Progress report for Brighton & Hove Towards Zero HIV Taskforce

1.1 Background

Brighton & Hove (B&H) became a Fast Track City, the first FTC in the UK, just over 5 years ago. This status has provided us with the infrastructure to accelerate the journey and better measure progress towards ZERO HIV stigma, ZERO new HIV infections and ZERO deaths from HIV within the city. Being a part of the Fast Track Cities Initiative has given us an opportunity to become more connected with other UK Fast Track Cities, share best practice and support each other through joint initiatives. As a direct consequence of being a FTC we were visited by the HIV Commission to gather evidence which informed the National HIV Action plan; have been visited by Winnie Byanyima, the Executive Director of UNAIDS; Maria Caulfield, Conservative MP for Lewes and lead minister for Sexual Health and HIV during HIV testing week (2022), all of which provided media and awareness raising opportunities to tackle stigma, improve knowledge and start conversations.

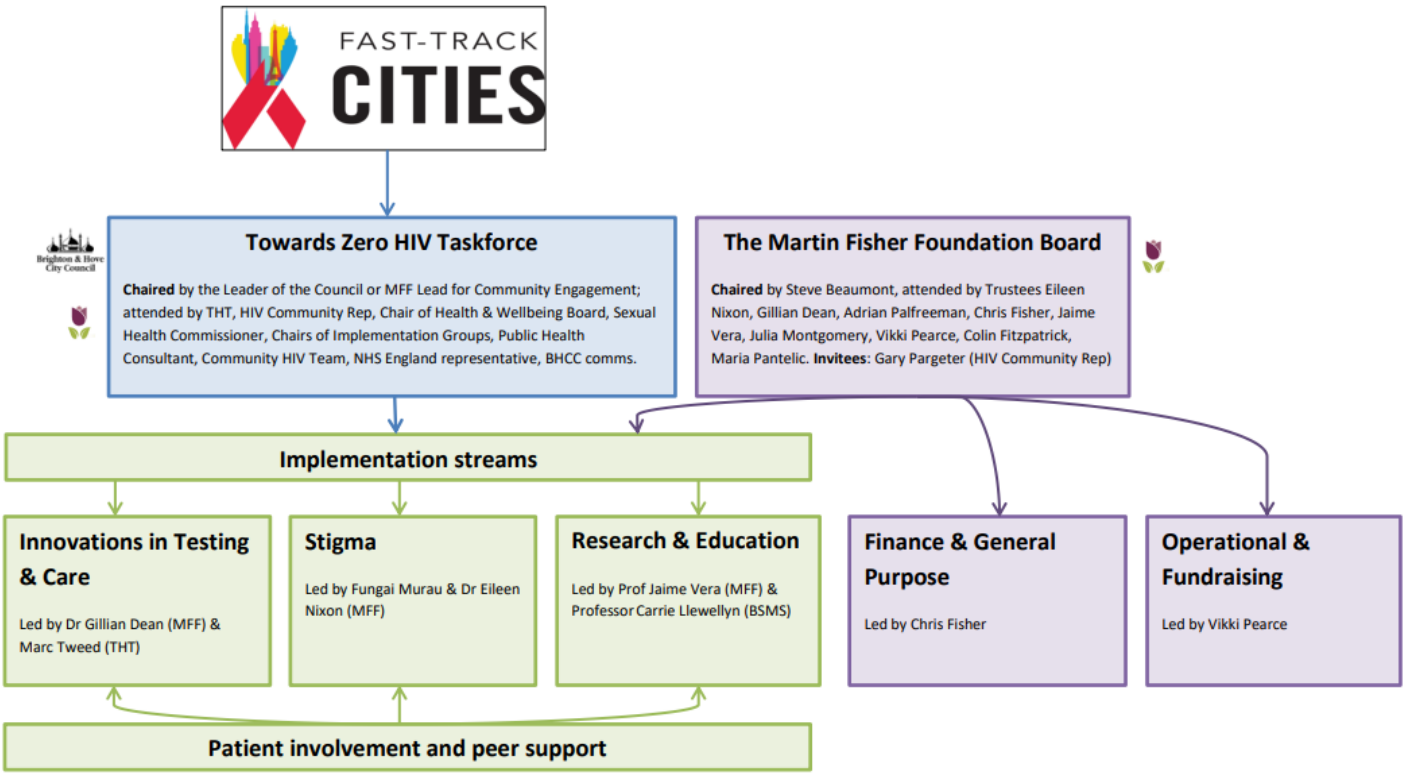
The Taskforce has provided a mechanism for us to intensify HIV prevention and treatment efforts, and ensure all key players are involved, aligned and working together towards the common goals:

- To improve patient involvement and peer support
- To deliver innovations in HIV testing and care
- To increase research and education
- To eliminate HIV-related stigma

The National HIV Action plan released in December 2021 sets out four core themes: Prevent, Test, Treat, Retain. In B&H we have been focused on these aspects of HIV prevention and care for many years now, and progress in these areas is illustrated in this short report. We are fortunate in this city to have an exceptionally well-developed community and voluntary sector working closely with B&H City Council as well as integrated clinical services (HIV/sexual health) unimpeded by tendering due to effective and sensitive commissioning for last 20 years. The clinical service has a long history of national and international research, innovation, and joined up approach across all sectors, listening to and working with the patient group and the community has always been paramount.

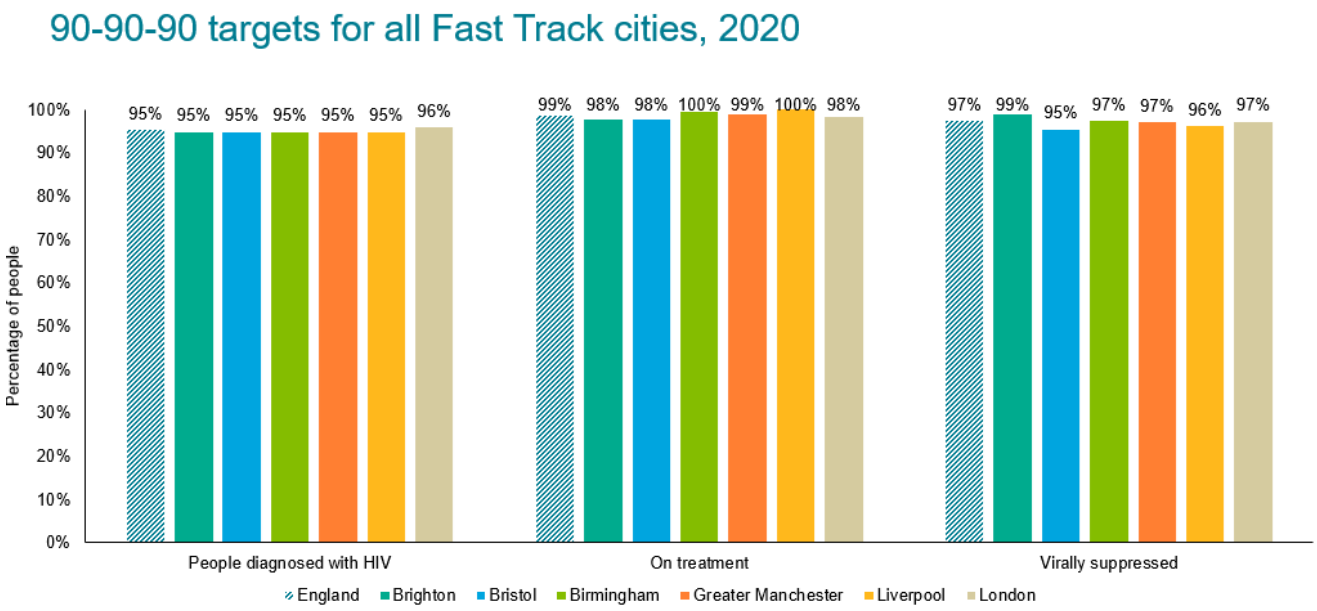
1.2 Structure

The Taskforce meets quarterly and is jointly chaired by either the Leader of the Council or the Martin Fisher Foundation lead for community engagement. Broad membership with many viewpoints and perspectives ensures issues are progressed effectively. Working collaboratively and in partnership, people with HIV are actively involved within the strategic and delivery processes; drawing upon their lived experience and connectedness to the communities we aim to reach.



1.3 Data

Nationally UKHSA provide us with annual data comparing across the six FTCs in England. It is noteworthy that since becoming a FTC the local data quality and ability to monitor progress has improved substantially. Data relating to new diagnoses are collected in real time, as well ongoing clinical and virological outcomes. For all new cases missed testing opportunities are recorded and raised supportively with the practice or department concerned. A previous late diagnosis 12-month audit in 2018/9 showed £332,803 extra costs incurred by late diagnosis for just 8 patients.



We have also developed baseline metrics to enable us to monitor progress towards zero HIV stigma and conducted a detail audit of HIV deaths as one of the key 'getting to zero' targets is to reach 'zero HIV related deaths' by 2030. From 2017 to 2020 there were 75 deaths; the cause of death was ascertained for 99%; only 5 (7%) were HIV related (2 AIDS-malignancies, 1 pneumocystis pneumonia (PCP), 1 progressive multifocal leukoencephalopathy (PML), 1 untreated HIV) which compares to 18% nationally. However there were 24 (32%) potentially preventable non AIDS deaths: 20 due to lifestyle risk factors; smoking (8) alcohol excess/substance misuse (12); suicide (2); complications of HCV infection (2), indicating there is more work to do. In 2021, there were 25 deaths, of which 8 were due to non-AIDS cancers, and none were HIV-related.

1.4 The social value of being a Fast Track City

Active involvement of the local third sector has been central to strategic planning, delivery and development of outputs, as well as reaching out to residents. Participant organisations are wide ranging, including those led and delivered by, or expressly supporting PWHIV. Over **2,000 volunteering hours** have been given during the year towards planning and delivering Fast Track City activities. New volunteering roles have been created, involving and empowering PWHIV and the wider community. New and additional voluntary activity has been undertaken by individuals, community groups and local charities, many of these small and micro-organisations, who have now incorporated greater awareness of HIV and Fast Track City strategy into their mission.

Examples of practice, impact, and learning from the delivery of activities have been shared with the wider Fast Track City network. They have also been widely disseminated within the local community and voluntary sector demonstrating examples of collaborative working, patient and public voice, innovating models of delivery and reach within communities experiencing health inequalities. This sharing has contributed to the overall robustness of the voluntary sector, and this expertise has been expressly called upon to contribute towards the development of the role and voice of the voluntary sector within integrated health structures

PWHIV voice and representation has been increased, together with a significant growth in understanding and reach of intersectionality. PWHIV voice and representation has given opportunity to influence wide-ranging local policy. With clear messaging and greater alignment of HIV and other organisations towards strategic goals, there has been sustainable expansion of HIV community engagement within the voluntary sector, increased testing to unreached groups, raised HIV awareness, reduced HIV stigma; and improved societal, social and health outcomes for PWHIV.

1.5 Co-design & co-production (to be added)

Strengthening links – sharing learning – social value

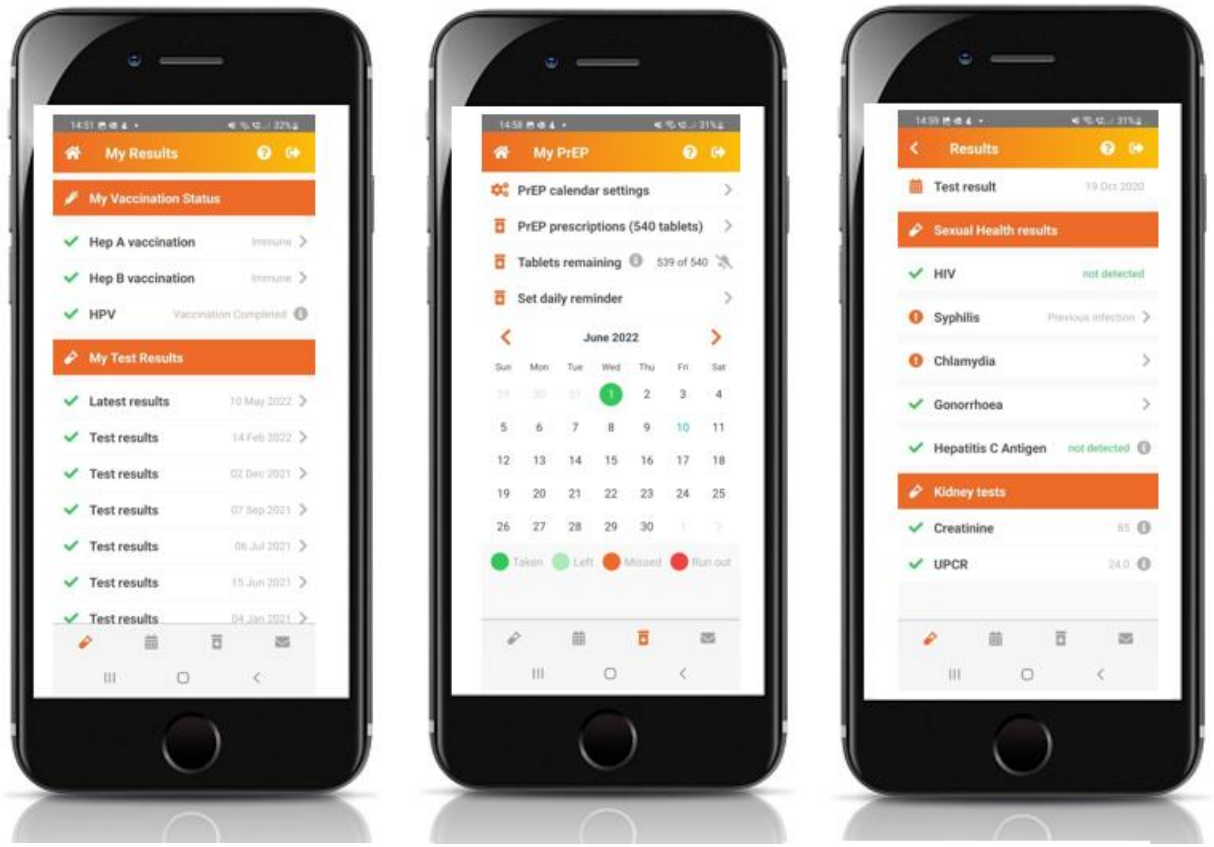
PREVENT

2.1 Pre-exposure prophylaxis (PrEP)

Over the last five years the PrEP landscape has changed significantly for the better. In 2017 potential users either had access to a very limited number of research places (IMPACT study) or had to import their own drugs, often taking medication without monitoring. In October 2020 PrEP was commissioned by NHS England and since this time the service has flourished and numbers of incident (new) infections in users become a rarity. By the end of June 2022, 1844 individuals were receiving PrEP through SHAC (60%/40% daily/event based); this means we have a PrEP uptake rate of 85% (1844/2169) in men who have sex with men (MSM) and bisexual males attending SHAC services.

2.2 Pre-exposure prophylaxis application (PrEP app)

The PrEP app has been co-designed locally and is currently being rolled out for the remote management of PrEP (stage 1). The platform provides secure access to STI/blood results, appointments and medication information (when the last script was issued, how many remaining tablets) and allows reminders for daily/event based therapy, and communication with clinical services. For 395 users without co-morbidities or vulnerabilities face-to-face follow-up has reduced to 6-12 monthly. Evaluation shows high levels of acceptibility and usability. Stage 2 (once funded) will again be co-created with users and will aim to utilise digitally enabled pathways to improve access for seldom seen groups in non-clinical settings, which again will improve capacity and provide alternative options in the menu of care.



2.3 PrEP2U

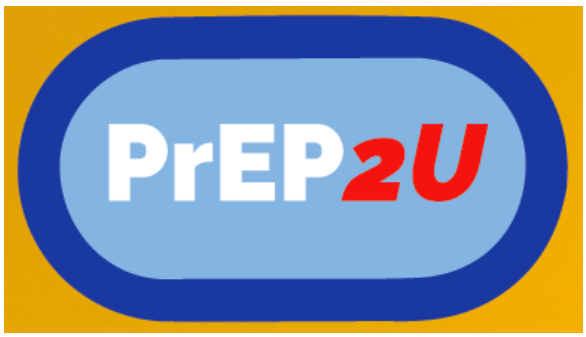
A co-designed partnership between the clinical services and THT saw the launch of a community HIV-PrEP service aimed at marginalised communities in Apr 22. THT outreach workers identify people from key populations (transgender community, hidden/silent MSM, racially minoritized communities, people experiencing homelessness) aiming to reduce barriers to healthcare and inequalities. Attendance at this weekly one-stop-shop service is facilitated; early data (n=52) shows that the majority were PrEP naïve, have not previously accessed services and seek partners online or at sex on premises venues. The service has created destigmatised experience of sexual healthcare which supports (re)engagement with mainstream services and reduces triggers linked with previous traumatic healthcare associated events.

The PrEP co-design team sought to understand the experiences of people who prefer not to access NHS sexual health services due to lack of trust and safety, as well as other recognised accessibility issues. This together with clinical and community experiences of supporting people during Covid-19 and the move to remote care caused by lockdown, made the team acutely aware of people for who experience barriers to accessing care.

Digital health service innovations can deepen health inequalities through the digital exclusions they produce. The EmERGE PrEP team recognised they needed an equal and parallel effort to reach people who have complex needs, have a distrust of mainstream services, are digitally excluded, or prefer not using digital services. Learning from the digital transformation of services that occurred during lockdown showed that strong, place-based community connections are vital for ensuring that people who are isolated and cannot (or prefer not) to use digital technologies to access care remain supported and able to access health services. Existing local networks of community groups ensured that people with complex needs and people excluded by the rapid move to digitally supported, remote care remained connected to care and support.

Based on their learning about the importance of reach and the impact of digital inequalities the PrEP EmERGE team developed the PrEP2U community care pathway and co-delivered a face-to-face service. Using their knowledge of care pathway, the co-design team have created a service via which people can access the whole PrEP pathway – from testing to prescription and medication collection – in a community setting rather than in clinic. The service has been designed and promoted to people who are least likely to use mainstream sexual health services recognising that it is these people who are likely to experience compound and complex inequalities.

Terrence Higgins Trusts experience of supporting people to access sexual health services and use PrEP shows us that groups who fall outside those normally highlighted through population-based analysis of HIV incidence, who may benefit from using PrEP, are often invisible when using quantitative, survey-based methods. Combinations of intersecting behaviours, practices and identities that change over time, together with being clinic-adverse means that identifying people who may benefit from PrEP requires alternative strategies.



TEST

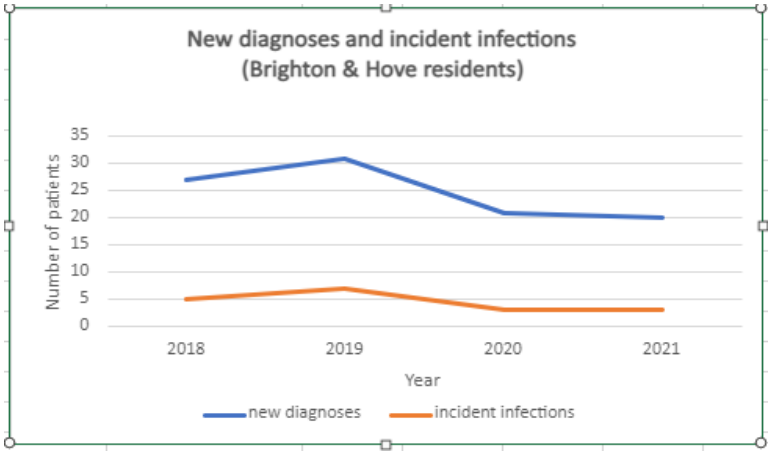
3.1 Expanding HIV testing

Our long-term goal of introducing Emergency Department opt-out testing was realised in April 2022 as a direct result of the recommendations made by the HIV Commission, followed by the National HIV Action Plan and associated funding announcement in Dec 2021. This project has raised the HIV profile within University Hospitals Sussex NHS Trust. Hepatitis B and C screening will be introduced later in 2022. In 2021/22 with funding from Gilead, we are piloting NICE guidance - that all people having blood tests in primary care should be offered an HIV test - in three Primary Care settings (Wellsbourne Health Centre, Pavilions Surgery, Brighton Health and Wellbeing Centre). This has been done with no additional workload for GPs, and simply entails the phlebotomist offering an HIV test and taking an extra vial of blood. In April 21 we also secured funding to incorporate opt-out HIV testing as part of the glandular fever screen bundle requested by GPs and secondary care. However there remains much work to be done to normalise testing in ALL settings to reach the undiagnosed.

To encourage self-testing we continue to expand the digital vending machines across the city which are now available at eight convenient locations across B&H. Further testing options in the community are clearly signposted across the city, and two decades of systematic education in primary and secondary care (bespoke HIV education course) has ensured the majority of settings feel confident in offering HIV tests.

3.2 New HIV diagnoses

The number of newly diagnosed and incident (newly *acquired*) infections continues to fall, with a concomitant increase in the proportion diagnosed with late disease (CD4<350cells/mm^3). The reduction in new infections is attributable to effective combination prevention (pre-exposure prophylaxis, treatment as prevention and increase testing coverage).



	2018	2019	2020	2021
Total no. new diagnoses	33	42	25	24
No. new diagnoses B&H residents	27	31	20	20
No. incident infections (B&H residents)	5 (19%)	7 (23%)	3 (14%)	3 (15%)
Proportion of late diagnoses (B&H)	33%	39%	43%	50%

In 2020 the rate of new HIV diagnosis per 100,000 population among people aged 15 years or above in Brighton & Hove was 12.4 (reduced from 18.3 in 2017) and compared to 5.7 in England.

3.3 Creating an 'explainer animation' to encourage testing

Since becoming a FTC we have endeavoured to ensure our residents are aware that "if everyone tests for HIV, commences prompt HIV treatment if diagnosed positive, or accesses effective prevention initiatives if negative and at ongoing risk" then we can end new HIV transmissions. The National Aids Trust's 2021 report 'HIV: Public Knowledge and attitudes' high-lighted how poor or outdated many people's understanding of HIV is. The Towards Zero HIV Taskforce identified that we needed a concise, clear 'explainer animation' to convey this message to the public.

Connections Animation Studios created the animation. The company has a strong record of working in health communications and translating complex ideas into simple messages through animation. The animation was co-produced with clinicians, HIV community workers, members of the public and people living with HIV (PLWH).

The film is being used in healthcare education and training packages. Wider dissemination through websites, on GP/dental information screens, and as part of school education packages is needed. The film will update knowledge, increase testing, and will go some way to tackling HIV related stigma and discrimination. A version with a British sign language interpreter has been produced by THT.

3.4 Testing and working during the pandemic

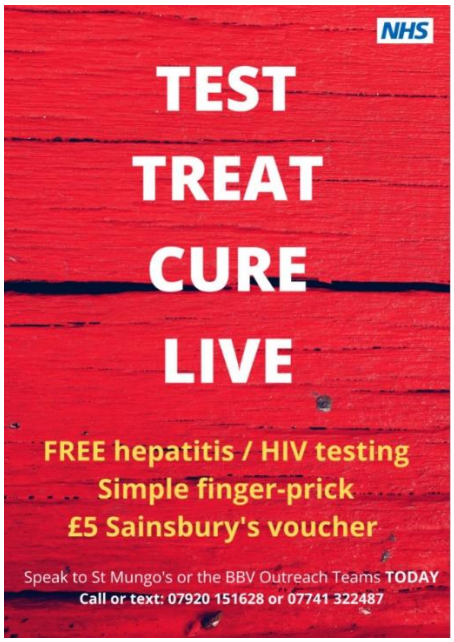
Different ways of working were adopted quickly: HIV outpatients became 100% paperless; increased repertoire of contacting patients including phone consults and Attend Anywhere; on-line HIV/STI testing expanded; website significantly improved; rapid innovation over months rather than years; many examples of resilience. HIV testing was reduced in sexual health services, now back to baseline; secondary care testing was maintained but 50% fewer new diagnoses as most tests were carried out in the Emergency Department as part of the Covid protocol where an older population were tested. The **Sussex Covid study 2020** (n=653) noted growing needs to support physical and mental health; recognised the impact was disproportionate for some e.g. if living alone, if younger but also noted enhanced resilience for many – that living with a long term virus increased coping strategies and allowed individuals to better put pandemic into context. Also reported emotional strength and good peer support networks

3.5 BBV screening in housed street homeless

During the first Covid-19 lockdown rough sleepers were accommodated in hotels in B&H. This gave us a unique opportunity to access this traditionally 'hard-to-find' group. Two experienced outreach workers collaborated with trusted keyworkers and implemented blood borne virus (BBV) screening using dried blood spots (DBS). Clients were offered a £5 food voucher. 95% were approached (256/270) with 72% uptake (192/270); median age 40 (range 18-69); 83% male; 85% white British/white other, 5% black African; 93% heterosexual, 3% GBM, 2% other; 28% previous IDU, 20% other drug use; 48% stated prison as risk factor.

Overall, 36% had not previously tested for HIV and hepatitis. 16% were hepatitis core antibody positive; 7% hep C RNA positive. All were made aware of the results; 4 started treatment; 3 deferred; 2 considering; 3 not engaged (key workers/GPs aware); 1 left area (f/u with NHS number). No cases of HIV were identified. All testers said they would recommend the project, 80% found it 'very useful'.

This project brought together professionals from different sectors to reach common goals with a large cohort sensitised to the concept of testing for HIV and HCV. New outreach testing opportunities identified. There was re-engagement of 2 known HIV patients, and other vulnerable clients were engaged with SHAC services. It was reassuring there was no undiagnosed HIV in this marginalised cohort.



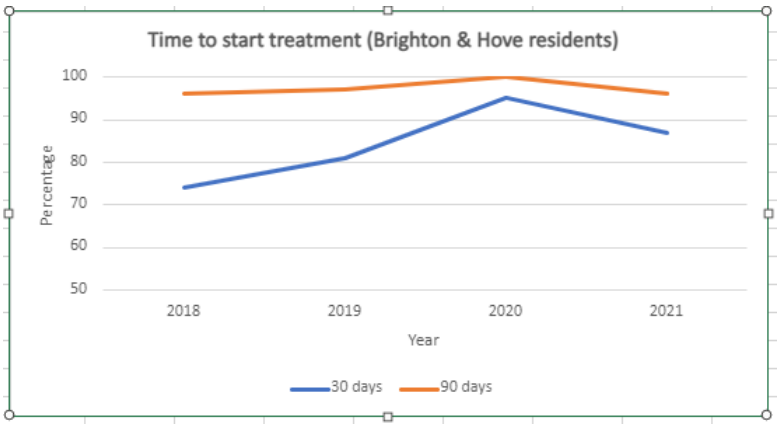
TREAT

4.1 Prevalence and time to start treatment

In 2020 the HIV diagnosed prevalence rate was 7.33 per 1,000 population aged 15-59 years (compared to 2.31/1,000 in England). This is the 8th highest unitary authority rate in England and the highest outside London, although shows a downward trend since a peak of 8.1/1,000 in previous years. In Brighton & Hove 95% of people living with HIV know their status; 99% of those are on treatment and 98% of those on treatment have undetectable virus. We estimate the undiagnosed proportion equates to ~120 individuals in the city.

Our clinic cohort size is 2,412 of whom 1,629 live in Brighton & Hove. Overall, our cohort is 82% men who have sex with men (MSM), 9% women and 9% heterosexual men

	2018	2019	2020	2021
Proportion starting treatment by 30 days (B&H)	74%	81%	95%	87%
Proportion starting treatment by 90 days (B&H)	99%	97%	100%	96%



4.2 Managing the medically stable HIV cohort

Development of the EmERGE application (EmERGE app) was a 5-year project (2015-2020), involving 5 sites in Europe led by Brighton. The project outcome was a co-designed digital health pathway of care for people living with medically stable HIV providing access to their own data (results, medication, appointments, messages) with a person-centre option in the menu of care; 2251 individuals participated in the evaluation at the five sites (3891 years of follow up). The findings were that the health app was clinically safe; that face-to-face appointments were reduced by up to 30% and 96% would recommend to a friend**.** In the B&H cohort 25% are managed through the EmERGE app and 18% through Connect (the email-based predecessor); so, 43% in total being supported in self-management and helping clinics to manage capacity.

4.3 Digi-PROMs

Patient reported outcome measures (PROMs) measure a patient's health status or health-related quality of life at a single point in time, and are collected through short, self-completed questionnaires. The POSITIVE OUTCOMES PROM has been co-designed, developed and validated in UK and European settings to ensure person-centred HIV care. In Brighton & Hove, the PROM is currently in use in paper format in one HIV clinic for complex patients.

There is interest from clinics and communities nationally (and internationally) in exploring the role of such a PROM in informing and enabling person-centred care [rather than just as an outcome measure at service level]. It is anticipated that the PROM will be used to guide person-centred care across whole clinic cohorts. The PROM would be completed prior to or during the clinic visit and be used to guide person-centred pathways of care.

There is increasing use of telemedicine & digital pathways in healthcare, including HIV, which has been accelerated by the COVID pandemic. This project will enable the co-design of a digital health pathway for the PROM, ensuring that the digital delivery of the PROM is person centred and is acceptable to PLWH and their clinicians, as well as exploring digital inequalities and ensuring usability and accessibility of the digital PROM.

The creation of a digital health pathway is important as currently the PROM tool is only available for use as a hardcopy questionnaire that can only be accessed in person at the time of the clinic appointment. This creates a delay for the patient and healthcare professional and is a barrier to timely holistic care. The creation of a digital health pathway will make this process more accessible and efficient and enable the research project to be delivered to patients in a healthcare setting of their choice.

It is intended that a digital PROM will benefit PLWH in several different ways, including by:

- Creating a co-designed digital pathway for the delivery of the POSITIVE OUTCOMES PROM that will enable PLWH to report outcomes that are important to them outside the clinical setting.
- Ensuring that the digital PROM tool and pathway are accessible, usable and acceptable in a real-world situation
- Ensuring that PLWH are involved in the co-design of their person-centred services. This is particularly important to assess the service re-set post Covid of the many changes that were implemented rapidly during the pandemic.
- In the context of digital inequalities this project will ensure that “no-one is left behind” as the PROM is introduced digitally and that appropriate adjustments are available for those who may not be as digitally literate or engaged.

RETAIN

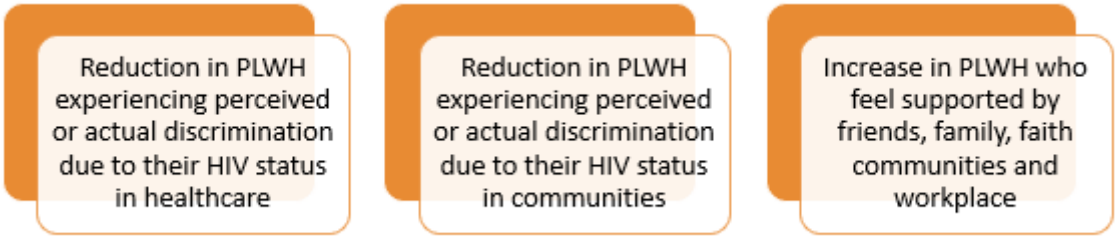
5.1 Retention in care

Once diagnosed rapid referral into treatment and retention in treatment over time is essential to achieving good health outcomes and preventing onward transmission. The proportion of our cohort lost to follow-up remains very low at 1.5% in 2020. Following intensive efforts, a proportion have since returned to care leaving the true figure at 1.1%). This compares to England figures in 2019 of ~4% (3570/90,436).

5.2 HIV Stigma

A city-wide strategic plan to reduce stigma and discrimination was developed as part of the FTC initiative by the stigma implementation stream. The aim to address HIV stigma at a multi-sectoral level in three work streams: reduce stigma among healthcare workers; empower PLWH and build resilience; develop further public awareness campaigns following on from the B&H stigma campaign in 2018.

Baseline stigma metrics have been developed using local data extrapolated from national datasets, leading to stigma reduction targets that will be utilised to evaluate forthcoming interventions and as stigma process indicators.



5.2.1 Stigma Free Hospitals & Healthcare

University Hospitals Sussex have agreed to upload the animation and a stigma flier on the induction portal for September 2022. The stigma group are scheduled for a face-to-face slot at the corporate induction in January 2023. The stigma group have secured Health Education England (HEE) funding for 4 study days in the next year for HIV education / stigma workshops to focus on stigma reduction training across our hospitals. UHS is expecting to participate in a national HIV knowledge and attitudes survey for hospitals later this year.

HIV Allies have been identified across many departments and a mandatory training module for healthcare staff is in production. A 'train the trainers' structure will be used to cascade information throughout the Trust, aiming for all workers to be aware of 'Can't Pass It On' and using a 'Train, don't Shame' approach. The "10 things" project has secured funding and will involve PLWH in the training of healthcare workers similar to successful developments in diabetes care leading to safer care and improved patient confidence.

A bespoke educational package for dental staff has been created including the animation, patient films, summary slides and pre and post questionnaires. The package is designed to take only 10 minutes to complete. Engagement and positive feedback indicate an interest amongst dental staff in B&H although qualitative work is required to identify the most effective form of intervention to significantly influence HIV-related stigma amongst this group.

5.2.2 Empowering PLWH and building resilience

The People Living with HIV Stigma Index Survey results for Southeast England (mostly from Brighton) have shown progress: in 2015, 36% of PLWH experienced gossip reducing to 19.2% experiencing gossip in 2019. Further data from the national survey is expected. To work towards B&H becoming a Stigma-free city we need to empower PLWH to speak freely about their health, and feel supported by friends, family, faith communities and workplaces. HIV needs to be viewed in the same way as any other chronic health condition so that PLWH can better access clinical, community and emotional support. Co-designing workshops with MIND are in progress, to support resilience, manage disclosure, and tackle anticipated and enacted stigma. There will be focus on intersectional vulnerabilities. All B&H HIV organisations are on the same page and collaborating well.

5.2.3 Public awareness & stakeholder engagement

2019 saw the launch of the magnificent Martin Fisher Foundation bus, a brilliant collaborative effort of the Foundation, Daniel Locke (Designer) and Brighton & Hove buses. We believe we're the first city in the world to have an HIV themed public information bus, allowing passengers to read up to date information about HIV testing, treatment and prevention.

There have been two large stakeholder events to engage the grassroots community that have helped to map ongoing public awareness plans. Suggestions have included using high profile venues to promote messages (Amex, Brighton Station, cinemas, concert venues), encouraging high visibility of PLWH reflecting diversity, and ensuring a presence at Pride, football, and other festivals. One such aim is to collaborate with the Brighton Festival presenting an HIV theme at events using art, music, drama, and poetry.