HIV, as well as clinicians, microbiologists, immunologists, public health practitioners, sexual health advisors, occupational health doctors, nurses and other colleagues who contribute to the surveillance of HIV and STIs and the monitoring of HIV care in the UK.

INSIGHTS: Reflections from experts by experience

Caroline Emmerson
Volunteer Coordinator, Blue Sky Trust

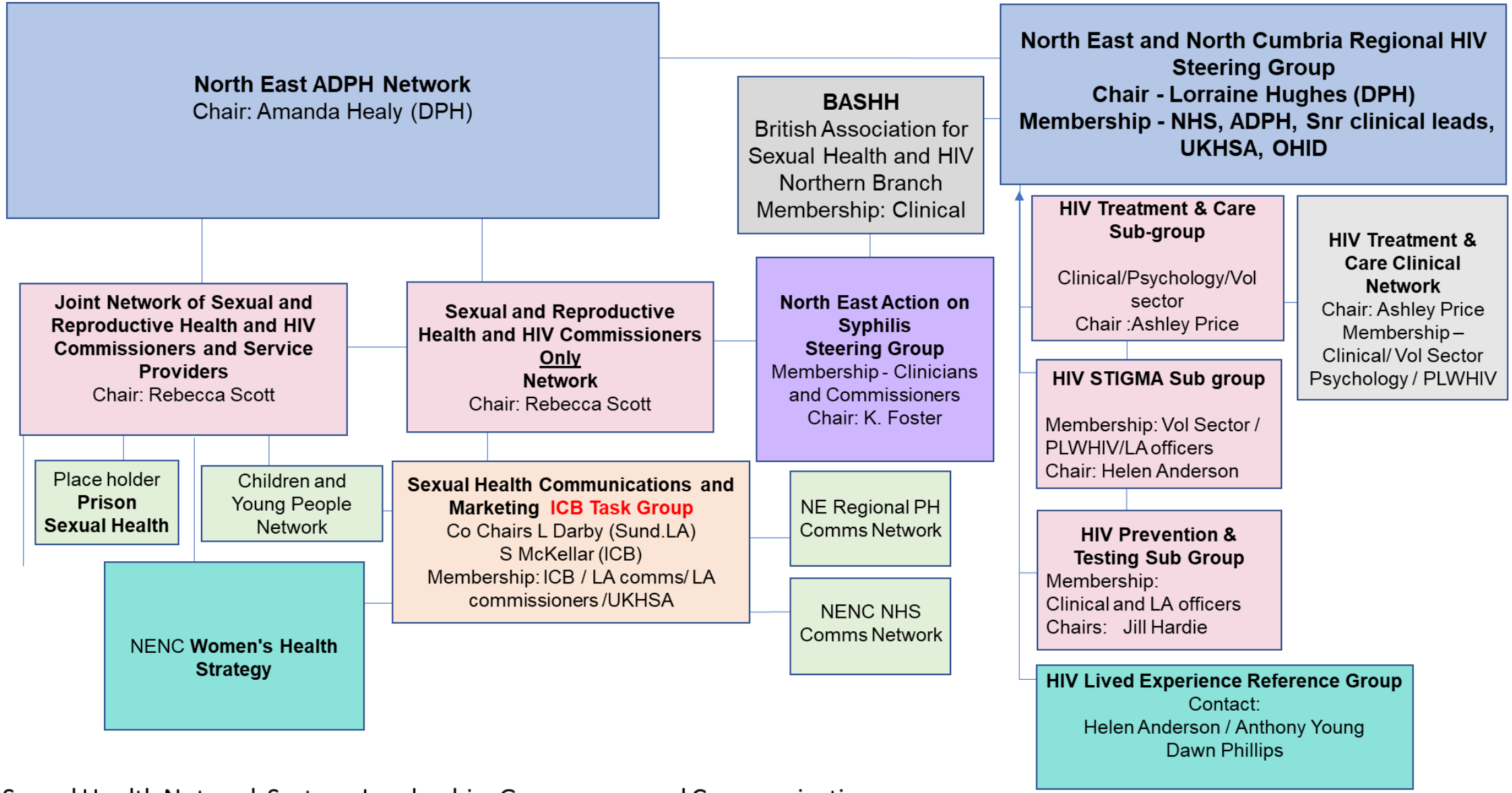
Nigel Bullock
Advocate, Blue Sky Trust

Anthony Young
Service Manager, Terrence Higgins Trust Teesside

INSIGHT: Reflections from Experts by Experience

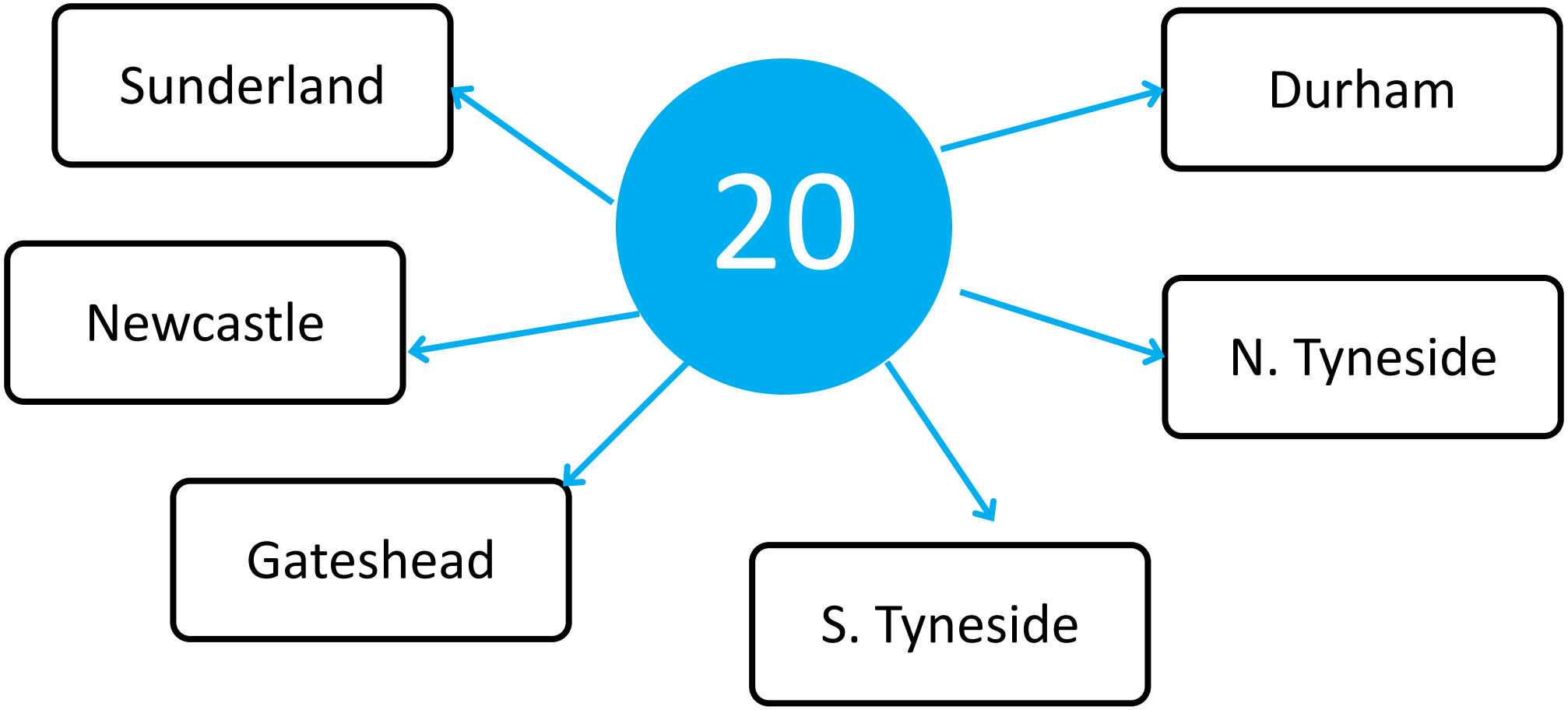
Caroline Emmerson, Volunteer Coordinator
Nigel Bullock, Advocate

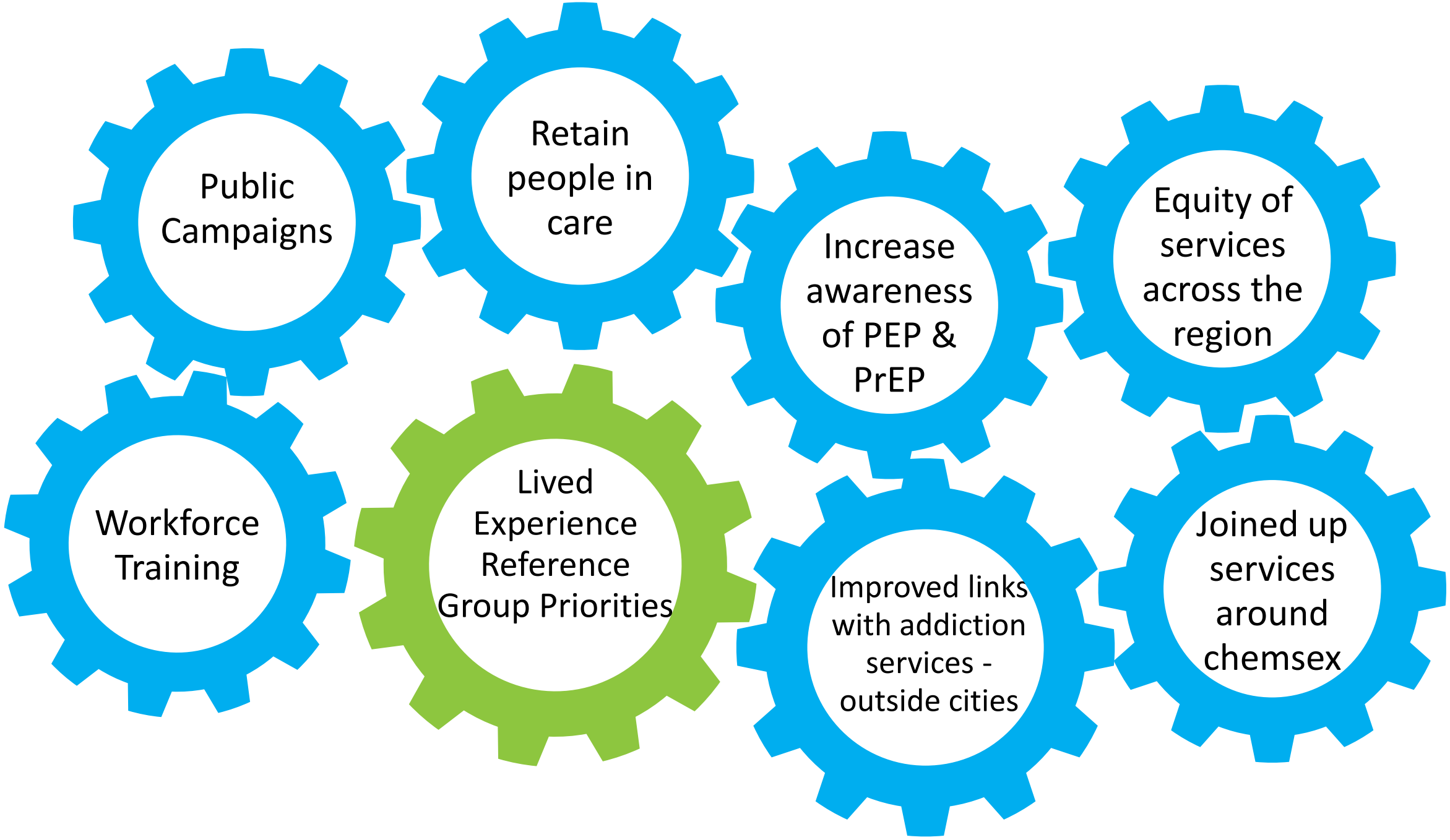
Zero HIV Transmission and Zero Stigma, 2026



Sexual Health Network System: Leadership, Governance and Communications
Overview 24.04.2026

Lived Experience Reference Group: The North




Public Campaigns
Retain people in care
Increase awareness of PEP & PrEP
Equity of services across the region
Workforce Training
Lived Experience Reference Group Priorities
Improved links with addiction services - outside cities
Joined up services around chemsex

Workforce Training

- Social Care/ Care Homes / Care Commission
- Primary Care
- Mental Health Services
- Addiction Services
- Police Criminal justice
- Universities Colleges
- Tattoo & piercing venues

We want to have confidence that the professional infront of us understands about HIV and is not going treat me differently because of it

HIV CONFIDENT



More than a POCT service – the seeds of change

Anthony Young
Service Manager
07342 949138
www.tht.org.uk
e-mail Anthony.Young@tht.org.uk

Outreach - Opportunities & Connections









Terrence Higgins Trust

“I’ve never met anyone else with HIV”

- Coping with diagnosis
- Feelings of loneliness and isolation
- Mental health & emotional wellbeing
- Fear of status disclosure in NHS settings, especially hospitals for care other non-HIV related
- Stigma and prejudice
- Dating with HIV
- Travelling abroad with HIV - issues with travel insurance
- Ageing with HIV
- Finances and pensions
- HIV and other long-term health conditions
- HIV treatment and other medication interactions
- New treatment -HIV Injectable treatment regimes

Terrence HIGGINS TRUST

STIGMA: Making sense of stigma and trauma; and the HIV Confident Charter

Dr Kate Reilly

Clinical Psychologist, Newcastle upon Tyne Hospitals NHS FT

The Newcastle upon Tyne Hospitals
NHS Foundation Trust

Making Sense of Stigma and Trauma

Dr Kate Reilly
Clinical Psychologist in HIV

katereilly@nhs.net
0191 2824081

Aims

- Understanding the mental health challenges for people affected by stigma and trauma
- Considering good practice for making your service more accessible
- What you can be doing within your role to support engagement, build trust and challenge stigma

What are we talking about?

What is Trauma?

- Physically or emotionally harmful or life-threatening events
- Overwhelming a person's ability to cope in the moment
- Without good support, the trauma has lasting adverse effects
- The core impact is a heightened sense of threat
- If I feel under threat then I can't listen to you properly, I can't follow what you say, I won't remember it..
- Equally, if all I know is threat and risk, feeling cared for can itself feel unsafe and not to be trusted

What is stigma?

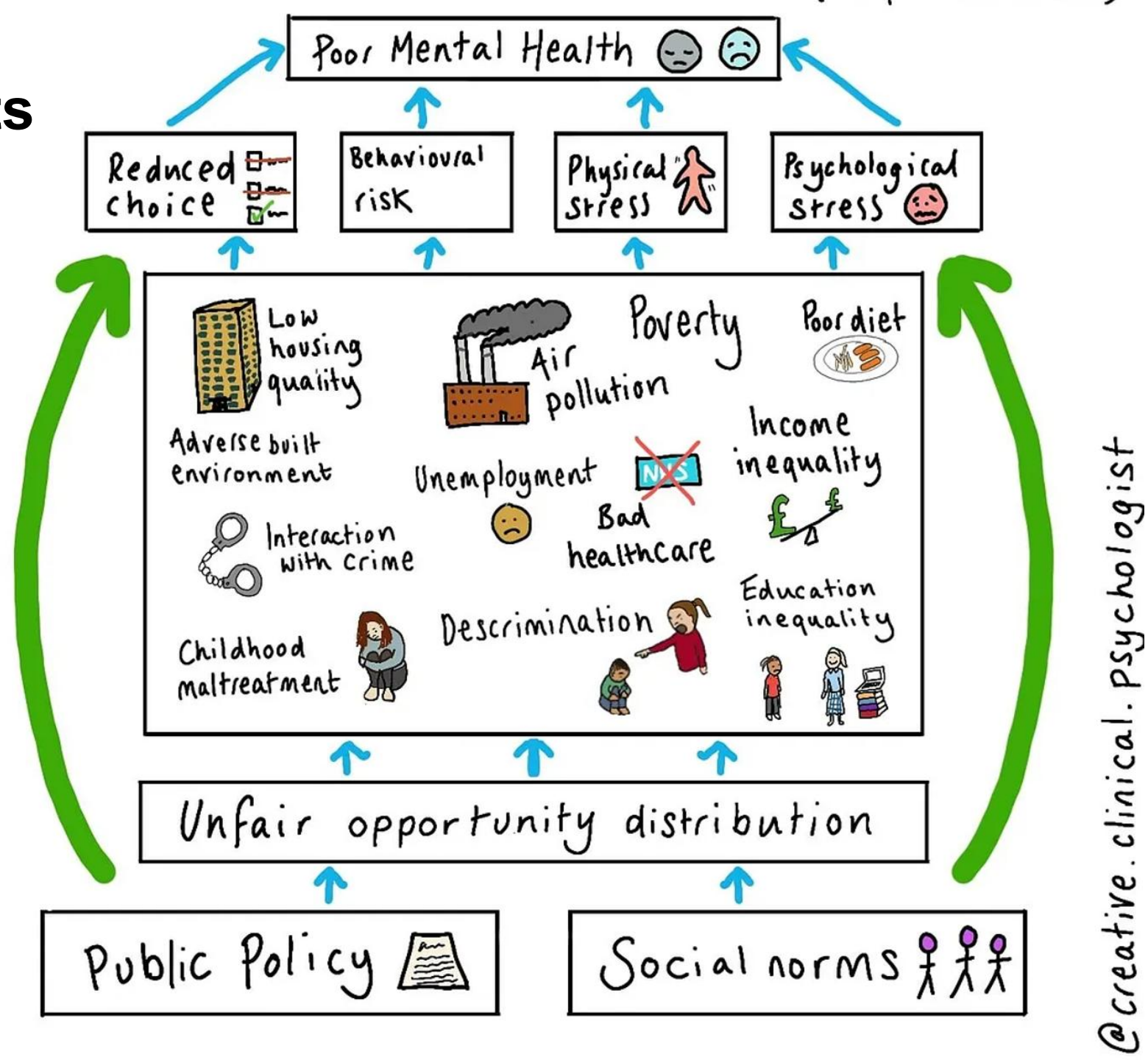
- "a mark of **disgrace** associated with a particular circumstance, quality or person"
- Stigma can be understood as the negative perception of a person based solely on the stigmatized identity
  - Living with BBV, homelessness, experience of sex working, using substances
- Experienced stigma, or discrimination, occurs when people with these identities experience negative or unfair treatment based on these perceptions

As a woman living with HIV, I find that stigma and self stigma are sometimes more of an issue than the HIV itself.

Jo Josh, UK-CAB, BHIVA Standards, 2018

Trauma and stigma disproportionately affect marginalised populations and is inseparably bound up with systems of power and oppression

Social determinants of mental health



Understanding Our Threat System

- Simple old brain jumps to conclusions – automatic emergency response
- Amygdala rings the alarm bell



- We react instinctively: fight, flight, freeze, flop, fawn
- Bodily response can itself feel scary – heart thumping, short of breath
- Following trauma, this alarm can become overactive
- We become hypervigilant to danger

We don’t choose this. Our brains do what they need to protect us

What Makes Trauma Manageable



Effective Action



Somewhere safe to escape to and make sense



Caregivers calm and responsive



Flexible use of imagination

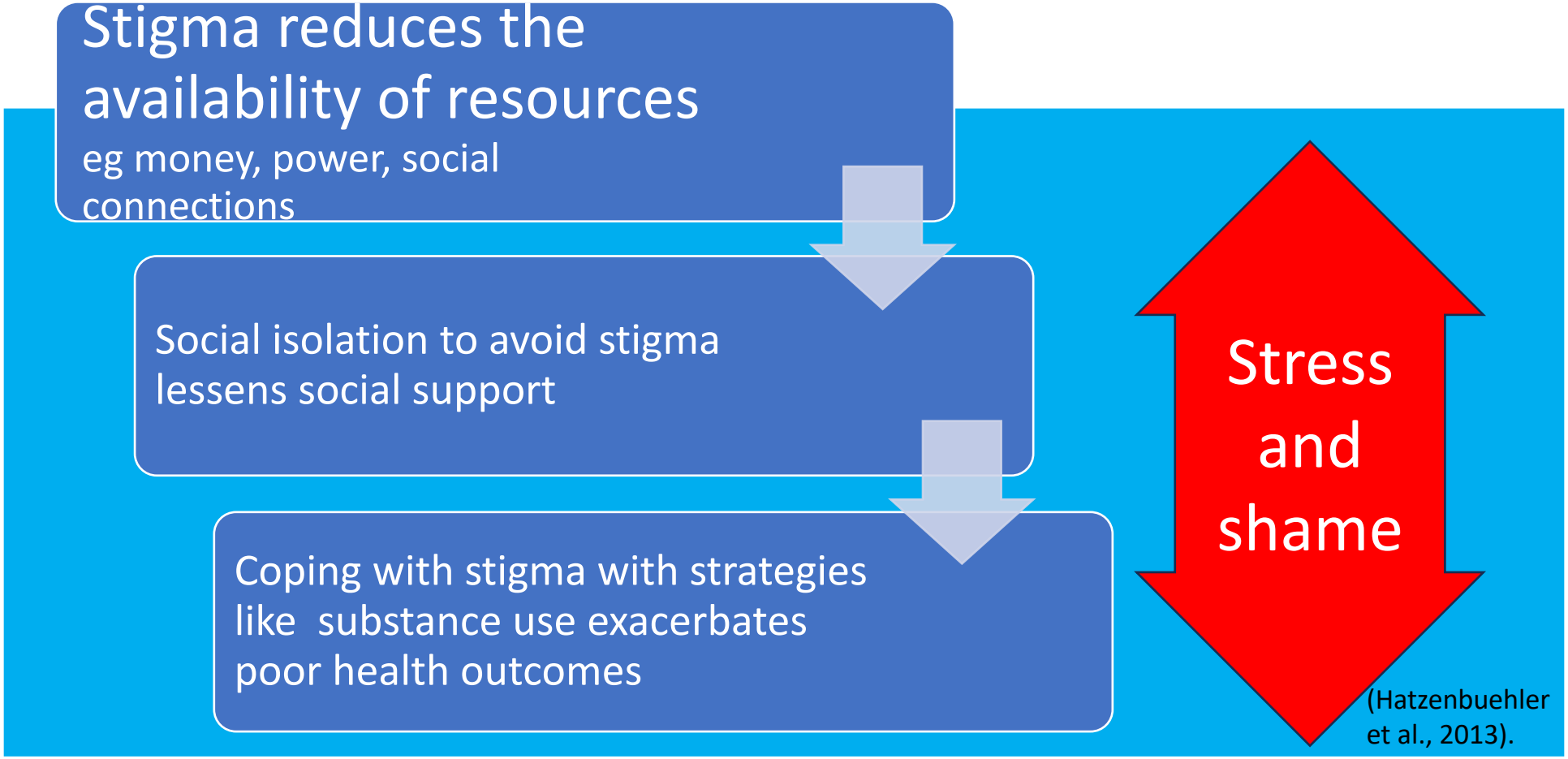
Van der Kolk, Bessel A. The Body Keeps the Score: Brain, Mind, and Body in the Healing of Trauma. Viking, 2014.

When that can’t happen…

- Avoidance
- Withdrawal
- Hyper vigilant to threat
- Quicker to startle or to become aggressive
- Little sense of pleasure or enjoyment
- Impact on sense of hope for future
- Memory problems
- Concentration & organisation
- Poor sleep
- Poor health



Then stigma & self stigma on top



(Hatzenbuehler et al., 2013).

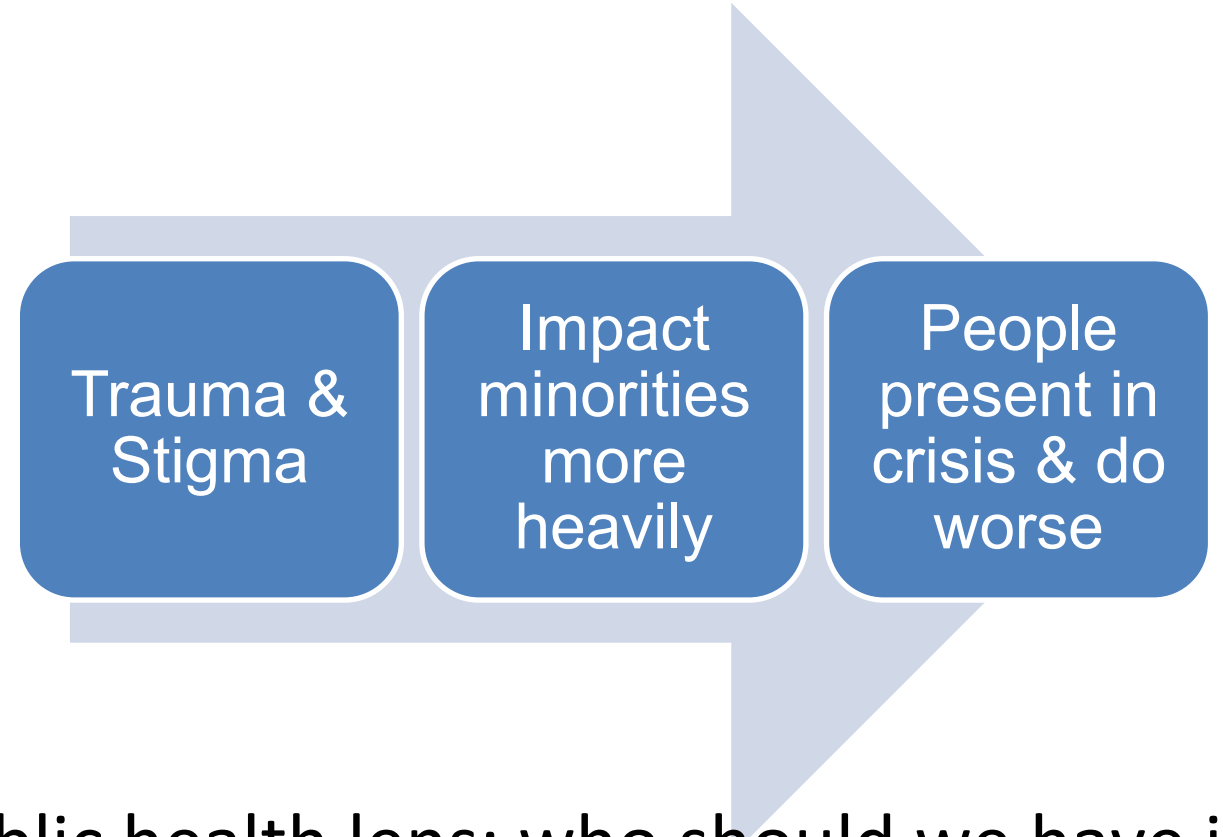
How do we see HIV Stigma impacting care?

Stigma associated with:
People not knowing their status
Hesitancy to share status with support networks & sexual partner
Delayed care seeking or non-engagement
Deferred ART or non-adherence
Mental health problems
Poorer quality of life

(Relf, Holzemer, Holt, Nyblade & Caiola, 2021)

Trauma and Stigma

- Not just psychological events but consequences of systemic injustice



- Need to understand this and support engagement
- Need to focus on earlier support & prevention

- Public health lens: who should we have in services, who are we missing and how do we reach them?

Can we help people to make sense of why they do what can hurt them?

- All of us have adapted expertly, and unconsciously, to survive
  - If it hurts to be inside my body I'll leave it through drugs/alcohol/risk taking highs
  - If I have no control, I'll find it through restricting my eating or not taking my medication
  - If people I love hurt me, I'll lose trust, I'll test new people out or withdraw from others totally
  - If no-one showed me how to handle distress, I'll avoid it and deny it, I'll miss appointments
  - If I grew up with disappointment and abandonment, I'll learn not to hope
  - If I grew up with criticism and ridicule, I'll learn to berate myself with nastiness
  - If I grew up ignored or excluded from services, I will not trust what is offered
- These strategies sit inside the old brain, not as amenable to reason and update. Often people "know" what they are doing is unhelpful, but their body takes over and they "feel" they have to do what hurts to survive

Why do people do what can hurt them?

Withdrawal from the world

- Offers protection from further harm or disappointment

Self harm eg cutting or overdose

- Adrenaline can calm
- Release feelings, communicates distress and gives a sense of control

Why do people do what can hurt them?

Verbal and physical aggression

- Aggression can make us feel powerful and in control
- It may be the way we were shown to deal with distress

Condomless sex

- A sense of power and a way to seek affection and connection

Why do people do what can hurt them?

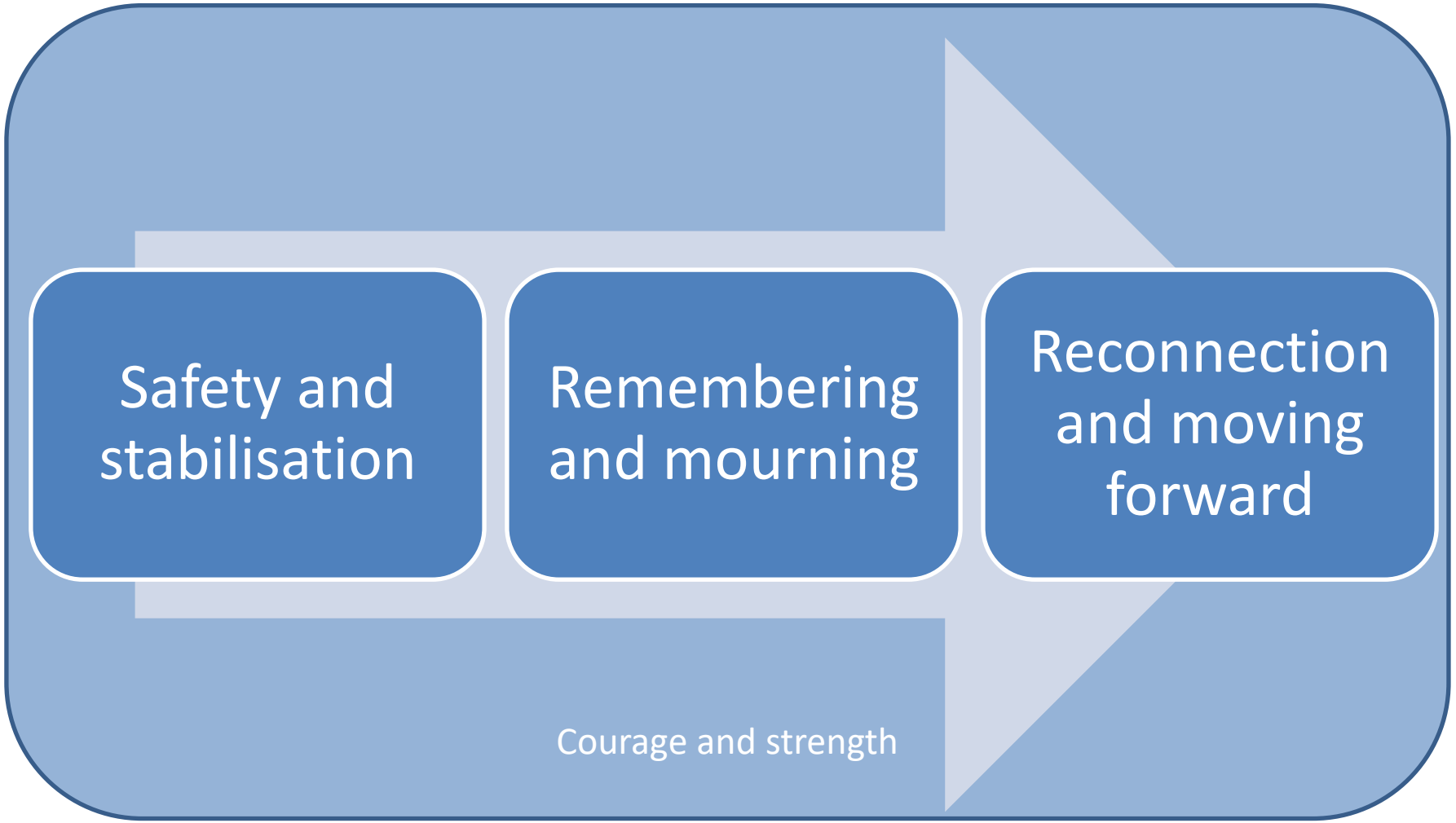
Avoiding what is pleasant or helpful

- Avoids guilt from not feeling you deserve it or fear of letting people down

Self loathing, self blame

- Helps us make sense ‘must be my fault’
- Can help protect family who told us we were to blame

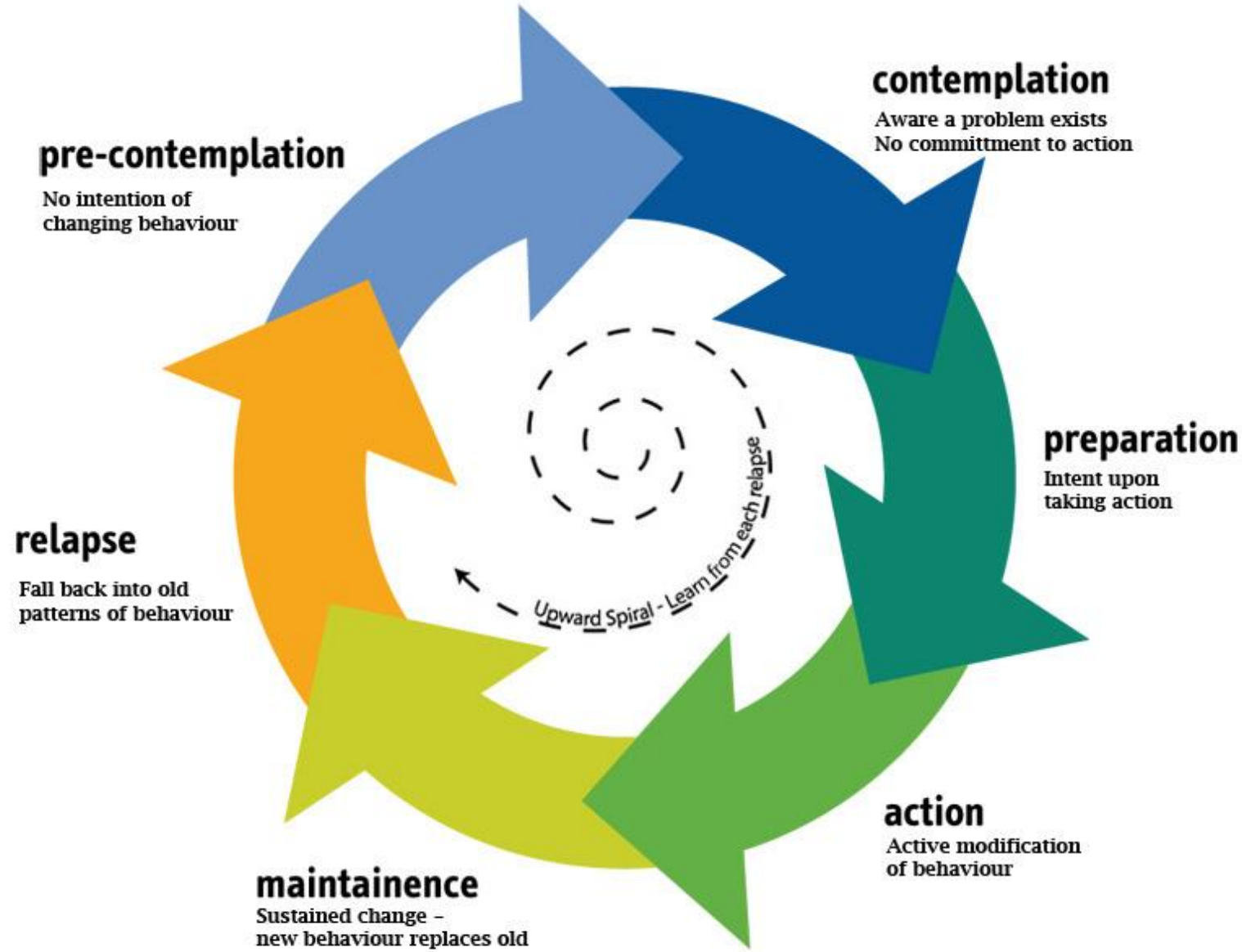
Moving Forward with Trauma



Meet people where they are

Supporting Change

Only push where it moves



Transtheoretical Model of Change

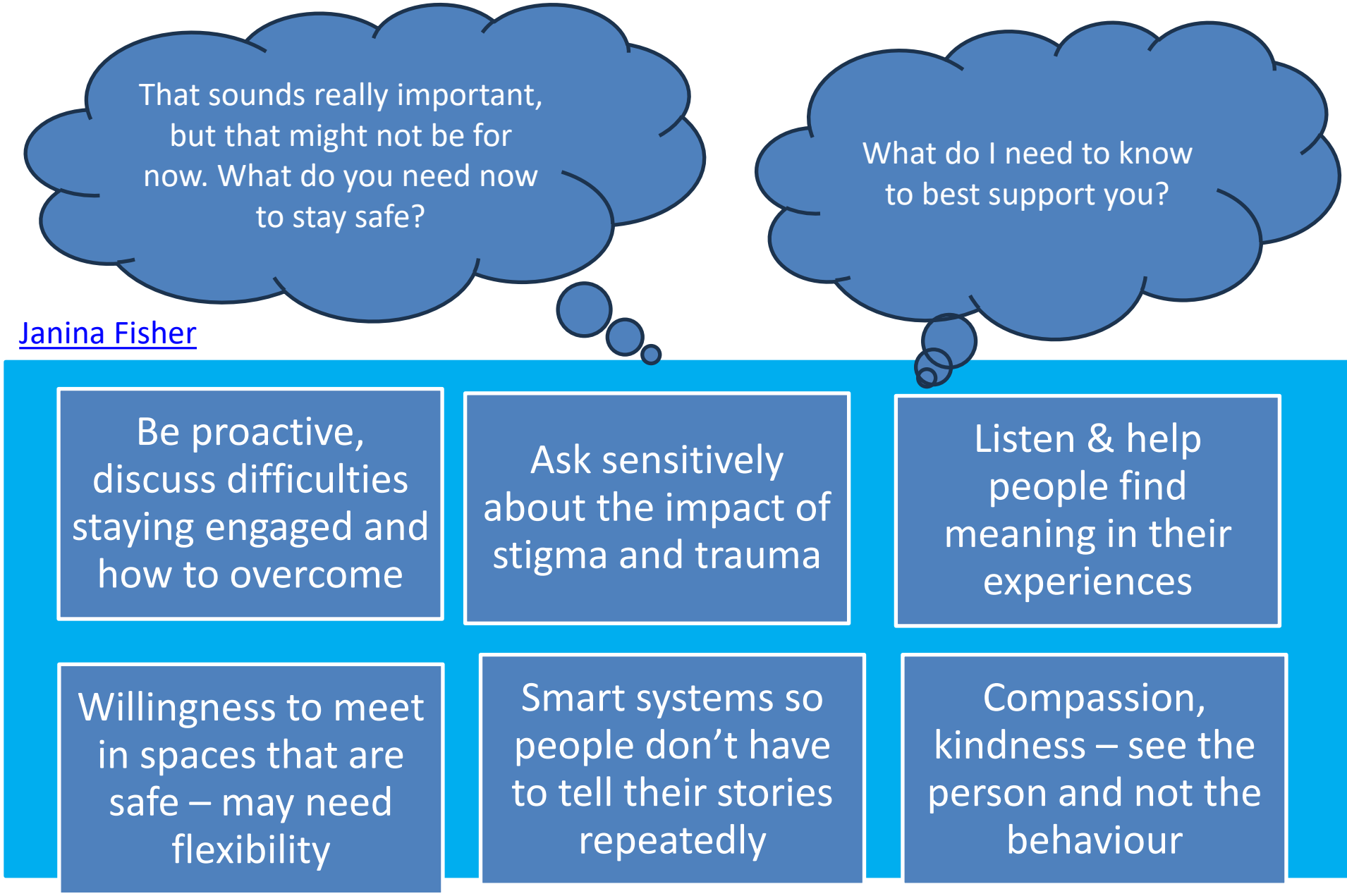
Prochaska & DiClemente

Acknowledging our own responses

Having a judgemental or biased thought is human and understandable – we can't 'train' this out of ourselves

However we can:

- **Actively, honestly reflect on our own biases**
- **Educate ourselves in areas/practices/cultures we are unfamiliar**
- **Ensure this does not translate into our interactions with people**
- **Speak up if we think others are acting in stigmatising/discriminatory ways**



So, what can I do?

Focussing on maintaining safety and engagement

- Support with planning, organisation, motivation & emotional regulation
  - Reminders, use of calendars, breaking down plans into steps
  - How do they want to be reminded?
  - Who shall we contact if we don't see you?
  - What other services should we be talking to?
  - Should we make a voice note about why you want things to change to listen to when feeling overwhelmed?
  - How can you record what you have achieved, perhaps what you are grateful for and who can support you?
  - How do you respond when stressed? When you do that, how can I best help? Eg if I withdraw and start to shut down, tell me you can see it's hard, remind me you're still there, pause what we're doing and get me a hot drink; if I get angry…..; if I start to pretend everything is fine….
  - "when people have been let down in the past they can find it really hard to trust. How can we help with that?"

Fine balancing act…

Connect people to peer support

Connect people to psychosocial support – housing, immigration advice, debt management, substance support



Encouraging people to take responsibility for themselves

Advocating for them within damaging systems



HIV CONFIDENT

Increasing employee knowledge about HIV,

Improving employee attitudes towards people living with HIV,

Tackling stigma and discrimination within their organisation, and

Providing people living with HIV a way to report any stigma or discrimination they experience.



The Newcastle upon Tyne Hospitals NHS Foundation Trust

HIV CONFIDENT

First non-London Trust to become HIV Confident

- We surveyed staff attitudes & behaviour – 900 responses
- Reviewed our policies to ensure they are appropriately worded and non-discriminatory
- Introduced a fantastic 20minute elearning module on HIV for all staff
- Set up a reporting pathways for any staff or patient to report HIV stigma of any kind, anonymously or not

What we have learnt

The Newcastle upon Tyne Hospitals NHS Foundation Trust

- Support and energy needed from the top and across a team – HIV Confident Steering Group to be relaunched in Autumn
- Clever use of comms and existing networks to promote across the Trust – screensavers, engagement events, staff briefings
- Governance of stigma reporting is key – we have made changes to align reporting with existing mechanisms and changed our HIV Confident Champion – now Kris Park from Patient Experience Team
- Resources are really high quality and trigger personal recommendations

I would really recommend people complete the HIV confident Training even if you don't come into contact with people living with HIV as part of your role because you never know who could be affected by HIV. Its such a brilliant training session and possibly one of the best e-learning sessions I've done

Why it matters… BST Members opinions

The Newcastle upon Tyne Hospitals NHS Foundation Trust

- I will feel safe accessing treatment and know that I am getting the best care.
- It will be nice to visit now – maybe the staff I see will have done the training
- It makes me feel more confident accessing treatment. However, are there gaps? My partner is a nurse and wasn't very aware of HIV.
- It should be mandatory for all staff to be trained – otherwise how can we be confident that it is a safe place to access.

What can we all be doing in our practice to challenge and eradicate stigma and become more trauma informed?

Does our role end in the consulting room or do we have a responsibility, and capacity, to do more?

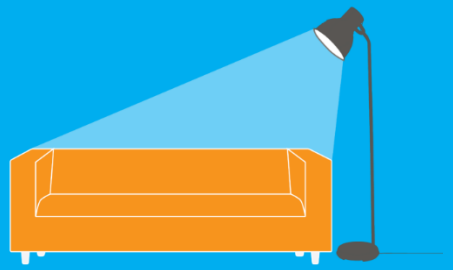
Please consider making a pledge today to support Zero HIV Stigma Day 21st July 2026



Thank you

Any questions?

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Fleischer L, Avery A. Adhering to antiretroviral therapy: a qualitative analysis of motivations for and obstacles to consistent use of antiretroviral therapy in people living with HIV. SAGE Open Med. 2020;8:2050312120915405. 10.1177/2050312120915405 - DOI - PMC - PubMed

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National AIDS Trust (2016) Tackling HIV Stigma, What Works?

National AIDS Trust (2021) 'HIV: Public knowledge and attitudes' report

Relf, M. V., L Holzemer, W., Holt, L., Nyblade, L., & Ellis Caiola, C. (2021). A Review of the State of the Science of HIV and Stigma: Context, Conceptualization, Measurement, Interventions, Gaps, and Future Priorities. *The Journal of the Association of Nurses in AIDS Care : JANAC*, *32*(3), 392–407. https://doi.org/10.1097/jnc.0000000000000237

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Stigma: survey of people living with HIV Monitoring implementation of the Dublin Declaration on partnership to fight HIV/AIDS in Europe and Central Asia: 2022 progress report, 2022. accessible: https://www.ecdc.europa.eu/sites/default/files/documents/hiv-stigma-survey-monitoring-dublin-declaration.pdf

Vaccari et al (2023) accessible: https://www.bhiva.org/file/645cfa438a747/P113.pdf

PERSONAL COMMITTMENTS

ADDRESSING HIV STIGMA

"Never underestimate the impact of how you made people feel safe and feel heard" Jack

Know the Facts. Share the Facts.

Stigma grows in silence but weakens when people speak up. Learn accurate facts about HIV to replace common myths with truth.

MY PLEDGE:

- ❑ I will correct misinformation when I hear it.
- ❑ I will speak up against stigmatising comments.
- ❑ I will tell 5 people that U=U (Undetectable = Untransmittable).
- ❑ I will discuss PrEP with women in higher-risk contexts.
- ❑ I will ask others, "Do you know your status"?

TRUSTED RESOURCES:

Can't Pass It On training (Terrence Higgins Trust)

HIV Testing: Taking every opportunity (NHS)

Treat with Respect. Create Welcome.

Stigma hides in stereotypes. Listen with empathy and always respect confidentiality. Never share anyone's status without consent. Use person-first language.

MY PLEDGE:

- ❑ I will build trust and see the person first.
- ❑ I will pause and challenge my assumptions.
- ❑ I will use respectful, person-first language.
- ❑ I will respect confidentiality at all times.

TRUSTED RESOURCES:

HIV Language Guide (Blue Sky Trust)

People First Charter HIV/STI language guide

The power of language - Salamander Trust

Show Visible Solidarity.

Small acts of support communicate powerful acceptance. Simple visible statements make sure people never have to feel isolated or alone.

MY PLEDGE:

- ❑ I will take one visible action this month to show support.
- ❑ I will share 3 ribbons and what I've learned.
- ❑ I will actively support an awareness event this year



ADDRESSING HIV STIGMA

Stigma weakens when institutions take a stand and lead by example.

Create Safe, Welcoming Spaces.

Incorporate inclusion directly into organisational structures to build places where everyone feels welcome and completely secure.

OUR COMMITTMENTS:

- ❑ We will audit and remove outdated, biased HIV content
- ❑ We will sign our organisation up to HIV Confident
- ❑ We will provide anti-stigma training to all teams.
- ❑ We will design safe, welcoming and equitable pathways.

TRUSTED RESOURCES:

HIV Confident (National AIDS Trust)

Anti-stigma e-learning: HIV and Hepatitis C

Involve Lived Experience.

Active design includes working side-by-side with experts of experience. Build systems that prioritise peer perspective, training and ongoing service adaptations.

OUR COMMITTMENTS:

- ❑ We will host a lived experienced speaker to guide and inspire staff
- ❑ We will map clear, accessible pathways to peer networks and support.

HIV ORGANISTIONS:

Blue Sky Trust

Teesside | Terrence Higgins Trust

LEAD WITH ACTIONS.
INSPIRE CHANGE.

Visible Organisational Solidarity

Make it structural. Ensure your organisation's social responsibility aligns openly with global movements that break down discrimination in health, and public domains.

OUR COMMITTMENTS:

- ❑ We will mark World AIDS Day (1 December) in the workplace
- ❑ We will share a message of solidarity on #ZeroHIVStigmaDay (21 July)
- ❑ We will use our influence to challenge structural HIV stigma and build safe places.

TRUSTED RESOURCES:

Zero HIV Stigma Day

Engaging Policymakers



BREAK: networking and refreshments

11:15 | 11:35

PREVENTION: HIV prevention

Anthony Young

Service Manager, Terrence Higgins Trust Teesside

Sean Barry

Public Health Advanced Practitioner, Durham County Council

Mark Ellerby-Hedley

Senior Health Promotion Practitioner, Newcastle Sexual Health

Jane Telfer

Public Health Manager, Northumberland County Council

HIV Testing and Prevention Subgroup

15/07/2026

Who are we?
How can you get involved?

- The multidisciplinary subgroup consists of individuals from across the region with a passion for HIV Prevention and Testing and includes clinical and non-clinical staff.

- Talk to any representative from the subgroup following this presentation.

- Email Jill_hardie@middlesbrough.gov.uk

This document was classified as: OFFICIAL

Priority actions (March 2026)

- Develop and implement a regional communication and awareness plan focused on HIV, including PrEP, aligned with key dates such as World AIDS Day, National HIV Testing Week and the release of annual HIV data.

- Increase access to and take up of HIV testing outside Sexual Health Services e.g. drug and alcohol and abortion services.

Progress to date

- Raising awareness of HIV Prevention and Testing activity
- Regional (NENC) HIV Communications Plan approved
- PrEP Survey in development
- Chemsex offer in development in collaboration with sexual health provision and drug and alcohol services – piloting across Teesside
- Share examples of best practice in relation to community HIV testing in excluded communities
- Supported the development of a regional Young Person specific resource, promoting **condom use** with a landing page that directs people to free condoms Elephant in the room - sexual health campaign

This document was classified as: OFFICIAL

Communications plan: areas of focus

- National HIV Testing Week
- PrEP Equity and awareness
- World AIDS Day
- Condom use and acceptability
- U=U

The strategic goals of the communications plan are to:

- **Raise awareness** about HIV transmission, treatment and prevention
- **Normalise testing** as a routine part of sexual health and wellbeing
- **Combat stigma** through lived experience and inclusive messaging
- **Promote prevention** tools including PrEP and condom use

We will achieve our goals through:

- **Leadership & co-ordination**: Appoint a designated lead officer for each of the three priority campaigns to ensure strategic oversight, timely execution and alignment with national messaging.
- **Timely stakeholder engagement:** Develop a shared calendar of deadlines and deliverables to support timely input and transparency across agencies.
- **Amplification of national messaging:** Encourage all Local Authorities and Service Providers to proactively engage their local community groups and networks to amplify national HIV campaign messages.

This document was classified as: OFFICIAL

HIV Testing Provision across North East Stocktake Findings

(June – October 2025)

- 12/13 Local Authorities responded to the stocktake
- 100% of Local Authorities in NE offer HIV Testing in clinical services / online HIV Testing
- 8/12 Local Authorities have signed up to the National HIV Testing framework

Drug and Alcohol services

- 8/12 Local Authorities offer HIV Testing in this setting – **more work to do with workforce and confidence work needs doing on .**

Abortion services

- 9/12 Local Authorities have HIV Testing – **limited uptake!**

This document was classified as: OFFICIAL

HIV Testing Provision across North East - Stocktake Findings

General practice

- Limited awareness of HIV testing in this setting

Hospital settings

- Limited awareness of HIV in this setting other than ED opt out testing

How can we close this knowledge gap?

This document was classified as: OFFICIAL

The National HIV Action Plan 2025 – 2030

The national HIV Action Plan suggests local HIV prevention activity should be able to show:

- PrEP, PEP, condoms, HIV testing and U=U are clearly promoted
- HIV prevention information is reaching people at greatest risk
- Underserved groups are being reached
- Awareness activity is equitable and culturally appropriate
- Prevention activity is linked to testing and treatment pathways
- Local work is being evaluated, not just delivered
- Stigma reduction is built into prevention activity

This document was classified as: OFFICIAL

HIV Prevention Activity across North East - Stocktake Findings April – July 2026

- 11/13 North East and North Cumbria Local Authorities responded to the stocktake
- 100% of ALL Local Authorities deliver HIV Prevention Activity – even those who did not engage with stocktake



This document was classified as: OFFICIAL

Overview of HIV Prevention Activity Across the North East (Stocktake: April - July 2026)

- **Sexual health promotion** is a core HIV prevention route across the region, delivered through schools, colleges, universities, family hubs, community venues, outreach, websites and social media.
- **Condom schemes** provide a consistent prevention offer, including C-Card, DOINK/SH.UK, online ordering, pharmacies, schools/colleges and community distribution points.
- **Workforce education and partner training** are reported frequently, including frontline workforce training, community partner sessions and training linked to asylum/refugee teams.
- **PrEP** is increasingly visible across local prevention offers, promoted through sexual health services, websites, posters, leaflets, digital resources, consultations, outreach and partner networks.
- **Targeted outreach** is reaching key populations, including GBMSM, young people, people who inject drugs, migrants/asylum seekers/refugees, Black African communities, LGBTQ+ communities, sex workers and people in supported/community settings.
- **Campaigns and partnership working** provide a regional platform through HIV Testing Week, World AIDS Day, Pride, U=U, Eyes Open, Elephant in the Room and local communications activity.

Source: NE HIV PREVENTION Stocktake MASTER - 13 July 2026; findings based on self-reported Local Authority responses.

This document was classified as: OFFICIAL

Examples of HIV Prevention Activity That Stand Out

Northumberland model

Schools/colleges, PrEP resources, PrEP survey, asylum/refugee community outreach awareness training /team training

Gateshead partner reach

Information shared with GPs, pharmacies and social care; links with Changing Lives, D&A services schools and Comfrey Project.

Teesside outreach

HIV-specific migrant/asylum seeker activity, links with African communities, people seeking asylum, church groups, food banks and LGBT communities seeking asylum

Newcastle targeted offer

LGBTQ+ clinic, gay-scene outreach, university outreach, targeted work with marginalised and at-risk groups including sex workers, migrants and asylum seekers

County Durham and Quality Improvement

Planned HIV exhibition with ‘The national HIV Story Trust’. Outreach worker and mobile young people's bus, sexual health pack for Migrants, NG60 Baseline assessment

Promising activity is strongest where prevention combines visible information + targeted outreach + partner pathways + workforce confidence.

Source: NE HIV PREVENTION Stocktake MASTER - 13 July 2026; findings based on self-reported Local Authority responses.

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Newcastle Sexual Health

Newcastle Sexual Health – Testing Outreach

- Rainbow Home
  - Charity supporting LGBTQ+ people in the North of England who are seeking sanctuary
- Be-North
  - Charity supporting Trans people across the North-East
- Number 52 Sauna & Newcastle Gay Scene
  - Gay Sauna in Newcastle
  - Work in partnership with Blue Light Services on Newcastle Gay Scene

- Newcastle Pride
- Newcastle University
- Northumbria University
- Newcastle College



blue sky TRUST

Working in partnership with the Melissa Bus & Blue Sky Trust



Teesside HIV Prevention & Support Service

Anthony Young
Service Manager
07342 949138
www.tht.org.uk
e-mail Anthony.Young@tht.org.uk

HIV Prevention & Support Service Pilot

- 12-month pilot
- Fact finding led
- Listen to needs and concerns of PLWHIV on Teesside
- Peer Led Support for PLWHIV – Terry Talk
- Understanding the barriers to treatment with those people lost to care
- Helping them re-engage with treatment
- Support for partners, carers and families
- Peer Reference Group – Terry Talk Plus

Terrence HIGGINS TRUST

Terrence Higgins Trust

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Your Voice Matters



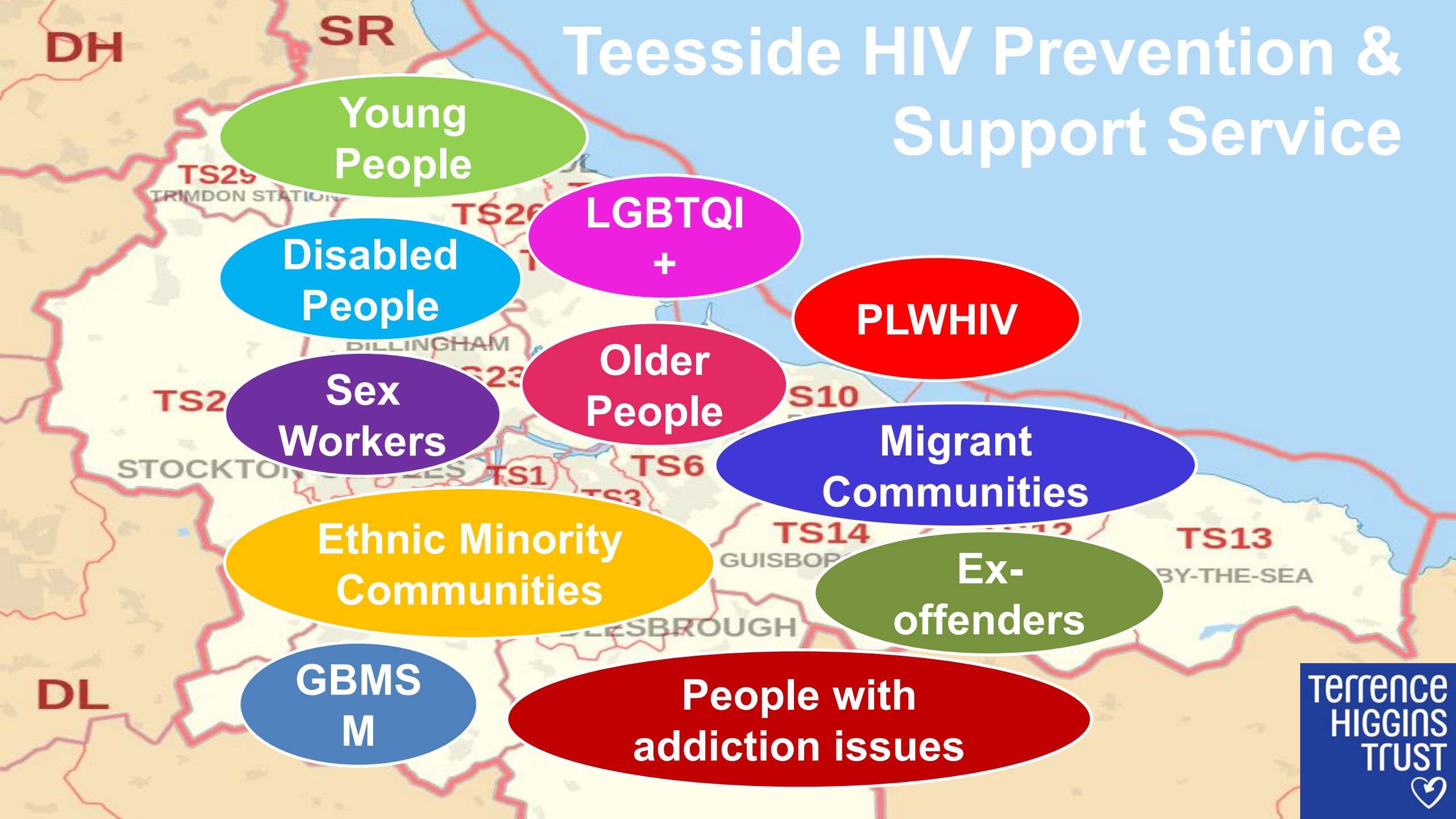
surveymonkey.com

Take our short survey

Learn more

Terrence Higgins Trust Teesside

- HIV Prevention work in colleges and workplaces
- HIV Awareness
- Chemsex Awareness
- Understanding PrEP
- U=U Can’t Pass It On
- Challenge Stigma
- Collaborative working with CCI and Teesside Together
- Working towards 2030 goal Zero new HIV Transmissions


Teesside HIV Prevention & Support Service
Young People
LGBTQI +
Disabled People
PLWHIV
Older People
Sex Workers
Migrant Communities
Ethnic Minority Communities
Ex-offenders
GBMS M
People with addiction issues
DH
SR
DL
TS29
TRIMDON STATION
TS26
BILLINGHAM
TS2
STOCKTON
TS1
TS3
TS6
S10
TS14
GUISBOR
TS13
BY-THE-SEA
LESBROUGH
Terrence HIGGINS TRUST

Do you know your status?

- Don’t assume
- 5% of people living with HIV **do not know their status**
- Testing is the only way to find out

Terrence Higgins Trust

Useful Websites

- www.tht.org.uk
- www.teessidetogether.co.uk
- www.sh.uk/condoms/teesside
- www.startswithme.org.uk
- www.chemsex.co.uk
- www.i-base.info
- www.aidsmap.com

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Eyes Open HIV – Positive About HIV

- Eyes Open have been working across the region since 2003 to raise awareness of HIV and reduce stigma.
- The website includes:
- Oral Histories of People Living with HIV
- Signposting to services and free HIV Testing across the region
- Overview of all activities across the region over the years
- Link to Eyes Open HIV Stigma Survey

This document was classified as: OFFICIAL

Reflections

If we get HIV prevention and testing right across the North East - what would it look like?

This document was classified as: OFFICIAL

Reflections

What are the **OPPORTUNITIES** surrounding HIV Testing in your area of work?

What are the **CHALLENGES**?

What are the **SOLUTIONS**?

This document was classified as: OFFICIAL

Reflections

Consider your knowledge of PrEP – who is PrEP aimed it? How do you access PrEP?

Ask yourself the same for PEP.

COLLABORATION: Panel discussion

Chaired by: -

Dawn Phillips

Sexual Health Facilitator, UK HSA

Ian Advocate Blue Sky Trust	**Jack** Advocate Blue Sky Trust	**Gary Besterfield** Head of Service Delivery, STRIDE	**Vicki Bignall** Clinical Lead for With You, STRIDE	**Jane Curtis** Area Manager, Waythrough



LUNCH: networking and pledges

12:35 | 13:25

TEST: Opt-out testing for HIV in emergency departments

Dr Ashley Price

Consultant Infectious Disease, The Newcastle upon Tyne Hospitals NHS Trust

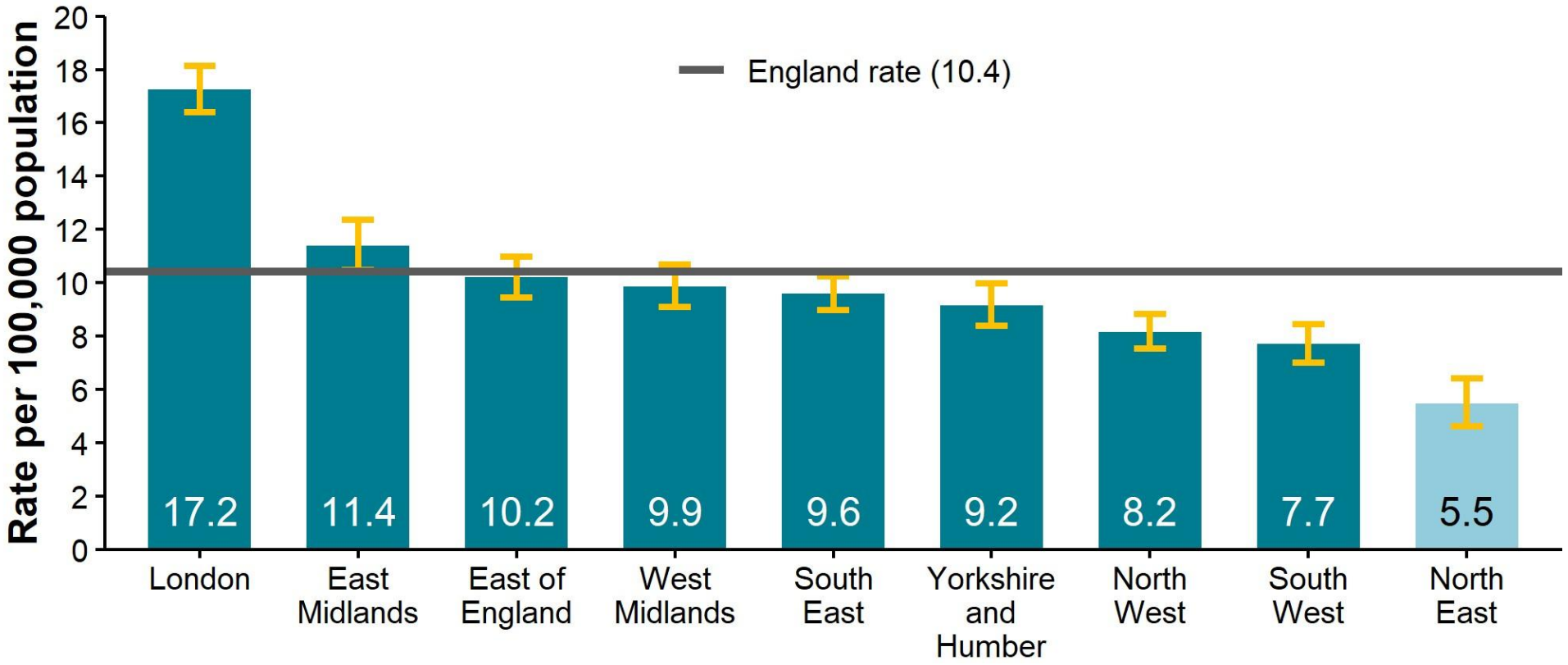
Dr David Chadwick

Consultant in Infectious Diseases, The James Cook University Hospital

ED BBV OPT OUT TESTING AT NEWCASTLE

Dr Ashley Price

Rates of New HIV diagnosis 2023



619 new HIV diagnoses in the North East 2018-2023

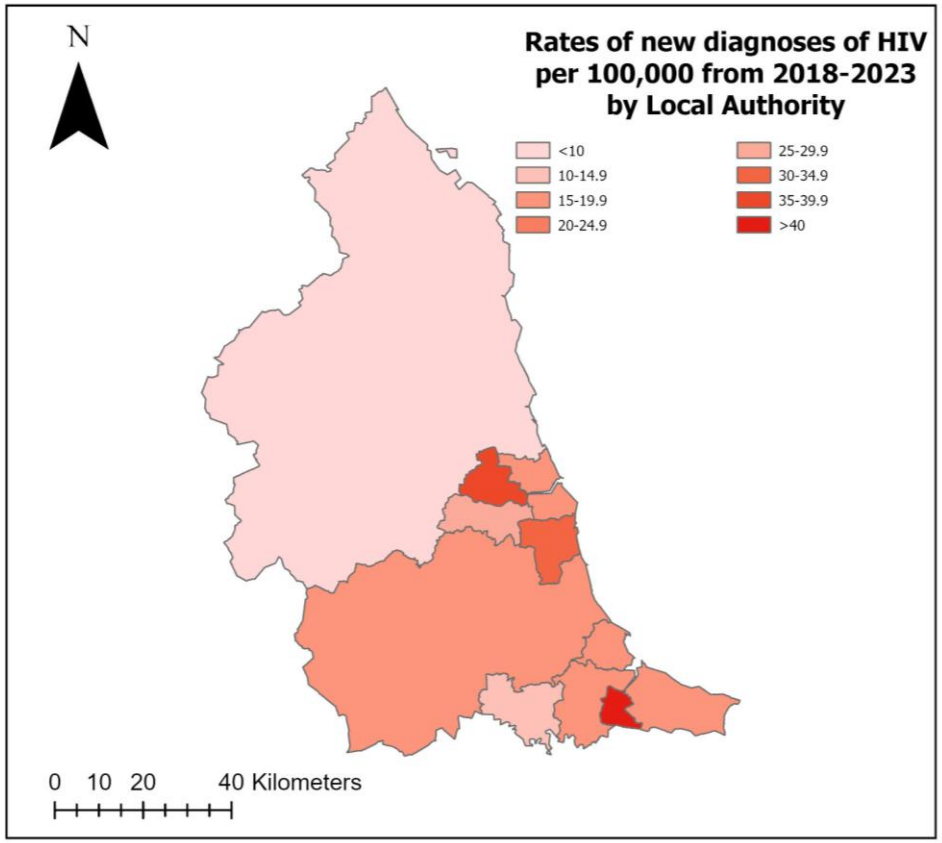


Figure 3: Rate of HIV diagnoses per 100,000 by Local Authorities in the North East created using ArcGIS pro

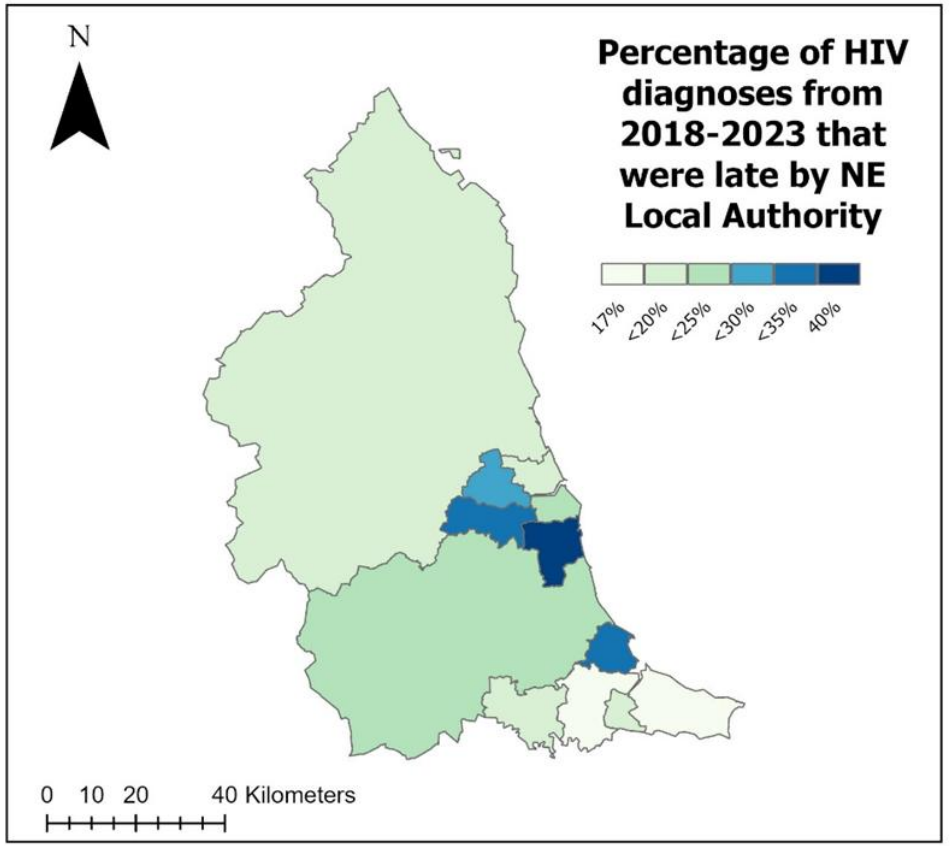


Figure 4: proportion of late HIV diagnoses by Local Authority in the North East created using ArcGIS pro

ED Opt out testing

- 2022- started in ED in areas of V. high prevalence >5 per 1000
  - London
  - Brighton
  - Manchester
  - Blackpool
- 33 EDs 857,117 HIV tests, 473,723 hepatitis C virus (HCV) tests and 366,722 hepatitis B virus (HBV) in 1 yr
- In 16 hospitals: 646 (1.1%) new HBV diagnoses , 175 (0.2%) new HCV diagnoses- 141 known HCV and not in care, 78 (0.9%) new HIV diagnoses- 59 known HIV and not in care.
- Cost HIV test was £6·31. Assumptions over 20yrs:
  - 0.29 new diagnosis per 1000 tests
  - Avert 187 HIV-related death
  - 28 secondary acquisitions (26–52) over 20 years,
- Cost £18 630 per QALY gained <£35 000 per QALY
- Under a lower test yield scenario of 0·20 new diagnoses per 1000 tests intervention remains cost-effective at £25 000 per QALY.

Expansion

Programme success- >7000 new BBV diagnosis: > 1000 HIV, >4600 HBV, >1600 HCV

30 more ED selected in areas with high prevalence >2:1000 at end of 2024

Newcastle among these

ED BBV OPT out testing setting up

Leadership and team work

OPT out

Posters

On-line information

IT systems

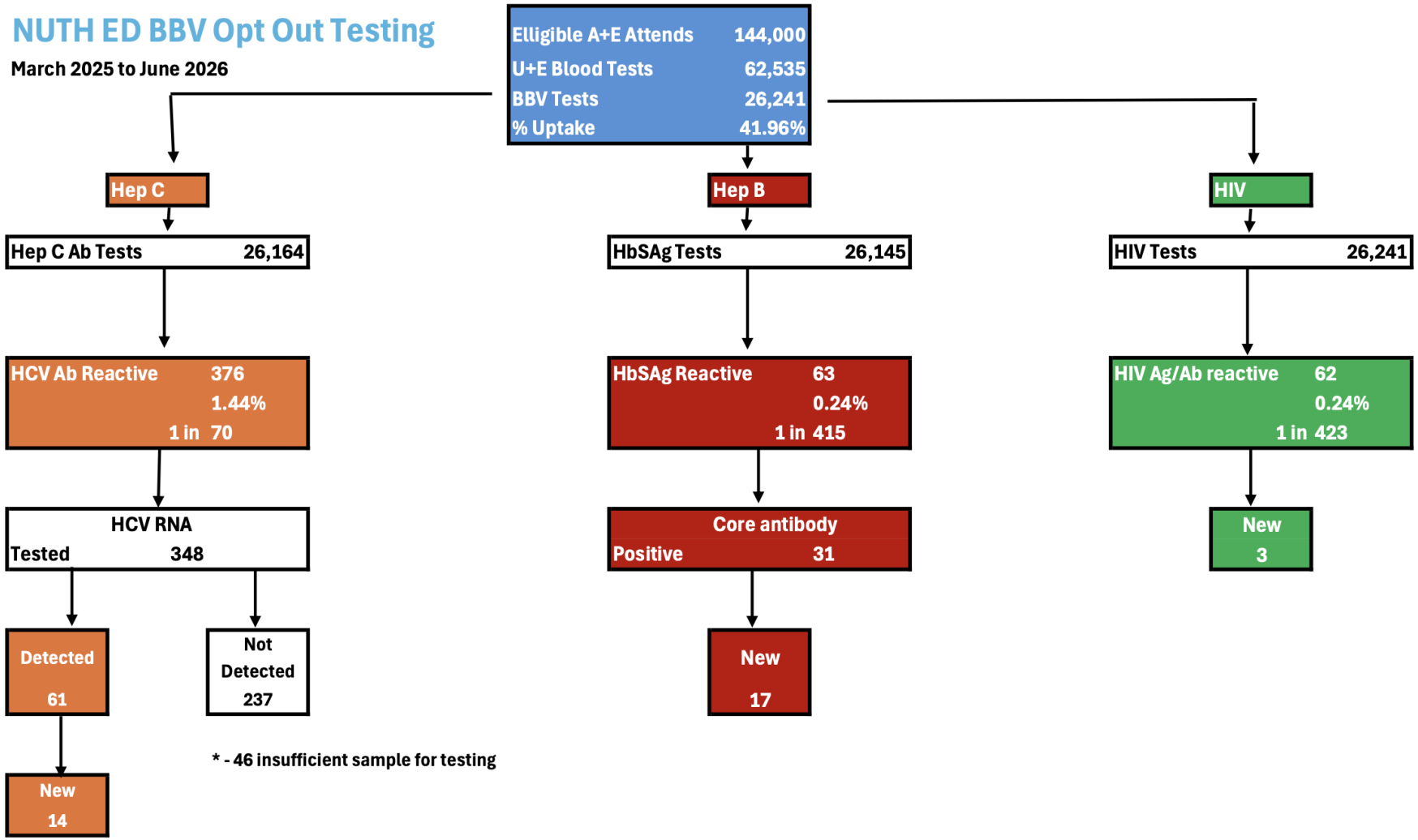
Laboratory

Result management

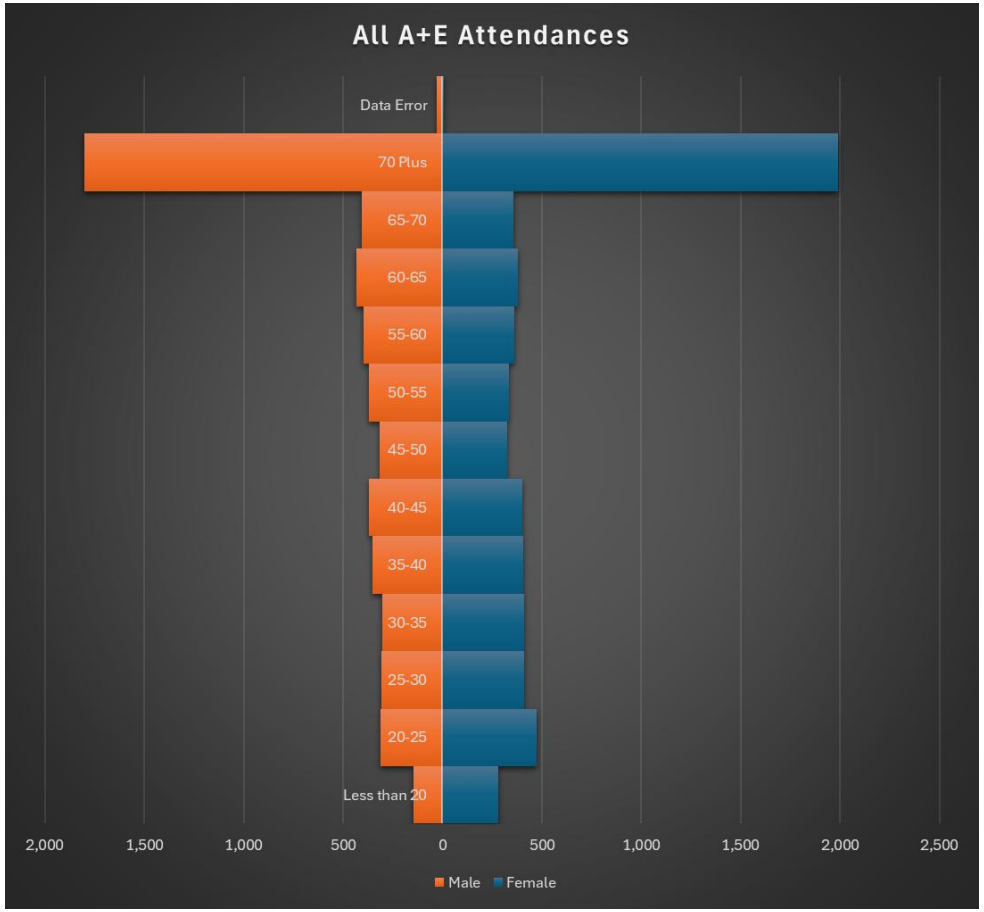
Patient identification and linkage to care

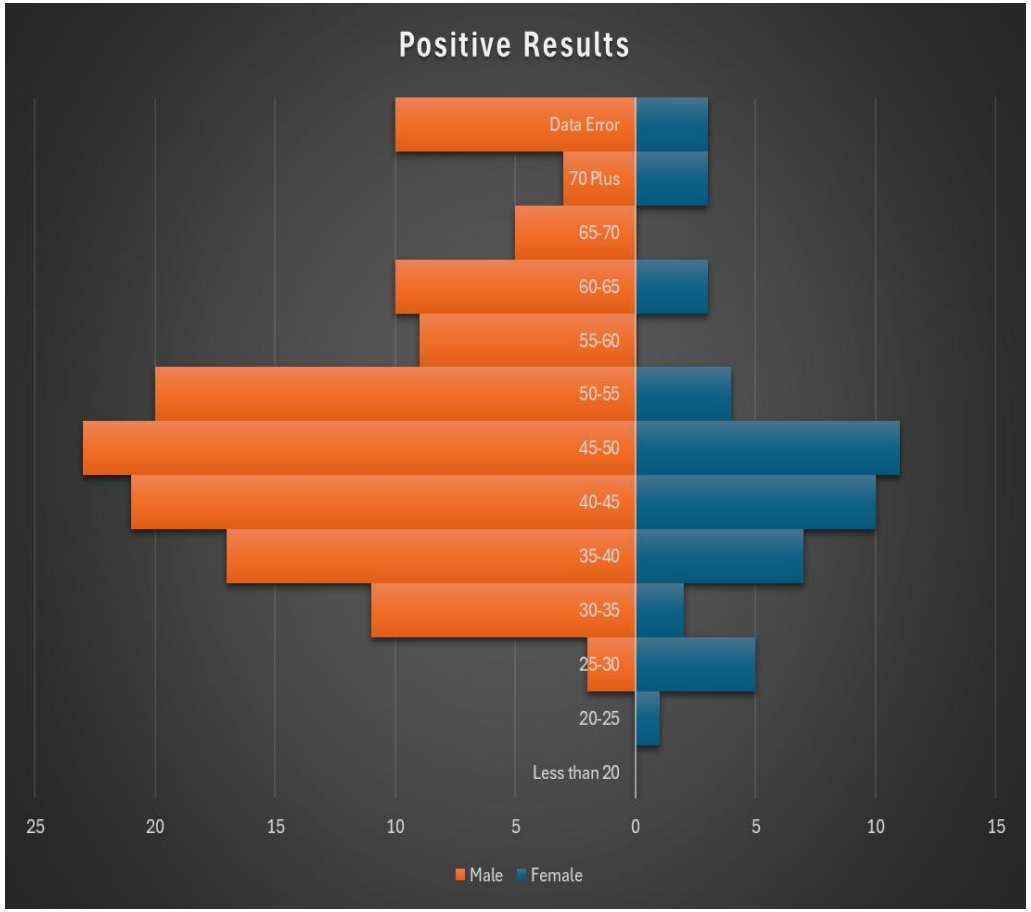
NUTH ED BBV Opt Out Testing

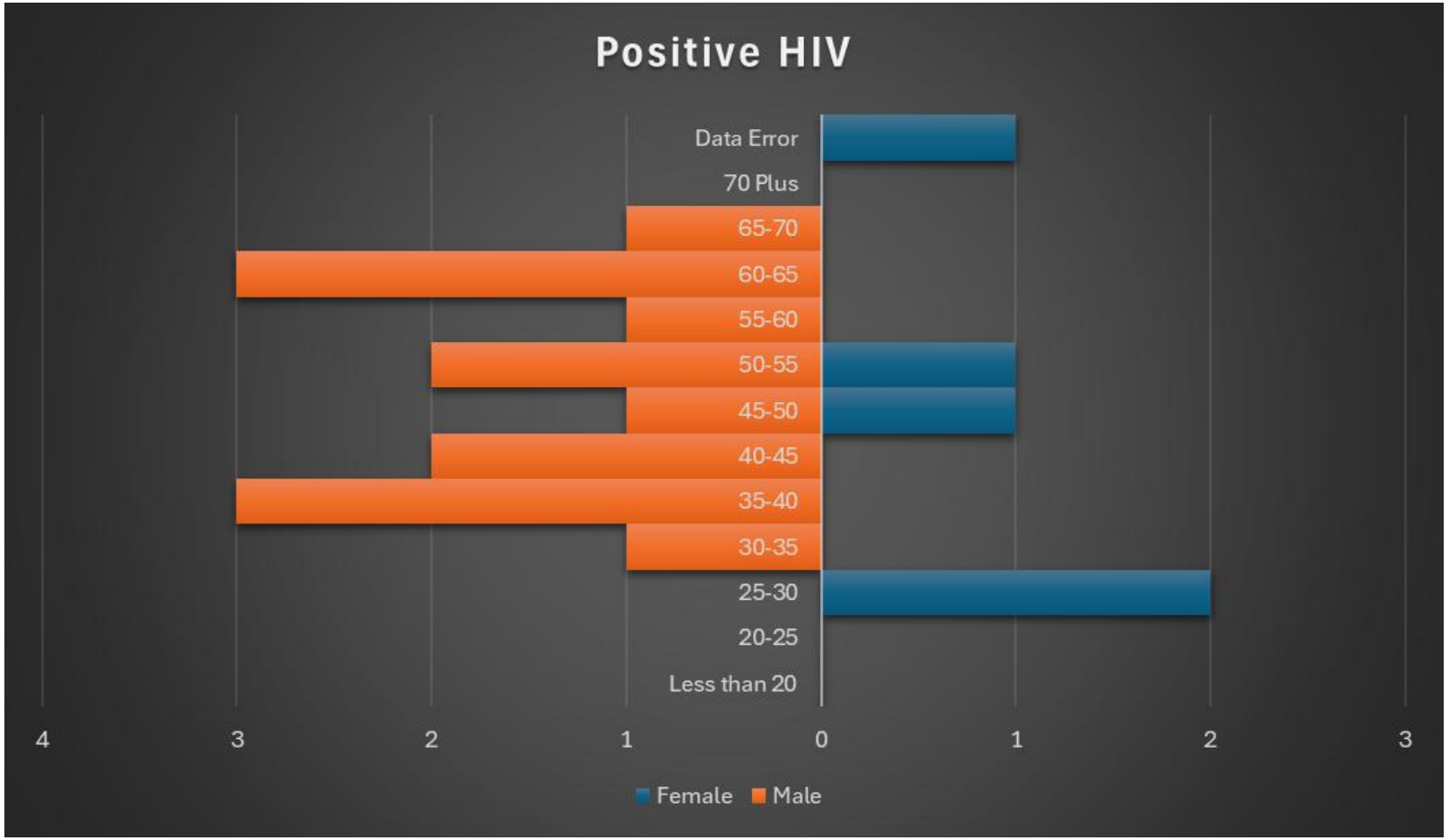
March 2025 to June 2026



* - 46 insufficient sample for testing


All A+E Attendances
Data Error
70 Plus
65-70
60-65
55-60
50-55
45-50
40-45
35-40
30-35
25-30
20-25
Less than 20
2,000
1,500
1,000
500
0
500
1,000
1,500
2,000
2,500
Male
Female


Positive Results
Data Error
70 Plus
65-70
60-65
55-60
50-55
45-50
40-45
35-40
30-35
25-30
20-25
Less than 20
25
20
15
10
5
0
5
10
15
Male
Female


Positive HIV
Data Error
70 Plus
65-70
60-65
55-60
50-55
45-50
40-45
35-40
30-35
25-30
20-25
Less than 20
4
3
2
1
0
1
2
3
Female
Male

Positive cases

1. Female brought in by ambulance with reduced GCS, treated for mixed overdose, left without providing details, not traceable.

2. Male with laceration brought into HIV care.

3. Male with and ITU admission.
Partner tested and also positive.
Both in HIV care.

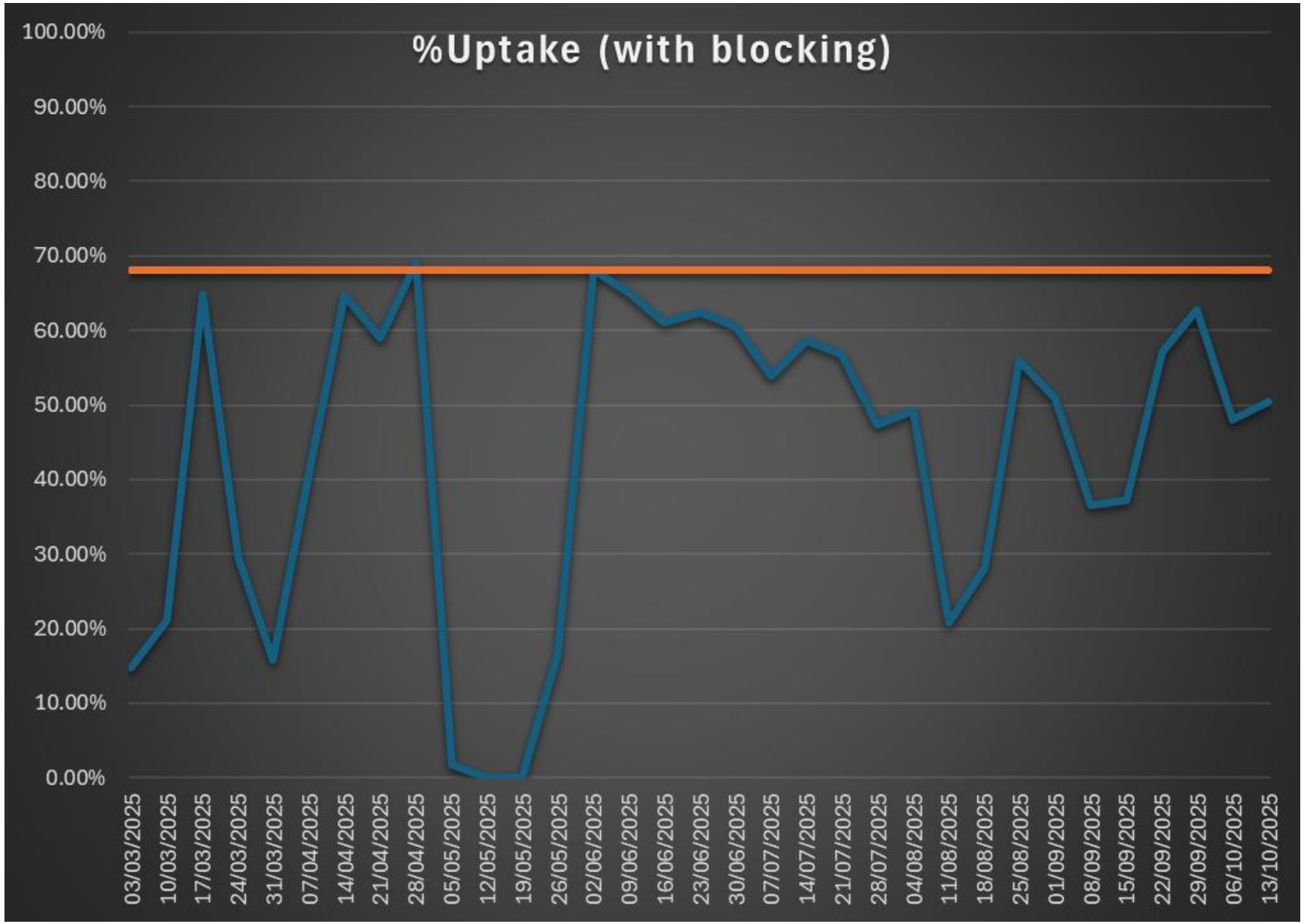
Belongs to a risk group

None had an indicator condition

```
     2022  19:45   Dried Blood Spot

Request Reason :

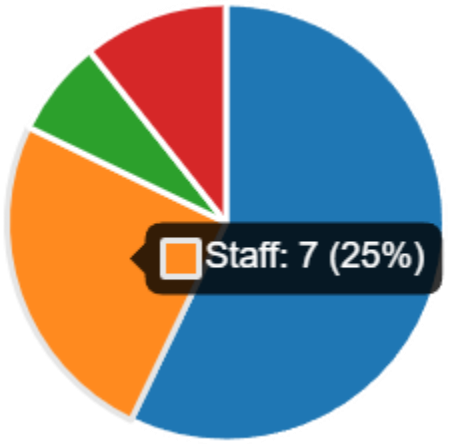
HIV 1+2 antibody/p24 antige    Insufficient specimen for testing        Auth
HEPATITIS B SURFACE ANTIGEN    Insufficient specimen for testing        Auth
HEPATITIS C ANTIBODY           Insufficient specimen for testing        Auth
```


%Uptake (with blocking)
100.00%
90.00%
80.00%
70.00%
60.00%
50.00%
40.00%
30.00%
20.00%
10.00%
0.00%
03/03/2025
10/03/2025
17/03/2025
24/03/2025
31/03/2025
07/04/2025
14/04/2025
21/04/2025
28/04/2025
05/05/2025
12/05/2025
19/05/2025
26/05/2025
02/06/2025
09/06/2025
16/06/2025
23/06/2025
30/06/2025
07/07/2025
14/07/2025
21/07/2025
28/07/2025
04/08/2025
11/08/2025
18/08/2025
25/08/2025
01/09/2025
08/09/2025
15/09/2025
22/09/2025
29/09/2025
06/10/2025
13/10/2025

Staff survey

Where will patients find information on ED BBV Opt Out?

Posters	16
Staff	7
Banners	2
Other	3



- 50% unaware of exclusion criteria
- 1:10 did not know implied consent
- 25% not aware of which blood test the BBV is attached to
- 19/20 aware of which blood tube required

Discussion

- Problems:
  - IT
  - Testing in ED
  - Samples and labels
  - Tests not done and eRecord

Future

- Funding for 2026-2027
- IT review
- Syphilis testing
- Increasing testing
- Lower prevalance areas?

Universal Opt-Out BBVS Screening in James Cook ED

David Chadwick

National ED (NHSE-funded) opt-out BBV testing programme April 2022 - April 2026

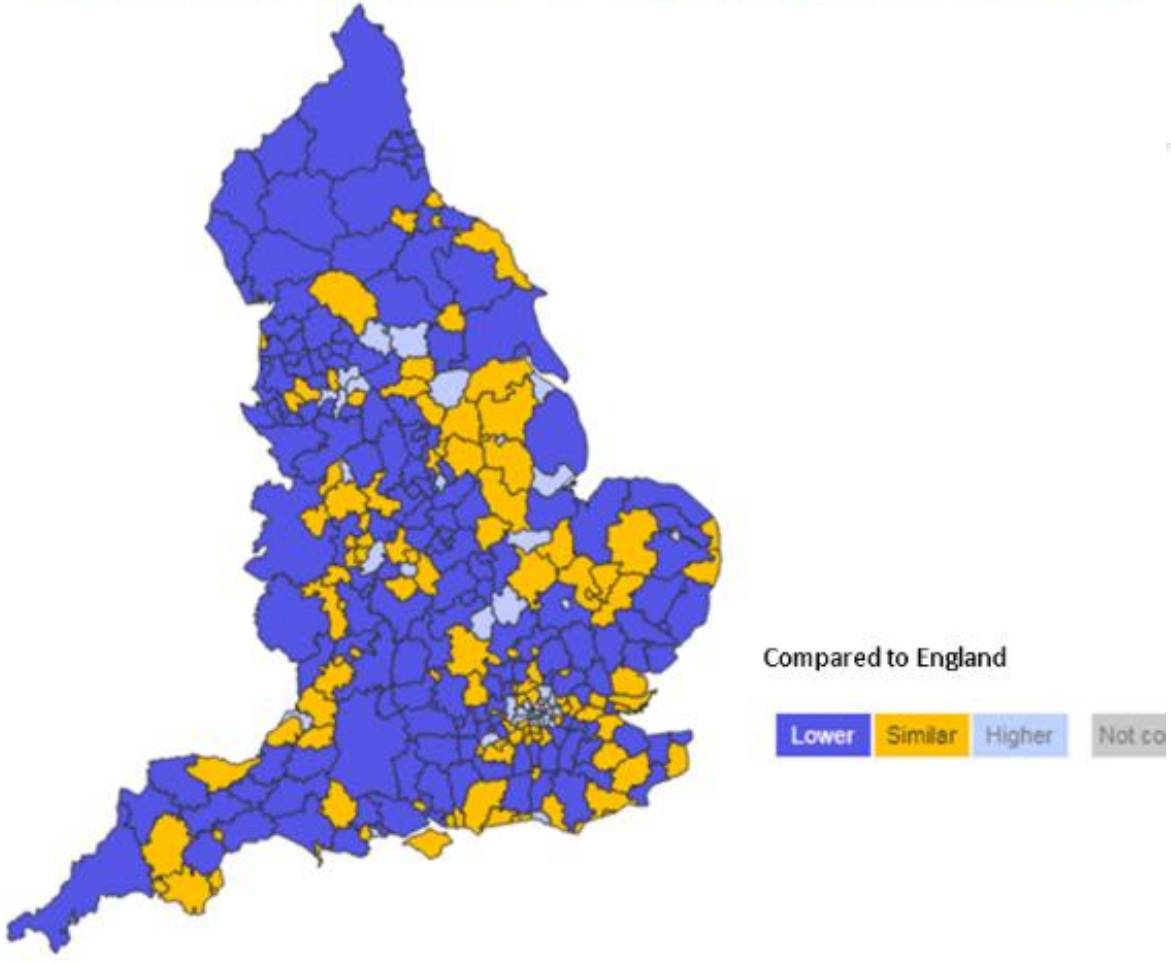
ED attendees (participating centres):	12.1 million
ED attendees with blood drawn*:	7.8 million
HIV tests:	6 million
HBsAg tests:	5 million
HCV Ab tests *(with reflex RNA if +):*	4 million

Originally 43 EDs (2022-2024) – just in v. high HIV prevalence areas - expanded to 84 EDs by this year with additional NIHR study looking at cost-effectiveness & patient experience…

** After blocking*

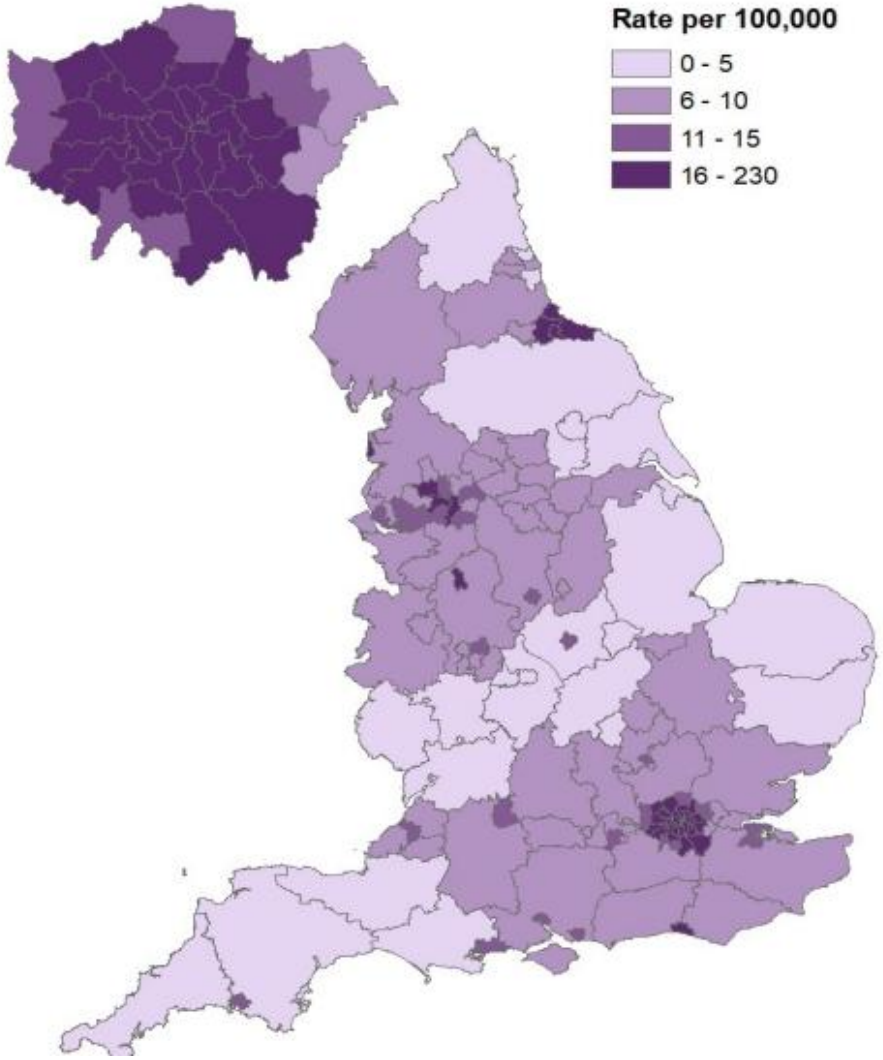
What about Teesside?

Figure 4: Map of chronic hepatitis C detection directly standardised rate,



Map of chronic hepatitis C detection directly standardised rate across Englis
and unitary authorities compared to England in 2016.

Figure 8. Rates of new infectious syphilis diagnoses made in sexual health services by Upper-Tier Local Authority (UTLA) of residence, 2019, England*



BBVS Screening Project at JCUH: Jan 2024 – July 2026

- **High prevalence of hepatitis C and syphilis in Teesside; moderate HIV levels**
- **Funding for scheme obtained from regional ODN & several other sources**
- **All adults aged 18-70 having blood taken in ED, who don't opt-out, tested for HIV, HBsAg, HCV IgG (+ reflex RNA) & syphilis via automated ordering on ICE pathology system; *hepatitis B screening stopped in October 2024; North Tees ED added late 2025, but some capacity issues in lab…***
- **HIV, HBV and HCV reactive results actioned by Centre for Clinical Infection team; for syphilis, positives referred to Teesside Sexual Health (regional SHS provider) – *now Teesside Together***
- **For pilot stage - main outcomes of interest: prevalence in ED population and linkage into care of new/out-of-care diagnoses - to justify cost-effectiveness of continued screening)**

Results **(up to May 2026)**

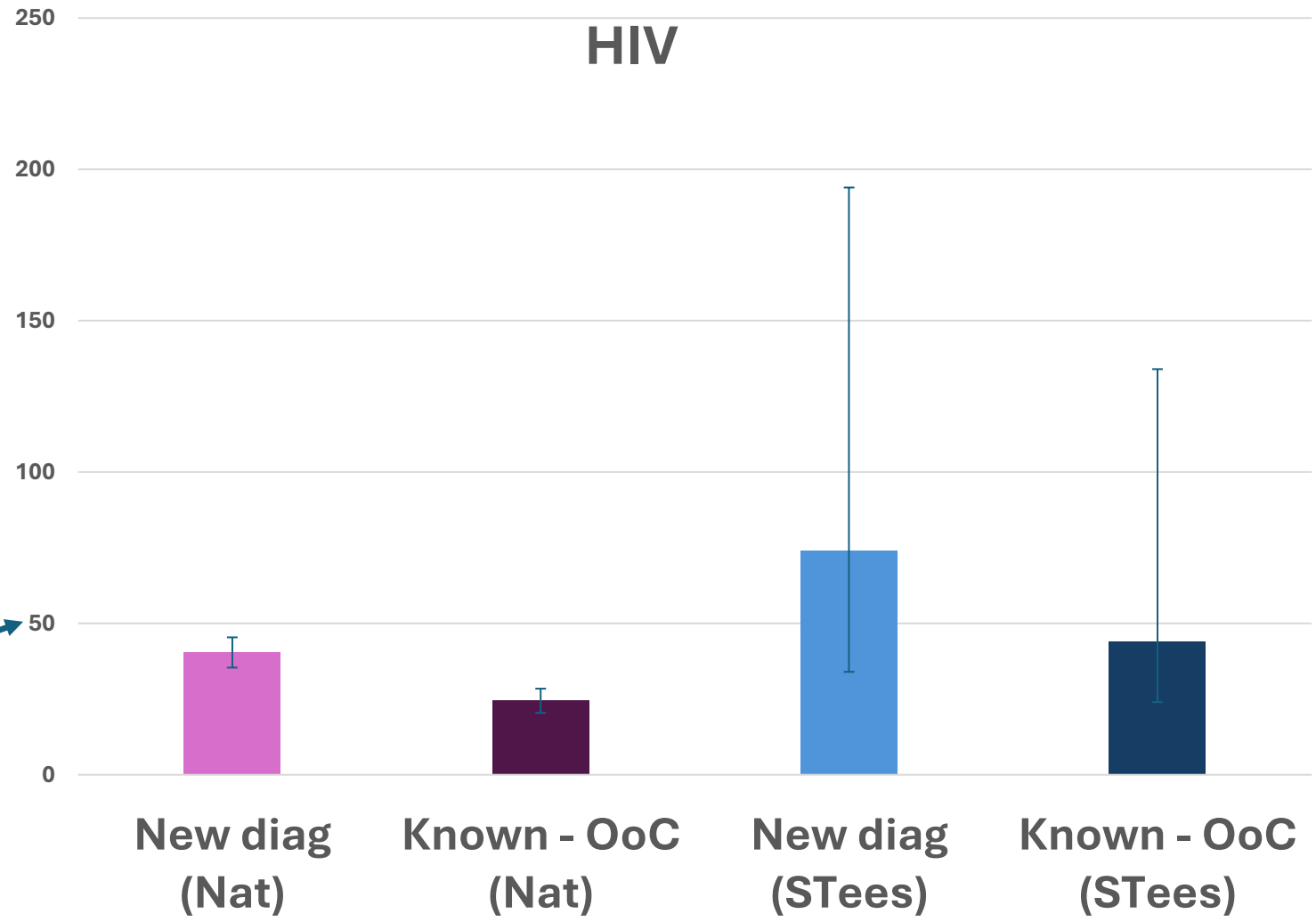
Number tested: 11,516 patients with valid tests

	Confirmed positive antibody/Ag tests	**Patients with new diagnosis *(or needing treatment for HCV/ syphilis)***
HIV	42 (0.33%)	7 (0.1%)
Hepatitis C IgG	274 (2.4%)	82 (0.8%)
RNA+	69 (0.6%)	
Syphilis	177 (1.7%)	81 (0.8%)

HIV (to late 2025)

- 42 reactive tests
- 29 confirmed positive, 13 indeterminate (all subsequently negative)
- 7 confirmed new diagnoses; 5 previously diagnosed – lost to care, 11 previously diagnosed – engaged in care
- 6 of 7 with new diagnosis engaged in care
- All new diagnoses PWH migrants to UK from Africa
- 3 male; 4 female; ages 22-56 yrs

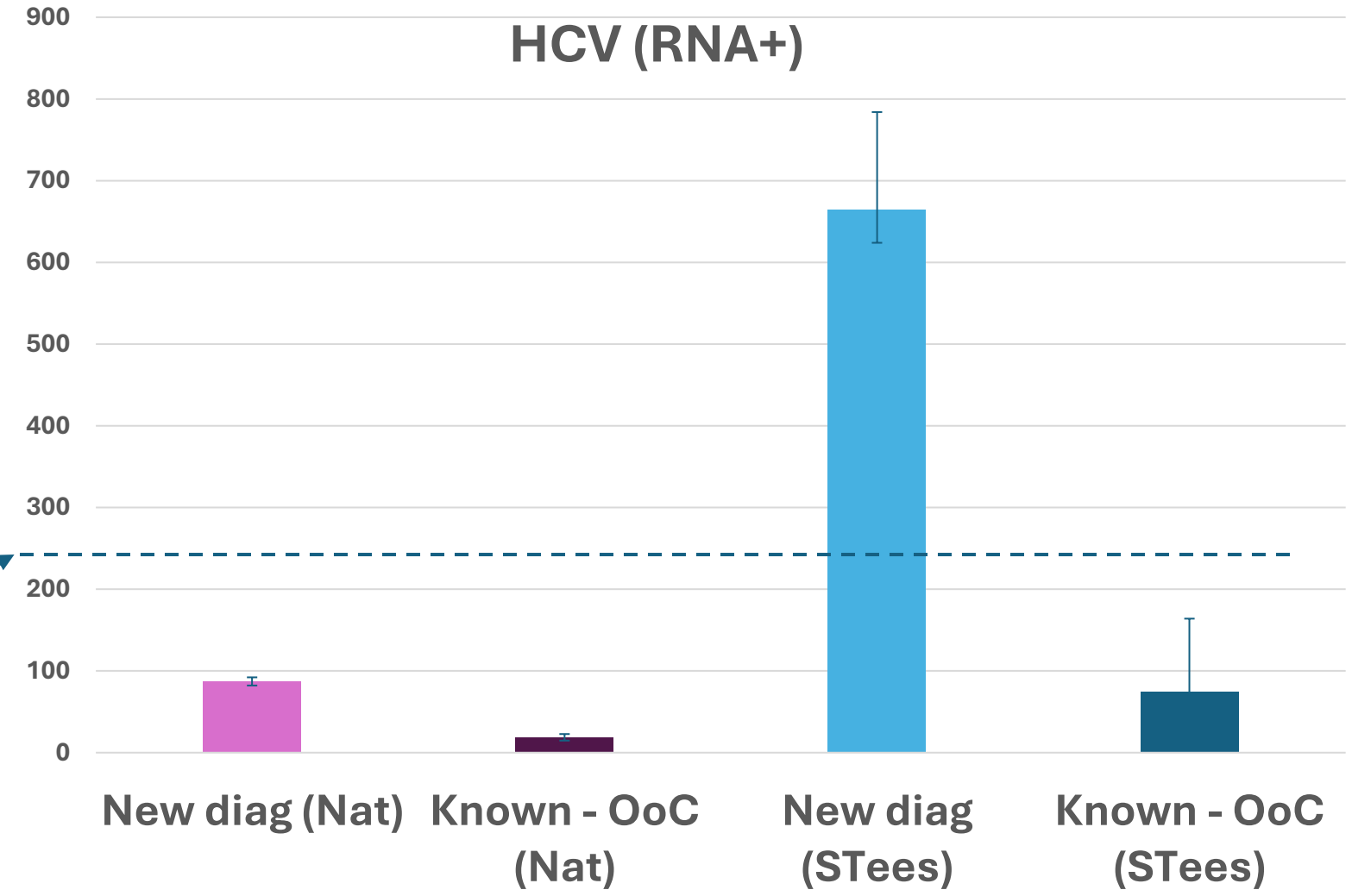
Comparison of South Tees ED and national ED programme (pooled means) for tests (rate positive per 100,000)



Prevalence above which screening likely to be cost-effective

Comparison of South Tees ED and national ED programme for HCV RNA+ tests

(rate per 100,000)



Prevalence above which screening likely to be cost-effective

Syphilis results

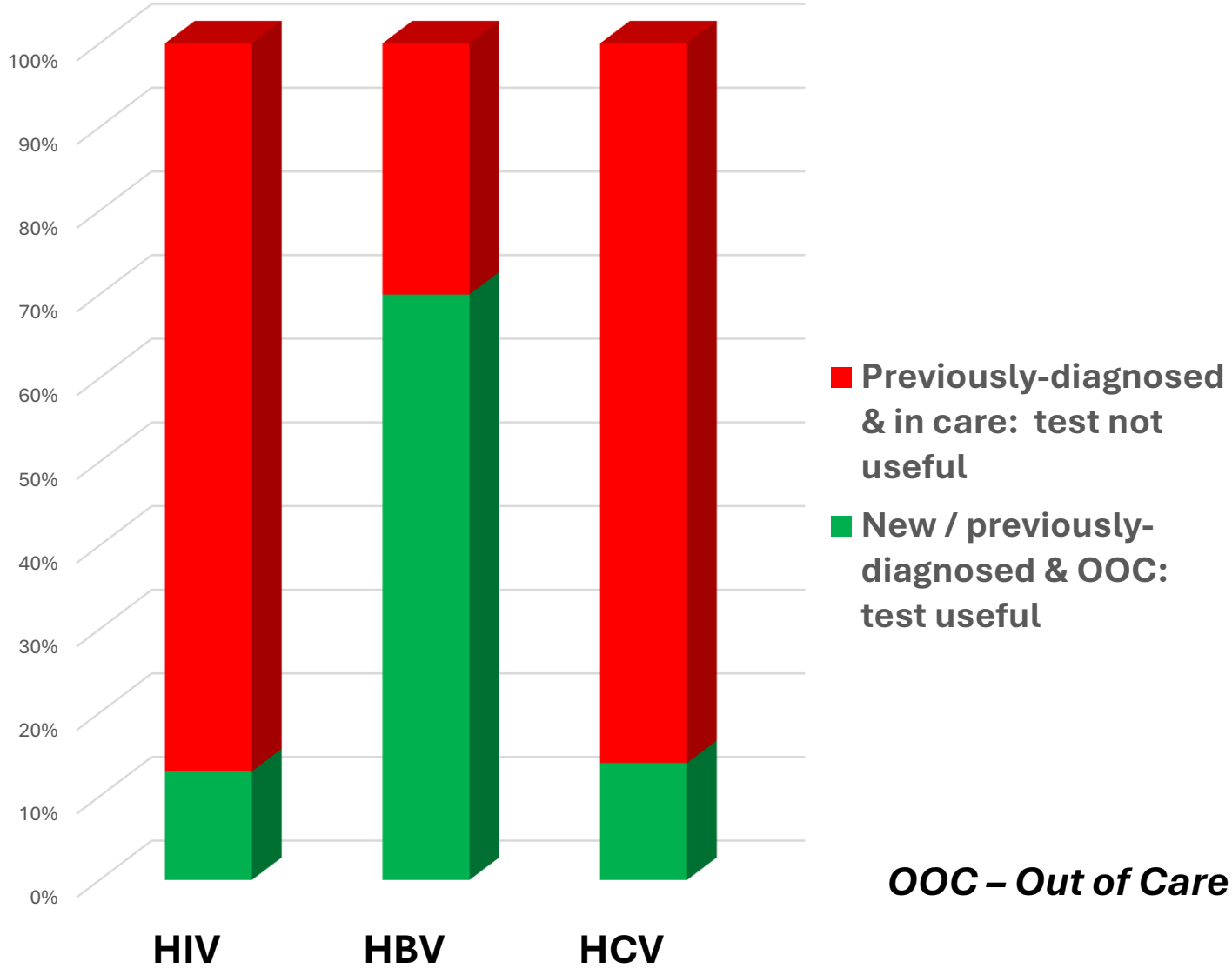
- 177 reactive tests
- 81 RPR + (hence likely to need treatment)
- Approx. 70% contacted and assessed for treatment (or not)
- Compared to people with syphilis diagnosed in SHS
  - More likely to be heterosexual (75%) and female (40%)
  - 95% white ethnicity
  - More likely to live in lower IMD Quintile areas

Summary

- Continued ED opt-out testing probably justified for HIV, HCV & syphilis for time being, particularly for latter two infections
- Inclusion of North Tees ED has extended reach of programme across Teesside
- Lab capacity remains an issue, especially with uncertain funding model i.e. doing a screening programme on a shoestring

NHSE ED opt-out Screening 2024: breakdown by category

Are there other options for testing/screening?

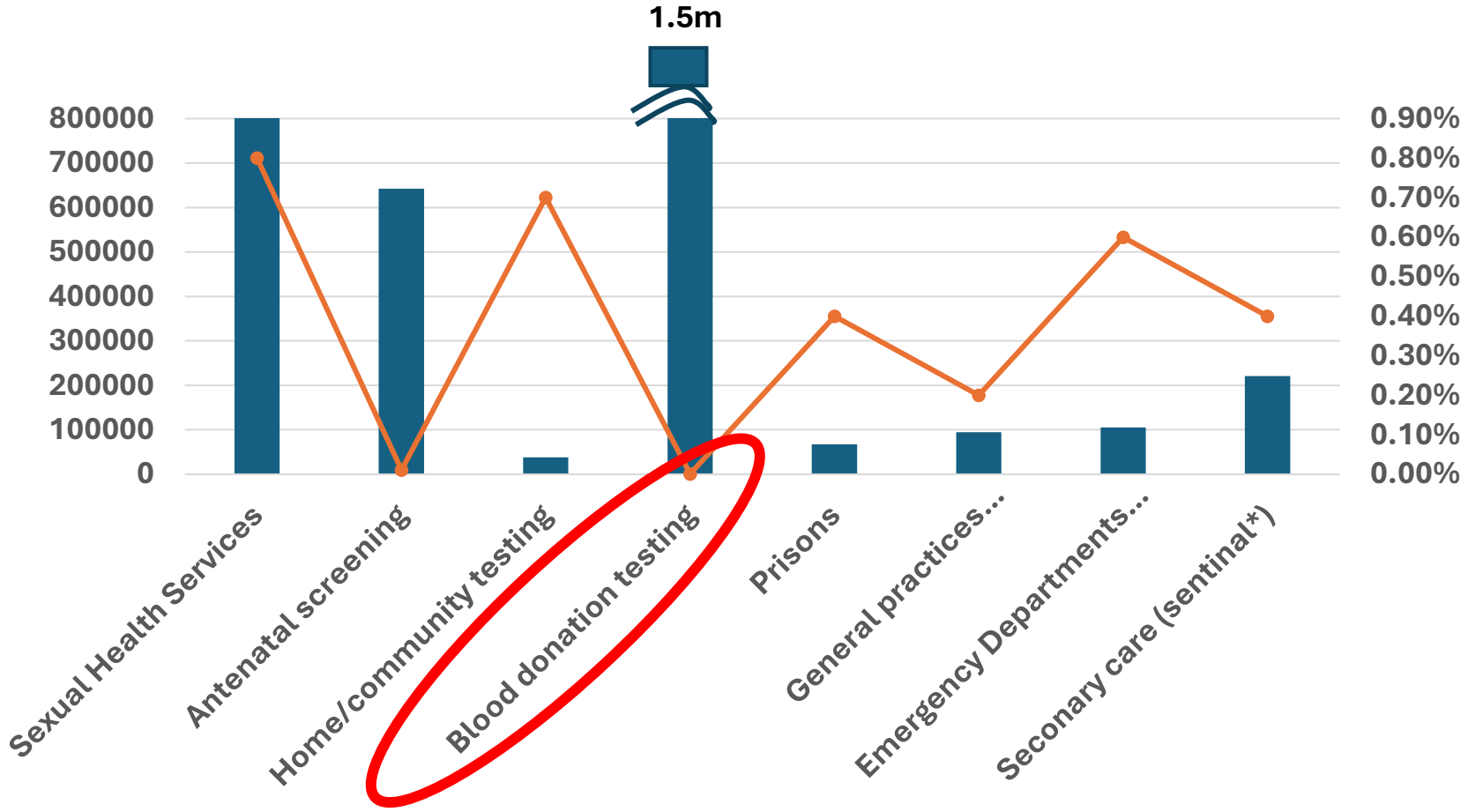


OOC – Out of Care

Challenges with sustainability of current ED testing programme

- **Cost of BBV tests:** ***currently £10.50 paid to labs for each person tested for 3 BBVs; real cost possibly higher…***
- Preventing re-testing ('blocking') – *IT/EPR systems*
- Workload locally – handling reactive results including chasing tests from patients with known BBVs – *e.g. HCV IgG+, insufficient sample for HCV RNA….*

Annual numbers of HIV tests done in UK & proportion positive across various services



NHSBT BBV Screening of blood products

- Initial NAT (Roche triplex) plus HBsAg
- If reactive – confirmatory (antibody) tests ‘in house’
- Result sent to GP...

NAT vs EIA-based BBV screening

	Advantages	Disadvantages
EIA-based (current standard)	**Tried and tested technology** Done in all Virology/Pathology labs Potentially rapid results	Usually not fully-automated **Cost**
NAT (+/- pooled)	**Cheaper (*with optimised pooling*)** Only picks up 'active'/ untreated BBV infections – less positives to process *Possibility of automated mass testing regional labs* – takes pressure off local lab **Can pick up early seroconversions** Possibly less indeterminates and false+	**Misses some patients – e.g. HIV elite controllers, HBV (low DNA)*** Costs associated with sample transport Batching - hence ? slower results Will need change in messaging in EDs – re. screening system

** Roche Triplex LLD for HBV DNA 4 IU/mL – hence if using pools of 12 or 24, LLD becomes 48 IU/mL and 96 IU/mL respectively (approx. 10-15% of PWHBV not on treatment have HBV DNA <100)*

Current System for ED BBV Screening

ED





Serum tube sent to local lab

Local Pathology Lab – BBV testing with antibody/antigen tests



Result sent

Local Department e.g. ID; SHS; hepatology…



Results management

Negative results – no action; Positive result – trace patient for confirmation blood tests (if not known to service) or make contact if known and out of care

Alternative System for NAT-based BBV Screening

ED





EDTA tube sent to regional lab, via standard daily runs to NHSBT

Regional NHSBT Lab e.g. Manchester – pooled NAT tests



Result sent

Reporting: result sent (via Labgnostics software)

Local Department e.g. ID; SHS; hepatology…



Results management

Negative results – no action; Positive result – trace patient for confirmation blood tests (if not known to service) or other actions if known to service

Proposed feasibility study (late 2026/2027)



ED1

ED2

ED3

ED4

Local Pathology Lab



Regional NHSBT Lab e.g. Manchester – pooled NAT tests



Reporting: result sent (via Labgnostics software)



Local Department e.g. ID; hepatology…

EDTA tube sent directly (after sample logged) to NHSBT within 72 hours – using same established transport system for other NHSBT samples; ***Still need serum tube sent to local lab – as per normal process***

What are the aims of the feasibility study?

1. **Establish operational feasibility in 4-6 sites – i.e. whether the NAT testing system works**

2. **Assess frequency/clinical impact of discordant results (between standard tests and NAT tests), in terms of case ascertainment**

3. **Determine acceptability of NAT screening process to patients (attending ED) and clinical staff – Tom May (Bristol University)**

4. **Evaluate cost-effectiveness of NAT screening – *Josephine Walker, Peter Vickerman (Bristol University)***

TREAT: HIV treatment and care

Amanda Madine

Assistant Psychologist, Newcastle upon Tyne Hospitals NHS FT



A 12-month evaluation of a new Out of Care Pathway in the HIV Service at NuTH NHS Foundation Trust

By AMANDA MADINE

Background and rationale



OUT OF CARE
A person living with HIV that has not attended an HIV clinic appointment for > 12 months

1) To reduce inequitable care within our service
2) To reduce the rates of onward transmission in line with national and global initiatives

BECAUSE:

Patients who are lost to follow-up (OOC) compromise their own health and the long-term success of ART programs.

(Berheto a et al., 2014)

WHO 95-95-95 objectives – there is a local, national and global focus on preventing patients from becoming OOC

(World Health Organisation, 2022)

WE MUST:

Reduce the rates of Out of Care patients

TO ENSURE:

- Reduction in the rates of onward transmission
- Reduction in the number of people presenting when they are very unwell
- Inequalities in access and outcomes are addressed

Health inequalities



White Gay and Bisexual men: Testing has increased and diagnoses have decreased

Gay and Bisexual men from Asian and other ethnicities: Diagnoses have increased

Women: Less likely to be offered HIV testing, lower test uptake, more likely to have a late diagnosis

Black African backgrounds: Over representation in terms of HIV diagnoses (54%)

(UK Health Security Agency, 2025)

UK Out of Care Demographics



Age
?

Gender
?

Black
populations

Addressing inequalities: How does this present locally?

Aims of the pathway



In accordance with British HIV Association (BHIVA) guidelines (Standards of Care for People Living with HIV, 2018), the aims of the pathway were:

AIMS OF THE PATHWAY

- Standardise how patients that DNA are managed and followed up
- Identify patients that are 'at risk' of becoming OOC and prevent disengagement
- Re-engage patients who have become OOC
- Establish a range of outcomes to better understand the OOC cohort locally (how many people DNA, how many re-engage, and demographics.)

Aims and Method



A service evaluation was conducted using descriptive statistics to analyse a range of data from the first 12 months of the pathway, to determine:

1. Who is most likely to be at risk of becoming OOC within our local cohort?

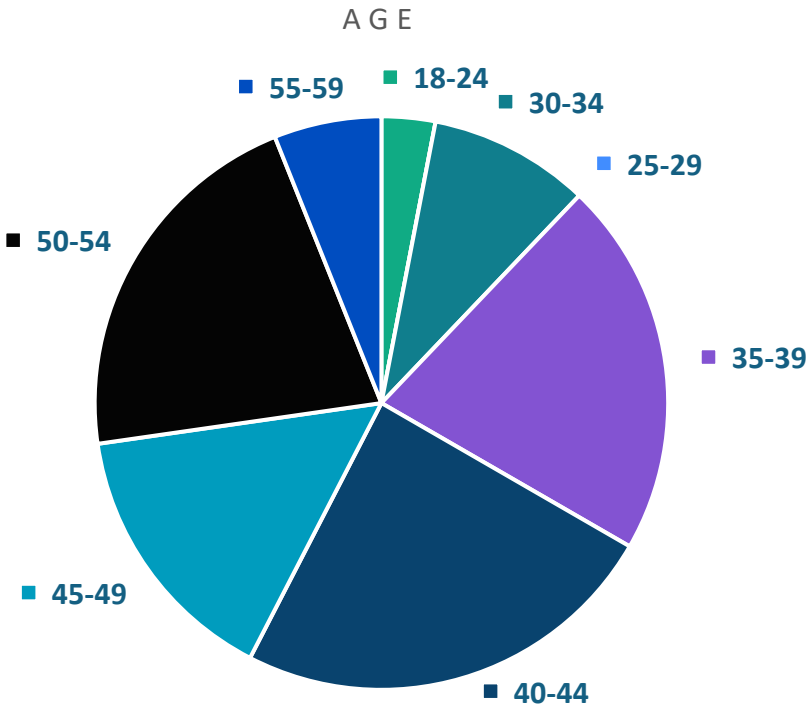
2. Outcomes of patients who are 'at-risk' of becoming OOC (patient outcomes)

'AT-RISK' OF BECOMING OUT OF CARE

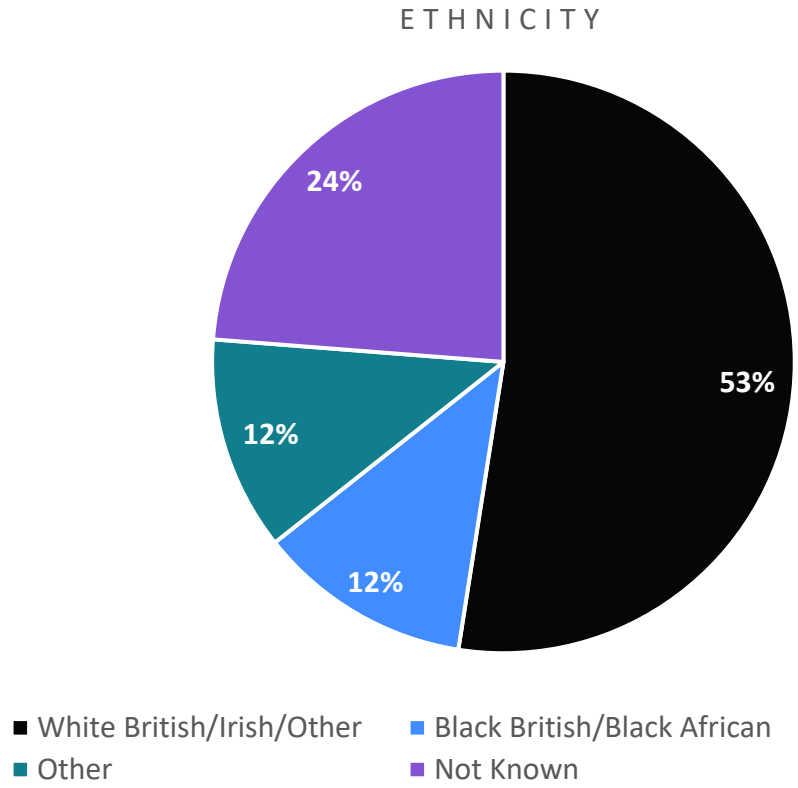
Patients were considered 'at-risk of becoming OOC if they had not re-booked a missed clinic appointment within 12 weeks of non-attendance

1. Who is most at risk of becoming OOC in our local cohort? (August 2024-August 2025)

Ethnicity: **White British/Irish/Other** - Gender: **Male** - Age: **40-59**

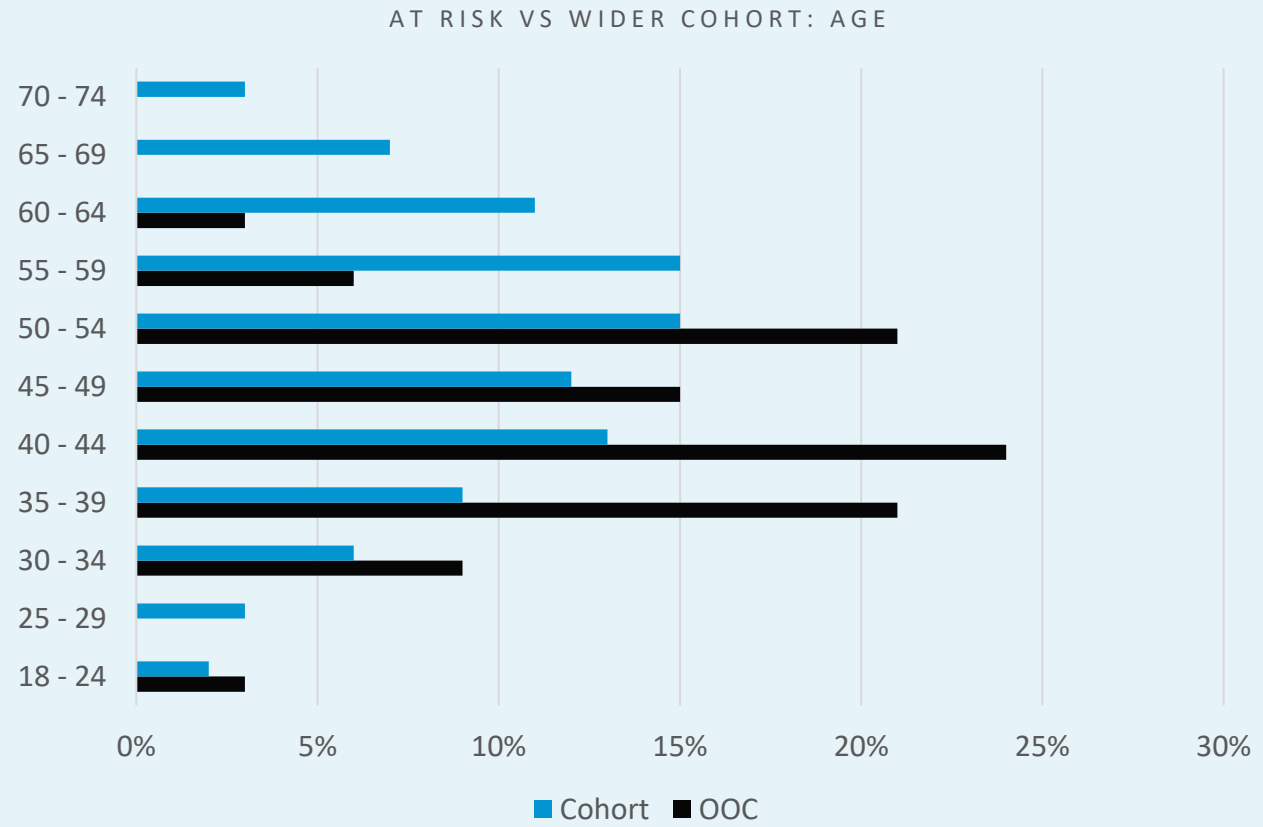


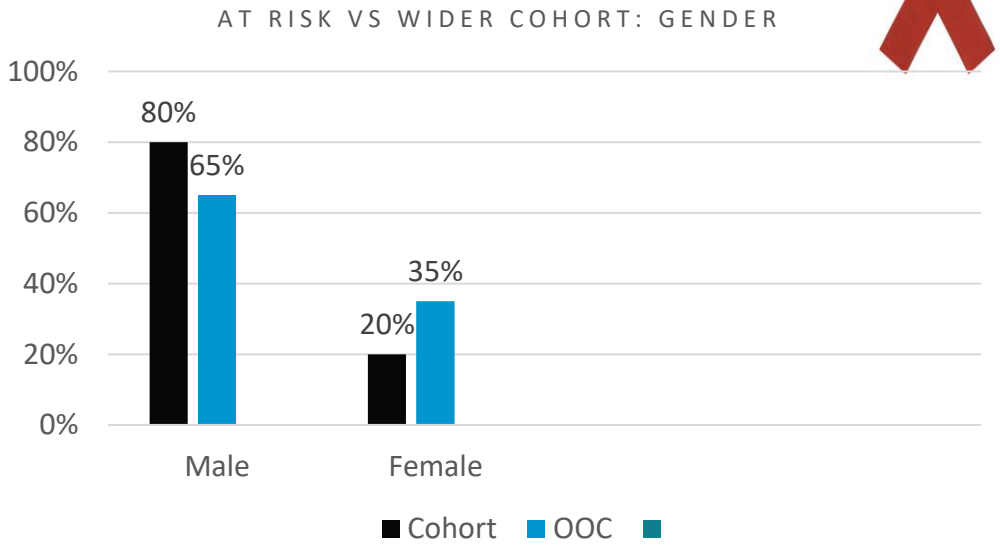


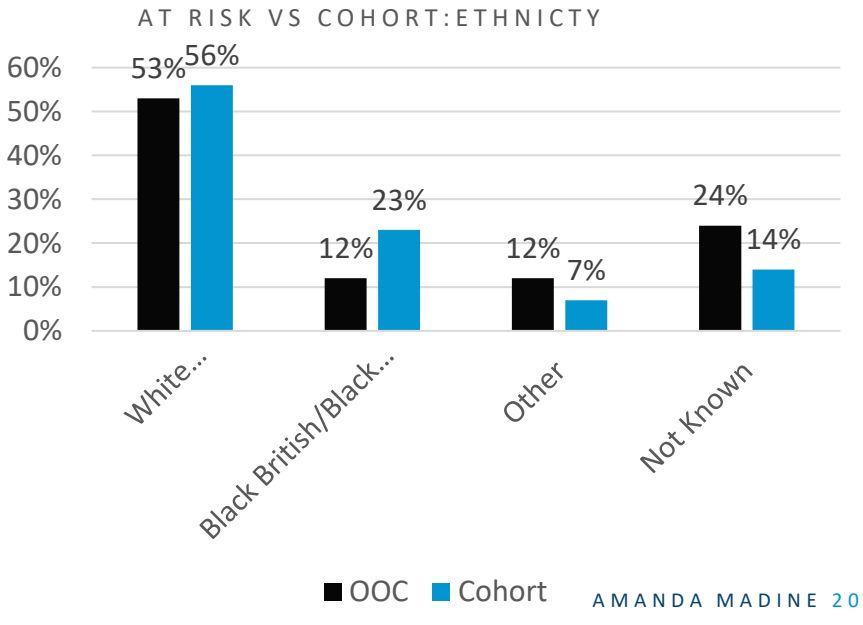


Mean = **44.24**, Standard Deviation: **7.81**, **65%** of patients aged between 40 and 59 years old

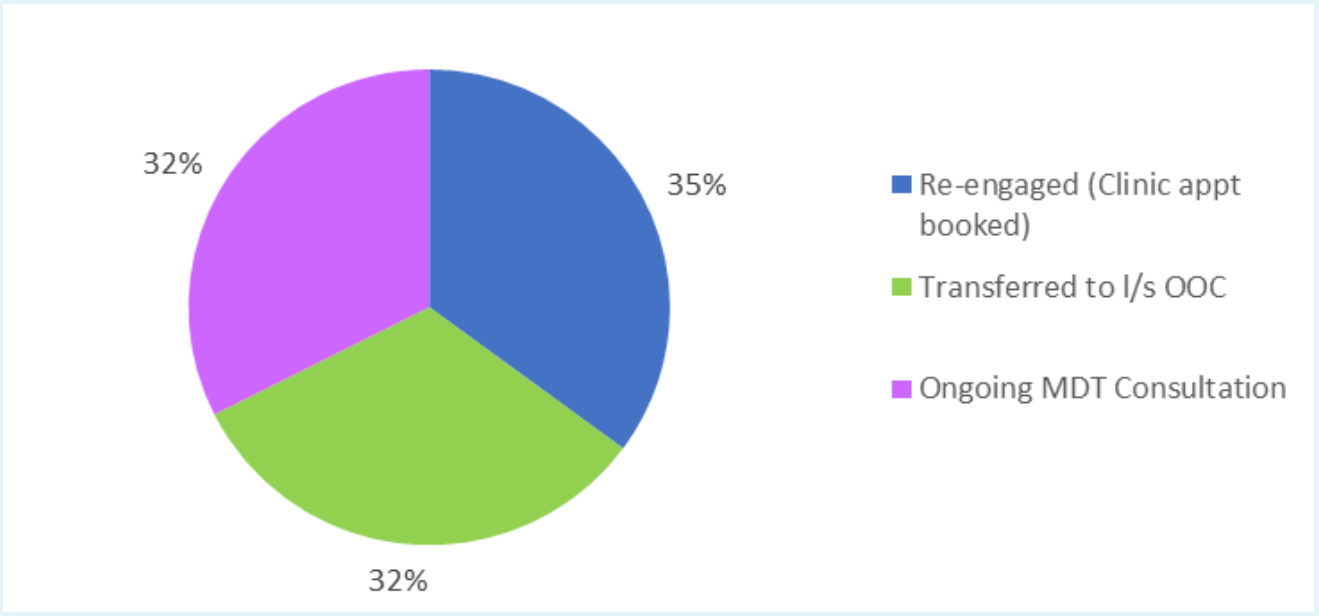
Sample representativeness





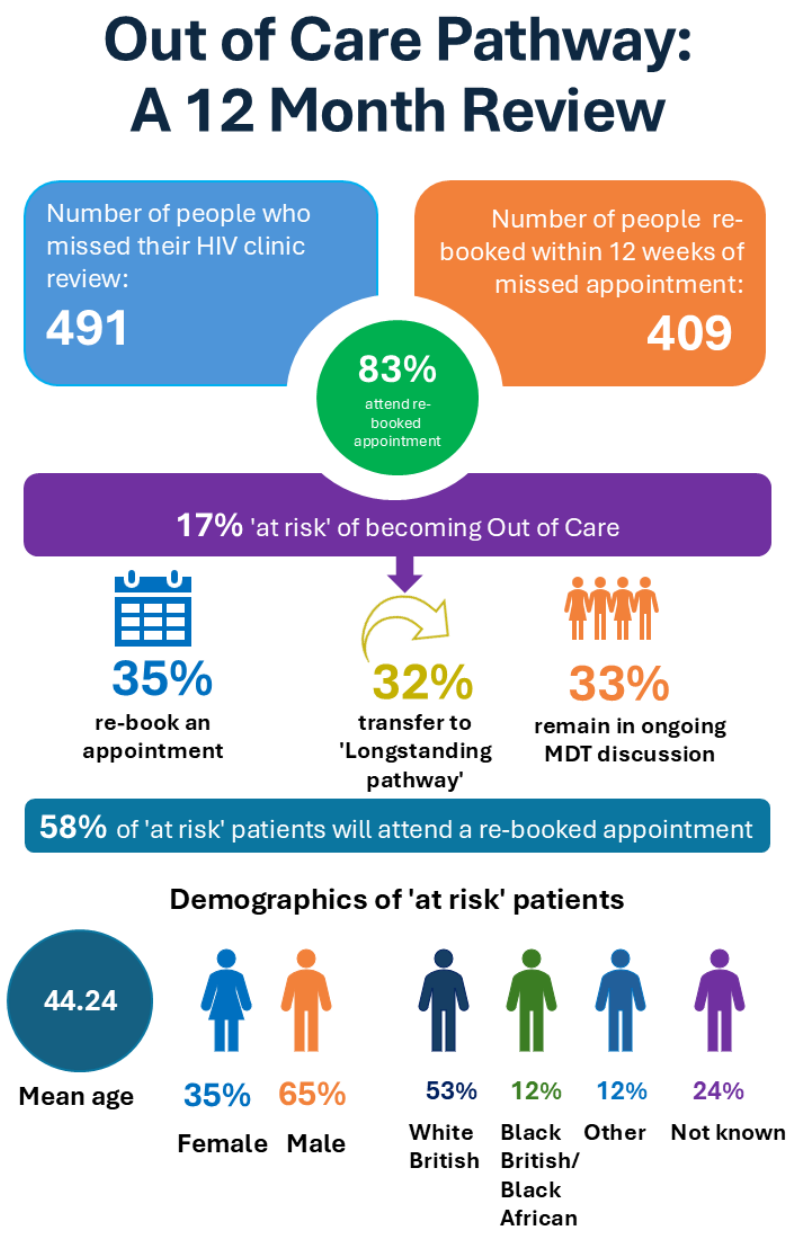


2. Outcomes of patients 'at risk' of becoming OOC (August 2024-August 2025)



Patients that attended a re-booked appointment: 58%

Summary of results



Service implications and next steps



Improved equity – our established pathway can now tell us specifically who is at risk of becoming OOC and we have a standardised procedure for monitoring and tracking these individuals

- Why?
- Next step – Qualitative research
- Then – address systemic barriers and co-develop effective engagement strategies

Dissemination:

BHIVA national conference, MDT, service user representatives, local and regional committee groups

Reflections on Equality, Diversity, and Inclusion



- Shift from individual non-engagement narratives to focus on systemic barriers
- Importance of considering local cohort when setting up services
- We know who our 'at risk' patients are; but are there further discrepancies in outcomes? Are we inadvertently furthering health inequalities?
- Limited demographic data considered
- Service user representative involvement
    - Assumption of homogeneity
    - Consulted, but not co-developed
- Inaccessibility of research within populations that services have difficulty reaching – inequalities are perpetuated
- Contribution to the evidence base

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More people with HIV in England have dropped out of care than remain undiagnosed | aidsmap

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full-final-who-ghss-hiv-vh-sti_1-june2022.pdf



Thank you and any questions?

MANDY MADINE

THRIVE: HIV stigma and quality of life

Helen Anderson & Matt Thornton

Chief Executive & Peer Support Worker, Blue Sky Trust

Tony & Lucy

Advocates, Blue Sky Trust

Anthony Young

Service Manager, Terrence Higgins Trust Teesside

THRIVE: Stigma & Quality of Life

Helen Anderson, Chief Executive
Lucy, Advocate
Tony, Advocate
Matt Thornton, Peer Support Worker

Zero HIV Transmission and Zero Stigma, 2026

Regional stigma subgroup

Bringing together stakeholders to strategically tackle stigma

- Set up Lived Experience Reference Group in North
- Supporting set up of Fast Track Cities Newcastle

153

Eyes Open: Public Attitudes Survey

- 25% know nothing about HIV
- 42% think can pass HIV on with undetectable viral load
- 29% wouldn't feel comfortable working with someone with HIV
- 31% wouldn't feel comfortable having a close friend with HIV
- 77% never had an HIV test

Improve knowledge across sectors

- Raised awareness of HIV & stigma at 2 Drug & Alcohol services
- Supported HIV CONFIDENT & similar initiatives
- Co-delivered a webinar : BBV stigma, trauma & impact on retention in care
- Shared updates at 4 GP time out events
- Guide to free HIV resources & training
- Regional Directory of services

HIV Action Plan for England 2025 to 2030

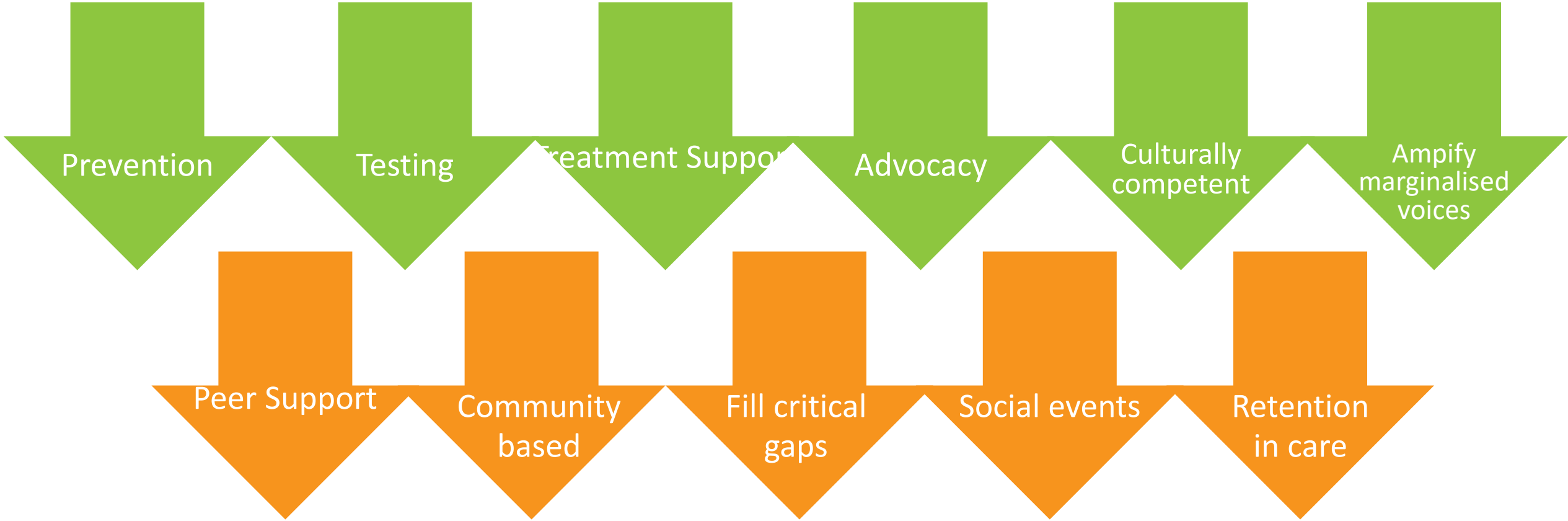
Thrive

TRAINING	Ensure all health & social care staff receive training on HIV awareness, stigma reduction & inclusive care. Scale up HIV Confident Charter & similar initiatives
HOLISTIC INTEGRATED SUPPORT	Commissioned, integrated person-centred support services to improve **quality of life, especially for those living into older age and individuals with complex needs. Address structural inequalities and discrimination within health services, employment, housing & society. Support changes to national guidance & commission services such as peer support & chronic disease management**
WOMEN	**Ensure all women living with HIV are supported to manage their needs through tailored care pathways & peer support**

HIV Action Plan for England
2025 to 2030

“A strong voluntary sector remains vital”

“They are key partners in ending transmissions and enabling people with HIV to thrive”



HIV Services at the Crossroads, NAT – precarious position of HIV voluntary sector


Healthy living
Peer Support
Alcohol
Hate Crime
Mental Health
Stigma
Appointments
Domestic Violence Discrimination
Healthy living
Peer Support
Debt
Stigma
Chemsex
Friendships
Advocacy
Mental Health
Nutrition
Hate Crime
Relationships
Adherence
Chemsex
Appointments
Family
Housing
Learning about HIV
Nutrition
Stigma
Alcohol
Advocacy
Work
Housing
Learning about HIV
Work
Peer Support
Debt
Advocacy
Benefits
Adherence
Housing
Housing
Benefits
Work
Mental Health
Alcohol
Navigating systems
Treatment
Navigating systems
Peer Support
Disclosure
Hate Crime
Chemsex
Nutrition
Advocacy
Benefits
Chemsex
Mental Health
Benefits
Friendships
Debt
Drugs
Family
Grief
Relationships
Benefits
Stigma
Friendships
Alcohol
Debt
Navigating systems
Adherence
Advocacy
Housing
Mental Health
Stigma
Drugs
Peer Support
Peer Support
Disclosure
Discrimination
Appointments
Benefits
Grief
Discrimination
Appointments
Relationships
Relationships
Disclosure
Discrimination
Advocacy
Debt
Family
Mental Health
Family
Peer Support
Healthy living
Grief
Family
Learning about HIV
Advocacy
Mental Health
Disclosure
Learning about HIV
Chemsex
Treatment
Discrimination
Treatment
Relationships
Disclosure
Benefits
Debt
Self Stigma
Disclosure
Benefits
Relationships
Housing
Appointments
Work
Debt
Navigating systems
Debt
Friendships
Drugs
Self Stigma
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Alcohol
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Alcohol
Appointments
Housing
Appointments
Adherence
Learning about HIV
Domestic Violence
Chemsex
Adherence
Treatment

Our Values: Kindness | Individuality | Integrity | Excellence | Collaboration

blue sky TRUST

Support & empower people living with HIV

Educate Key Communities

Educate Professionals & Organisations

System-Wide Collaboration Driven by Lived-Experience Insight

Our Activites

Peer Support
Advocacy
Living Well Programmes
Volunteer opportunities

HIV education at community events & organisations

Involvement of people with lived experience

Improved workforce confidence & knowledge

Improve services & workplaces for people living with HIV

Improved system wide collaboration & impact

Increased involvement of people living with HIV

Our Outcomes

- ↑ Health & well-being
- ↑ Engagement in care
- ↑ Increased confidence, knowledge & skills
- ↓ Reduced isolation & self stigma

- ↑ Awareness of HIV
- ↓ Fear & stigma
- ↑ Access to sexual health services, prevention & testing

- ↑ Awareness of HIV
- ↓ Stigma & discrimination
- ↓ Non-stigmatising policies & practices

- ↑ Lived experience shaping the sector
- ↑ Equitable joined up care pathways
- ↑ System wide collaboration

People with HIV thrive



Communities are HIV aware



Services are stigma free



Strong HIV Sector shaped by lived experience



Thriving HIV community | Zero stigma | Zero new HIV infections and AIDS


Lucy

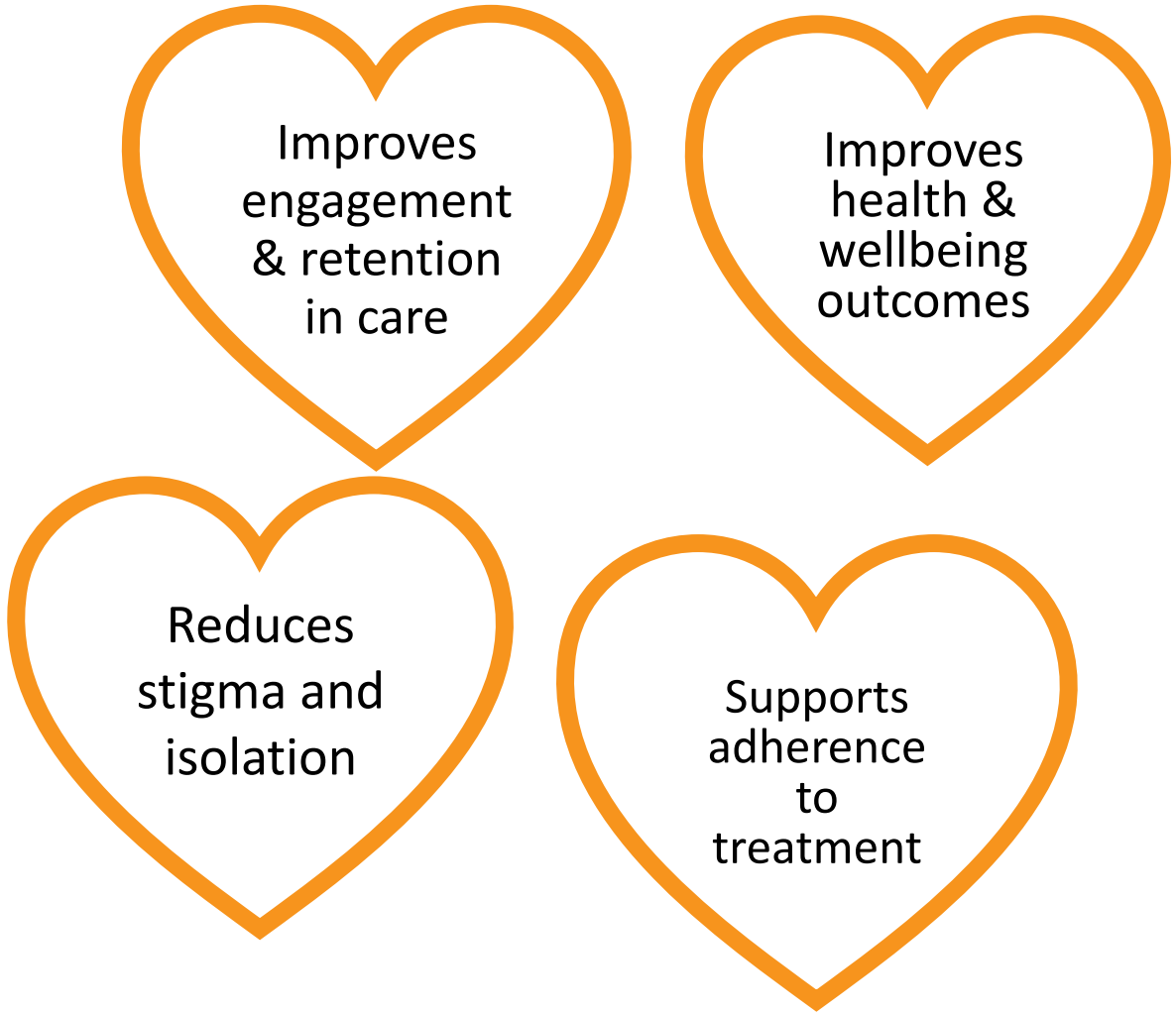
Peer Support

BHIVA Standards of Care:

Peer support should be…

- Embedded as a routine part of care pathway & offered at diagnosis unless the person opts out
- Integrated into clinical care
- Equitably available to all
- Delivered in partnership with VCSE organisations

Structured peer support ….



In Clinic Peer Support

What Does It Look Like?

- A Blue Sky Trust staff member is based in the RVI for 2 clinics a week,
  - Supported by a team of volunteers with a wide range of backgrounds and lived experiences.
- People living with HIV offered to meet peer mentor during their clinic appointments.
- If beneficial, the patient can be referred for broader BST support, and can then be paired with a volunteer peer mentor.

Why Imbed in Clinic?

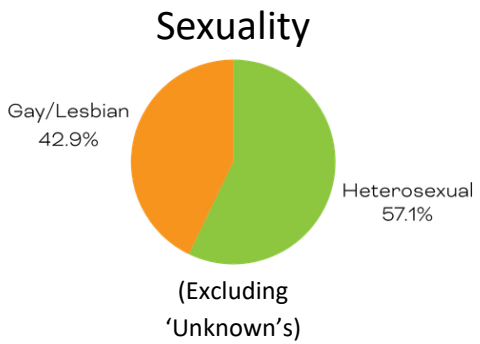
- Makes peer support accessible at key points in a person's HIV care journey,
- Helps identify and address practical, emotional and social barriers to care,
- Improved relationships with clinic/clinicians,
- More efficient use of clinical time,
- Stronger clinic–voluntary sector collaboration,
- Standardised, high-quality support

Who Has Been Seen?

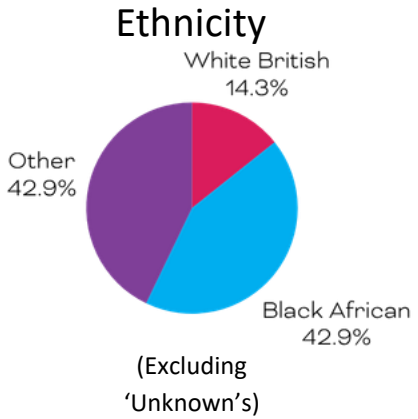
- Since 23 January 2026:
- 14 people supported,
  - 43% referred to broader Blue Sky Trust support.
- 33 sessions:
  - 22 in clinic,
  - 11 sessions with BST volunteers.

71.4% Male
28.6% Female

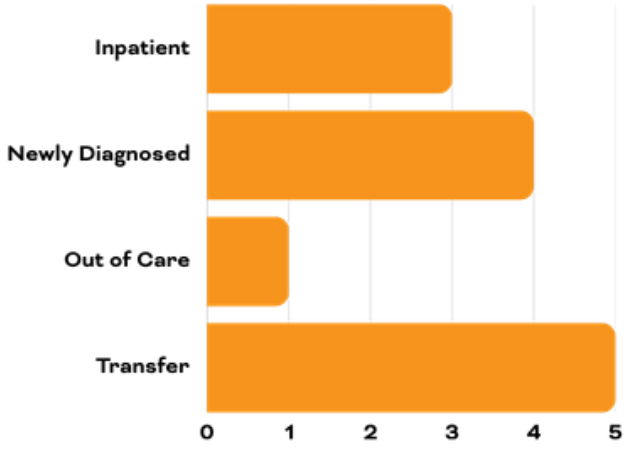




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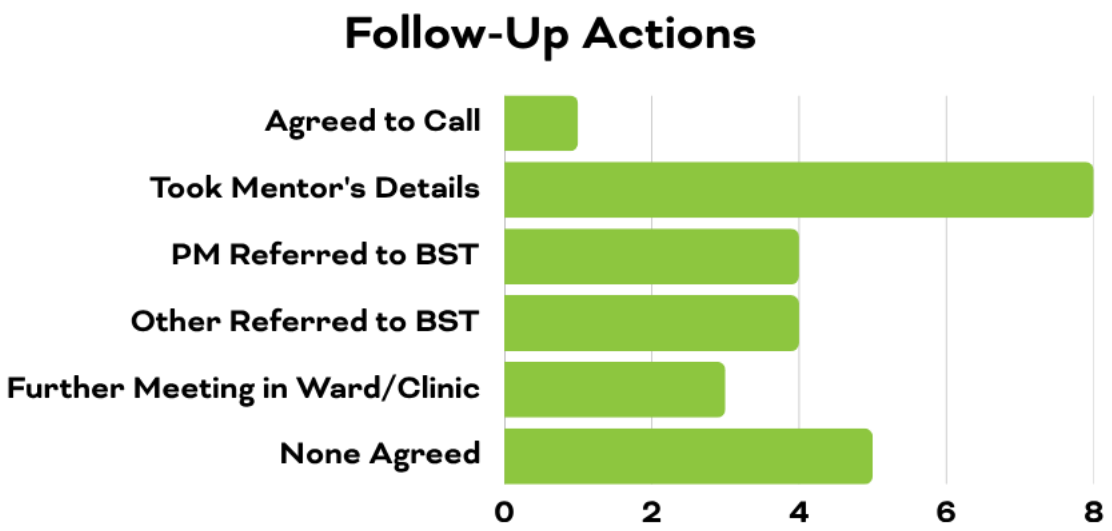


(Excluding 'Unknown's)



In Clinic Peer Support: Impact

"It made me feel that I was being heard and treated as an individual, rather than another patient on the list”

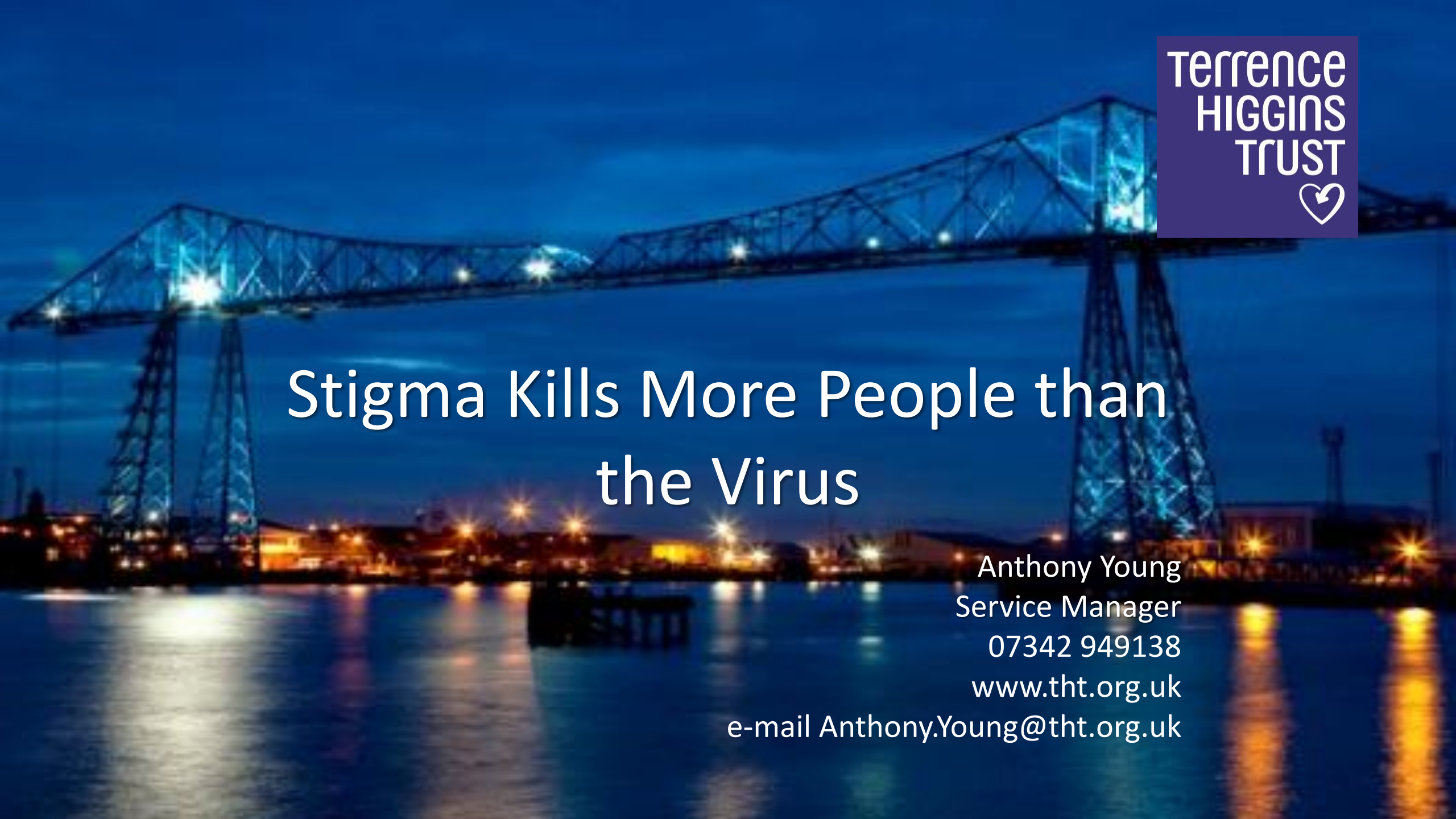


"Something has been lifted from my heart - a great weight"

Case Study 1:

- I met an inpatient who was newly diagnosed.
- Our initial sessions centred on myth-busting and normalising the diagnosis (dismantling self-stigma).
- I was able to refer and register the mentee whilst still an inpatient, enabling her to access full BST support as soon as discharged.
- Just before discharge, I arranged for her to meet a female peer mentor from BST.
- They then completed a block of 6 peer mentor sessions, during which time the mentee was supported to attend our peer support groups with other members.
- They are now approaching the end of a second batch of sessions, and are confident they have achieved their goals.


Tony



Stigma Kills More People than the Virus

Anthony Young
Service Manager
07342 949138
www.tht.org.uk
e-mail Anthony.Young@tht.org.uk

H is for Human

“I’d never let him touch me. He’s got HIV.”

George –
quote from the TV series Tip Toe aired on C4 9th June

Terrence Higgins Trust

16:11 5G 83

Terrence Higgins Trust
19 Jun ·



attitude.co.uk
Alan Cumming supports HIV charities with Tip Toe-inspired initiative

Alan Cumming in his Spit & Polish T-shirt via Attitude Magazine ! Order yours by going to tht.org.uk/tshirt

Alan, who plays Leo in Channel 4's Tip Toe, has urged support for HIV charities Terrence Higgins Trust and George House Trust in a new video posted on his Instagram.

Together, we've launched a new fundraiser inspired by Spit and Polish, the gay bar run by Cumming's character Leo in the Channel 4 drama. In Tip Toe, Leo's been living with HIV since 1994. He now takes just one pill a day.

In his video, Alan says the T-shirt will help build a "lasting legacy" for Tip Toe.

Write a comment...

16:08 5G 84

Terrence Higgins Trust
25 Jun ·



Hello Richard thank you for the T shirt I don't use social media but feel free to use the picture how you wish (dart board ?) MC
12:19

Terrence Higgins Trust
Charitable organisation
Shop now

Doesn't our Patron Martin Clunes look great in

Write a comment...

16:10 5G 83

Terrence Higgins Trust
1 Jul ·



Testimonials for our Spit & Polish T-shirts, raising money to support people living with and affected by HIV, are IN!

"I loved you since the day I first saw you," says Melba to their T-shirt. With Denise Welch's Diane saying Clive looks "smart" in his Spit & Polish T-shirt.

Either that or these are some random lines from Tip Toe taken out of context. But we've loved

Write a comment...

Terrence HIGGINS TRUST

WORKSHOP: Breakout session to identify HIV regional priorities

Dawn Phillips

Sexual Health Facilitator, UK Health Security Agency

Victoria Morris

Regional BBV Facilitator, UK Health Security Agency



PRIORITIES: What are the THREE most important priority actions that our region could do together to reduce HIV transmission and reduce stigma?

COLLABORATION: How do we make these priority actions happen?

ACTION: What is one action you or your organisation could commit to within the next year for each of these identified priorities?

Choose your table discussion

Find your focus

Prevent: 1	Sean Barry
Prevent: 2	Zoe Johnstone
Test: 1	Rebecca Scott
Test: 2	Melissa Brown
Treat: 1	Kirsty Foster
Treat: 2	Mark Ellerby-Hedley
Thrive: 1	Caroline Emmerson
Thrive: 2	Anthony Young

Please reserve your space at a table before finding the refreshments

Questions

PRIORITIES: What are the THREE most important priority actions that our region could do together to reduce HIV transmission and reduce stigma?

COLLABORATION: How do we make these priority action happen?

ACTION: What is one action you or your organisation could commit to within the next year for each of these identified priorities?

FEEDBACK: Breakout session feedback

DAWN PHILLIPS

Sexual Health Facilitator, UK Health Security Agency

Victoria Morris

Regional BBV Facilitator, UK Health Security Agency

Feedback

Your tables priorities and 1 key action

Prevent: 1	Sean Barry
Prevent: 2	Zoe Johnstone
Test: 1	Rebecca Scott
Test: 2	Melissa Brown

Treat: 1	Kirsty Foster
Treat: 2	Mark Ellerby-Hedley
Thrive: 1	Caroline Emmerson
Thrive: 2	Anthony Young

CLOSING REMARKS:

Lorraine Hughes

Director of Public Health, Darlington Borough Council