Jonathan Mann Clinic HIV Peer Navigator Service

Evaluation Report April 2024

POSITIVELY UK

HOMERTON SEXUAL HEALTH

This evaluation was authored by
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Foreward

The Jonathan Mann Clinic (JMC) at Homerton is a pioneering leader in developing and delivering a model of holistic, person-centred care, seen by many as the "Gold Standard" for today's health and care systems. This report, giving us high quality data on the value and impact of clinic-based, HIV specific peer support, is a crucial addition to the evidence base, enabling others to replicate best practice.

Why is this so important? When I began my medical career in 1984 almost everyone diagnosed with HIV died. Today, in 2024 in the UK almost everyone with HIV lives. Technical and biomedical advances have revolutionised HIV treatment and prevention.

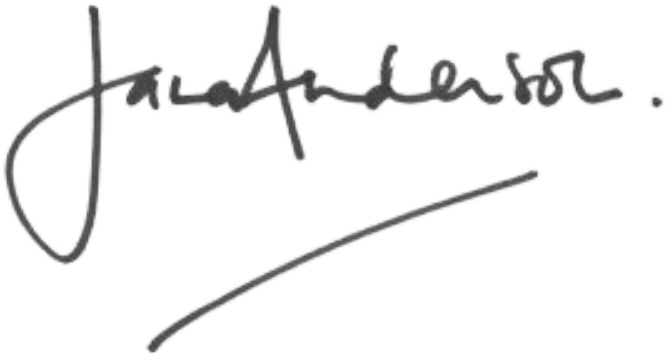
But what about the realities of living with HIV in 2024 and for the long-term? Public knowledge and attitudes lag far behind the technical advances and people with HIV must come to terms with what is still an incurable, stigmatising, complex long-term condition. People tell us that a diagnosis of HIV can make them feel fearful and isolated. HIV can cut people off from one another, interrupting intimacy, compromising self-worth and self-belief. The most up to date clinical expertise alone is not enough to solve the myriad problems that HIV presents.

The report explores how co-located, JMC based peer support, with a programme of work delivered from and for people living with HIV is fundamental to the care pathway. The central role of the lived experience of people with HIV within the team is transformative and, as this report describes, adds a critically important dimension. Because the peer introduction comes from within the safety of the clinic, people engage. As confidence rises, uptake of other services for people with HIV increases. Encouraging people's sense of self-worth and agency allows more involvement in other aspects of self-management and participation. Resilience is fostered and people's existing assets are maximised. The visibility of people living with HIV demonstrates the possibility of living openly and well with HIV, something that many people have never believed to be a reality. And visibility is a powerful tool in reducing HIV associated stigma, promoting a wider understanding of what it means to live with HIV. It is all this together that empowers every individual to navigate their particular journey with HIV.

What about the challenges? Appropriate and sustainable funding is highlighted as a critical threat. At the beginning the charity MACAIDS, saw the value and donated funds to get the service established. But now the JMC peer navigator service relies on ad hoc year by year fundraising. This is both a grave threat for the future and also diverts and undermines the team's capacity. It is my profound wish that this evaluation, demonstrating the enormously beneficial impact on both service users and providers of co-produced, partnership working will enable health and care commissioners to support this approach at Homerton, across our city and beyond.

Our shared ambition to end new HIV transmissions by 2030 and ensure best quality of life for people living with HIV will only succeed with this type of effective partnership working that has people living with and affected by HIV at the centre.

I extend my deepest gratitude to all those who have contributed to this report, in particular to the many people who shared their experiences and stories about living and working with HIV. Thank you to those who have funded, designed, and implemented the evaluation exercise, analysed the findings, and drafted such a comprehensive report. And a huge thank you to the people and organisations that have tirelessly worked to establish and sustain the peer navigator programme. It is a privilege to be a part of this work.



Professor Jane Anderson, CBE, PhD, FRCP

Professor Jane Anderson, CBE, PhD, FRCP is a London based physician and researcher (Homerton Healthcare NHS Foundation Trust, Barts Health NHS Trust and the London School of Medicine and Dentistry) who has worked in the field of HIV since the 1980s and has been a consultant at Homerton since 1990. Jane is co-chair of London's HIV Fast Track Cities Leadership Group, which works to stop new HIV infections, tackle HIV-associated stigma, see the end of preventable deaths from HIV and secure the best quality of life for Londoners living with HIV. Jane is Chair of The National AIDS Trust, the UK's HIV and Rights charity, and in 2023 she became Chair of Paintings in Hospitals, the charity that works to bring the power of the visual arts into the health and care sector. She is a past Chair of the British HIV Association.

Acknowledgements

We are grateful to the participants for taking part in this study and for allowing us to share their experiences. We would also like thank the Jonathan Mann Clinic and Homerton Healthcare NHS Foundation Trust for hosting the evaluation focus groups.

The Jonathan Mann Clinic would also like to thank the following partner organisations who worked closely with the Peer Navigator Service:

- Positive East
- The Helios Centre
- Alongside You
- Body and Soul
- The Food Chain
- Fast Track Cities
- Terrence Higgins Trust
- METRO Charity
- YMCA Positive Health Programme
- Birth Companions
- Hackney Children & Baby Bank
- Maternity Mates
- Living Well
- 4M Mentor Mothers
- NAM Publications (aidsmap)
- HIV i-Base

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Executive Summary

Introduction

People living with HIV commonly experience clinical and non-clinical comorbidities associated with HIV. These challenges highlight the need for peer support which promotes bio-psycho-social wellbeing for people living with HIV. This document reports the findings of an independent service evaluation of the Jonathan Mann Clinic HIV Peer Navigator Service.

Summary of Work and Impact

Two part-time Peer Navigators offered Peer Navigation clinics 5 days per week and offered one-to-one peer support for people living with HIV, providing support and guidance on a variety of issues. Additionally, the Peer Navigator Service supported nurse-led ward-based outreach activities, HIV specialist maternity teams, and hosted a monthly HIV 'Patient Forum.' Peer Navigators occupied a significant role in multidisciplinary team meetings and were a significant resource for the clinical team. Peer Navigators acted as patient advocates and provided the multidisciplinary team with the perspectives of people living with HIV.



HIV Peer Support Service Success

The Jonathan Mann Clinic HIV Peer Navigator service succeeded in achieving its initial aims set out at the initiation of the service, during the evaluation period. The service provided 2,209 consultations between 1st April 2021 to the 11th December 2023.

Recommendations and Future Needs

This evaluation recommends the following points for consideration in future service provision:

- Securing long-term funding of the Peer Navigator Service.
- A continued focus on secondary prevention/health promotion.
- Utilisation of demographic data provided in this report to tailor future activity.
- Increased Peer Navigator support to the HIV specialist maternity team.
- Linking with the Clinical Nurse Specialist home visiting team.
- Expansion and development of the Peer Navigator role in the service.

Introduction

HIV Epidemiology and Comorbidities

Globally, 39 million people live with a diagnosis of human immunodeficiency virus (HIV). [1] In England, a total of 94, 397 people living with a diagnosis of HIV received HIV care in 2022. There were 3, 805 diagnoses of HIV in England in 2022, a 22% increase since 2021. [2]

People living with HIV can access treatment in the UK. HIV treatment aims to reduce the viral load (amount of HIV present in the body) to 'undetectable' via blood test. This reduces the chance of someone living with HIV from becoming seriously unwell due to HIV complications and prevents the virus from being passed on to another person. [3] HIV treatment has evolved substantially since the first reported case of acquired immune deficiency syndrome (AIDS) in the UK in December 1981. However, despite substantial progress in treatment options, some people living with HIV today may still experience the impact of living with HIV on their health and wellbeing in their daily lives. [4] People living with HIV are at an increased risk of developing comorbidities such as cardiovascular disease, renal disease, diabetes and other metabolic conditions, pulmonary conditions, hepatic conditions, central nervous system conditions, bone conditions and issues relating to sexual function. People living with HIV also have an increased risk of developing mental health issues including anxiety and depression. [5]

Additionally, people living with HIV have an increased risk of developing cancer. The incidence of AIDS defining cancers (Kaposi Sarcoma, Non-Hodgkin's Lymphoma and Cervical Cancer), in people living with HIV has significantly declined since the introduction of antiretroviral therapy. [5]

Until recently, the incidence of non-AIDS defining cancers (Hodgkin's Lymphoma, Anal Cancer, Liver Cancer, Lung Cancer), remained higher in people living with HIV as compared to the general population, due to delayed starting of antiretroviral therapy. However, recent early research findings demonstrate that commencing antiretroviral therapy in all people living with HIV, at the earliest possible opportunity and regardless of CD4 count, has reduced the incidence of non-AIDS defining cancers in people living with HIV. This highlights the importance of antiretroviral education, timely commencement and adherence for all people living with HIV. [5]

People living with HIV may also experience additional challenges relating to antiretroviral therapy including drug resistance, drug related risks for co-morbidities, toxicity, and potential drug interactions. [5] People starting antiretroviral therapy (within the first six months of treatment) are also at a risk of developing immune reconstitution inflammatory syndrome (IRIS). [5]

Additionally, the complex, non-clinical social/welfare impact of living with HIV is significant with 46% of people receiving

treatment for HIV in the UK reporting a social/welfare need, and 62% of those people reporting that their needs remained unmet. [6] Furthermore, some people living with HIV might be diagnosed with HIV in another country and seek refuge in the UK for their own safety, but struggle to navigate the National Health Service (NHS), and/or may have uncertain immigration status and possibly no recourse to public funds. [6]

Stigma remains a significant and ongoing concern. People living with HIV sometimes experience stigma in health care settings and from the wider public. People living with HIV, who also belong to minority groups (such as men who have sex with men and African or Afro-Caribbean people) may have an increased risk of experiencing stigma. Stigma might also include self-stigma (internalised stigma), stigma from partners, and/or family. Additionally, stigma may lead to reduced engagement or disengagement from HIV clinical care and may also impact mental and social wellbeing. [7]

The Need for Peer Support

The complex bio-psycho-social challenges experienced by some people living with HIV highlight the need for promoting self-management strategies alongside peer support. The British HIV Association Standards of Care for People Living with HIV 8 (Standard 2, Self-management and Peer Support) advise that: *"In keeping with the management of other long-term health conditions, people living with HIV should be enabled to optimise self-management and access peer support opportunities to promote their physical and mental health, and overall well-being."*

Peer support describes a supportive relationship between two (or more) people who are living with HIV and where one person shares advice and knowledge with the other person/people. The sharing of advice and knowledge is often based on the peer's personal experience of living with HIV, alongside their individual strategies. [9]

Peer support for people living with HIV today, is rooted in the AIDS epidemic of the late 1980's, when early HIV activists formed community support groups, advocated, and lobbied for treatment, and shared emerging knowledge with their communities. [9]

Peer support for people living with HIV most commonly includes four key principles:

- Providing links and rapid access to medical/nursing care.
- Networking with community HIV resources/organisations.
- Social and emotional support.
- Support and encouragement of service users in their daily self-management. [10]

International studies report that peer support combined with routine clinic follow-up, compared with routine clinic follow-up only, demonstrated superiority in measurable outcomes, including antiretroviral adherence, viral suppression, CD4 count, and retention in care, alongside quality of life and mental wellbeing. [11]

Despite a significant body of evidence demonstrating the clinical benefits of

peer support for people living with HIV internationally, there is a paucity of literature relating to generalised peer support for people living with HIV in Europe, with only two European studies being published to date which discuss generalised HIV Peer Support. 1 study was undertaken in the Netherlands, [12] and 1 study was undertaken in Spain. [13] As far as we are aware, to date, nil studies have been published which relate to generalised HIV peer support for people living with HIV in the United Kingdom. However, 1 study discussing specialised maternity support only (trained volunteer mentor mother peer support) in England has been published. [14]

About the Peer Navigator Service

Peer support, referred to as The Peer Navigator Service in this evaluation, is a joint project between Positively UK who recruit, employ, and train Peer Navigators, and the Jonathan Mann Clinic where the Peer Navigators provide support to people living with HIV.

Positively UK

Positively UK is an organisation that was founded in 1987 by two women living with HIV. In response to the lack of peer-led services for women living with HIV, the two women began providing support services from their own homes under the organisation named Positively Women.

Over time, and in response to the increasing need for support across multiple communities, the organisation has continued to evolve and grow. Today, the organisation is known as Positively UK. It provides peer-led support, advocacy, and information to all people living with HIV, alongside their work to shape and influence policy in the UK. Positively UK first piloted peer mentoring programmes in 2012. Currently, Positively UK provide outreach peer support in several clinics across London including the Jonathan Mann Clinic, at the Homerton University Hospital. Positively UK, also published the UK National Standards for Peer Support in HIV. [9] These standards provide a benchmark for best practice in peer support for people living with HIV.

Jonathan Mann Clinic

The Jonathan Mann Clinic for HIV Care and Treatment is situated within the Clifden Centre at Homerton University Hospital. The clinic opened in 1996 and was originally known as the Symonds Clinic. The name of the clinic changed in 2014, following a rebranding to reflect the emphasis of the clinic's person-centred approach to supporting people living with HIV.

Today, the clinic employs a multidisciplinary team to provide holistic care to people living with HIV including Peer Navigators, Social Care Co-Ordinators, Doctors, Nurses, Health Advisors, Community Specialist Nurses, Inpatient Ward Liaison Nurses, Pharmacists, Specialist HIV Midwives, Psychologists, Psychiatrists, Dieticians, and Dermatologists. Additionally, the clinic enjoys relationships with community based and voluntary organisations.

Peer Navigator Service

The Peer Navigator Service commenced in 2012, following the introduction of a Social Care Co-ordinator role in 2010. The Peer Navigator Service was originally funded by the MACAIDS foundation, which provided 100% of the total funding for the initial 6 years of the project. Today, the project is funded by MSD (2023 Grants Programme) for 85% of the total service cost (Grant Agreement Reference: UKGHH-SOP-0010H) and by the NHS Blood Borne Virus Screening Programme in Emergency Departments at 15% of the total service cost.

Peer Navigation Service Aims

The following Peer Navigator Service Aims were developed at the initiation of the service in 2012:

- Increase patient engagement.
- Encourage adjustment to HIV diagnosis.
- Connect patients to HIV community services.
- Assist patients to navigate through healthcare systems.

Peer Navigator Role at the Jonathan Mann Clinic

The Peer Navigators are employed by Positively UK and based at the Jonathan Mann Clinic provide peer support as part of the multidisciplinary team. The Jonathan Mann Clinic is currently supported by two Peer Navigators who are employed at 0.6 full time equivalent (FTE). They offer Peer Navigation Clinics five days per week. Peer Navigators provide a wider range of support to people living with HIV to promote physical, psychological, and social wellbeing. Common reasons for multidisciplinary team referral and self-referral into the service are detailed in the results section of this evaluation, but typically include supporting people living with HIV with the following:

- A new diagnosis of HIV.
- Psycho-social needs (including adjustment to diagnosis/isolation/loneliness/mental health/immigration/work).
- Financial and housing needs including advocacy and support with applications, or referrals to external organisations such as food banks.
- Domestic abuse.
- Stigma (including self-stigma).
- Treatment adherence.
- Secondary prevention of comorbidities and promotion of physical wellbeing, including referrals to external organisations such as gyms, nutritional programmes, and holistic therapies.
- Nurse-led ward-based outreach activities.

The Jonathan Mann clinic provides dedicated rooms for the Peer Navigator Team. All appointments are held in this private space, to ensure confidentiality and promote a feeling of safety for service users. Additionally, Peer Navigators record all consultation notes in the service user's medical record. This promotes multidisciplinary team communication and continuity of care.

An additional unique and specific focus of the Peer Navigation service at the Jonathan Mann Clinic is the provision of maternity support to pregnant people.

Pregnancy in people living with HIV is considered a 'complex pregnancy,' with medical management largely focusing on the prevention of vertical transmission of HIV. People living with HIV who are pregnant, may face additional challenges such as real or perceived stigma, [15] alongside clinical complexities relating to potential vertical HIV transmission, which may limit their choices relating to delivery and neonatal feeding. [16]

Pregnant people living with HIV desire a normalised maternity experience which both reduces the risk of vertical transmission of HIV to the neonate, but also allows for a holistic, patient centred, and positive experience for the pregnant person. [15] Clinical guidelines advise vaginal delivery including water births should be supported (where clinically safe to do so). However, controversy remains around choice of feeding method. Bottle feeding is considered to be the safest method due to zero risk of ongoing transmission, however guidelines advocate supporting people who chose to breast feed (where clinically safe to do so). People who chose to breastfeed must be informed of the low risk of HIV transmission and the need for additional neonatal monitoring. [16] The Jonathan Mann Clinic employs an HIV specialist midwife who is able to support people in achieving their chosen birth plan and provide support in neonatal feeding. Alongside the multidisciplinary team, their knowledge and experience of HIV contributes to creating a positive maternity experience. [15]

Additionally, a specialist Peer Navigator, utilising their own experience of pregnancy and childbirth, provides support to pregnant people as recommended by the British HIV Association clinical guidelines. [16] Support includes reducing anxiety around vertical transmission of HIV, promoting informed decision making around delivery and feeding methods, and encouraging antiretroviral therapy adherence which contributes to the clinical safety of vaginal birth and breast feeding.

Additionally. Peer Navigators act as advocates and in some cases as chosen birth companions during delivery. People who are advised or choose not to breastfeed, are provided with free milk formula vouchers by the Peer Navigators. [16] Additional practical, social, and financial support is provided by Peer Navigators including referrals to other specialist organisations.

The Jonathan Mann Clinic holds specialist multidisciplinary team meetings (MDT) to ensure the provision of optimal care for service users with additional and specialist needs, such as the Psychosocial MDT and the Maternity MDT. The Psychosocial MDT aims to ensure joined up working between psychosocial practitioners who are supporting service users with complex care needs. It is attended by Psychologists, Clinical Nurse Specialists, Health Advisors, and the Social Care Co-Ordinator. The Maternity MDT aims to ensure safe, patient centred, and holistic pre-natal and post-natal care for pregnant people living with HIV. It is attended by Paediatric Doctors, Obstetric Doctors, HIV Specialist Doctors, HIV

Specialist Pharmacists, the Social Care Co-ordinator, and Specialist Midwives. The Peer Navigators attend all multidisciplinary team meetings relating to the provision of care for all people living with HIV.

Alongside, the provision of peer support for people living with HIV, the Peer Navigators are a significant resource for the clinical team, providing the team with the perspectives of people living with HIV, and challenging stigmatising behaviour.

In addition to the provision of one-to-one support of people living with HIV and the contribution Peer Navigators provide to the multidisciplinary team, the Peer Navigators host a monthly 'Patient Forum.' The patient forum is a dual-purpose, group-based social and educational meeting. It aims to act as a social support group for service users, as well as promoting wellbeing through knowledge sessions relating to living well with HIV, and the medical treatment of HIV. The Patient Forum is hosted at the Jonathan Mann Clinic. The Patient Forum is held in a private meeting room within the hospital estate.

Peer Navigator Training and Supervision

All Peer Navigators receive training. Peer Navigator training is delivered by Positively UK. The training includes a 3-day NVQ Level 2 qualification. The programme structure includes the following key topics: defining mentoring, boundaries and safeguarding, communication skills, discussing HIV with others, HIV treatment and transmission, motivational interviewing skills, goal setting and action planning, and monitoring outcomes.

Upon completion of the training, Peer Navigators undertake a 2-week induction in the Jonathan Mann Clinic. Peer Navigators are required to have a Disclosure and Barring Service (DBS) screening and undertake regular mandatory training including adult safeguarding. Ongoing support is provided by the Social Care Co-ordinator who supervises the Peer Navigators, providing regular monthly supervision and ongoing support as required. Peer Navigators also benefit from external supervision, which is arranged by Positively UK. Additionally, Peer Navigators attend monthly case supervision meetings with all of the peer support workers at Positively UK. This provides Peer Navigators with an opportunity to share their own expertise and simultaneously to learn from other peer support workers. This is particularly helpful when dealing with complex cases, where sharing of specialist knowledge and resources is beneficial.

About the Evaluation

The evaluation was conducted by Jonny Edwards (Clinician and Researcher) on behalf of the Jonathan Mann HIV Clinic and Positively UK between December 2023 and April 2024. It covers the period of the HIV Peer Navigator Service 1st April 2021 to the 11th December 2023. The purpose of the evaluation was to:
1) Provide a summary and evaluation of work undertaken by the HIV Peer Navigator Service.
2) Provide a summary of the impact of the HIV Peer Navigator Service on service users compared to the service objectives.
3) Collect and reflect on feedback that may improve the service.

Evaluation Funding

This evaluation was funded by MSD (Grant Agreement Reference: UKGHH-SOP-0010H).

Method

The Jonathan Mann Clinic and Positively UK partnered with Jonny Edwards, in December 2023, to undertake an evaluation of the Peer Navigator Service. Work was undertaken to decide on the aims of the evaluation and identify any existing gaps in data collection. Qualitative data was then collected between 31st January 2024 and 1st February 2024. Data for evaluation was collected from the following sources:

- Positively UK Service User Outcome Data.
- Jonathan Mann Clinic Staff Focus Group.
- Peer Navigator Focus Group.
- Service User Focus Groups.

Service User Data

Data relating to service users was collected by Positively UK between 1st April 2021 to the 11th December 2023. This data was provided to Jonny Edwards, which was reported by Salesforce. The data provided a detailed analysis of anonymised demographic data of each consultation, provided by the Peer Navigator Service.

Focus Groups

Four focus groups were undertaken which included: 1 Jonathan Mann Clinic Staff Focus Group, 1 Peer Navigator Focus Group, and 2 Service User Focus Groups. All focus groups were conducted face-to-face by Jonny Edwards and were undertaken at the Jonathan Mann Clinic. Topic guides were developed prior to focus groups to provide a semi-structured, flexible approach to discussions. Participants were provided with a Participant Information Sheet.

The participants verbally consented to the recording of the focus group discussions. A verbal consent method was chosen to increase accessibility for participants. All participants verbally consented to their information being used in evaluation dissemination activities such as publications, reports, and conferences. Verbal consent was recorded. Participants were advised that they could freely withdraw from the evaluation at any point and that their personal information would not be used in the study. Focus groups lasted one

hour, and service users were reimbursed for their time and travel. 22 service users were recruited; however, 1 person did not attend. In total, 21 service users participated in the focus groups. 1 Peer Navigator Focus Group was held on the 31st January 2024 (4 participants). 2 Service User Focus Groups were held on the 1st February (11 participants) and 1 Jonathan Mann Clinic Staff Focus Group was held on the 1st February (6 participants).

Ethics

Formal ethical approval via an ethics committee was not obtained (formal ethical approval is not required for service evaluations). [17] However, the evaluation was carried out ethically and in accordance with United Kingdom law. The evaluation adhered to the Declaration of Helsinki. [18] Data was stored in accordance with The Data Protection Act. [19]



Results (Service User Demographics and Referral Data)

Data Limitations

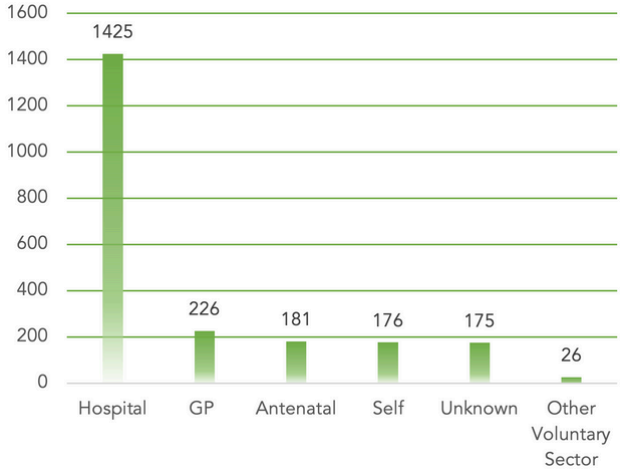
Due to restricted availability of clinic data, the following results represents service user data for individual consultations, rather than an analysis of the service user cohort. It is probable that an individual service user may have had multiple consultations. Therefore, one service user may represent multiple data points within the following analysis. Consequently, the results should be interpreted as most common demographic groups to attend individual consultations, as opposed to an analysis of demographic groups amongst the clinic's registered service user cohort.

Typical Service User Profile

Service users attending consultations were most likely to be referred in-house from clinicians at the Jonathan Mann Clinic (65%). Service users were mostly likely to identify as Black African ethnicity (64%) and hold UK nationality (32%). Typically, service users were Female (73%), and Heterosexual (81%), and were most likely to be Unemployed (59%). Service users were usually aged in their mid-forties (average age 47 years old) and were most likely to have received a diagnosis of HIV in the previous 0-5 years (27%), or 15-20 years (24%).

Sources of Referral

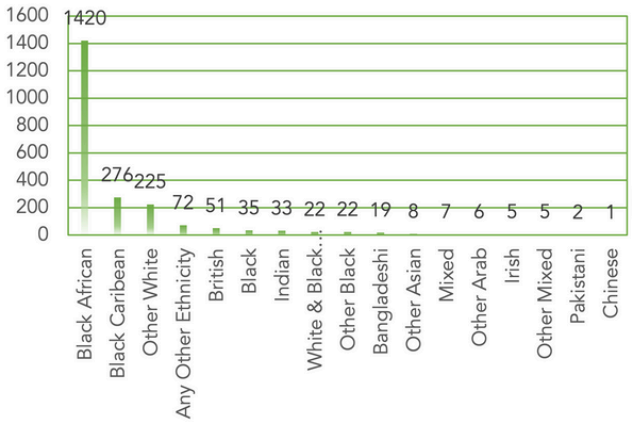
In total, there were 2,209 consultations provided by the Peer Navigator Service between 01/04/2021 and 11/12/2023. Sources of referral included: 1,425 in-house hospital sexual health clinic referrals (65%), 226 GP referrals (10%), 181 referrals generated as a result of antenatal testing (midwifery) (8%), 176 self-referrals (8%), and 26 referrals from other voluntary organisations (1%). 175 referrals were from an unknown source (8%).



In-house hospital referrals from clinicians at the Jonathan Mann Sexual Health Clinic represented the largest proportion of referrals (65%).

Ethnicity

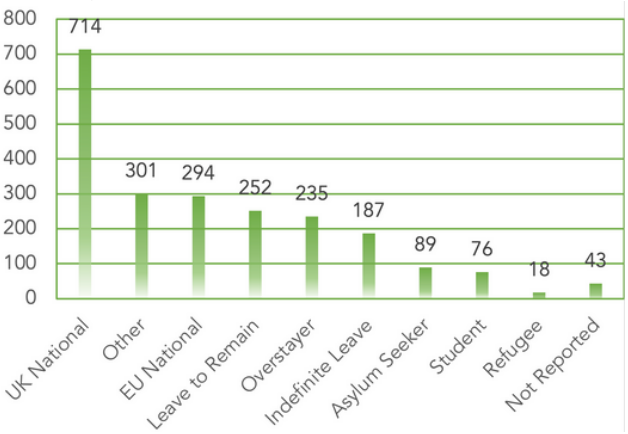
The service provided consultations to service users whose self-reported ethnicities included: 1,420 Black African service users (64%) and 276 Black Caribbean service users (12%). 225 service users identified as Other White (10%) and 72 service users identified as Any Other Ethnicity (3%). There were 51 British service users (2%), 35 Black service users (2%), 33 Indian service users (1%), and 22 White and Black Caribbean service users (<1%). There were 22 service users who identified as Other Black (<1%), 19 Bangladeshi service users (<1%), and 8 service users who identified as Other Asian (<1%). 7 service users identified as Mixed (<1%) and 6 service users identified as Other Arab (<1%). There were 5 Irish service users (<1%), 5 service users who identified as Other Mixed (<1%), 2 Pakistani service users (<1%), and 1 Chinese service user (<1%).



Service users who identified as Black African represented the largest proportion of service users attending consultations (64%).

Immigration Status

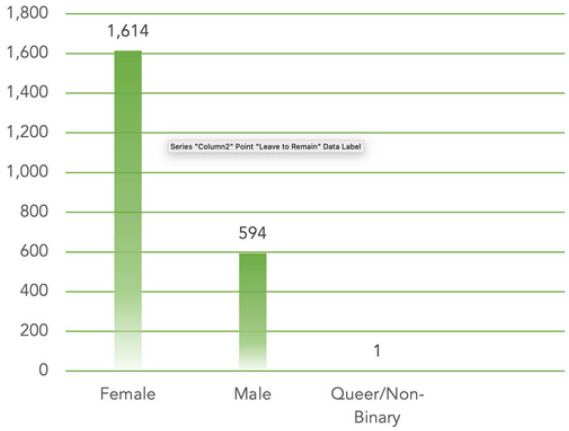
The Peer Navigator Service provided consultations to service users whose self-reported immigration statuses included: 714 United Kingdom nationals (32%), 301 Other nationalities (14%), 294 European Union nationals (13%), 252 service users with Leave to Remain (fixed term) (11%), 235 services users who had overstayed (11%), 187 service users with Indefinite Leave to Remain (8%), 89 Asylum Seekers (4%), 76 Students (3%), and 18 Refugees (1%). 43 service users did not report their immigration status (2%).



Services users who were UK nationals represented the largest proportion of service users attending consultations (32%).

Gender

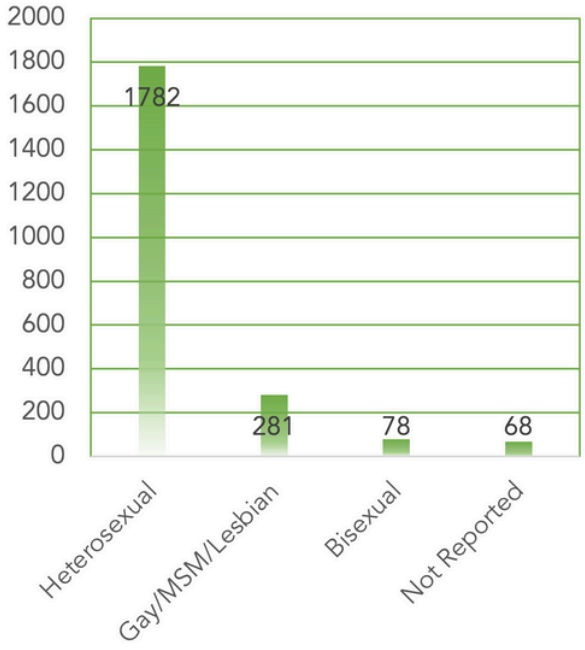
The Peer Navigator Service provided consultations to service users whose self-reported gender included: 1,614 Female service users (73%), 594 Male service users (27%), and 1 Queer/Non-Binary participant (<1%).



Service users who identified as Female represented the largest proportion of service users attending consultations (73%).

Sexuality

The Peer Navigator Service provided consultations to service users whose self-reported sexuality included: 1,782 Heterosexual service users (81%), 281 Gay/MSM/Lesbian service users (13%), 78 Bisexual service users (4%), and 68 service users who did not report their sexuality (3%).

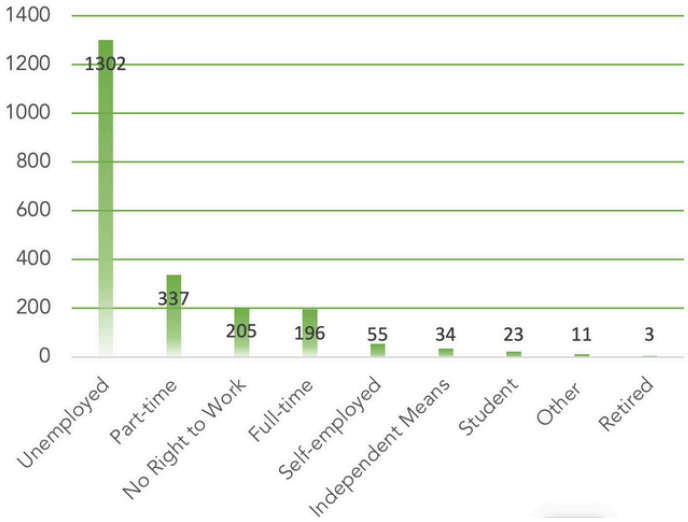


Service users who identified as Heterosexual represented the largest proportion of service users attending consultations (81%).

Employment Status

The Peer Navigator Service provided consultations to service users whose self-reported employment status included: 1,302 Unemployed service users (59%), 337 Part-Time service users (15%), and 205 service users with No Right to Work (9%). 196 service users were in Full-Time Employment (9%), 55 service users were Self-Employed (2%), 34 service users had Independent Means (2%), and 23 service users were Full-Time Students (1%). 11 service users reported their employment status as Other (<1%) and 3 service users were Retired (<1%).

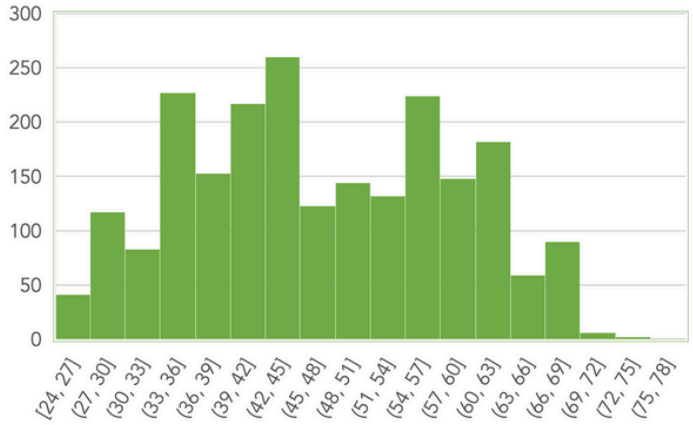
43 service users did not report their employment status (2%).



Service users who were Unemployed represented the largest proportion of service users attending consultations (59%).

Age

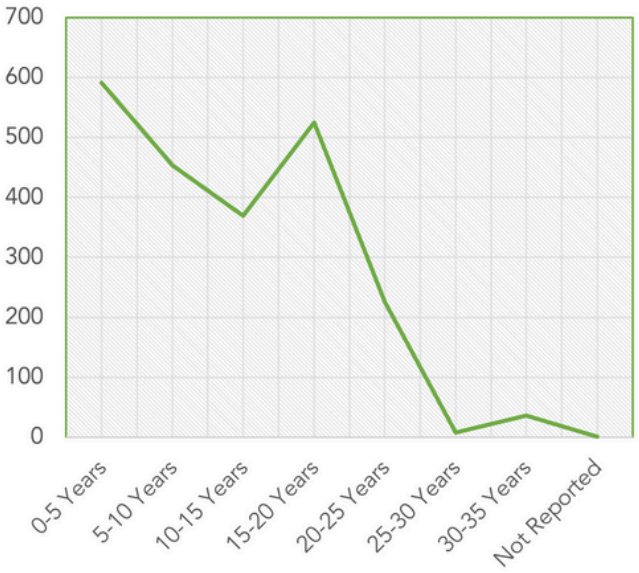
The Peer Navigator Service provided consultations to service users whose self-reported age included: 41 service users aged 24-27 years old (2%), 117 users aged 27-30 years old (5%), and 83 service users aged 30-33 years old (4%). 227 service users aged 33-36 years old (10%), 153 service users aged 36-39 years old (7%), and 217 service users aged 39-42 years old (10%). 260 service users aged 42-45 years old (12%), 123 service users aged 45-48 years old (6%), and 144 service users aged 48-51 years old (7%). 132 service users aged 51-54 years old (6%), 224 service users aged 54-57 years old (10%), and 148 service users aged 57-60 years old (7%). 182 service users aged 60-63 years old (8%), 59 service users aged 63-66 years old (3%), and 90 service users aged 66-69 years old (4%). 6 service users aged 69-72 years old (<1%), 2 service users aged 72-75 years old (<1%), and 1 service user aged 75-78 years old (<1%).



Service users who were aged 42-45 years old represented the largest proportion of service users attending consultations (12%), followed by service users were aged 33-36 years old (10%), 54-57 years old (10%), and 39-42 (10%). The average age of service users attending consultations was 47 years old.

Time Since Diagnosis

The Peer Navigator Service provided consultations to service users whose self-reported time since diagnosis included: 591 service users who had received a diagnosis in the preceding 0-5 years (27%), 453 in the preceding 5-10 years (21%), 369 in the preceding 10-15 years (17%), 525 in the preceding 15-20 years (24%), 226 in the preceding 20-25 years (10%), 8 in the preceding 25-30 years (<1%) and 36 in the preceding 30-35 years (2%). 1 Service user did not report time since diagnosis (<1%).



Service users who had received a diagnosis in the last 0-5 years represented the largest proportion of service users attending consultations (27%) followed by service users who had received a diagnosis in the preceding 15-20 years (24%).



Results (Focus Groups)

Staff Motivation to Refer into Peer Navigation Services

Common reasons for clinical staff at the Jonathan Mann Clinic to refer into to the in-house Peer Navigator Service included the following:

- People who had received a new diagnosis of HIV and/or are new to the clinic.
- Migrants and people with no recourse to public funds or who needed support with immigration applications.
- People who had social and/or financial needs such as support with an application for social housing, white goods, or food banks.
- Support with reading letters or completing forms for people with low levels of literacy, or whose first language is not English.
- Pregnant people, during the antenatal period who wished to discuss delivery options, feeding options, and any concerns relating to potential HIV transmission during labour.
- Pregnant people in the post-partum period who required support with milk vouchers/equipment or referral to pregnancy/family specific support groups.
- People who were experiencing stigma and/or self-stigma, or who needed support in discussing their diagnosis with family, friends, or work colleagues.
- People who were experiencing domestic abuse and/or intimate partner violence.
- People who were experiencing loneliness or isolation.
- People who were experiencing poor mental health.
- Challenges with adherence to HIV medication, particularly where clinicians felt there may be underlying social needs.
- Support for clinical staff during clinical outreach activities such as visiting acutely unwell patients on the ward.
- People who benefited from ongoing psycho-social support, for short-term period during adjustment to diagnosis, or long-term support for people with complex needs.

> ***"Often patients with mental health problems do not have recourse to public funding, may not have work, usually have a mouldy single bed house, and sometimes have a very violent partner (Clinician)."***

> ***"She was late because she had to walk because she didn't have money for the bus. She hadn't taken her insulin that morning because she didn't have any food left to eat (Clinician)."***

> ***"If you haven't got a roof over your head, your priority is not to take your medications, it is where are you going to sleep that night (Peer Navigator)."***

"People who are so scared about other people finding out about their diagnosis, and can't live their life, they won't apply for a job, and their life is stuck (Clinician)."

"When I have a patient on the ward who is newly diagnosed and unwell, it is powerful to introduce them to somebody who is living with HIV and who is well. Because, at that moment, they think they are never going to get better (Clinician)."

"The Peer Navigators know all of the resources that are out there for people depending on their need (Clinician)."

"I link really closely with Peer Navigators, and always offer peer navigation support at the first patient visit and explain about their roles and what they can offer (Clinician)."

Service User Motivation to Access Peer Navigator Services

Common reasons for service users to access the Jonathan Mann Clinic in-house Peer Navigator Service included the following:

- Support with mental health.
- Support with housing.
- Access to support in obtaining white goods/small financial grants.
- Resource of local service knowledge.
- Information and support with breast feeding.
- Support during pregnancy.
- Support with childcare.
- Referral to foodbanks.
- Isolation and loneliness.

"To get support around my mental health during the lockdown (Service User)."

"I got to point that I felt suicidal. I was going through so much and was on the verge of just giving up on life (Service User)."

"I left my real world, and I found myself in a strange place (Service User)."

"I felt like I was sinking, I said I have had enough, I am thinking about giving up (Service User)."

"I just felt that I had had enough, and it was better just to die. Just stop taking my medication - that was a short cut for me. I didn't see the point (Service User)."

"I was very depressed with the way the housing situation was. I couldn't get any help with the Council (Service User)."

"The doctor referred me to the Peer Navigator Team, mainly to do with housing (Service User)."

"They have all the information from solicitors, to massage, to where to go for counselling. They are just on top of everything (Service User)."

"My first contact with Peer Navigators was when I was pregnant. I wanted to make the decision to breast feed my baby. For a long time, you couldn't breast feed. Things were changing and I wanted to be able to breast feed my child (Service User)."

"I was feeling very lonely and isolated (Service User)."

Removing the Patient-Clinician Barrier

Peer Navigators provided an opportunity for people to have conversations with non-clinical staff, who were trained to support people living with HIV. The removal of the patient-clinician barrier through the sharing of lived experiences with Peer Navigators, often enabled people to discuss personal and intimate information, which was often pertinent to their clinical care. Peer Navigators offered an extended time to talk, which enabled service users an opportunity to process complex information and ask questions in a safe space.

"Having a peer navigator brings out that honesty and gets rid of the patient-clinician barrier (Clinician)."

"That relationship that they are able to build with someone that is not clinical, it's good for them to have that sideways step of a peer, that they can have discussions with and be open with, in ways that they may find difficult with a health care professional (Clinician)."

"Most of our non-adherent patients come to the clinic for Peer Navigator appointments but miss their medical appointments, which says a lot about the value of the service to them (Clinician)."

"A doctor or nurse will provide a lot of information about medication, but very little is decoded and remembered by patients, because of stress impacting memory. So, a longer time with Peer Navigators where listening is combined with telling to reiterate is important (Clinician)."

"Just to speak to someone who has been on that journey (Clinician)."

"It's difficult for medical staff to be believed by patients sometimes (Clinician)."

"I felt more comfortable sharing what I was going thorough, with someone who is in the same position as myself, compared to someone who is different (Service User)."

"They are able to make you feel so very welcome and you feel as if you are not being a burden. They are like a friend, a normal person, who can help me better (Service User)."

Continuity of Care

Multidisciplinary staff members and service users reported that Peer Navigators increased continuity of care. In-house Peer Navigator team members provided an extra link between hospital services and service users which increased two-way communication and internal information sharing which supported the provision of holistic, patient centred care.

> ***"I know there is continuity in patient care (Clinician)."***

> ***"They follow you throughout the entire process, when you don't even know that you are being looked after. Even though there are so many of us, whenever I approach one of the Peer Navigators, they seem to know exactly what is happening. It is so nice to know that you are being thought of, looked after, and cared for (Service User)."***

> ***"As soon as I walked in, they knew what I had spoken about with the doctor. I didn't need to go through it again (Service User)."***

> ***"You can go away, and look after yourself, and come back when you need to. They are there if you need them (Service User)."***

The Impact of the Peer Navigator on the Wider Multidisciplinary Team

The benefits of employing Peer Navigators were not limited to the service users themselves but extended to the clinical members of the multidisciplinary team. All staff members commented on the invaluable contribution that Peer Navigators bring to the multidisciplinary team. Collaboration and team working with Peer Navigators were highly valued by clinicians. This was particularly evident in discussions relating to the holistic management of service users with complex psycho-social needs, where staff valued the opportunity to seek advice and share ideas with Peer Navigators.

Clinicians explained that the addition of Peer Navigators to the multidisciplinary team, reduced time spent by clinicians on non-clinical tasks, such as supporting patients with social needs, and enabled them to focus on the provision of clinical care. The expert knowledge of local HIV specific services combined with the Peer Navigator's lived experience of HIV was seen as a vital contribution to the team. Peer Navigators acted as a source of knowledge, but also as advocates and representatives of the HIV community within the multidisciplinary team meetings.

> ***"We work very closely as a team throughout the clinic (Clinician)."***

> ***"It's always about collaboration (Clinician)."***

“The more complex patients are, the more likely that we deal with that together (Clinician).”

“They are so approachable, easy to talk to, and just get advice from really (Clinician).”

‘We look at the same person from a different angle (Clinician).”

“It gives us space to actually sit, and think, and to share ideas as to what is helpful (Clinician).”

“The time saving that Peer Navigators provide, is enormous (Clinician).”

“Peer navigators inform the practice of the wider team (Clinician).”

“Peer Navigators take that knowledge and bring it to the multidisciplinary team meetings (Clinician).”

“I am a great advocate of them (Clinician).”

“We learn from them; they learn from us (Clinician).”

Supporting Service Users Receiving a New Diagnosis

Consultations for people who had received a new diagnosis of HIV, represented a significant portion of workload for Peer Navigators. 27% of service users (largest proportion of service users attending consultations) had received a diagnosis in the last 0-5 years.

Multidisciplinary team members and service users highly valued the peer support provided to people who had received a new diagnosis of HIV. Peer Navigator appointments were offered very soon after diagnosis, sometimes on the same day, where required. The Peer Navigators provided people with a real-world example of a person living well with HIV and challenged myths about HIV. Peer Navigators supported people to adjust to their diagnosis, both in the immediate period following diagnosis and during the long-term period of adjustment required after receiving a diagnosis of HIV.

"We have a big impact on newly diagnosed people (Peer Navigator)."

"Every person with a new diagnosis is encouraged to see a Peer Navigator (Clinician)."

"Some people are hit like a ton of bricks by the diagnosis, and that's where peer support comes in (Clinician)."

"We still meet people who are absolutely devastated (Clinician)."

"With new diagnosis there is the shock involved (Clinician)."

"It was hard for me to accept my new identity. My whole life collapsed (Service User)."

"My world came to an end (Service User)."

"Everything just went blank (Service User)."

"At the time of diagnosis, if they had told me to come back two weeks later to go and see somebody, more than likely my mother would have buried me. Because I would have taken tablets, I would have just killed myself (Service User)."

"The Peer Navigators are often available to see (newly diagnosed people) straight away. It doesn't stop the shock, it doesn't stop the questions, but it does give patients the sense that people do live normal lives with HIV now (Clinician)."

"If someone is newly diagnosed, they don't just want to hear from the doctor about the diagnosis. That peer is really important. They want it that day, to talk to someone about the diagnosis (Clinician)."

"They are the lived experience of what you are going through or what you might go through (Service User)."

"From day one that you are diagnosed, you start a journey, you start a different journey of life, and you can't do without them (Service User)."

"Myth busting with a physical example is really powerful (Clinician)."

"The way that that day is handled, in terms of the people who support you, in terms of your belief that you can move past that and return to your whole self is vital (Peer Navigator)."

"It just calms them straight away (Clinician)."

"It's tangible, you can sense that a weight has been lifted-okay there is hope here (Clinician)."

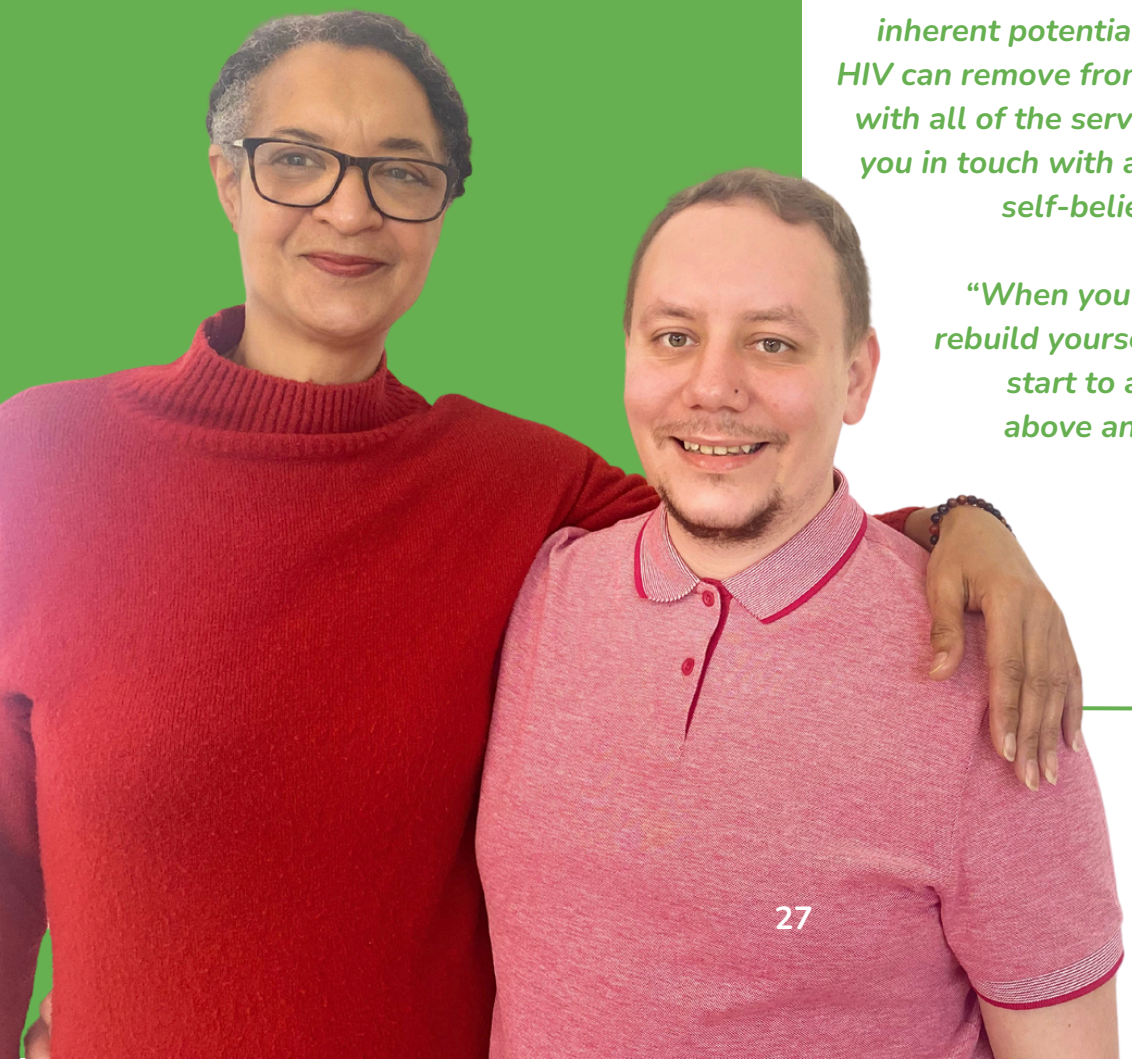
"At least for me, having them was really, really important-a complete game changer (Service User)."

"It's so refreshing to know that someone is able to experience peer navigation and benefit in the way that I have (Service User)."

Overcoming Stigma Through Empowerment

HIV related stigma from partners, friends, family, colleagues, and the wider public, alongside self-stigmatisation, was a challenge for many people accessing the Peer Navigator Service. For some people, stigma had a significant impact on their lives, including social isolation, withdrawal from their community, and poor mental health. Peer Navigators empowered people by challenging incorrect beliefs about HIV, mentoring through example, and supporting people on their journey to acceptance.

"There is so much that you can learn that is beneficial as a human being, through living with HIV. It's a challenge that you meet and, in some sense, overcome (Peer Navigator)."



"I was fighting my own stigma (Service User)."

"I still had that gravestone image in my head from the 80's and 90's (Service User)."

"A patient would bleach herself before her granddaughter came, for fear of HIV transmission-she doesn't do that anymore (Peer Navigator)."

"Having a Peer Navigator, helps you to at least be at ease with your own stigma (Service User)."

"It was because of the help and the confidence that I built through here, that I had that encouragement to tell my mum (Service User)."

"As Peer Navigators we are here to say, there is not any ambition, nor any inherent potential that you have, that HIV can remove from you. If you engage with all of the services that we can put you in touch with and just rebuild your self-belief (Peer Navigator)."

"When you realise that you can rebuild yourself, and actually just start to achieve maybe even above and beyond what you thought was possible before diagnosis-it's a lot to be proud of (Peer Navigator)"

Promoting Psychological Wellbeing

Mental health issues were common amongst service users accessing the Peer Navigation Service, with people often experiencing a mental health crisis and sometimes experiencing suicidal thoughts. Peer Navigators were able to share their own lived experiences of the psychological impact of living with HIV and provided service users with empathy and compassion. Peer Navigation enabled service users to discuss their situations and explore strategies to improve their wellbeing. The service acted as a safety net for people in crisis, often reducing the risk of self-harm. This was always supported by rapid referrals to clinical and psychological support services at the Jonathan Mann Clinic. Additionally, service users felt secure in the knowledge that the Peer Navigation Service would be an ongoing place of support into the future.

> *"I couldn't really see the light. I was suicidal. I was just about to do it and somehow, by accident, I made contact with them (Service User)."*

> *"You can feel very alone in what's happening to you and you can think no one will understand and no one will appreciate it, and you feel as if you can't express your feelings (Service User)."*

> *"Speaking to someone who was in the same boat as me, it was two of the Peer Navigators, who gave me a lot of support. It got me back to being able to carry on (Service User)."*

> *"I came and I met other people that were going through the same thing that I was going through. They understood what was happening (Service User)."*

> *"They make you feel like a whole person (Service User)."*

> *"It made a huge difference to my mental health and confidence (Service User)."*

> *"They went out of the way at the time that we had difficulties to get an appointment for counselling (Service User)."*

> *"I am not feeling suicidal anymore. I have really benefitted so much, and it has helped me to adhere to my medication, because I was giving up (Service User)."*

> *"Without Peer Navigation, guidance, and this new family, it would be very difficult for me to continue (Service User)."*

> *"The Peer Navigator removes all of the risk of hurting yourself (Service User)."*

> *"Each time I am sinking, I just fall back to the Peer Navigators (Service User)."*

Promoting Financial Wellbeing

Service users benefitted from a variety of financial support from the Peer Navigators including help with achieving and remaining in employment, referrals to external organisations such as foodbanks, applying for grants, and advocacy on behalf of service users. Peer Navigators also referred to external organisations such as the Positively UK/Positive East Welfare Service who provide specialist welfare support to people living with HIV. Both Positively UK and Positive East provided in-clinic specialist welfare advice and support.

> *"I have support with work (Service User)."*

> *"I can't describe how much help I have received, finding a job, creating a CV, having job interviews (Service User)."*

> *"They really helped me with a lot of things such as with foodbanks when times were tough, and I couldn't feed my children (Service User)."*

> *"I applied for white goods, and they turned me down. The Peer Navigators appealed on my behalf, and we won the appeal (Service User)."*

Promoting Social Wellbeing

Many service users experienced isolation and loneliness as a result of receiving a diagnosis of HIV, as well as difficulties discussing living with HIV with family, friends, and colleagues. The Peer Navigation Service acted as a resource linking people living with HIV to support groups and organisations that specialise in promoting social networking.

> *"I came here new. I had no friends and I felt lonely. So, the Peer Navigator introduced me to someone from Positively UK (Service User)."*

> *When I had problems with a relationship, I got support from them (Service User)."*

> *"I couldn't even contact my old friends. I built up a wall around me deliberately. I wanted to be by myself. I didn't want anybody to see me. Gradually, that was overcome and since then I joined several groups (Service User)."*

> *"My social life has improved exponentially. It's impossible to describe (Service User)."*

> *"They signposted me to different organisations that helped me with childcare at weekends (Service User)."*

> *"That's where Peer Navigation comes into its own, because it really connects you to other resources outside (Service User)."*

Promoting Physical Wellbeing

Promoting physical wellbeing, as part of a holistic approach to the clinical management of patents living with HIV was a key function of the Peer Navigator team. Peer Navigators viewed the promotion of wellbeing alongside secondary prevention of potential HIV related complications as essential in supporting people's adjustment to a diagnosis of HIV. Peer Navigators often provided referrals to gyms and exercise programmes, nutritional education programmes, and to complementary therapy clinics. Additionally, Peer Navigators empowered people to develop confidence in self-care through education. Furthermore, Peer Navigators acted as advocates, liaising with clinical staff to raise medical problems with clinicians on behalf of service users.

> *"Helping people to create a greater understanding of how-to self-care (Peer Navigator)."*

> *"There is more to HIV than just taking a pill, there is more to wellbeing than just taking a pill (Peer Navigator)."*

> *"My diet is much more balanced. I eat the right portion of protein, vitamins, and minerals (Service User)."*

> *"They challenge you to look after yourself (Service User)."*

> *"My gym membership was recommended (Service User)."*

> *"I was struggling with the medication."*

> *"The Peer Navigator passed this information to the doctor, and she gave me a new medication (Service User)."*

> *"It has been a great help for the Peer Navigator to be able to liaise with the doctor about a particular issue (Service User)."*

Supporting Service Users in Pregnancy

Peer support for pregnant people was a unique and specialist focus of the Jonathan Mann Clinic Peer Navigator service. Staff explained that people accessing their services had often experienced negative and traumatic experiences during earlier pregnancies, and often had little input into their birth plans and choice of feeding modality. Peer Navigators empowered women to make choices about their pregnancy, labour, and feeding options. This was achieved through education such as the discussion of clinical research and the sharing of personal experiences. Peer Navigators often attended midwife/medical appointments and in some instances attended births, when requested to do so. Peer Navigators were also able to provide practical support through the provision of baby formula vouchers and breast-feeding equipment. This is a non-means tested offering which is made available to all pregnant patients living with HIV and receiving maternity care at the hospital. Additionally, the team provided referrals to pregnancy support groups/ organisations and to family-focused organisations that supported parents who were living with HIV.

"There is a lot of anxiety around pregnancy and HIV (Peer Navigator)."

"The journeys are individual; some women have easier pregnancies than others (Clinician)."

"Every woman that gets pregnant is always worried about transmission (Peer Navigator)."

"There was a history of positive women having caesareans or formula feeding (Peer Navigator)."

"I have done the homework. I have done the breastfeeding. Breastfeeding is something that was taken away from me before and I wanted to take it back. You feel like there is no bond with your child, so it was really important to me (Service User)."

"They gave me leaflets to read about breastfeeding research (Service User)."

"Empowering women to be as involved in the decisions that are in their realm to make (Peer Navigator)."

"I have supported many women to choose to breastfeed (Peer Navigator)."

"Balancing low medical risk and a women's need to have a fuller experience of birthing and nurturing their baby (Peer Navigator)."

"Some of the women nominate a Peer Navigator to stay with them during labour (Receptionist)."

"Some of the women don't have anything when they come in and find out that they are pregnant (Receptionist)."

"Just a fantastic support. In the past Peer Navigators have accompanied women that I am looking after to appointments to do with housing, or a benefits appointment, and that's just not something that I could offer within my role as a midwife (Clinician)."

"Because of the excellent care they receive at the Jonathan Mann Clinic for HIV, they want to have their baby here because they trust the team, and they know the team (Clinician)."



Supporting Migrants

Many of the people who accessed the Peer Navigator service were migrants, some of whom did not have leave to remain in the United Kingdom, and therefore no recourse to public funds. A significant proportion of service users attending consultations had overstayed (11%), were asylum seekers (4%), or refugees (1%). Many had experienced trauma during the migration process and often experienced significant financial hardship. Peer Navigators provided a trusted resource to migrant people and often supported people with adjusting to life in the United Kingdom, medication, applying for grants, referrals to food banks, and other social assistance. In some instances, Peer Navigators referred people to legal charities to support people with immigration applications, and often provided literacy support to people whose first language was not English.

> *"A lot of people who have been through the migration process have been let down by the officialdom and come with so much trauma (Peer Navigator)."*

> *"Many of our patients are migrants, so It's not just HIV adjustment, it's a bigger adjustment: new country, new society, new culture (Clinician)."*

> *"A lot of people are diagnosed late with HIV because of immigrations issues, they are too afraid to access healthcare services (Peer Navigator)."*

> *"Peer Navigators create a level of trust that that person has not felt before in this country (Peer Navigator)."*

> *"Often the change can be remarkable, especially for women who are new to the country. They came with nothing and to see how Peer Navigators support them through that transition-it's really nice to see (Clinician)."*

> *"Peer navigators come in and show them the way to move forward (Receptionist)."*

> *"He made me feel so familiar with everything, I felt it wasn't going to be difficult. It was going to be very easy to live here and have all the support that I needed for medical problems (Service User)."*

> *"I got help with food because I can't work (Service User)."*

> *"They helped me with my immigration, how to take medication, and even talk to my husband about my diagnosis (Service User)."*

The Patient Forum

For many, the Patient Forum, represented more than a clinical service. It offered HIV focused education alongside a community and a place to be their authentic selves and to feel safe. The Patient Forum offered an opportunity for people to give and receive support to, and from peers.

> *"Every forum is different to the last one (Service User)."*

"Experts will come in and talk to us about medication, our diet, and lifestyle, and being able to live well with HIV, and not let it overwhelm us (Service User)."

"Someone from pharmacy came to give a talk. They informed us about the types of medication, what is in each medication, and which medication interacts with other medication (Service User)."

"We had a session about stigmatising language. It was very informative (Service User)."



"We get information every time we have a patient forum (Service User)."

"The medication talks and information that we get during the forum has been so great because it allows me to understand a bit more about what is happening (Service User)."

"They cover such a wide range of topics-no two weeks are the same. It's a rest for the next month. We look forward to it. We make friends, we make acquaintances, and we meet people who are going through the same thing (Service User)."

"You feel very at home and like you can be yourself (Service User)."

"You can share and unburden (Service User)."

"It gives you more personal power to make more decisions (Service User)."

"I don't feel that I am alone (Service User)."

"It lets you regroup (Service User)."

"You look forward to that one Tuesday in the month (Service User)."

Positive Feedback about the Peer Navigator Service

Feedback about the service from multidisciplinary team members and service users was overwhelmingly positive, with participants holding the service in high regard. Service users discussed the often life changing impact that the Peer Navigator Service had on their lives, and reflected on feelings of being looked after, and part of a community or family. Peer Navigators often brought hope to people who were experiencing significant personal challenges. Service users expressed their feeling of satisfaction and gratitude for the Peer Navigator Service.

"I just feel so very lucky (Service User)."

"I couldn't ask for more (Service User)."

"They are really, really brilliant (Clinician)."

"Invaluable (Clinician)."

"We have the best service (Service User)."

"Its excellent (Service User)."

"Life giving (Service User)."

"Oxygen for your mind (Service User)."

"The work they do is incredible (Clinician)."

"I don't think they realise how valuable they are to us (Service User)."

"I don't know what I would have done without a Peer Navigator (Service User)."

"They have done such an amazing job for my life (Service User)."

"Peer Navigators changed my life (Service User)."

"Peer Navigators have been my lifeline (Service User)."

"They look after us when we don't even know (Service User)."

"You come in and they give you all the information that you haven't even asked for. They think of you and it's so lovely. You never feel pressured, you can always make a choice (Service User)."

"The time that they give to us, it's so fulfilling, you feel like you belong. It's like family, you can't undo a family (Service User)"

"That fear in your heart, that problem you have, you just drop it (Service User)."

"There is hope, Peer Navigation gives you hope (Service User)."

"I am so satisfied with what they are doing (Clinician)."

"I couldn't be more grateful. I feel so privileged for what has happened (Service User)."

"I thank the Peer Navigator team endlessly (Service User)."

"Thank you to Professor Anderson, wherever she is (Service User)."

Preference of In-House Provision of Peer Navigator Support

All of the participants who participated in this evaluation stated a preference for the provision of in-house Peer Navigator services compared to external services provided outside of the organisation. In-house presence removed potential barriers to attendance, through established trust with the Jonathan Mann Clinic and the ease of access to in-house Peer Navigators. The in-house Peer Navigation Service supported clinicians, reduced barriers to access, supported follow-up and continuity of care, and enabled a person-centred approach.

"In-house presence is essential (Clinician)."

"It is essential that Peer Navigator services are embedded in a clinic (Clinician)."

"The Peer Navigators are very, very good to have in this clinic (Clinician)."

"We are lucky to have the Peer Navigators here to help the patient though their journey (Clinician)."

"Every clinic should have services like the Jonathan Mann Clinic (Clinician)."

"Quick exchange between clinicians, which doesn't happen with external services (Clinician)."

"We are a bridge between the HIV community and the clinic (Peer Navigator)."

"Having somebody on-site - even to just run things by them (Clinician)."

"To have them on-site - it's so much richer for us as clinicians (Clinician)."

"Just to have a service under one roof (Clinician)."

Recommendations for Future Service Provision

Participants who took part in this evaluation, strongly supported the continuation of the Peer Navigator service within the Jonathan Mann Clinic, and also wanted to see the Peer Navigation model introduced into other clinics across the UK and internationally. Participants felt that hospitals and clinics should provide Peer Navigator Services as standard and view the service as a health promotion/prevention programme. Unsecure funding of the service was a concern for all participants, with recommendations for seeking secured funding identified as priority.

Recommendations for future clinical service provision included: extending the peer support maternity offering and providing Peer Navigation as routine and an integral part of antenatal care and

supporting the Clinical Nurse Specialist on home visits.

Additionally, clinicians were keen to utilise Peer Navigators in extended roles such as undertaking quality improvement activities, outreach activity to people who are currently not engaged in care, and roles in research and promotion of the Peer Navigation model.

Furthermore, educational activity outreach activities to clinicians from other specialities (such as primary care), would be highly valuable in reducing stigma and supporting clinicians to support people living with HIV in other clinical areas.

"It should definitely continue (Service User)."

"Every hospital should have something like this (Clinician)."

"Put it in every hospital (Service User)."

"This should be widespread across the UK (Peer Navigator)."

"The whole system should be set up how it is here (Service User)."

"We have got to make known the model and then we have got to fund the model (Clinician)."

"I would like hospitals to own this (Clinician)."

"It should be looked upon as a preventative programme (Peer Navigator)."

"We are just stringing together charity funding to make this good thing happen (Clinician)."

"Adequate wage, part of the NHS service (Clinician)."

"More funding and more hours for the Peer Navigators (Clinician)."

"Guaranteed funding for them (Clinician)."

"Have Peer Navigators seeing women a couple of times in pregnancy, maybe at the beginning and end as part of routine care (Clinician)."

"Linking with Clinical Nurse Specialist/Outreach service (Clinician)."

"A role for Peer Navigators to drive research and quality improvement (Clinician)."

"I would like to see more advocacy, talks, papers, and conference presentations by Peer Navigators (Clinician)."

"It should be funded as a statutory service within the NHS (Peer Navigator)."

Overall Project Achievements and Impact

This evaluation analysed the service achievements and impact by comparing the service's activities and outcomes with the service's initial aims. The results of this evaluation demonstrate that during the evaluation period (1st April 2021 to the 11th December 2023), the Peer Navigator Service has achieved its initial aims, which were developed at the initiation of the Peer Navigator Service in 2012. In total 2,209 episodes of care were provided by the Peer Navigator Service during the evaluation period.

Evaluation findings demonstrate that Peer Navigators helped remove the patient-clinician barrier and provided a vital and sometimes life-saving service for service users who were often in crisis. Peer Navigators supported people by promoting physical, psychological, social, and financial wellbeing. Peer Navigator's also supported people to overcome self-stigma, stigma from family members/partners, and stigma from wider society.Peer Navigators also provided specialist support to pregnant people and provided much needed supported to migrants who often had no recourse to public funds. Additionally, Peer Navigators had a significant role in the support of people receiving a new diagnosis of HIV. Aside from the significant and direct patient benefits, Peer Navigators supported the continuity of clinical care and occupied a significant role in the wider multidisciplinary team. Peer Navigators reduced the non-clinical workload for clinicians and enabled clinicians to focus on medical tasks. Feedback from evaluation participants was overwhelmingly positive, with all participants supporting the continuation of the service. This evaluation demonstrates the significant and ongoing need for the continuation of the Peer Navigator Service.



Recommendations for Future Service Provision

Peer Navigators, clinicians, and service users reported their concerns regarding the unsecure funding arrangements of the Peer Navigator Service. This evaluation demonstrates the significant benefit that Peer Navigation provides to both Service Users and the multidisciplinary team. This evaluation therefore encourages commissioners, hospital management, governmental and non-governmental organisations to support the ongoing delivery of the service through the provision of secure funding arrangements.

Peer Navigator's occupy a unique role as non-clinical members of the multidisciplinary team. Evidence reported in this evaluation demonstrates their ability to positively influence service users' wellbeing, by removing the patient-clinician barrier. This evaluation demonstrated the significant impact that Peer Navigators had on service users' physical and mental health. This evaluation therefore recommends a continued focus on promoting wellbeing and the prevention of comorbidities through the promotion of wellbeing, and lifestyle interventions (through workshops and one-to-one support) and supporting adherence to medication.

Demographic data provided in this report should be used to support the design of future interventions and service delivery. For example, 59% of consultations were for unemployed service users. Service users who are medically fit and would like to return to work may benefit from targeted workshops designed to support people living with HIV to return to work, which may further promote individual wellbeing. [20]

Peer support is currently offered to pregnant people as an additional option by clinicians. However, the clinical team felt that moving forwards, peer support should be included as routine, and an integral part of antenatal care, with Peer Navigators attending routine antenatal appointments. This evaluation recommends considering this development within the context of clinical need, alongside a consideration of the current availability of Peer Navigators.

Clinicians suggested that a potential future expansion of the role, might include supporting the Clinical Nurse Specialist on home visits with service users who are unable to attend clinic. This evaluation recommends considering this development within the context of operational and clinical need, alongside a consideration of the necessary compliance requirements, such as insurance.

Clinicians were keen to utilise Peer Navigators in extended roles such as undertaking quality improvement activities, outreach activity to people who are currently not engaged in care, and roles in research and promotion of the Peer Navigation model. Additionally,

clinicians felt that educational outreach activities to clinicians from other specialities (such a primary care), would be highly valuable in reducing stigma and supporting clinicians to support people living with HIV in other clinical areas. This evaluation recommends considering the operational need of these developments, and where necessary recommends appropriate training and support to enable Peer Navigators to undertake these extended roles.



Recommendations for Clinics Considering Introducing Peer Navigation

Alongside this document's purpose as an evaluation of the service, it is intended that this document will act as an introductory guide to other clinics and services considering introducing peer support services.

Key Recommendations:

- Seek secure and continued funding for the duration of the service to avoid premature discontinuation of the service, and/or interrupted provision of support to service users.

- The efficacy of Peer Navigation is highly dependent on the interpersonal relationship between the Peer Navigator and service user. As such, the recruitment process and selection of team members is vital for the success of the service. We recommend that interview panels should include Peer Navigators as key decision makers, and that recruiters prioritise communication skills and empathy when evaluating potential candidates.

- Peer Navigators require peer navigation training and should also comply with mandatory training (such as safeguarding), and legal/professional compliance requirements such as Disclosure and Barring Service (DBS) screening.

- Onward referrals to external agencies and partner organisations are a key part of the Peer Navigation process. Therefore, networking with organisations who offer specialist support in relevant areas is vital.

- Consider the source of potential inbound referrals and inform them of the service and the support that it can provide. This might include in-house sources (sexual health clinics, maternity departments, emergency departments, acute wards) and external agencies (GP's, charities), alongside self-referral.

- Embrace Peer Navigators as part of the multidisciplinary team. Educate clinical and other team members about their role, encourage Peer Navigators to attend multidisciplinary team meetings, and create a safe space for Peer Navigators to act as service user advocates and representatives of the HIV community.

- Ensure that Peer Navigators have access to the service user's medical record, and any relevant mandatory training relating to medical records access. This will enable Peer Navigators to document interventions

which will encourage multidisciplinary team working and provide continuity of care.

- Provide Peer Navigators with a dedicated confidential space for consultations.

- Engage in ongoing collection and analysis of service user demographics and regular qualitative service evaluations to ensure that the services and interventions meet the needs of service users.



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