November 2019

Bringing Fast Track Cities to Cardiff & Vale and to Wales

A report from the Fast Track Cardiff & Vale Steering Group

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The Data Report

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Key findings

- Notwithstanding challenges to surveillance data in Wales, Cardiff has the highest HIV prevalence in Wales and at around 1000 cases is comparable to similar size UK cities that have active HIV prevention programmes.

- The proportion of those diagnosed with HIV “late” is higher in Cardiff than the UK average (62% vs 42%). This means that those people will be more dependent on hospital care and more likely to pass on their HIV to other partners as they are not aware of their status nor on treatment.

- Findings suggest that HIV related stigma is worse in Wales than rest of UK.

Introduction

Fast Track Cities (FTC) is a relatively new phenomenon; cities with substantial levels of HIV commit to working across organisational boundaries to reduce HIV transmission and improve life for people living with HIV. Following on from the first Fast Track City in Paris, there are now cities signed up to the programme in England (Brighton, London, Manchester, Liverpool and Bristol) and Scotland (Glasgow) but none yet in Wales.

Every UK city that has worked within FTC has seen a substantial decline in new HIV diagnoses.

The purpose of this report is to outline data we have about HIV in Wales, focussing on Cardiff and South East Wales in which services see the highest number of residents for HIV clinical care. The information sources are varied and focus on what we know of the epidemiology of HIV, prevalence of late diagnosis (known to increase mortality) and outline what we know about HIV related stigma.

There are gaps in evidence which if remedied would help to focus FTC resources to enable us to understand the whole picture and ensure that government, health services and communities can work together to eliminate new HIV transmissions by 2030.

In this report we have examined three key questions that are necessary to consider as part of any Fast Track City initiative in Cardiff.

1. How many people are accessing care for their HIV in Cardiff and Vale and surrounding areas and who are they?
2. How much of an issue is late diagnosis of HIV infection in this region?
3. What do we know about HIV related stigma in Wales?

1) How many people are accessing care for their HIV in Cardiff & Vale and surrounding areas?

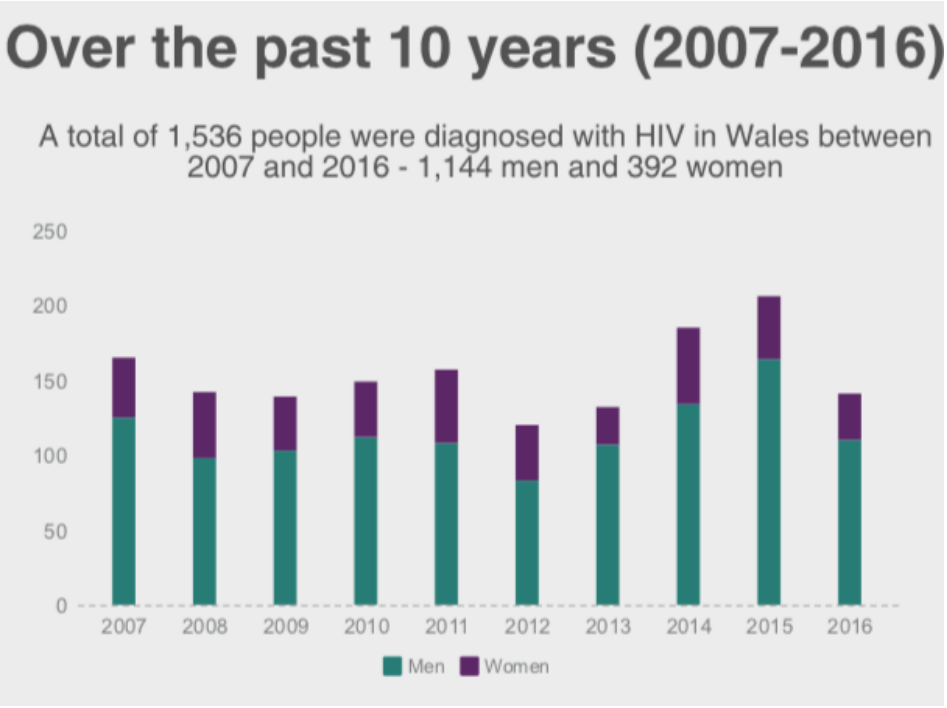
Data available from Public Health Wales

Healthcare in Wales is a devolved power and therefore the health service operates differently from the English service. In particular, English clinics are commissioned centrally by NHS England for HIV care and provide attendance data as part of their individual service level agreements. This purchaser-provider split is not present in Wales.

Data on HIV diagnosis and ongoing care in Wales is collated by Public Health Wales and currently uses a variety of sources rather than a single database. These include the Sexual Health in Wales Surveillance Scheme (SWS), managed by Public Health Wales directly and data reported to Public Health England through the SOPHID system. This may not include data from other sources in Cardiff i.e. when services do not submit SOPHID data to Public Health England.

Plans are currently underway to reform the data collection for Wales so the data here represents what is the best current approximation.

This graph from the Public Health Wales website demonstrates the trend in HIV diagnoses over the 10 years leading up to 2016.



Note that 2016 is lower due to delayed return of notifications at the time of publication of this table rather than a reduced number of new infections once this was taken into account

The following table answers a recent Freedom of Information request into HIV care by health board residence and is presented below:

Table 1: Number of individuals receiving HIV care resident in Wales by local health board of residence, 2013-2017

	Health board of residence							
Reporting Year	Abertawe Bro Morgannwg University	Aneurin Bevan University	Betsi Cadwaladr University	Cardiff & Vale University	Cwm Taf University	Hywel Dda University	Powys Teaching	Total
2013	292	290	286	503	136	127	44	**1,678**
2014	312	321	322	589	136	130	47	**1,857**
2015	334	342	330	587	157	151	40	**1,941**
2016	339	353	343	596	183	164	50	**2,028**
2017	361	381	370	604	168	176	54	**2,114**

This may help to understand the population spread of HIV care within Wales but appears to substantially underestimate the Cardiff & Vale resident individuals by approximately 350 patients, as explained further in the clinic data.

This data is divided by health board of residence rather than health board of attendance. For example, a patient who attends a clinic in Newport for HIV care but is resident in Cardiff would come under the Cardiff & Vale column. Similarly, there is no HIV clinic provision in Powys and so all their patients will be attending clinics out of county. Patients who live in border areas but attend English HIV services that are closest (e.g. Shrewsbury, Chester and Bristol) would also not be included in this data.

The most recent data we have is provided by Public Health Wales and is correct as of December 2018.

- In 2018, 135 people were diagnosed with HIV in Wales and men made up the majority of the cases (83%).
- Most cases of diagnosed HIV were in people aged between 35-49 years old (38%)
- At least 45% of those reported were men who have sex with other men. There were no injecting drug users diagnosed with HIV in Wales in 2018

Data from Cardiff & Vale UHB

Sources from Cardiff & Vale show that there are currently 637 HIV positive patients under active care at the Department for Sexual Health (DOSH) at the Cardiff Royal Infirmary and approximately 350 attending the clinic at UHW. There are plans to move to electronic patient records on both sites currently underway and so more exact figures should follow once this has been implemented.

A recent clinic audit suggested that in the DOSH cohort, 98% of those patients were on treatment and 97% of these had undetectable viral loads. Similar figures from UHW suggest that 98% are on treatment and of those 95% are undetectable. This is confirmed by current but as yet unpublished data from Public Health Wales.

A recent Welsh government audit was conducted into new HIV diagnoses and the Cardiff findings are summarised below:

- There were 13 new HIV diagnoses seen at the Dept of Sexual Health (DOSH) unit in CRI during 2018. Due to the sample size it is not possible to further detail these patients.

- There were 20 new HIV diagnoses seen by the Infectious Disease team at UHW during 2018. However, it is worth noting that data were not readily available and relied on manual extraction.

Note that at around 1000 patients being seen for care in total in the Cardiff and Vale UHB services, that is substantially higher than any other region of Wales.

2) How much of an issue is late diagnosis of HIV infection in this region?

When a person presents to health services with either an AIDS defining condition or an initial CD4 cell count less than 200 cells/mm^3 this would be termed a "very late" HIV diagnosis. With a CD4 cell count less than 350 cells/mm^3 this would be termed a "late" diagnosis. In some publications "very late" is termed "advanced" HIV but to present this report I am only using the two terms "late" and "very late".

This influences an individual's health because:

- Late diagnosis of HIV can have a major impact on the individual, risking clinical deterioration and opportunistic illness. Mortality within a year of HIV diagnosis is ten times higher for late diagnosed individuals than those diagnosed promptly.

- Individuals who present late show a reduced response to HIV treatment, in comparison with those diagnosed earlier in the course of the infection.

- Late diagnosis represents a missed opportunity to initiate treatment which prevents onward transmission of HIV, as well as benefiting the individual.

- Costs of care are significantly higher for individuals diagnosed late. Direct medical costs in the first year after HIV diagnosis are twice as much for late diagnosed individuals, largely due to higher inpatient costs.

- Although not well quantified, late diagnosis of HIV is also likely to be associated with avoidable costs of care *before* the diagnosis is made. This is because individuals may respond poorly to treatment for other conditions and/or undergo unnecessary investigations if HIV is not recognised as an underlying factor contributing to their present condition.

The British HIV Association (BHIVA) in 2015 published a good practice position statement on prevention of late diagnoses following on from their 2013 Standards of Care document which states that all HIV services should be undertaking reviews of their late diagnoses. This is not currently routine clinical practice in Cardiff.

BHIVA National Audit 2016

BHIVA undertook a survey of specialist HIV services' activity in conducting "look backs" and a case-note review of 773 individuals diagnosed with "very late" HIV (i.e. initial CD4 count less than 200 cells/mm^3).

Key pan-UK findings

- Most services had not conducted an organised systematic “look-back” review of late diagnoses, but of those doing so nearly all had found areas for improvement in HIV testing practice.

- Recording of health care use during the two years preceding diagnosis was generally good. Overall, 46.2% of audited individuals were considered to have had earlier missed opportunities for diagnosis.

- Most missed opportunities were due to clinicians not offering an HIV test, rather than the individual declining one. Some follow-up action had been taken in respect of 66.2% of cases with documented missed opportunities.

It has been suggested that improving HIV testing outside of sexual health services would reduce late diagnoses. The main hospital areas suggested are medical admissions, dermatology, haematology and gastroenterology. Increased HIV testing in primary care was also suggested as an area for improvement.

BHIVA audit findings for Cardiff & Vale

Recording of health care use in the two years preceding HIV diagnosis was good — use or non-use of GP care was recorded for more than three quarters of individuals and use or non-use of secondary/specialist services for more than four fifths. This means that prior to their HIV diagnosis, multiple opportunities were available to test earlier than when the diagnosis was made. It is also worth noting that HIV treatment services currently do not routinely perform look back analysis on their new diagnoses.

Looking specifically in Cardiff, 12 of the 18 patients diagnosed very late in the time period were judged to have had earlier missed opportunities for diagnosis. This was defined in the questionnaire as an occasion when the person was seen in a UK clinical setting and when HIV testing would have been clinically appropriate but was not done, regardless of the reason.

Although the numbers appear small, many of the late or very late diagnoses for HIV incurred high treatment costs through intensive care admissions and prolonged stays in hospital (and readmissions) as opposed to outpatient management which is the majority of cases where the HIV is diagnosed when someone is clinically well.

Although this is not part of the audit the inpatient clinicians feel that late or very late presenters can often be in those who are not often seen as high risk for HIV and are therefore not tested. This would include heterosexual Caucasian women and older men who do not identify as men who have sex with other men. There is literature to suggest this is the case elsewhere in the UK.

What other data do we have from Cardiff & Vale?

An audit which included questions on late HIV diagnoses was recently undertaken by the Welsh Government. This revealed:

- Of the 13 new HIV diagnoses seen at the Glossop unit in CRI during 2018, 7/13 (53.8%) had a CD4 count below 350 at the time of diagnosis. Of the 20 new HIV diagnoses seen at UHW during 2018, 14/20 (70%) had a CD4 count below 350 at the time of diagnosis. These results averaging 62% are significantly higher than the 42% reported by Public Health England in 2016.

- Both departments have undertaken informal look-back reviews to inform interventions to reduce late diagnosis, and contact has been made with relevant healthcare providers, including general practitioners, but a formal process is not current in place.

- It is noted that data were not readily available and relied on manual extraction by clinic staff.

- Due to a lack of surveillance data it is not possible to look at the “at risk” profiles of those diagnosed. For example were they people from the MSM community or were they regular testers previously?

3) What do we know about HIV related stigma in Wales?

"I want to remember what it's like to live again, to feel free"

Gareth Thomas on revealing his HIV diagnosis to the general public in September 2019

Positive Voices Study

Positive Voices 2017 was a survey of people living with HIV receiving care in England and Wales funded and administered by Public Health England. It was implemented in 73 HIV clinics and recruited 4422 participants.

Questions in the questionnaire covered the following areas:

- education and employment
- housing and religion
- sex and sexuality
- alcohol, tobacco and drug use
- adherence to HIV medication
- quality of life
- experiences with HIV stigma and discrimination
- use and satisfaction with NHS services

Some of the main national findings include:

- Mental health problems were reported by half of people living with HIV, twice the rate of the general public.

- The relationship between mental health and drug use is well established and 23% of people with HIV reported recent use of recreational drugs (compared to 9% in the general public), rising to 40% in gay and bisexual men with HIV. This suggests a significant need for drug and alcohol services in people with HIV. (There are no specific services in Wales targeting those who engage in chemsex.)

- Navigating the benefits system can be difficult when dealing with addiction and mental illness. Overall, about 1 in 3 (37%) of people with HIV in 2017 lived in poverty and a similar proportion currently claim benefits based on low income or disability. Services that provide

help with claiming benefits, financial and employment advice, housing support and meal and food services remain important for people
with HIV.

- HIV stigma still exists in the NHS. One in 9 (11%) people living with HIV in the UK have been refused healthcare or delayed a treatment because of their HIV status. HIV is a protected characteristic under the Equality Act 2010 and differential treatment based on HIV status is illegal discrimination. Despite this, discrimination persists. ***"11% reported being refused healthcare or delayed a treatment due to HIV status"***

- In addition to experiences of discrimination in the health care setting, issues around pain and discomfort, anxiety and depression, and mobility and self-care can greatly affect people living with HIV and can further exacerbate experienced and perceived stigma. 16% of people reported at least some problems with mobility and 40% said they have ever been diagnosed with a mental health condition. On any given day, 1 in 4 people with HIV report feeling anxious or depressed.

The two clinics in Wales that participated were DOSH in Cardiff and the Royal Gwent Hospital in Newport. In total 4,422 people responded to the survey across the UK from 73 HIV services.

The key findings from the Welsh participants are as follows:

- Around 1 in 7 Welsh participants reported that they have never told anyone about their HIV status outside a healthcare setting, contrasting with 1 in 8 in the UK as a whole. 57% had disclosed to family and only 46% reported disclosing to friends. This suggests that HIV positive people in Wales are more likely to feel isolated and suffer with their mental health and wellbeing.

- 21% of Welsh respondents said they had avoided seeking healthcare when they had needed it in the preceding year, which is more than double the UK average of 10%. This means that HIV positive people in Wales are less likely to proactively manage their own health and co-morbidities.

Overall this suggests that HIV related stigma in South East Wales is on average worse than elsewhere in the UK.

Summary

In 2019, HIV is a treatable and preventable condition where those infected should have a life expectancy similar to those who are HIV negative. We have two biomedical interventions in Treatment as Prevention (TasP) and Pre-Exposure Prophylaxis that have been shown to reduce or effectively eliminate new transmissions of HIV when offered to and used by those at risk. Both these interventions are available free to Welsh residents although not all who are at risk currently access these services.

There are gaps in knowledge including an accurate understanding of the total number of people who are HIV positive in Wales, which is unfortunately similar to some other developed and developing countries. Particularly concerning is the lack of real time knowledge about late diagnoses which makes interventions to reduce this difficult to target. Whilst this is not unique to Wales, it identifies the areas where we can focus existing resources and potentially provide new resources although more work is required to target these effectively and ensure the right programmes cover the right people. The role of the community is crucial, as is a focus on stigma which is very relevant for Wales given the research outlined earlier.

Recommendations for Fast Track Cities

- Co-ordinate a pathway to produce prospective real time data on new and established HIV infections, with a focus on both the UNAIDS 90:90:90 targets and the frequency and characteristics of those diagnosed late with HIV.

- Focus resources on diagnosing people with HIV who are not aware of their status to prevent late diagnosis and onward transmission. This could be through targeted testing, upscale of biomedical HIV prevention such as PreP and promoting testing in clinical services outside of the typical areas such as sexual health and infectious diseases.

- Lead a community developed and delivered stigma project to cover either Cardiff & Vale or Wales wide to ensure people working in healthcare and the wider community and those at risk are aware of key messages such as the benefit of early treatment, biomedical prevention and quality of life.

November 2019

Getting to Zero

Bringing Fast Track Cities to Cardiff & Vale and to Wales

A report from the Fast Track Cardiff & Vale Steering Group

Contents

Please note that there is a companion report on epidemiological and other helpful data on HIV in Cardiff & Vale.

Introduction

This report outlines the potential for the Fast Track Cities initiative to be used as a catalyst for reaching zero new HIV transmissions by 2030 in Wales – a target which is being adopted globally in the fight to eradicate new cases and late diagnoses.

A draft paper on Sexual Health Priority Areas 2020-2024, prepared for the Welsh Government by Public Health Wales and a number of clinical associations (BASHH Wales, FSRH Wales, GPC Wales and CP Wales) proposes to “reduce long term healthcare and social costs by adopting strategies to eradicate new HIV transmissions and prevent late diagnosis”. Many of the practical strategies promoted by Fast Track Cities are included in the deliverables of this draft paper, making Fast Track Cities an appropriate tool to reach them in as cost effective and collaborative a manner as possible.

This report should be read in conjunction with the accompanying Data Report outlining what we know (and don't know) about HIV in Cardiff & Vale or in Wales. It outlines the opportunities presented by Fast Track Cities and their implementation elsewhere. It maps current HIV prevention and care services across the Cardiff & Vale Health Board area and the opportunities and sometimes challenges that they and the data present. It goes on to consider a number of options for future developments through collaborative working across the health, social care and community sectors.

Executive Summary

- Fast Track Cities is a proven useful tool for cities to improve their ability to hit World Health Organisation and local targets in the elimination of new HIV diagnoses and its treatment and prevention

- It requires cooperation between local authority, health and community sectors but is highly flexible in actual implementation, depending on local needs and circumstances

- It offers many opportunities to learn from existing programmes elsewhere about what might, or might not, work for Wales

- Although it operates chiefly via individual city hubs, it has the potential, particularly within smaller nations, to become a countrywide initiative over time

- Cardiff & Vale (and Wales in general) does very well on some key targets but data shows that it has identifiable areas for improvement in data collection; high levels of late diagnosed HIV; access to and take-up of HIV testing; and people with HIV report higher than average levels of HIV stigma, resulting in few people willing to be open about their status

- Without action on these it will be difficult to reduce late diagnoses and achieve long term elimination of new HIV diagnoses

- In discussion with clinicians, councillors and community organisations a number of low to no cost initiatives have already been identified which could be effective locally in tackling late diagnoses and stigma. Public Health Wales is already seeking to increase access to quality data on HIV in Wales

- We should seek to take Fast Track Cities further by establishing a Leadership Group, liaising with the Fast Track Cities network and consulting widely within Cardiff & Vale about how services can best respond to the current challenges and reduce new diagnoses to zero.

What are Fast Track Cities?

The Fast Track Cities initiative (hereafter FTC) is a global partnership whose core partners include the International Association of Providers of AIDS Care (IAPAC) and the Joint UN Programme on HIV/AIDS (UNAIDS). Since 2014 the network has grown to more than 300 cities and municipalities that are committed to attain the UNAIDS 90/90/90 targets:

- 90% of all people living with HIV **diagnosed**
- 90% of all people diagnosed with HIV being **on treatment**
- 90% of all people on treatment having **undetectable**, untransmissible viral load.

Achieving **zero stigma** is now a fourth target and attainment of the targets is seen as as the starting point towards zero new infections and zero AIDS-related deaths. Furthermore, many cities which have reached 90/90/90 are now aiming for the UNAIDS target of zero new transmissions by 2030.

Currently there are more than 300 FTCs across the globe, with six in the UK (Glasgow, Brighton, London, Manchester, Liverpool and most recently Bristol) but none in Wales. Every UK city that has adopted the FTC initiative has seen a substantial decline in new HIV diagnoses.

FTC works through key cities where HIV services are concentrated and emphasises collaborative working between sectors. In some countries, such as Ireland and Scotland, the ambition is to extend this to a countrywide support system and the potential feasibility of this for Wales is considered below. It involves a collaborative effort between all concerned parties in the city/region to fight HIV together.

As a basis, the initiatives are usually formally steered through the office of the local Mayor or political leadership but always include health services (both clinical and public health) and local non-governmental organisations (NGOs) or community groups providing related services and supporting key populations most at risk. Other partners are involved depending upon local circumstances and need.

IAPAC supports all FTCs (at no fee) with:

- technical assistance to local health departments on data generation, monitoring, and reporting
- implementation planning among key local stakeholders
- capacity-building support for clinical and service providers, community-based organizations, and affected communities
- eliminating HIV-related stigma in healthcare settings
- assessing quality of life for people with HIV.

There is already a network established of the UK cities which have signed up to FTC and Cardiff & Vale have been invited to participate in this. Participation will enable lessons to be shared and joint work undertaken e.g. setting standards for combating institutional stigma.

How is it managed in cities?

Mayors and other leading city/municipal/health officials designate their cities as Fast Track Cities by signing the *Paris Declaration on Fast Track Cities*, which outlines a set of commitments to achieve the initiative's objectives. More information on that is here: https://www.iapac.org/files/2018/07/FTCI-FAQs-111915.pdf

It is important to note, though, that this is not just a charter or a symbolic gesture – it is a new way of working. Each city commits to forming a **Leadership Group** which meets regularly and should include, alongside political and health sector leadership, health planners, clinics and key community groups/NGOs. It could include e.g. pharmacists, primary care and researchers to lead on evaluation.

Some cities have a large group which meets very often (like London with multiple members meeting weekly) while others have a smaller group or meet monthly or bi-monthly. FTC is free to join and its services are free, but cities that sign up are expected to work collaboratively and continuously towards the targets.

The actual way in which services choose to do this work varies between cities, because each will have a different set of priorities, different key populations and challenges. Some will have more financial resources than others, who may instead to find ways to work smarter and more collaboratively. Potential options for Cardiff & Vale are considered below.

Fast Track Cardiff/Fast Track Wales?

The choice of Cardiff as the initial city in Wales to join Fast Track Cities was an obvious one as, with almost a thousand residents with HIV in clinical care, it supports by far the greatest number of people diagnosed with HIV in Wales; almost half of them.

In discussion with potential partners, it became clear that the service network in both Cardiff and the Vale should be included, and was interested in being included, with one health board covering both and many services provided across the region. Most people with HIV in the Vale are seen either in Cardiff or in the smaller clinic in Barry.

This initiative could benefit not only Cardiff & Vale, but potentially work across Wales through other key cities with HIV services. Others with potential to become Fast Track Cities include Newport, Swansea, Wrexham and Bangor.

This approach to Fast Track co-ordinated countries works best with relatively small countries and we believe could work for Wales – Fast Track Cardiff could become Fast Track Wales over time, depending on interest from other cities and on appropriate support for coordination.

In both Scotland and Ireland, designating one or more cities initially as Fast Track has been used within a wider framework to cascade the programme to others across the country, as they wish to join. In Scotland, Fast Track Glasgow is up and running and several other cities are working towards a Fast Track Scotland network which is supported by government funding to a policy NGO, HIV Scotland. In Ireland, Dublin, Cork, Limerick and Galway have signed jointly as Fast Track Ireland, supported by substantial new government funding to run the network.

What are Cardiff's particular issues and needs?

In Cardiff, according to the latest and most reliable information (see Data Paper), we appear to be doing very well on two of the initial FTC 90/90/90 targets – getting people into treatment (98% of those diagnosed) and getting them to undetectable (96% of those on treatment across the two clinics). This is a credit to our Welsh NHS, which provides good quality treatment, easily accessible to all those diagnosed and pre-exposure prophylaxis (PrEP) on demand to prevent the acquisition of HIV to all those eligible. The latter is not yet the case in England and many other countries in Europe.

However, on a preliminary analysis it is clear that in order to get to zero new transmissions by 2030, Cardiff & Vale (and Wales in general) needs to focus on creating greater opportunities to test for HIV, including targeting testing to those most at risk. Removing barriers, particularly stigma, is crucial as this prevents some people from testing and deters some non-specialist NHS and social care staff from offering tests. It also allows false ideas about HIV to remain in circulation. To do this well, we will also need to increase our ability to access accurate data on who has HIV; how they acquired it; and why those who test late do so.

Leaving people living with HIV undiagnosed is not only dangerous to their own health (and costly for the NHS in the long run) but also enables onward transmission of the virus. While it is difficult to know precisely how many people with HIV remain untested, a major indicator that we are not yet reaching people in a timely fashion is the proportion of those diagnosed who have tested late i.e. after they should have started treatment. This is currently defined as people with a CD4 count in their blood of 350, while people with a CD4 count of 200 or less are considered to have advanced HIV.

As shown in the accompanying Data Report, although relatively low levels of new diagnoses are reported in Wales compared to England, the level of late diagnoses appear to be substantially higher (averaging 62% of new diagnoses across the two Cardiff & Vale hospitals in 2018 as opposed to 42% reported by Public Health England across England). If these people were diagnosed earlier, they would be healthier and less likely to pass the virus on, since successful treatment would render them unable to transmit it.

A substantial percentage of these late diagnoses are understood, through examination of records, to have had opportunities for earlier diagnosis if a test had been appropriately recommended by another part of the healthcare system. Additionally, while three quarters (78%) of new diagnoses in Wales in 2016 were in men, and the majority of these attributed to sex between men, a substantial number were not of obviously identifiable origin, which indicates that some people may have difficulty in recognising, disclosing, or coming to terms with their own risk behaviours.

HIV stigma is a major driver of late-diagnosed HIV, whether through fear of testing, fear of offending patients by suggesting testing or simple ignorance of the advantages of knowing your

status. The data from Positive Voices shows that less than half of Welsh respondents (from Cardiff & Newport clinics) had disclosed their status to friends and only 57% to family. One in five had avoided seeking needed healthcare in the previous year for fear of the reception they would get upon disclosure.

Working as a Fast Track City gives us a chance to share expertise and see how others are reducing late diagnoses, sharpening their data and tackling stigma. It also enables us to judge what is cost-effective and appropriate for our situation.

Current HIV clinical care and testing services in Cardiff & Vale

Currently the HIV specific services situated in Cardiff & Vale (note that some C&V residents may be accessing services in Newport or even Swansea) are as follows:

Clinical care services for people already diagnosed with HIV are available at the following:

- The Department of Sexual Health (DOSH) Glossop Unit at the Cardiff Royal Infirmary has outpatient clinics which saw 507 patients with diagnosed HIV in the past year, with a further 275 with "open care episodes".

  Clinic attendees have access to specialist pharmacy, dietician support and a Mental Health Liaison Nurse.

- The Department of Infectious Diseases, University College of Wales has a weekly outpatient clinic which sees around 300-350 patients diagnosed with HIV. They also have in-patient facilities for people with advanced HIV and day-case facilities if needed.

  Part time staffing includes two specialist nurses and specialist pharmacist, dietician and mental health nursing support.

Testing services for those wishing to test are in the following sites:

- The DOSH Longcross Unit at Cardiff Royal Infirmary offers 12 clinical testing sessions a week. DOSH also hold an outreach testing clinic at Broad Street Clinic, Barry once a fortnight.

- Terrence Higgins Trust (THT) Cymru offer point of care testing (POCT or rapid testing, which gives immediate results) by appointment one afternoon a week. They also offer occasional testing in a gay sauna and regular testing support (emotional not clinical) at one DOSH session (City Clinic). None of their POCT testing is funded from statutory sources.

- Blood Borne Virus (BBV) testing, including HIV, is routinely offered to all prisoners entering Cardiff prison and in other outreach settings coordinated by the BBV nurses as part of the All Wales Strategy to meet the WHO target to eliminate Hepatitis C as a public health threat by 2030.

- GPs and practice nurses have the ability to request HIV tests, but no data was available on how many do this or how frequently.

- Postal testing and POCT testing are only currently available through THT and its charitable funding.

- Self-testing may be available from some pharmacies but there is no data on this.

Services other than testing and clinical care for people with diagnosed HIV:

- DOSH provides a pre-exposure prophylaxis (PrEP, or the HIV prevention pill) clinic which has been accessed by 310 people, with 178 under long term follow up. Some are not repeat users for a variety of reasons.

- THT Cymru offer a range of services including counselling; peer support (6 mentors currently); outreach at LGBT community events; training and access to their UK-wide services e.g. for women, trans people, around chemsex etc. Their long term condition management services saw 53 people in the most recent quarter including 15 new clients.

- Cardiff & Vale local authorities are both committed to including HIV and sexual health within the new Relationships & Sex Education (RSE) curriculum.

Current challenges in Cardiff & Vale

There are **data** issues in Cardiff and more widely in Wales. This is not unusual in cities joining the Fast Track programme and support is available on this issue. However, it is understood that Public Health Wales has already begun measures to increase our understanding of who has HIV, how they acquired it and where they are in Wales.

Additional information that would be very helpful within Cardiff & Vale, taking into account the sensitivities of dealing with a smaller cohort, would be to know who is being diagnosed late and how they may have contracted the virus, alongside a demographic breakdown of who is living with HIV here. This data would allow better targeting of both prevention and testing messages and educational activities.

The specialist clinic at CRI reports **pressure on existing HIV testing services** and community feedback regularly mentions the difficulty in getting timely appointments. There is understandable reluctance to undertake any new initiatives which may increase the workload of staff already working under pressure. However, there are ways to potentially improve access to the clinic while encouraging more people who have been at risk to test.

Currently, apart from some pilot activities and a relatively small amount of outreach by THT, neither rapid nor self-testing in its various formats is widely used, funded or promoted in Cardiff & Vale. Other UK and European nations have found them invaluable tools in improving sexual health and finding new diagnoses amongst people unwilling or unable to attend a clinic or to wait for results.

Rapid testing is strongly recommended as life-saving by the World Health Organisation (WHO). It can also be cost-saving and reduce pressures on clinics from those who wish to test regularly and those who have been at little to no risk. There are a range of options which have been tried and tested elsewhere, including rapid testing in clinic, outreach testing, community-run and based testing, postal testing and home testing via pharmacy-sold kits.

In talking to both public health and clinical staff, **targeting** of testing through outreach, community campaigns and other means has been widely raised. Where resources are scarce, it is important that they be aimed at those most likely to need them. Data on those who continue to acquire HIV and particularly those diagnosed late will help us to sharpen our focus on those people in the community who are most at need of hearing about testing or being offered easier ways to access it.

While there is a general awareness that gay men (or men who have sex with men) and BAME migrants are most likely to be at risk, there has been little recent **targeted prevention work** beyond the traditional THT activities in gay commercial venues. As Norman (now Lord) Fowler says, no commercial company would do one massive campaign over 12 months and go off the air for the next 10 years or more; new generations and new arrivals need appropriate messaging.

This lack of awareness also feeds into **stigma**, whose impacts are amply illustrated by the data from Positive Voices and by the personal testimonies of people like Gareth Thomas. Stigma appears to be disproportionately high in Wales and affects every step of the journey from denial of risk through being scared to test, unable or unwilling to disclose (because of other people's reactions or misplaced shame) and fear of rejection. Stigma also renders clinicians reluctant to recommend HIV as a differential diagnosis for fear of offending or simple lack of awareness that it might be likely.

There are a number of potential low cost/high impact options for reducing stigma, including peer education, positive role models, social media campaigning and a number of potential Fast Track City community partners who have expressed a strong willingness to do more in this area, with only a little support from those with existing expertise. This is one of the most fertile areas of Fast Track City imaginative new projects.

Potential opportunities for Fast Track City work in Cardiff & Vale

There are many new ideas within Fast Track Cities – HIV testing formats, novel ways of targeting high risk individuals, better use of data to reach those most in need, new ways to tackle stigma. Most of them do not require high levels of financial investment; but they do require the commitment of all parties to work together and consider new ways of working that will improve both lives and services and increase the sexual health of the city.

Below are some ideas which we believe could be considered for Cardiff & Vale, some of which have originated from other Fast Track Cities and some of which have been suggested in conversation with existing service providers, but more ideas are very welcome.

Data initiatives

We are aware that Public Health Wales are about to embark on work to ensure the best possible future **data** for HIV and sexual health. It would be helpful to ensure the learning from other Fast Track Cities on data needs and strategies is fed into this.

Further research into the **demographics and risk factors of those diagnosed late** in Cardiff & Vale, particularly those unsure/unclear at initial diagnosis about potential routes of transmission would enable us to target testing offers better and ongoing look-back exercises on medical records would enable us to train appropriate specialisms where HIV may be going undiagnosed.

Longer term, a useful though potentially more difficult piece of work would be to search GP databases for patients with **indicator conditions** who have not yet been tested (e.g. shingles, oral thrush with no obvious cause/difficult to treat) and suggest testing.

Testing initiatives

We know there to be an appetite amongst communities at risk of HIV in Cardiff for postal **testing**. In 2018-19, a ten month THT programme offered 23,000 free HIV self-tests by post, targeted to key communities (but not to Wales specifically) via social media. This was funded entirely from charitable, non-statutory sources. Data collected shows that Cardiff was the third most common source of requests (after Manchester and Glasgow) and had the joint highest number of positive results reported back (with Salford). The tests were particularly popular

with people who had never tested before, or not in the past year. For details of this programme's operation and results, see the Appendix.

Postal and self-testing options in general are particularly popular with people reluctant to attend a clinic or unable to do so because of a variety of access issues. Postal testing can be triaged online to identify risk and give appropriate advice; those testing can be sent six monthly or annual reminders to test again if they have been at risk.

Other ways of accessing **self testing kits** include promotion of availability at pharmacies (sometimes including incentives); vending machines at sites of sexual activity (this was particularly successful at the gay sauna in Brighton); or via community outreach (often through so-called “Checkpoints”). Tests can be bought privately from as little as £15 (THT's postal scheme) and social media promotion of their availability and ease of use could increase personal testing without putting further pressures on existing services.

Delivering **GP updates** at their cluster meetings on HIV news, including modern therapy, PrEP and testing would be a useful contribution to improved earlier diagnosis and appropriate prevention messaging to patients. Cluster meetings, with food as an incentive to attend, are an accepted way of engaging with GPs and have potential for pharmaceutical company sponsorship. This could be extended to specialist secondary care educational meetings for improved awareness about indicator conditions. Fast Track Cities Brighton & Hove has also had success with training people with HIV to attend surgery staff meetings and engage with nurses and other staff about the realities of living with HIV, both increasing appropriate messaging and reducing stigma.

European HIV Testing Week (now Eurotest)/National HIV Testing Week (HTW) are essentially promotional weeks which can be adapted to local/national use in a multitude of ways. Eurotest is European wide (not linked to the EU) and includes BBV testing more generally; National HTW is the original England-specific campaign from which Eurotest originated and which may leak over the border but has no formal role in Wales and is not promoted here. Both have a range of tools and anyone can join in, raising awareness of testing just before World AIDS Day. Both have also been evaluated for effectiveness.

Stigma responses

A **Positive** Images community media campaign of openly HIV positive Welsh people talking about living with HIV has been suggested. This low cost anti-stigma measure could be a poster format (as used by Pride Cymru in their popular Icons & Allies exhibition) but could also work in low-cost social media. The recent publicity surrounding Gareth Thomas has shown how much impact this messaging can have on both educational and anti-stigma work.

A community-based, clinically supported **BAME/migrant HIV awareness campaign** on the benefits of testing, again on social media and using peer volunteers, would address some of the concerns about increasing numbers of BAME people being seen both at THT and in clinics.

The same could be done for **trans people**, who are often at heightened risk of HIV but have received no targeted messaging about HIV in Wales.

Drag queen entertainers are a major established feature of gay venues in Cardiff and are often listened to when they have brief but serious social messages within their acts. Many MSM who otherwise do not engage with the organised LGBT community nevertheless attend these venues and offering a targeted training/information event for working drag queen entertainers on HIV messaging could be a novel way to address stigma and increase awareness.

The same could be said for messaging on a range of pick-up sites and **apps online** used by many harder to reach MSM, where messaging can be targeted to very specific geographic areas.

Simple stigma reduction and HIV education messaging can easily be built into existing **training programmes and events** and indeed may be best received as part of a wider event or ongoing programme. Providing frontline Council staff in areas such as the Hubs, Youth Services, Social Services and Housing with simple messages about HIV and referral routes would support them to approach conversations about sexual health sensitively. Events supported by communities where we know awareness needs raising can contain health messages.

HIV and sexual health education will also be included in the **Relationships and Sex Education** part of the new curriculum in Welsh schools and this is an excellent opportunity to discuss stigma and dispel myths in an appropriate context and at an early age.

You are invited to add to these ideas or adapt them.

What will it cost?

While money has helped cities to work together, most Fast Track Cities have not seen large injections of cash; it is often more about **using what you already have** in a more targeted way with collaboration and freeing up resources and staff time. Some cities like London have taken money saved by switching from patented to generic HIV treatments and repurposed it for other HIV and sexual health services through the Fast Track collaboration. At their recent conference, several FTCs spoke of it having been a lack of a **unified approach** that held them back more than financial constraints. When everyone is round the table, working together and sharing concerns and solutions, that approach can change.

Good ideas can also attract funding from a variety of statutory and non-statutory sources and in terms of charitable funding, cross-sector collaboration is almost always a positive factor. The community sector in particular can attract charitable funding and small grants can make big changes. Many ideas above require little or even no funding, being based on activity by existing staff or volunteers.

There is likely to be a need to identify resources to ensure at least a minimal level of ongoing coordination and management of FTC in Cardiff. A full Fast Track Wales programme would, as shown by Ireland and Scotland above, need greater resourcing.

Who might be involved?

Fast Track Cardiff already has in-principle interest and support from both Cardiff and Vale local authorities. Representatives of the Health Board and Public Health Wales have been supportive in helping us put this and the epidemiological report together and expressed interest in working together. It has enthusiastic buy-in from the voluntary sector (THT) and community groups (Pride Cymru, Glitter and others). Clinicians have been central in the planning which has got us this far.

Next steps include forming a Leadership Group, consulting as widely as possible with interested parties to increase participation and support and working towards a formal sign up to Fast Track Cities in late spring of 2020 with agreed initial projects and actions.

We believe that, with the public reaction to Gareth Thomas's story of living with HIV and the fear of stigma, there has never been a better time to do this. Will you join us?

How has this report been produced?

This report was produced with the help of a grant from Gilead Sciences. It was written for the initial Steering Group for Fast Track Cardiff, an ad hoc group of concerned local clinicians and community organisations, following desk research and many discussions with people from the sexual health sector, the local authority and community of Cardiff including people with HIV. We are grateful to everyone who provided insights and information. Any errors are entirely ours and we welcome feedback.

A companion report covers relevant epidemiological and other data about HIV in Cardiff & Vale

Appendix

THT Postal Testing Scheme

In the past few years THT has run a number of versions of HIV postal testing services. From May 2018 to the start of March 2019 (10 months), thanks to a generous legacy, they were able to offer free HIV postal testing kits by mail to those in need throughout the UK. After a short burst of initial targeted national publicity, the scheme continued to attract between 30-50 requests a day without any paid promotion.

These blood spot kits were of the kind that gives an immediate result, i.e. POCT tests. An earlier scheme had also operated with blood spot tests which had to be returned and laboratory tested, with results given by text message or phone.

Those ordering kits were assessed online to ensure that they were in genuine need i.e. that they belonged to a group deemed at high risk, had a sexual partner in such a group and/or reported risky sex. Kits were then mailed to them with instructions for use and support services if needed.

People using the POCT tests were encouraged to log on to a dedicated and confidential site after testing and report results to get further support. Of the 23,042 tests distributed, 59% reported their results back. The positivity rate of these reported results was 0.57% overall, of whom the vast majority (79%) were men who reported sex with other men exclusively.

People receiving a kit were also asked to donate to THT if they could, to keep the scheme running. Some 5.8% of recipients donated directly in response (i.e. through the campaign portal) with an average donation of £14.97p.

Despite no particular targeting of Cardiff or Wales, these kits proved particularly popular here. When local authority origins of those who had received kits was analysed, Cardiff (500 kits or 2.2% of all) had the third highest number after Manchester and Glasgow, both much larger cities with higher prevalence rates. Cardiff was also, with Salford, the joint highest source of reported positive results.

This free postal testing scheme was closed in March 2019 due to funds running out. It was replaced with another postal service which is marketed as costing £15, but offers free tests to those who say they are unable to pay (which is subsidised by the paid service). In just over six mon77ths, Cardiff residents have ordered a further 94 tests of which 40% were given free.

There are a number of postal testing schemes and formats which are tried and tested, with triaging, referral protocols and lab services already operating in community settings, which would be easily formally extendable to Wales.