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Post-diagnosis peer support in Emergency Department BBV opt-out testing: results from a Freedom of Information Request

Why National AIDS Trust made a Freedom of Information Request

Ensuring that everyone living with HIV is tested and supported appropriately following a new diagnosis is essential. The UK Government has committed to ending new HIV transmissions by 2030, and the Opt-Out testing programme for blood borne viruses (BBV) has been a flagship initiative towards achieving this.

As the programme has rolled out and expanded across England over subsequent years we wanted to ensure that the programme was being implemented properly and that the full breadth of the services provided for in the funding were being made available for people living with HIV. The freedom of information request was intended to gather relevant data to be able to share with stakeholders and partners to contribute to effective oversight of the programme and insight on the provision of post-diagnosis peer support.

The Opt-Out BBV testing programme and provision for post-diagnosis peer support

Opt-out testing for blood borne viruses (BBV) has been rolled out in nearly 80 Emergency Departments (EDs) across England with another 8 likely to start in the next few months.

This means that when adults have their blood taken and tested in an ED, it is also tested for HIV, hepatitis B and hepatitis C, unless they ask for it not to be. In 2025/26 an additional 10% of the funding from NHS England for ED HIV testing was allocated to ICBs to commission post-diagnosis HIV peer support to those diagnosed with HIV as a result of this programme.

The intention for providing this 10% of funding is to ensure that there is sufficient post-diagnosis peer support for people diagnosed through the opt-out programme by adding to any existing locally commissioned support provided by the HIV voluntary sector. This is in addition to the clinical post diagnosis support provided by the HIV nurses and doctors.

ICBs may commission the peer support directly, or flow the funding through to trusts or councils for them to commission. The NHSE viral hepatitis team commission the Hepatitis C Trust to deliver hepatitis C peer support.

Our FOI request

We sent Freedom of Information (FOI) requests to NHS trusts who have a hospital with an ED that was participating in the programme.

We recognise that FOIs are often a blunt tool in being able to gather full evidence. Not every FOI recipient responded, and there was variation in level of detail provided across the responses. We recognise that there may be trusts or ICBs delivering post-diagnosis peer support as intended, but that did not reply to our

FOI, or replied and where unable to provide data. Therefore, the information presented in this report is the best picture of what's happening on the ground with the available data that we have.

FOI questions

We asked trusts five questions:

1. For each of the years you have received any funding for BBV Opt-Out testing, please specify what proportion of the 10% allocation of overall funding has been spent on post-diagnosis support?
2. For each of the years you have received funding for BBV Opt-Out testing, please specify what proportions of the 10% of funding for post-diagnosis support has gone to supporting:
 - a) people living with HIV,
 - b) people living with Hepatitis C,
 - c) people living with Hepatitis B,
 - d) any other condition.
3. For each of the years you have received funding for BBV Opt-Out testing, please tell us which organisation/provider has provided post-diagnosis support under this funding, and what % of the 10% of funding has gone to each type of provider.
 - a) HIV Voluntary/community organisations
 - b) Other non-HIV voluntary support/community organisations
 - c) Spent internally within the trust
 - d) Somewhere else – please specify
4. For each of the years you have received funding for BBV Opt-Out testing, if not all of the 10% of allocated funding has been spent on post-diagnosis support, please confirm how that money has been used.
5. For each of the years you have received funding for BBV Opt-Out testing, please tell us how many people have accessed post-diagnosis support funded through the programme.

Who responded to the FOI request

We sent the FOI out to 59 trusts identified as being part of the BBV Opt-Out programme (some trusts cover multiple ED testing sites).

Some trusts responded saying that they did not hold this information and directed us to ICBS. We then sent the same questions to 12 ICBs when a trust indicated that they held this information - we received 10 responses from these ICBs which we have incorporated into the analysis below.

Analysis of responses

We are aware from information provided by NHS England that one of the trusts withdrew from the Opt-Out programme, and 7 were yet to start. Therefore, we should have been able to get information (either from the trust itself, or from the ICB) on funding for post-diagnosis HIV peer support for the programme being carried out at **51 trusts**.

From the information provided by either trusts or ICBs we are able to say that out of the 51 trusts where ED BBV Opt-Out programme had started:

- **100% of allocated funding** for post-diagnosis peer support was confirmed as being spent at ED sites for **20 trusts** (or by their relevant ICBs)
- **2 trusts** had used **some of the allocated funding** on post-diagnosis peer support
- **1 trust** said they had **not used any funding yet**
- **11 trusts (or their relevant ICBs) did not respond at all to the FOI** (10 of which we know from NHS England had started the testing programme and have an HIV clinic where post-diagnosis peer support could be provided).
- The remaining **17 trusts** (or their relevant ICBs) either said that they were **not funded to provide post-diagnosis peer support, or that they did not have this information**. (NB It should be noted that for **12 trusts** included here, the trust would be unlikely to be able to provide information as they do not have an HIV clinic and therefore funding for post-diagnosis peer support would be provided by another organisation).

Of the **20 trusts** (or relevant ICBs) that confirmed 100% of post-diagnosis peer support was spent:

- **17 trusts confirmed that 100% of the funding was used to support people diagnosed with HIV** (3 trusts also spent funding on post-diagnosis support for other BBVs as per flexibility provided by NHS England))
- **16 trusts used HIV VCSE organisations to provide these services**
- **3 trusts also spent funding internally within the trust, for example to fund a peer support worker role.**

Challenges and limitations

A key challenge was the significant number of trusts and ICBs who did not respond to the FOI request. As compliance with an FOI request is a legal duty, this is very disappointing, and means that we have been unable to gather as much information as we should have been able to.

A further challenge was that across the Opt-Out ED BBV programme, responsibility for post-diagnosis HIV peer support is split between trusts and ICBs. This meant that it was hard to gather consistent data, and in some cases both the trusts and their relevant ICBs told us that they did not hold information on the questions we asked.

Many trusts who did respond were not able to give a year by year breakdown, and instead said that 100% of the funding was being used for post diagnosis peer-support. It should be noted that 17 trusts had been conducting Opt-Out BBV testing for less than 12 months at the time of our FOI request and so would not have been able to provide information for previous years.

It was also often difficult to find out how many patients had used the post-diagnosis support offering as this was sometimes the number of total patients that accessed community/peer support, not just those diagnosed through opt-out testing in EDs. Some trusts also reported that the number of people accessing the service was small so risked breaching confidentiality by reporting this figure.

Our conclusions are limited by the understanding of post-diagnosis peer support in the trusts and ICBs we sent the FOI requests too. Some assumed that post-diagnosis HIV support was linking patients to HIV secondary care services and we had to clarify that it was community/peer support.

There is a chance that some trusts and ICBs did not understand the request or were unable to identify the appropriate person to respond and therefore responded that they did not hold the information. Some respondents were also unaware that 10% of funding was allocated to HIV peer post-diagnosis support.

Conclusions and recommendations

It is disappointing that many organisations could not or did not answer our request, and concerning that it appears that not all the funding for HIV peer post-diagnosis support has resulted in this vital service being delivered.

HIV post-diagnosis peer support is a crucial component of the opt-out ED testing programme and its inclusion in this flagship programme was seen as a real exemplar of well-thought through programme design. The fact that we have not been able to get reassurance that the money is being spent as intended – and therefore that some people are likely to have gone without peer support following an HIV diagnosis – is of real concern.

We were only able to confirm that 21 out of 51 trusts (or relevant ICBs) are using the allocated 10% of funding for HIV post-diagnosis peer support through these FOI requests. Therefore, this leaves two thirds of the funding unaccounted for. Our conclusions therefore are limited due to not having all the data that we were hoping to obtain, but there is sufficient evidence for us to provide some reflections and recommendations:

The lack of full information available on the amount of funding spend on post diagnosis support at ED opt-out testing sites must be addressed. The programme started in 2022, and as a flagship programme in the HIV Action Plan for England, immediate steps must be taken to ensure transparency and clarity on where, and how, money being allocated for HIV post-diagnosis peer support is being spent. We therefore recommend that:

- *All NHS Trusts, and ICBs, as part of the programme have reporting mechanisms in place to be able to report accurately how HIV post-diagnosis peer support funding as part of the ED opt-out programme is being spent.*
- *NHS England considers undertaking an audit of the ED opt-out testing programme to be able to collect data that we have been unable to find as part of this FOI request*
- *That NHS England consider alternative funding arrangements to commission HIV peer post diagnosis support for people diagnosed through the ED opt-out testing programme for 2027/28 if there is no further reassurance that the funding for post diagnosis support is being used appropriately at every site.*

Appendix 1

Full list of trusts and ICBs who were sent the FOI request

Trusts	Responded?
Royal Free London NHS Foundation Trust	✗
University College London Hospitals NHS Foundation Trust	✓
Whittington Health NHS Trust	✗
Barts Health NHS Trust	✓
Barking, Havering and Redbridge University Hospitals NHS Trust	✓
Homerton University Hospital NHS Foundation Trust	✓
Chelsea and Westminster Hospital NHS Foundation Trust	✓
Imperial College Healthcare NHS Trust	✗
London North West University Healthcare NHS Trust	✗
The Hillingdon Hospitals NHS Foundation Trust	✓
King's College Hospital NHS Foundation Trust	✓
Lewisham and Greenwich NHS Trust	✓
Guy's and St Thomas' NHS Foundation Trust	✗
Croydon Health Services NHS Trust	✓
St George's University Hospitals NHS Foundation Trust	✓
Epsom and St Helier University Hospitals NHS Trust	✓
Kingston and Richmond NHS Foundation Trust	✓
University Hospitals Sussex NHS Foundation Trust	✓
East Sussex Healthcare NHS Trust	✓
Manchester University NHS Foundation Trust	✓
Northern Care Alliance NHS Foundation Trust	✗
Tameside and Glossop Integrated Care NHS Foundation Trust	✓
Bolton NHS Foundation Trust	✓
Blackpool Teaching Hospitals NHS Foundation Trust	✓
Bedfordshire Hospitals NHS Foundation Trust	✓
Milton Keynes University Hospital NHS Foundation Trust	✓
Mid and South Essex NHS Foundation Trust	✓
North West Anglia NHS Foundation Trust	✓
Frimley Health NHS Foundation Trust	✓
Royal Berkshire NHS Foundation Trust	✓
University Hospital Southampton NHS Foundation Trust	✗
Portsmouth Hospitals University NHS Trust	✗
Hampshire Hospitals NHS Foundation Trust	✓
Medway NHS Foundation Trust	✓
Dartford and Gravesham NHS Trust	✓
Leeds Teaching Hospitals NHS Trust	✓
Sheffield Teaching Hospitals NHS Foundation Trust	✓
The Newcastle Upon Tyne Hospitals NHS Foundation Trust	✓
University Hospitals Coventry and Warwickshire NHS Trust	✓
University Hospitals of Leicester NHS Trust	✓
Sandwell and West Birmingham Hospitals NHS Trust	✓
The Royal Wolverhampton NHS Trust	✓
Walsall Healthcare NHS Trust	✓
University Hospitals Birmingham NHS Foundation Trust	✗
University Hospitals of Derby and Burton NHS Foundation Trust	✓

Kettering General Hospital NHS Trust	✓
Northampton General Hospital NHS Trust	✓
Nottingham University Hospitals NHS Trust	✗
University Hospitals of North Midlands NHS Trust	✓
University Hospitals Dorset NHS Foundation Trust	✗
University Hospitals Bristol and Weston NHS Foundation Trust	✓
North Bristol Trust	✗
Liverpool University Hospitals NHS Foundation Trust	✓
Surrey and Sussex Healthcare Trust	✓
Ashford and St Peters Hospitals NHS Foundation Trust	✓
East and North Hertfordshire NHS Trust	✗
The Princess Alexandra Hospital NHS Trust	✓
West Hertfordshire Hospitals NHS Trust	✗
Norfolk and Norwich University Hospitals NHS Foundation Trust	✗
ICBs	
North East London ICB	✓
South East London ICB	✓
South West London ICB	✓
Sussex ICB	✓
Cambridge and Peterborough ICB	✓
Frimley ICB	✗
Buckinghamshire, Oxfordshire and Berkshire West ICB	✗
Kent and Medway ICB	✓
North East and North Cumbria ICB	✓
Black Country ICB	✓
Derby and Derbyshire ICB	✗
Staffordshire and Stoke on Trent ICB	✓