# BHIVA Audit

Chairs:

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BHIVA

British HIV Association

# BHIVA-BASHH National Clinical Audit 2025

## HIV partner notification and testing of children

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on behalf of the BHIVA and BASHH audit sub-committees

# Background

## HIV Partner Notification

HIV partner notification (PN) is the process whereby contacts of people with HIV are identified and offered HIV testing.

PN is a key part of HIV elimination strategies, facilitating:

- HIV diagnosis and linkage to care
- Linkage to HIV prevention for those testing negative (PEP and PrEP)

*(BHIVA/BASHH/SSHA/NAT 2015)*

Previous audit on PN was in 2018.

# Background

## Testing of Children

In 2008, there was a lack of robust systems for identifying and testing children of adults with HIV attending clinics.

**Don’t Forget the Children** – 2009 joint CHIVA, BHIVA and BASHH report.

“All adult HIV care provider and support services must have protocols and referral pathways in place to ensure that all the children of [parents living with HIV] are tested.”

*('Don’t Forget the Children', 2009)*

# Aims

1. To determine the HIV and sexual health services' policies and procedures around partner notification and testing of children.

2. To examine how these policies and procedures are implemented in clinical practice.

3. To evaluate practice against relevant BHIVA, BASHH and CHIVA clinical standards and outcome measures.

# Current guidelines and standards

1. **Partner notification of adult contacts**

- BHIVA standards of care (2018)
- HIV partner notification for adults guidance (2015)
- BASHH statement on partner notification for sexually transmissible infections (2013)

2. **Testing of children**

- 'Don’t Forget the Children' guidance, CHIVA (2009)
- CHIVA standards of care (2025)

# Methods

- Audit of HIV and sexual health services within the UK
- Audit with two components:
  - **Service-level review:**
    - Completed once per service
  - **Case note review:**
    - Services with >40 eligible patients randomly selected 40 patients
    - Completed once per patient
- Pilot: late May-early June 2025
- Data collection: June-July 2025, covering the previous 12 months from date of data collection

# Methods

Service users included for the audit were those considered '**New to service and potentially in need of partner notification**':

- Newly diagnosed with HIV

  *or*

- Previously diagnosed and:
  - Transferring HIV care from outside the UK, *or*
  - Transferring HIV care from another UK HIV service with a viral load >200 copies/mL, *or*
  - Not seen at another UK HIV service in the past 12 months and had a viral load >200 copies/mL

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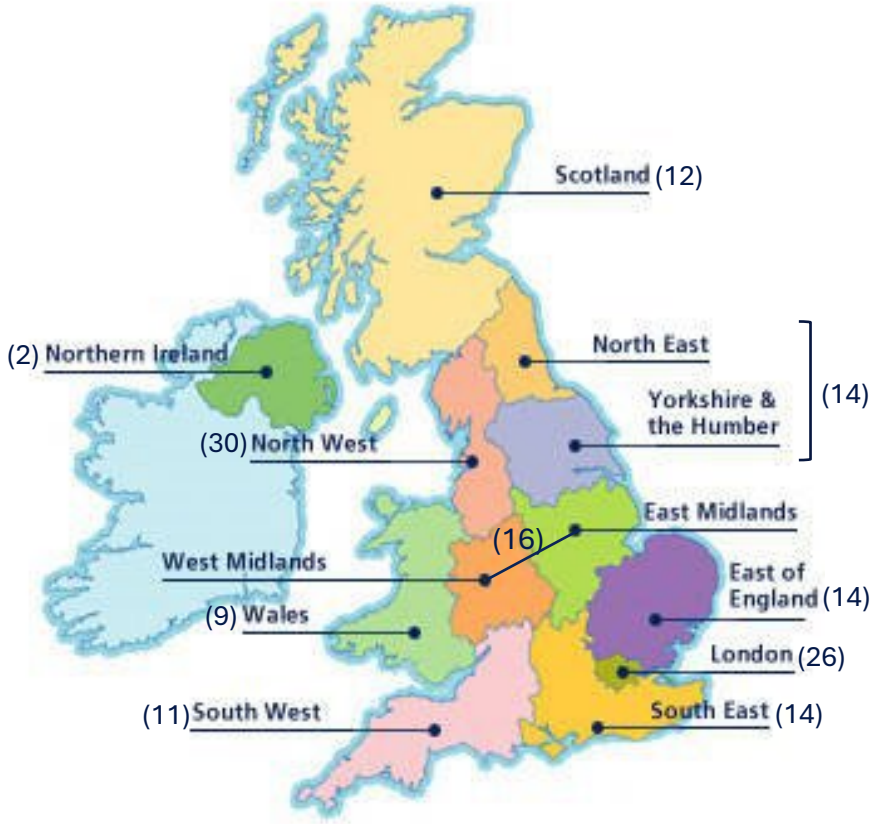
# Service and case note overview

# Service responses

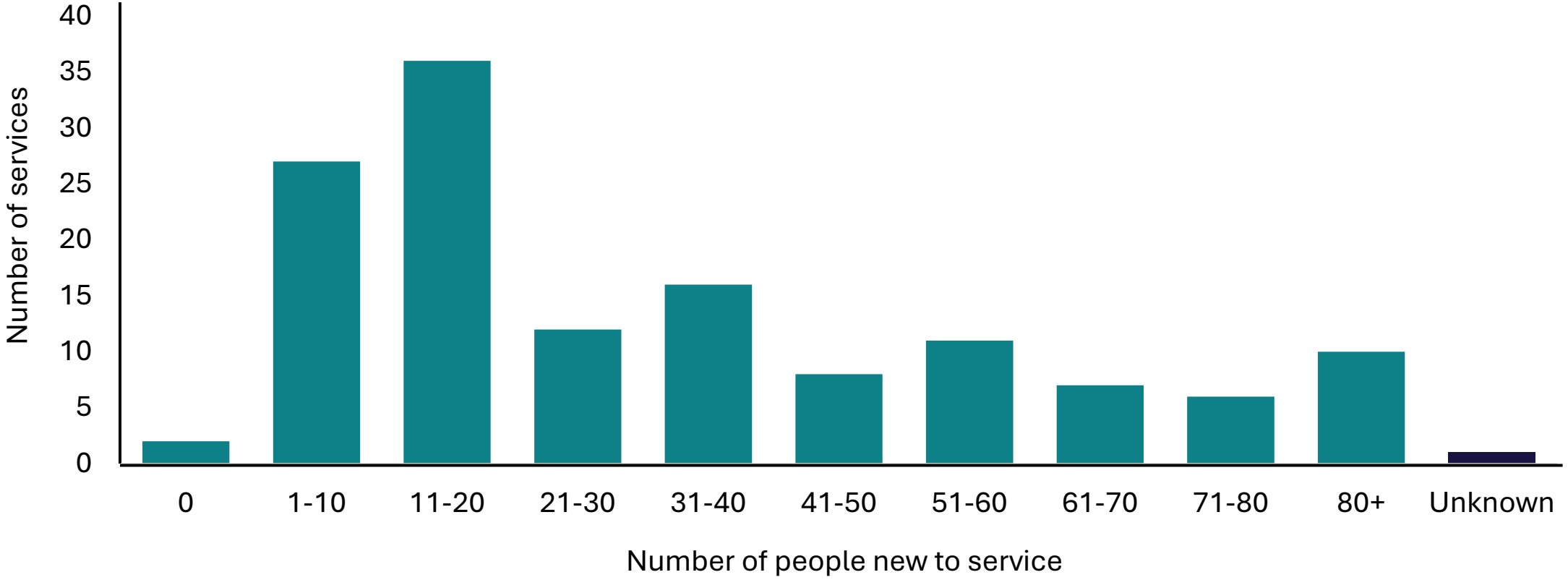
- **136** responses covering 143 HIV and sexual health services
- Covered all nations within the UK
- 91% (124) provided ongoing HIV treatment/care



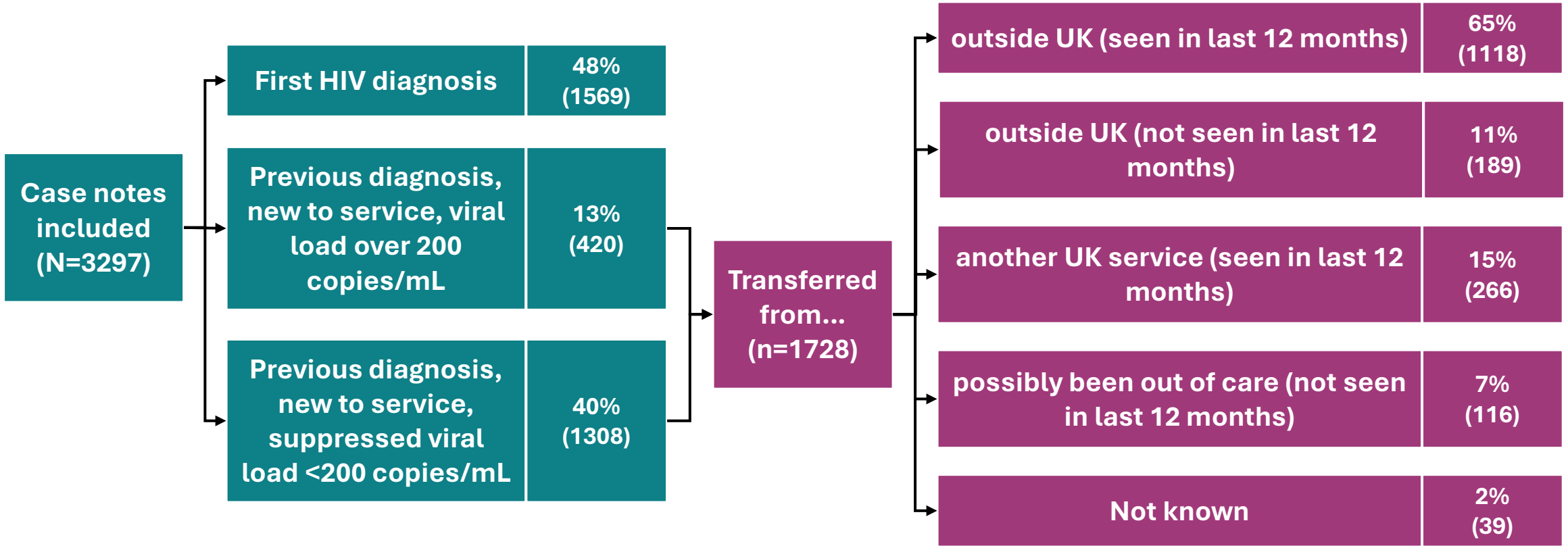

| Number of people accessing service with HIV | |
|---|---|
| Under 200 | 17% (21) |
| 200 to 499 | 30% (37) |
| 500 to 999 | 31% (39) |
| 1000 and over | 22% (27) |

# People new to services

Number of services reporting each range of number of people new to service (n=4611)



# People new to services




*People already registered at the service and people who transferred from another service within UK with viral load <200 were excluded. In services with >40 people "new to service", they submitted a maximum of 40 case notes, hence the n=3297, not 4611.*

# People new to services

**3297 people from 136 HIV and sexual health service**

**Median age (range): 41 (17-94) years old**

**1949 men (59%) (includes transgender men)**

| Ethnicity | N | % |
|---|---|---|
| Black or Black-British, -Caribbean, -African, other | 1730 | 52% |
| White British | 662 | 20% |
| White other | 298 | 9% |
| Asian or Asian British -Indian, Pakistani, Bangladeshi, other | 230 | 7% |
| Mixed | 103 | 3% |
| Other | 145 | 4% |
| Not known/not stated | 129 | 4% |

# People new to services

| Region of birth | N (3297) | % |
|---|---|---|
| Africa | 1740 | 53% |
| UK | 771 | 23% |
| Asia | 279 | 8% |
| Europe | 231 | 7% |
| Americas | 204 | 6% |
| Oceania | 9 | <1% |
| Unknown | 63 | 2% |

Of people born outside the UK, 62% had moved to the UK in the last two years, of whom a quarter were newly diagnosed in a UK service.

| Likely mode of acquisition | N (3297) | % |
|---|---|---|
| Heterosexual sex | 1966 | 60% |
| Sex between men | 975 | 30% |
| Vertical acquisition | 77 | 2% |
| Injecting drug use | 35 | 1% |
| Other | 46 | 1% |
| Not known | 198 | 6% |

1 in 5 people had evidence to suggest recent acquisition (<6 months)

# Prior ART initiation

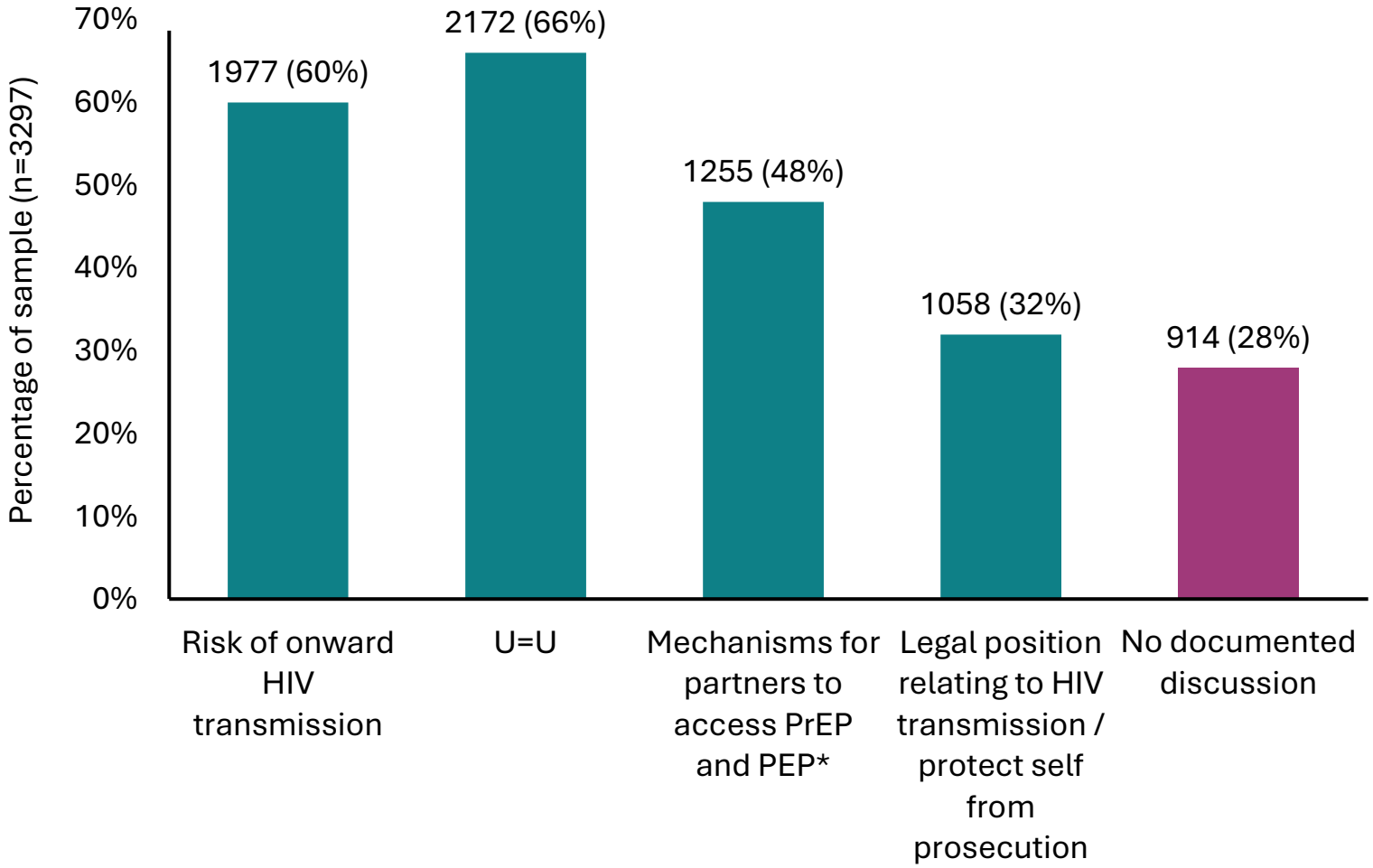
| Was the individual (n=1728) already on ART when they attended? | |
|---|---|
| Yes | 78% (1356) |
| Previously on ART but stopped (including supply disruption) | 14% (249) |
| No | 6% (105) |
| Other: elite controller, multiple treatment pauses whilst refugee in Europe, on ART but incomplete adherence, taking every other day to spread out supply | 1% (18) |

# HIV prevention discussion documented?

**Standard:**
Culturally- and age-appropriate written and verbal information should be provided to people about:

- onward transmission
- their legal position in terms of transmission and how to protect themself from prosecution

*(BASHH, 2013)*




* Excludes people with an undetectable viral load

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# HIV partner notification

# Partner notification provision

The need for PN support and guidance should be assessed and offered **at the time of HIV diagnosis**. This should be provided via sexual health services or within the HIV service by those **with sufficient expertise**. *(BHIVA, 2018)*

| | N=136 |
|---|---|
| Service provides HIV PN | 117 (86%) |
| *88 (75%) of whom provide specific guidelines for individuals with viral load >200 copies/ml* | |
| HIV PN provided elsewhere | 11 (8%) |
| 'Other': SHS team, local community SHS, "utilises various options", partially provide in-house and with local provider | 8 (6%) |

Health advisors and clinical nurse specialists were particularly involved in PN.

62% services had defined pathways for staff to access HIV PN training.

# Auditing of PN performance

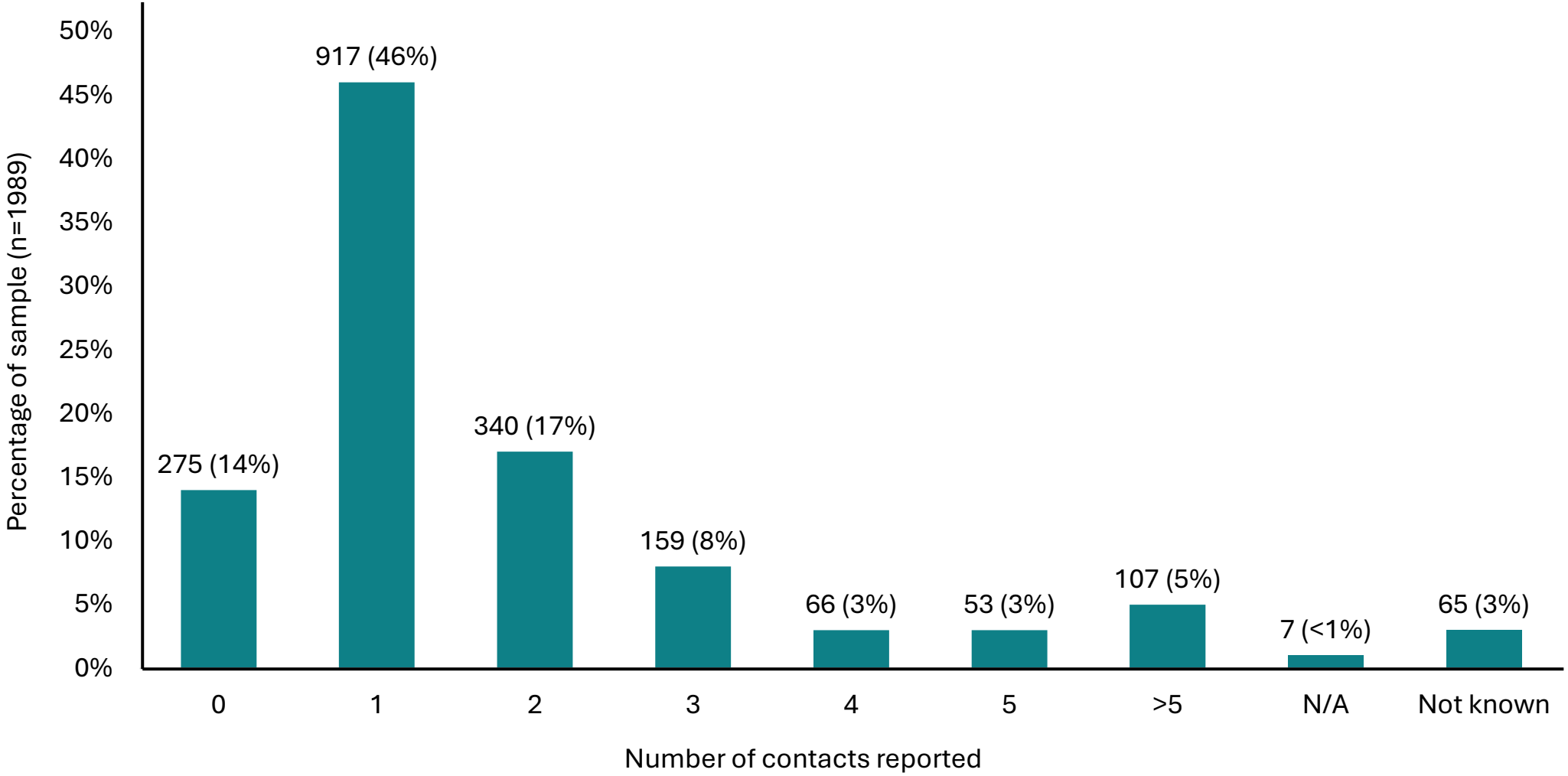
Performance in PN provision should be **included in service quality monitoring** and **audited at least annually** using the process outcome measures. *(BASHH, 2013)*

**Performance in HIV PN was included in 54/117 (46%) services' quality monitoring.**

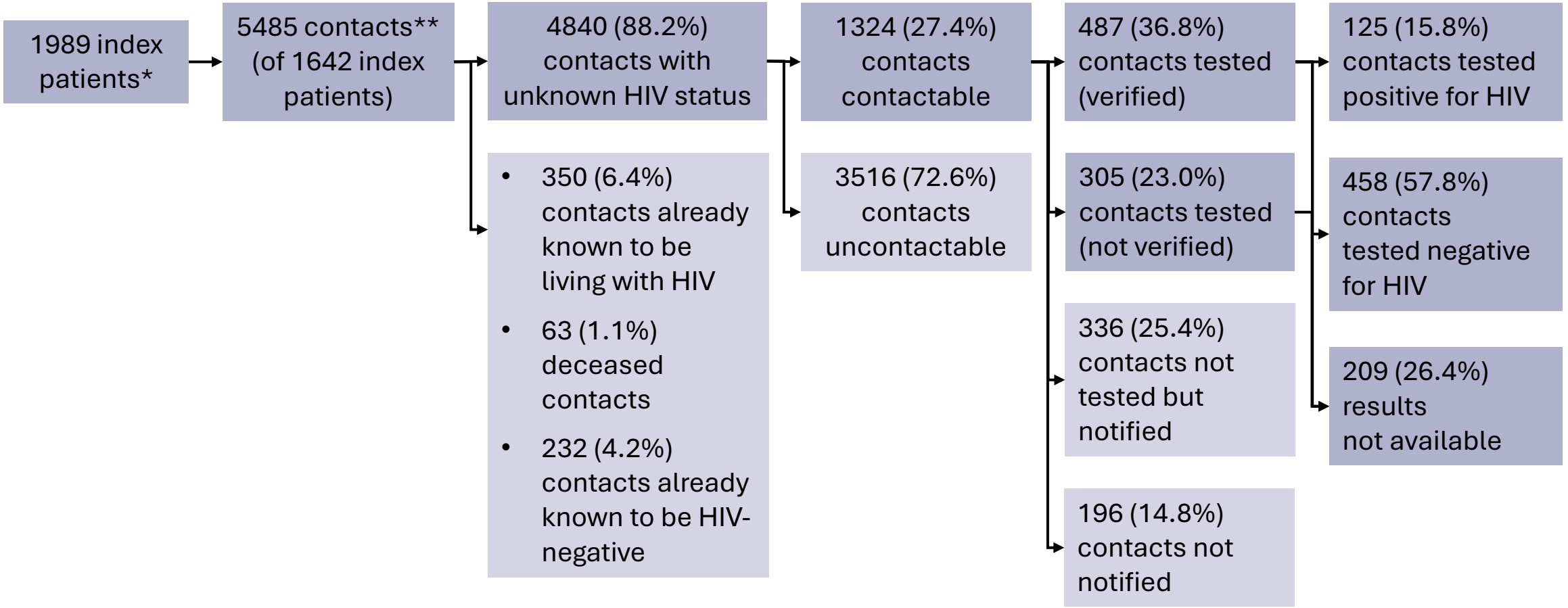
| PN audit frequency according to local policy/SOP (n=117) | |
|---|---|
| At least annually | 18% (21) |
| Every 12-24 months | 4% (5) |
| Not specified | 21% (25) |
| No local policy/SOP | 47% (55) |
| Don't know | 9% (11) |

| When was HIV PN last audited locally? (n=117) | |
|---|---|
| Within past 12 months | 22% (26) |
| Periodically but >12 months since last audit | 34% (40) |
| Not routinely audited | 44% (51) |

# Contacts per index patient



# Flow (all index patients)




*First diagnosis or previously diagnosed with a viral load over 200 copies/mL
**347 index patients had contacts that were zero, “N/A” or “Not known”

# HIV PN consultations

"The need for PN support and guidance should be assessed and offered **at the time of HIV diagnosis**. This should be provided via sexual health services or within the HIV service by those with sufficient expertise." *(BHIVA, 2018)*

"If the offer of discussion of PN is declined, the **reason for this should be documented** in the patient record." *(BASHH, 2013)*

**Did a HIV PN consultation take place?**

- **78%** of index patients had a documented PN consultation, 67% of whom had this within 72 hours of diagnosis.
- Of the 2% who declined testing,
  - 79% had a documented reason
  - 44% had a planned date/ opportunity to discuss in future

These data include people newly diagnosed with HIV and those who have transferred to the service with a VL > 200 copies/mL.

# PN measured outcomes

**Outcome 1**
Contacts tested for HIV per index patient

**Outcome 2**
Percentage of contactable contacts tested for HIV

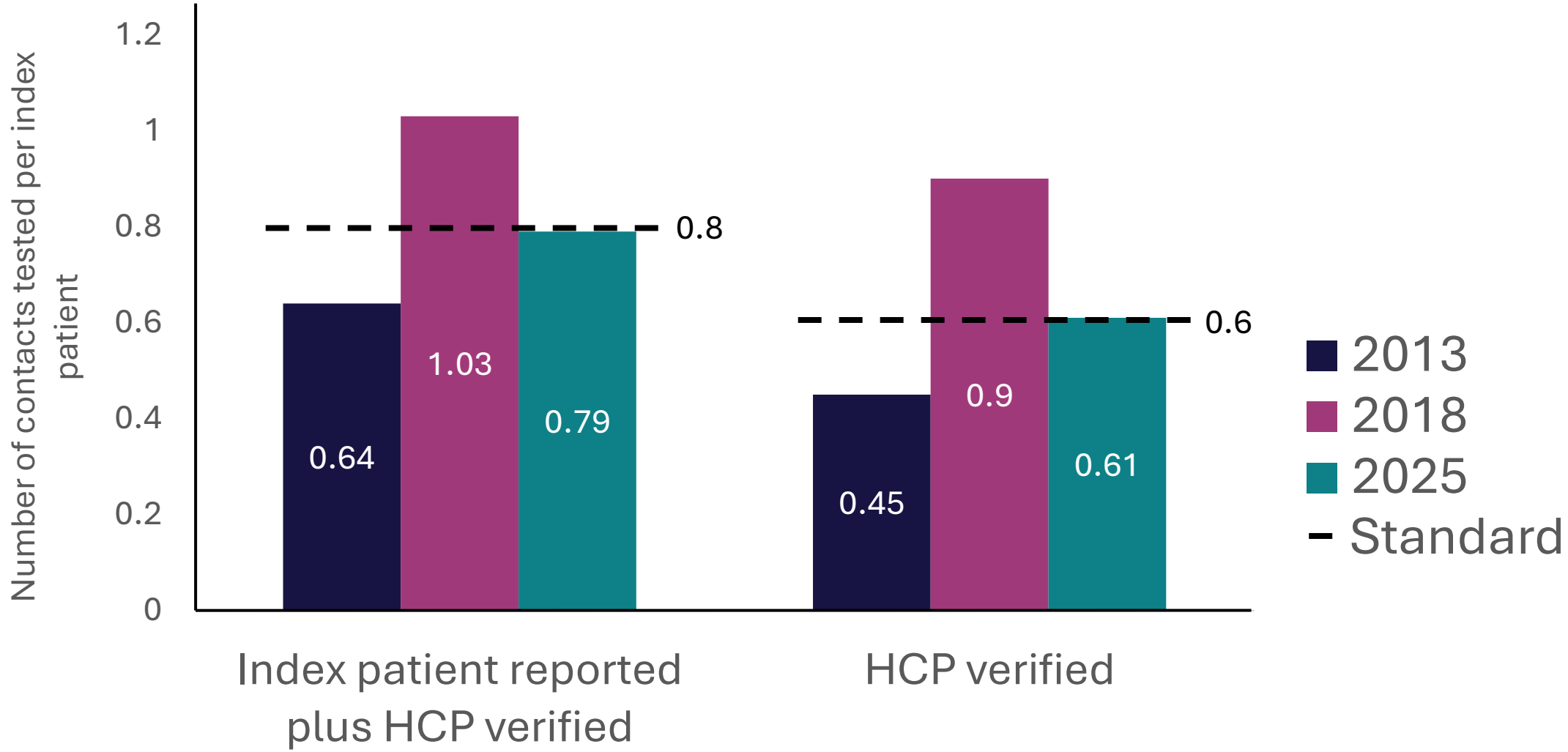
**Outcome 3**
Percentage of people first diagnosed with HIV with a PN plan in place within 4 weeks

**Outcome 4**
Percentage of index patients with whom PEP eligibility of contacts was discussed

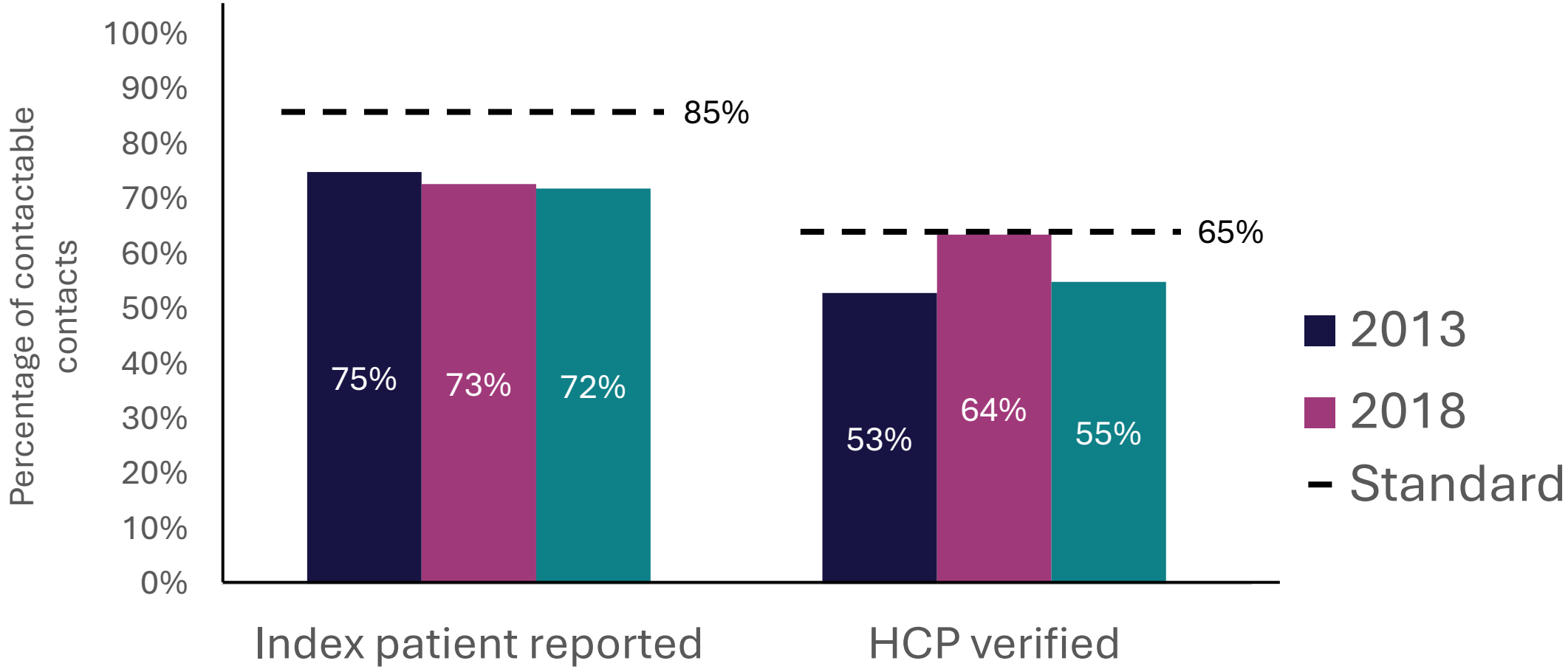
*(BHIVA, 2015)*

- *Outcomes 1 and 2 are reported as index patient-reported or as index patient-reported and HCP-verified contacts*
- *Outcome 3 is reported as whether there is a PN plan (including those that are resolved)*
- *All outcomes calculated for new diagnoses only*

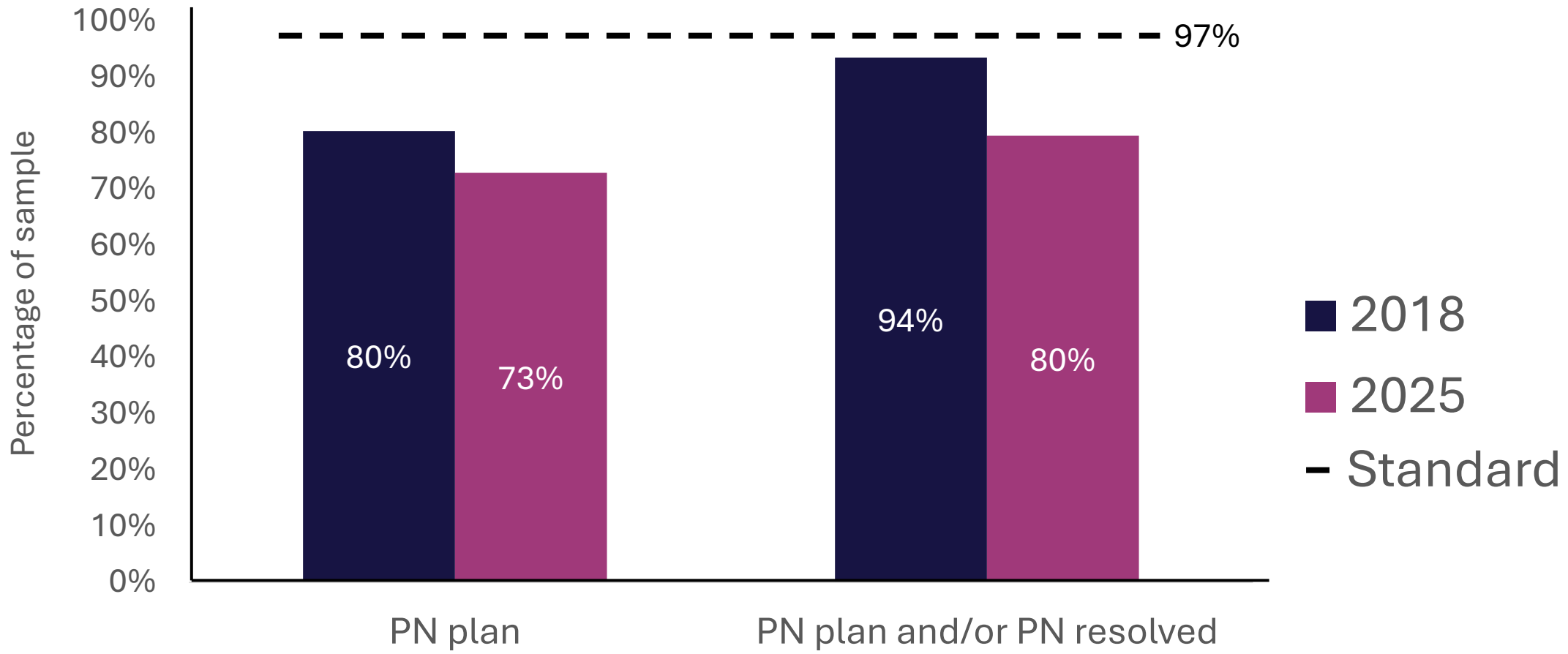
# Outcome 1: Number of contacts tested per index patient



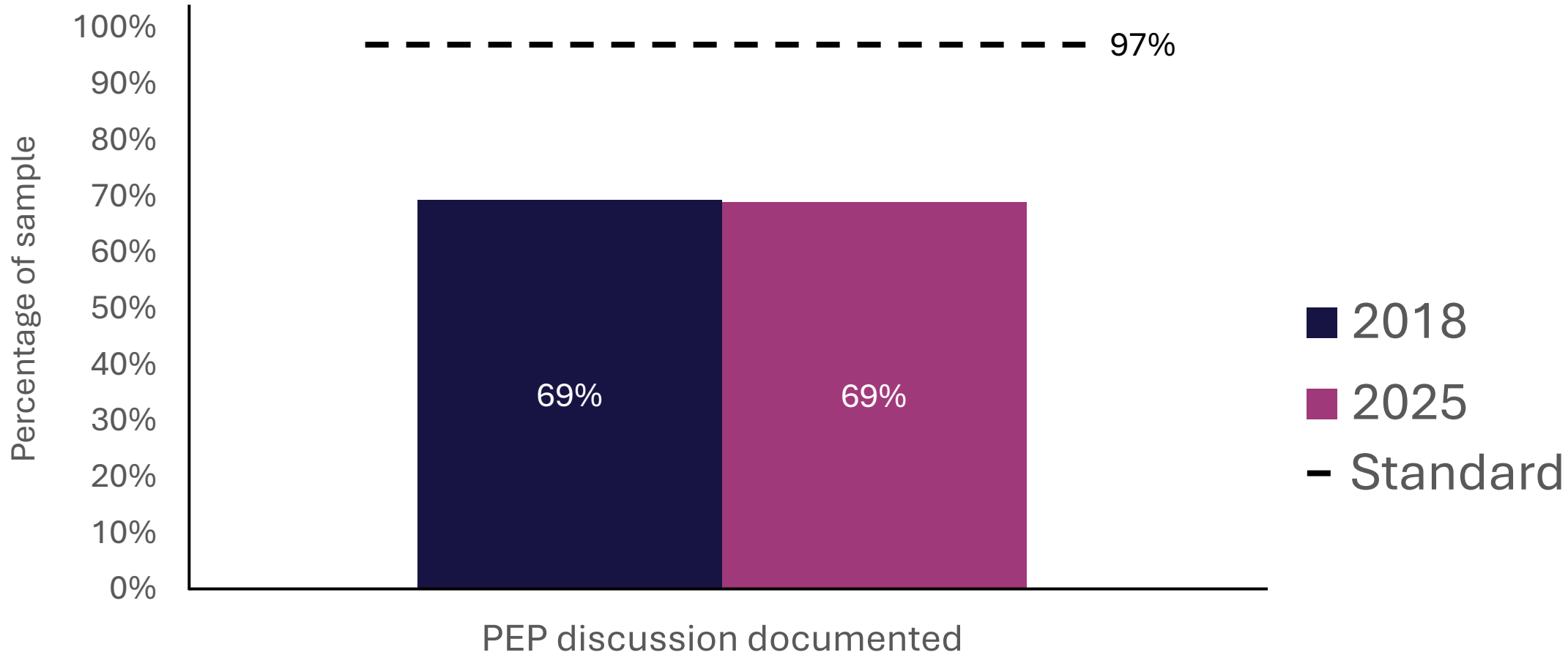
# Outcome 2: Percentage of contactable contacts tested for HIV



# Outcomes 3: Percentage of people first diagnosed with a PN plan in place within 4 weeks



# Outcome 4: Percentage of index patients with whom PEP eligibility of contacts was discussed



# Summary
## Partner notification

**Key points:**

- Around **16%** of people contacted and tested for HIV had a positive test.
- ~60% of contactable contacts were tested.
- 73% of all contacts were uncontactable.
- 1 in 5 people did not have a documented PN consultation.
- Most outcomes were short of the standards, and many saw a reduction in performance since the 2018 audit.

### Recommendations

Establish routes for HIV PN training within services.

Establish local protocols and SOPs re: auditing HIV PN performance.

Further prioritise HIV partner notification given its effectiveness in reaching people with undiagnosed HIV.

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# Testing of children

# Testing provision

All adult HIV services [...] must have protocols and procedures in place to ensure that all children of [parents with HIV] are tested for HIV. *(Don't Forget the Children (DFTC), 2009)*

| What type of HIV testing service is provided for children? (n=136) | |
|---|---|
| Can offer in-house and have an established referral pathway | 26% (35) |
| Can provide in-house | 1% (1) |
| Cannot provide in-house but have a referral pathway | 57% (77) |
| Unable to offer testing of children | 17% (23) |

| What referral option(s) do the services have? (n=112) | |
|---|---|
| GP | 30% (34) |
| Paediatric blood testing clinic | 49% (55) |
| General paediatric team | 48% (54) |
| Specialist HIV centre | 13% (15) |
| Lead HIV centre | 4% (4) |
| Other | 19% (22) |

# Testing provision

Where an adult HIV service has no nearby specialist paediatric HIV services, referral and advice pathways will need to be developed which include the regional HIV paediatric lead. *(DFTC, 2009)*

| What type of HIV testing service is provided for children? (n=136) | |
|---|---|
| Can offer in-house and have an established referral pathway | 26% (35) |
| Can provide in-house | 1% (1) |
| Cannot provide in-house but have a referral pathway | 57% (77) |
| Unable to offer testing of children | 17% (23) |

| If unable to offer testing of children locally, who is informed of the need for testing? (n=23) | |
|---|---|
| Parent or carer | 65% (15) |
| GP | 57% (13) |
| Paediatrician | 39% (9) |
| Don't know | 4% (1) |
| Other: BBV clinic, HIV care provider, if complex or GP declines contact made with paediatric specialist nurse | 39% (9) |

# Policies, procedures and audit performance

No stipulated audit frequency. However, it is recommended that "all HIV units and services develop effective systems to audit enquiries to patients about the testing of children." *(CHIVA, 2009)*

| Are there protocols and procedures in place to ensure children of people with HIV are tested for HIV? | |
|---|---|
| Yes, protocols and procedures in place for testing of children | 40% (55) |
| No, no formal protocol but this is usually done | 53% (72) |
| No, no formal protocol but this is not usually done | 4% (6) |
| Don’t know | 2% (3) |

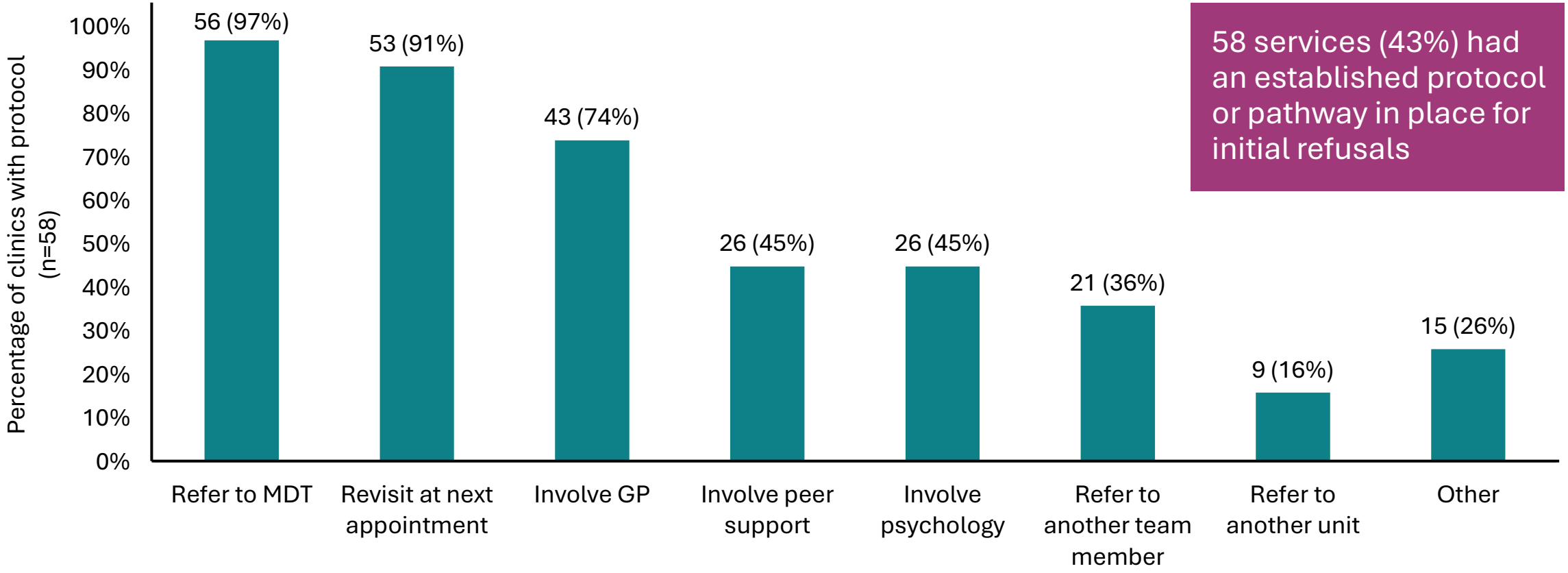
| When was the testing of children of adults with HIV last audited locally | |
|---|---|
| Within past 12 months | 12% (16) |
| Periodically but >12 months since last audit | 25% (34) |
| Not routinely audited | 63% (86) |

# Actions to ensure the testing of children

These actions should be always be recognised and/or performed. *(CHIVA, 2009)*

# Actions for when parent initially declines testing of child

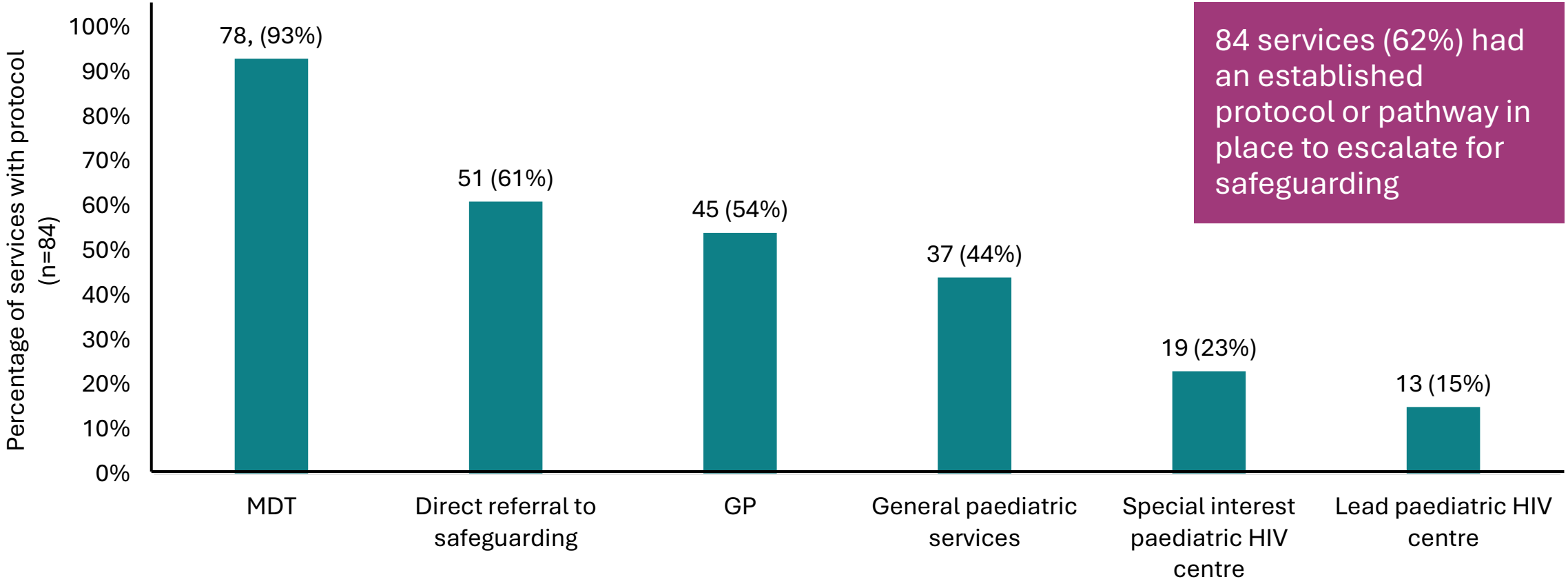
There need to be joint protocols in place between health and social care to manage those cases where parents **initially refuse** [...] A clear pathway of referral needs to be identified **within the multidisciplinary team**. *(CHIVA, 2009)*




58 services (43%) had an established protocol or pathway in place for initial refusals

# Protocol for escalating repeated declines for testing to safeguarding

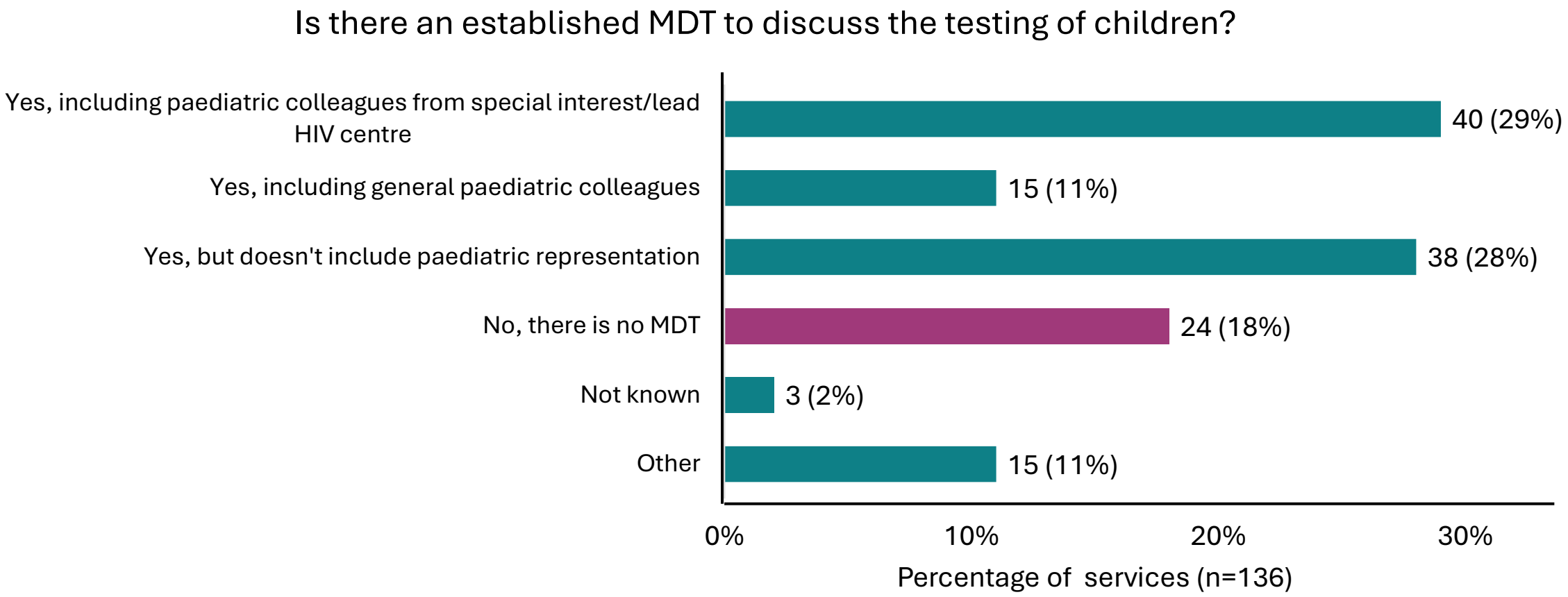
After approximately 6 to 12 months of negotiation, **if the test is still declined, there should be discussion** with the multidisciplinary team and social services. *(CHIVA, 2009)*




84 services (62%) had an established protocol or pathway in place to escalate for safeguarding

# MDT and testing of children

A multi-sector, multidisciplinary team needs to be identified for each HIV service [...] [If there is] no nearby specialist paediatric HIV services, referral and advice pathways will need to be developed [including] the regional HIV paediatric lead. *(CHIVA, 2009)*

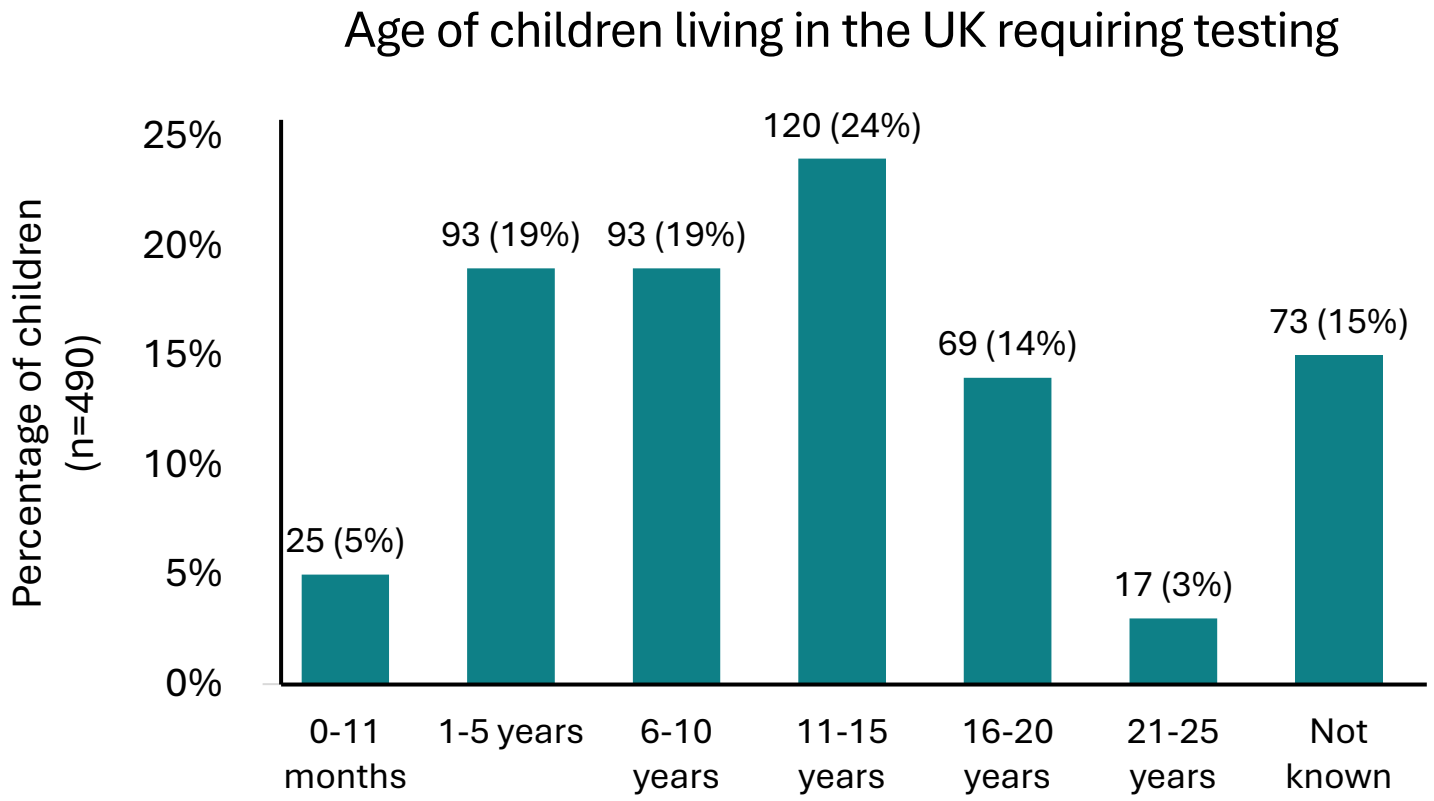


# Children of people newly diagnosed

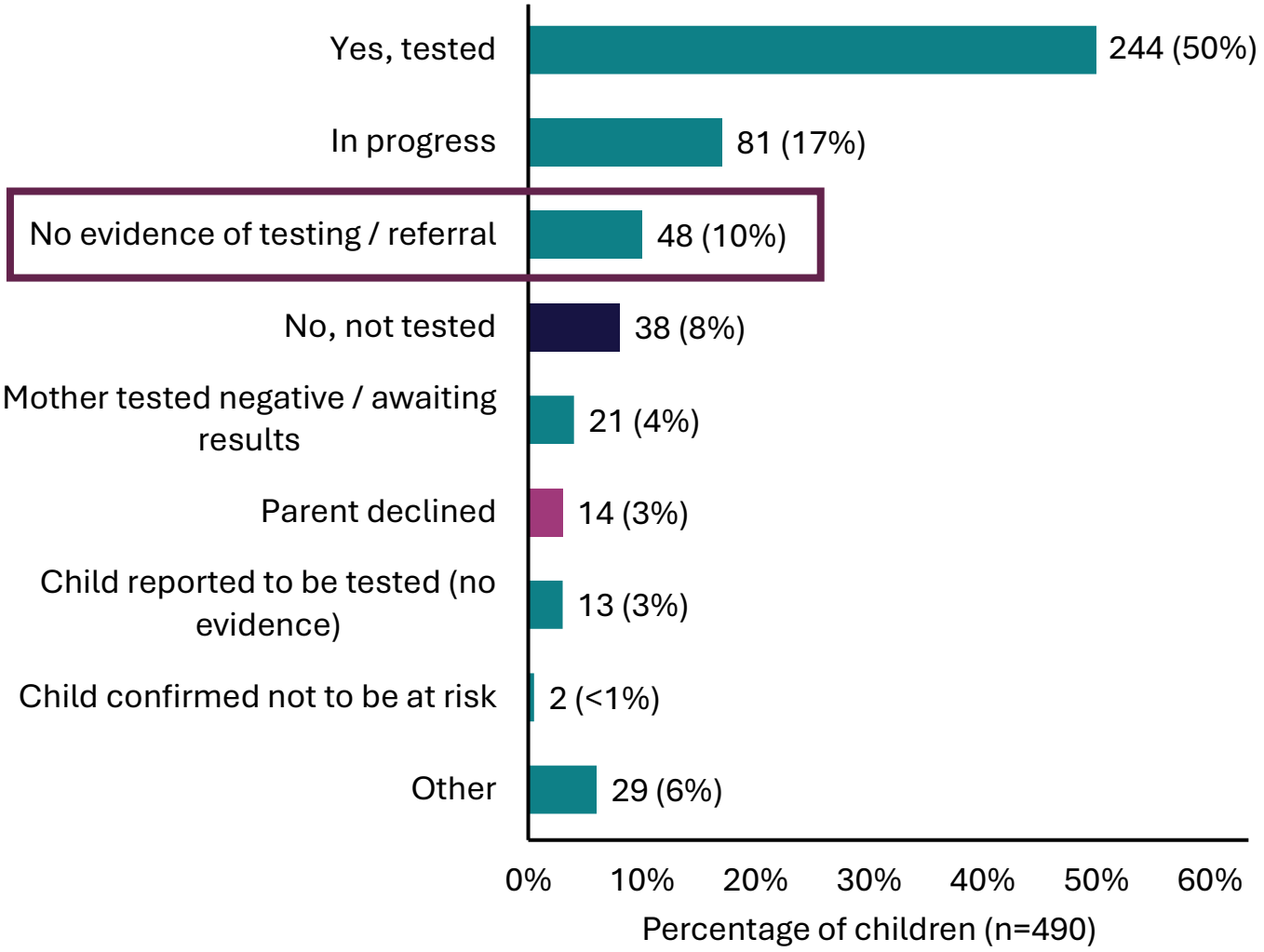
All [people newly diagnosed] should have any children identified, tested and [this] information clearly documented. *(CHIVA, 2009)*

27% and 21% of newly diagnosed people had children living in and outside of the UK, respectively

Among those children living in the UK, there were **490 birth children** (aged 0 to 25 years) identified as requiring HIV testing (possible vertical transmission and untested)



# Was the child tested?




**Reasons given for not testing when deemed at risk (n=38):**

- Advised/discussed with parent but not followed up
- Awaiting parental consent/more time to consider
- Estranged from child
- Moved out of the UK
- Transferred care

**If the parent declined (n=14):**

- 93% of notes documented to revisit at next appointment
- 64% referred to the MDT
- 100% had some form of action documented
- At the point of auditing, none had a referral to another team member, involvement of peer support worker, psychology involvement, GP involvement or a safeguarding referral

# Summary
## Testing of children

### Key points:

- **1 in 5** services do not provide nor have pathways in place for the testing of children of adults with HIV.
- **1 in 10** children had no documented evidence of any testing or referral for testing.
- 16 years on from DFTC, there is still a lack of policies and procedures to ensure the testing of children.

### Recommendations

Establish MDTs that include paediatric representation in line with clinical standards.

Establish policies and procedures, and pathways, to ensure that:

- Testing is completed for all children who require it.
- The urgency of testing key groups is acknowledged and acted upon.
- Performance and systems are audited regularly.

# Overall summary

## Discussion points

- Prioritising HIV partner notification.
- Don’t Forget the Children!
- A revisit of standards and outcome measures (outcome of 2018 HIV PN audit, DFTC 2025 is due next year).

## Limitations

- Documentation vs practice
- Question subjectivity
- “Not knowns”
- Estimates influencing outcomes?

# Thank you

- Lucie Stuart (BHIVA/BASHH Audit Co-ordinator)
- CHIVA
- Participating services

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# Questions?

# Mortality and very late diagnosis reviews

Email for support or further information:

**Mortality:**
hivmortality@ukhsa.gov.uk

**Very late diagnosis:**
hivlatediagnosis@ukhsa.gov.uk

https://bhiva.org/late-diagnosis-and-mortality-reviews/