

Improving care for people ageing with HIV in Greater Manchester



Introduction

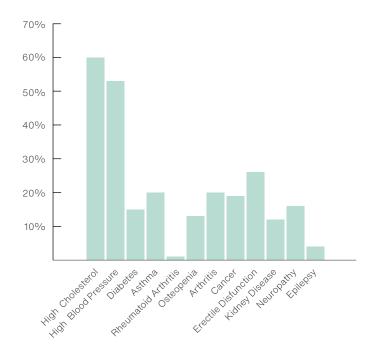
Given that the cohort of people living with HIV in the UK is ageing¹, the provision of integrated, coordinated care for older people living with HIV will become an increasingly pressing issue.

Positive Voices revealed that 72% of people diagnosed with HIV have at least one other long-term health condition.² As people living with HIV age, they are more likely to have multiple health conditions (comorbidities) as well as increased psychosocial needs. Some may also have difficulties with capacity for self-care and decision-making.

Responding to multiple needs requires an integrated healthcare system, complemented by coordination of the different elements of care required by any one person.3

Data for people over 50 living with HIV in the North East region show a range of comorbidities, with high cholesterol and high blood pressure (precursors of cardiovascular disease) especially common. Except for asthma and epilepsy, all the comorbidities in Figure 1 are age-associated.

Prevalence of common comorbidities among people over 50 living with HIV in the North West $(2017)^4$





By 2023, more than half the people living with HIV in the UK will be over 50. See Terrence Higgins Trust, 2017, Uncharted Territory: A report into the first generation

https://www.tht.org.uk/sites/default/files/2018-03/uncharted_territory_final_low-res.pdf

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report_2019.pdf

³See National AIDS Trust, 2020a, *Providing coordinated care for people living with HIV for more detail* https://www.nat.org.uk/sites/default/files/Providing%20coordinated%20care%20briefing_0.pdf



This report builds on previous work by National AIDS Trust (NAT) on providing integrated and coordinated care⁵, for which we continue to advocate nationally, for example, through work with NHS England's HIV Clinical Reference Group, as well as in specific local areas.

An example of that local work, this project is specifically focused on the needs of people living with HIV over 50. It is intended to recognise existing good practice and support action to improve the response to the needs of people ageing with HIV in Greater Manchester. It draws from workshops and face-to-face interviews conducted with 13 people living with HIV, aged 45 – 79, who access care in Greater Manchester (referred to as 'participants' throughout this report). The participants included people of white and Black African ethnicity, and people who are gay, bisexual and heterosexual. They were recruited to participate in the project with the support of George House Trust.

The health conditions (apart from HIV) of the participants included: high cholesterol, high blood pressure, cardiovascular disease, cancer, diabetes, neuropathy, hepatitis (B&C), porphyria, transverse myelitis, urinary problems, post traumatic stress disorder, irritable bowel syndrome, respiratory problems, chronic pain syndrome, paralysis, cognitive difficulties, enlarged prostate, hernia, hearing impairment and visual impairment.

As well as care from the HIV clinic and GP, the participants also access care from: urology, dermatology, cardiology, cardiac rehab, Physical Activity Referral System (PARS), diabetology, oncology, hepatitis C clinic, pharmacy, physiotherapy, district nurses, social care workers and agencies, dentists, and the local HIV support service (George House Trust).

We held a roundtable of health and care providers, commissioners, policy leaders and people living with HIV, to discuss the evidence drawn from the interviews and workshops and to identify opportunities and challenges in responding to current and future needs of people ageing with HIV in Greater Manchester.

Here we bring together the insights gained across the different stages of the project and propose next steps. This is not a detailed analysis of all the challenges for integration and coordination across the Greater Manchester healthcare system. But we aim to support the conversations that have already started in parts of the system around responding to ongoing need amongst people who are ageing with HIV.

Under the current shift towards greater devolution in healthcare, Greater Manchester Health and Social Care Partnership (HSCP) is in the process of establishing an Integrated Care System (ICS). The HSCP already has an important role to play in coordinating an integrated response to health and care needs in Greater Manchester and, under the new ICS structure, will have increased capacity to implement measures.

⁵ National AIDS Trust, 2020a, op. cit.; National AIDS Trust, 2020b, Improving and integrating HIV Care in South East London https://www.nat.org.uk/sites/default/files/publications/SELondon-ICS_FINAL.pdf

Findings

1. Integration of care

1.1 Holistic / shared healthcare provision

While some participants reported good relationships with their GP, most said that their HIV was managed separately by their HIV consultant and that the GP was not involved. This is different from most other health conditions where GPs are more involved.

Historically, participants were very used to going to their HIV clinic for all their healthcare needs. That option is increasingly not available to them, but they do not feel that the system has been replaced with an equivalent that they can trust. Especially as they age, some participants want to have annual reviews of their general health but are not offered that by the GP and feel that they no longer get that more comprehensive overview from their HIV service.

"If they want us not to go to the HIV clinic for everything, then there needs to be a system that we can trust."

There were particular concerns that healthcare providers in non-HIV services do not understand HIV. For example, participants reported loss of confidence in non-HIV specialists who discuss their HIV status openly in health settings without understanding the need for confidentiality.

1.2 GP understanding of HIV

Workshop participants expressed doubt that their healthcare could be properly integrated because their GP lacked understanding of HIV, and its impact on them. Some GPs had even expressed to patients that they did not feel confident on HIV-related matters, or on how it might affect other care they provide.

Many noted the difficulties that come from having no continuity of care at the GP and, for some, at the HIV service. This is especially relevant for recurring issues, which they felt would increase as they get older.

"My GP doesn't understand HIV. I'm the authority on my HIV."

"My GP is hypercautious. He thinks I'm more vulnerable than I am."

"You don't want to mention it [HIV] to your GP... you talk to your GP and just get a blank look back off him."

1.3 Polypharmacy and contraindications

Participants were concerned that if their HIV treatment is not well understood, it will not be taken into account during prescribing for other medications. They reported that they lose confidence in prescribing decisions when this happens.

These concerns were part of a larger worry about polypharmacy and contraindication and are not always HIV-related. Some felt that they should be having annual medicines reviews but did not know who they should ask to get that.

1.4 Impact of conflicting medical advice

One person described 'ricocheting' between their GP and HIV clinic after a heart attack, following disagreement between cardiologists and the HIV consultant about their HIV treatment. Beyond the immediate clinical concern, they described this experience as having a negative impact on their mental health and general wellbeing.

1.5 Responding to the needs of the whole person

Participants described how their broader life situation affected their access to treatment and care. A person seeking asylum said it was difficult to access healthcare services because of their immigration status and that they relied on support from George House Trust to make that possible.

A person who had previously injected drugs described their difficulty with nurses taking blood, which triggered high levels of anxiety for them. They are much more comfortable now that they have arranged for blood to be taken by phlebotomists, but this took a while to be arranged.

Some participants felt that logistical challenges, associated with managing impairments or physical distance from services, were not recognised and that they were not well supported to access HIV and other services.

For example, early morning appointments are made for people who are reliant on social care to get them ready and hospital transport to get them to appointments, meaning that it is very difficult to arrive on time.

Case studies

One person was prescribed medication by a urologist that should have had an adjusted dose because of his treatment for hypertension. He discovered this himself when he read the medication leaflet but struggled to get advice on what to do and did not know where to go for support.

One person was told by his GP that his HIV treatment was causing his high blood pressure, but he was then uncertain how to proceed as his GP and HIV clinician were in disagreement. This left him with concerns about polypharmacy and contraindication, which led to him stopping taking another medication for depression.



Opportunities for and barriers to integration of care

To facilitate the delivery of integrated clinical care, it would be useful to decide locally on a preferred model for coordination of care that is agreed and understood by GPs, HIV clinicians and people living with HIV.

It is important to distinguish between expectations for the GP to be involved in care coordination, as they are for other long-term conditions, and HIV care delivery. Potentially there is room for locally specific shared care models that do rely on some level of care delivery by the GP, but that would require changes in commissioning to fund GPs for this service.

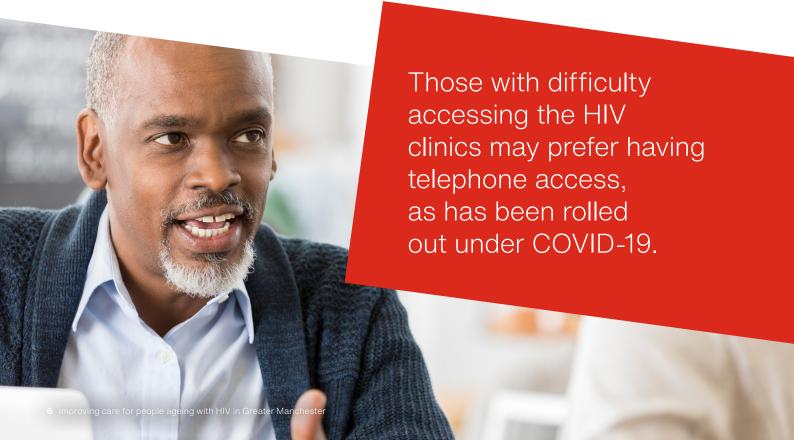
Even with agreement on roles, appropriate information systems and education are important for facilitating integrated care (see section on Information Sharing).

In terms of ongoing concerns around GPs checking for drug interactions, Manchester CCG's GP HIV Champion is already working with GPs and pharmacy teams to ensure HIV medication is properly coded, which automatically triggers an alert for contraindications. ICSs offer the opportunity for this type of work to be scaled up and is an example of how existing systems might be adapted to increase and improve integration. There is also the need to think about building flexibility into services so that they can meet the

specific needs of individuals. For example, those with difficulty accessing the HIV clinics may prefer having telephone access, as has been rolled out under COVID-19. Others may require face-to-face appointments. Innovations such as telemedicine need to be agreeable to both the person living with HIV and the HIV clinician as there are many reasons why telephone consultations, for example, may not be appropriate. Choice and adaptability are critical.

George House Trust's Intensive Support service, commissioned at Greater Manchester level, has been a great example of how a support service can maximise its value in terms of supporting integration and care coordination through being embedded within clinics and multi-disciplinary teams. The service is highly beneficial in supporting engagement with secondary care and supporting better adherence, health and wellbeing.

In Manchester there has already been a recognition that those who are most frail (with a frailty score of 4+) need additional, integrated service provision to stay in their homes. HIV clinical nurse specialists have started working with Active Case Management (ACM) teams within the Manchester Local Care Organisation that provide frailty services (usually with more of a general focus on primary care).



In turn, these teams work with social services, GPs, the voluntary sector, mental health services and so forth to ensure effective service delivery. HIV clinical nurse specialist involvement supports efficient referral into the service and management of people living with HIV who are also frail. Currently, this service is only available in Manchester and not across Greater Manchester.

While ACM services are only available for the most frail, lighter versions of integrated services, with preventive capacity are also available. The Greater Manchester area has several initiatives that are either targeted at, or encompass, an objective of health and wellbeing for older people. Some operate across the whole area whereas others are more local. Some are targeted at specific populations. Age Friendly Manchester is the City of Manchester's strategy for ageing well which includes work on sexual health. LGBT Foundation has a Greater Manchester-wide Pride in Ageing program that responds to issues related to isolation. Mapping of initiatives like these, and discussion about how they could be linked-up to clinical services, would help support whole person care.

The HSCP already has an important role to play in supporting the roll-out of innovative, and often cost-saving practices across Greater Manchester. As the new ICS is established and capacity to implement measures increases, there will be substantial opportunity to respond to care integration needs, including those among people ageing with HIV.

Recommendations on integrated care

- O1 HIV clinicians and GPs, with input from Clinical Commissioning Groups (CCGs) and Primary Care Networks (PCNs), should agree a model for delivery of coordinated care in consultation with people living with HIV. GP 'HIV Champions' should play a lead role.
- O2 Greater Manchester HSCP should consider their role in expanding and publicising Active Case Management teams and other preventive initiatives across the area (not only in Manchester).
- George House Trust's Intensive Support service should continue to be supported as a vital part of improving care coordination and integration of secondary care. Further consideration should be made for how this service, embedded in HIV clinics, can be better linked to primary care, social services and even the ACM.

2. Information sharing

2.1 Communication between healthcare providers

Participant experiences of information sharing across primary and secondary health services were mixed. For example, some reported good communication between the HIV clinic and their GP, while others said that their test results are not always shared and there is little follow-up.

People living with HIV often have to carry information between healthcare providers themselves. This can undermine patient confidence in the system. Participants worried that their capacity to remember everything accurately and convey the most important information could diminish, or was already diminishing, with age. And, as people tend to rely on a greater number of services as they age, this responsibility is likely to become more challenging to manage.

The perception was that information sharing is especially poor from the GP to the HIV consultant, and between services in different healthcare trusts. Given that these sorts of communications often relate to comorbidities, participants were concerned that interaction between multiple health conditions and treatments might not be picked up.

2.2 Patient understanding of information sharing

Participants reported that people generally do not know what health-related information is shared about them, and who with. Webs of healthcare information are likely to become more complex as people living with HIV age and rely on more healthcare providers, increasing the difficulty of keeping on top of who has access to information.

Some reported a loss of confidence in the system when specialists they attended for other comorbidities did not know their HIV status. While confidentiality remains a key concern, people often assume information is shared and can be surprised when this is not the case.

2.3 Patient access to information

Some participants want better access to their healthcare records to support greater involvement in their own care.

"I'm on statins. The GP manages that and sends the information to my HIV consultant. They work well together."

"I've had my bloods taken at the GP for a while now, but it's a different foundation trust [to the HIV clinic]. They only communicate because I've organised it."

Case study

One person reported having tests related to blood pressure and autonomic neuropathy with a specialist in London. He could not get the results because the GP told him to go directly to the specialist, but the specialist would only communicate directly with the GP. Eventually the person gave up on getting treatment.

Opportunities for and barriers to information sharing

IT and other information systems in the NHS are mostly managed at a local or regional level. This bring challenges, but there are local options for improving communications among healthcare providers, and between providers and people living with HIV.

With the shift to the ICS there is an opportunity to develop significant, Greater Manchester wide projects, so there is the possibility for developing a new information system with the patient at its centre. This should be designed to keep patients informed and equipped to understand and make decisions about their own care. Patient control over information is critical. People should not be, or feel, forced to have information on their HIV status generally accessible across all NHS services in the area.

Developing an ICS-wide system is a significant undertaking, but different providers across the ICS should be thinking about how they can integrate their existing information systems and improve data sharing. If technological solutions cannot be put in place to support this, then processes should be identified to support smooth flow of information together with patient control of their data.

Providers in primary and secondary care should consider their responsibility in sharing information more effectively. They can also start conversations with people living with HIV about who information is being shared with, and support patients to access their own information on whichever systems are in place locally, or via universal systems such as the NHS app.

Sharing healthcare information about people living with HIV is often, rightly, affected by concerns about confidentiality and stigma. Clinicians can adopt tailored strategies. For example, one described providing letters for patients to give directly to their GP if they are concerned about primary care administrative staff opening and seeing content of letters.

Clinician and support service led education programmes to tackle lack of HIV awareness and stigma, thus reducing concerns about information sharing, are already in place in some Trusts and could be expanded. However, as information systems become more integrated, open discussion about who can and cannot see information is vital, and capacity for people living with HIV to control access to their information must be seriously considered.

Recommendations on information sharing

- O1 Information systems that support effective communication between health and care providers must be in place. Providers across the Greater Manchester HSCP should be making plans for technological or administrative changes that support this within their existing systems.
- As the HSCP reaches ICS status, it should consider as a flagship project the development of an effective, patient-centred model of information sharing with considerations for patient control built-in. HIV clinics and people living with HIV should be involved in this process to ensure that specific concerns relating to stigmatised illnesses are properly considered.
- Healthcare providers should, routinely, discuss with people living with HIV who their information is being shared with, and how they can access it.
- O4 The Greater Manchester HSCP should consider bringing together partners across the area to establish responsibility for commissioning HIV education programmes.

3. Access to key services

3.1 Social care services

Participants who used social care reported that the services, on which they are dependent, are unreliable and inadequate to meet their needs. There is no sense that their clinical and social care is integrated. The shift to organisation of care by the ICS presents an opportunity to ensure that social care and clinical services are genuinely integrated and communication pathways between HIV clinics and social care services are improved.

3.2 Mental health services

Participants who attend the HIV clinic service at North Manchester expressed the value of having access to psychology services that are embedded in the clinic. They have a higher level of trust in this service compared with general mental health services. The service can also be accessed more quickly. This was not reported as widely available across Greater Manchester.

3.3 HIV support services

George House Trust is an effective and trusted source of support, but participants felt that there was a lack of understanding of its value from some healthcare providers and commissioners. Participants said that as well as supporting mental wellbeing, George House Trust helps people to stay physically well and to navigate the local health and care system.

Participants were conscious that the increasing pressure on George House Trust to support more complex needs or crises among the ageing population will affect capacity at the charity. They were concerned about potential consequences in terms of access to support both for the ageing population with more complex needs, and for those who may not have the same level of need but who still benefit significantly from support.



Opportunities for and barriers to access to key services

During the roundtable there was broad recognition that it is vital for key services to be available including, but not limited to, those mentioned by the workshop participants. Where these services can be embedded in HIV specialist services, they are more likely to be trusted and used.

Currently there are practical barriers to providing key services, in terms of guaranteeing availability of quality services and users being able to access them. For example, HIV clinicians who identify people living with HIV in need of crisis mental health support can only refer them to the GP or send them to A&E for onward access. There is no way for them to refer directly to community or crisis mental health services. This introduces delays and increases bureaucracy, inefficiency and the likelihood that a person will slip out of care.

Key services are not just essential at crisis point; they also have a preventive function. For example, triaging people into group counselling and peer support services could reduce the need for more intensive mental health support. George House Trust reduces more intensive needs through its programme

delivery, and effectively works as a social prescribing service to direct people to the support they need prior to crisis point.

These issues relate to commissioning decisions, both in terms of funding services and facilitating appropriate care pathways and referral systems. At a time when budgets are especially tight, the ICS has a role here in terms of recognising the economic (as well as social) value of providing these services, while also enabling economies of scale.

Especially where specialist services are not viable, pathways need to be planned. For example, the prevalence of poor mental health is higher among people living with HIV than the general population. Therefore, systems should be in place to ensure strong relationships and pathways between HIV clinics and mental health services.

Attempts to embed HIV support services (such as George House Trust) in HIV clinics have also met bureaucratic barriers. The charity has to undergo due diligence processes with each Trust, with volunteer peer supporters needing approval from multiple clinics and so forth. This duplication of process could also be addressed area-wide by the Greater Manchester HSCP.

Recommendations on access to key services

- O1 Local authority and NHS commissioners should collaborate, with leadership from the Greater Manchester HSCP, to support streamlined care pathways for key services, and facilitate provision of cost-saving preventive interventions.
- The Greater Manchester HSCP should facilitate the removal of bureaucratic barriers for support services operating across different Trusts by establishing processes that sit across the whole
- Within the new ICS structure, social care leaders must be involved in strategic as well as practical discussions about integration of care generally and, specifically, about service delivery for people living with HIV who also use social care.

4. Care coordination

4.1 Value of having a care coordinator

Participants reported different levels of interest in managing their own care, and even the most activated had concerns about their capacity to manage their care at some point in the future. Some reported being heavily reliant on friends and family for support and said they would not know what to do if that support was no longer available. Others were conscious that they had no family to rely on as they aged.

All participants said they do not feel like there is a single person (or team) managing or overseeing their care. They were generally unfamiliar with the concept of a 'care coordinator' but, when explained, they felt that it would solve some of their difficulties in terms of accessing appropriate healthcare.

"[When experiencing symptoms] I don't know if it's my cancer or my HIV. I don't know where to go for clinical advice. The GP refers me to oncology, to dermatology. The GP is trying to act as a coordinator, but it doesn't really work."

"There needs to be a new role created of an HIV coordinator who is known by all the relevant departments, who can liaise with them on your behalf and who keeps you in the loop. They can be the go-to person if you've got a problem, they can work with you and stop you getting lost in the system, especially if you're working between 2 or 3 different healthcare trusts".

4.2 Flexibility regarding who acts as the care coordinator

The participants had different preferences for who should act as their care coordinator and agreed ensuring flexibility in who could take on that role was vital.

Some said that their main support needs for managing their care are administrative, for example, arranging transport for clinic visits. However, others want more insight on clinical matters and support navigating the health and care system. Those with more comorbidities tend to be more concerned with having someone overseeing clinical integration and oversight of their care.

Some participants felt that HIV clinical nurse specialists are best placed to provide care coordination functions, but there appears to be uneven access to specialist nurses across Greater Manchester. Some said that while it might seem logical for a GP or a social worker to act as the care coordinator, especially as contact with the HIV clinic was reducing, they had concerns about their capacity in terms of time and understanding. Some people said they relied on George House Trust for advice and support in managing and coordinating their care.

4.3 Importance of continuity of provision

The participants expressed the need for access to a single person who understood their case history, and the importance of continuity in providing care coordination.



"The continuity is really important, especially for someone with HIV, to be able to feel confidence in the consultant. When I was first diagnosed, he was incredibly supportive and that's really important to me... he has a much better overview than my GP does."

Opportunities for and barriers to care coordination

A care coordinator is someone who oversees care delivery across multiple services and acts as a single point of contact for people living with HIV (or any long-term health conditions). Although the benefits of having a care coordinator are recognised, there is no obvious way to build it into the system, especially given the variation in need between different people living with HIV. As pointed out by one consultant, this is being considered around the country but noone has yet managed to find the solution. Where care coordination is happening for individuals it is despite, rather than because of specific commissioning arrangements.

A significant difficulty is that each person will require a different emphasis and therefore different skills. Simply put, a social care coordinator is not the right person for the role if the concerns are focused on sharing secondary care responsibilities; the HIV clinician is not the right person if the main barrier for a person living with HIV accessing care is their migration status, or homelessness.

There is existing provision for those with the most severe need, such as community nurses or the Active Case Management teams described above. But these are resource intensive and not designed to be universally available.

HIV clinical nurse specialists have often taken on care coordination work, but there are significant capacity issues. Social prescribers and George House Trust provide some elements of the coordination function, but they are not always formally linked with clinical services and records apart from through the Intensive Support service (see section 1). There can be bureaucratic barriers (see section 3) to these services being embedded as needed.

This care coordination need is not just for people living with HIV, but for anyone living with multimorbidity and/or wider psychosocial need. A system-wide approach could avoid piecemeal, ad hoc approaches spearheaded by single health conditions that will inevitably spring up in response to need. This is perhaps one issue that can only be solved at the ICS level and, as it increasingly takes on powers and responsibilities for service delivery, this could be the precise time to look to the ICS for a solution.

Recommendations on care coordination

- Greater Manchester HSCP should consider the best way to respond to the need for care coordination.
- HIV services should review their patient lists to identify which people living with HIV need care coordination support, and work with patients to establish how that service can best be provided.
- NHS Commissioners should ensure that 03 sufficient HIV clinical nurse specialist and other specialist support service resource is available to be able to meet care coordination demands already being placed on services.
- Greater Manchester HSCP should ()4consider their role in expanding and publicising Active Case Management teams and other preventive initiatives across the area (not only in Manchester).
- George House Trust's Intensive 0.5Support service should continue to be supported as a vital part of improving care coordination and integration of secondary care. Further consideration should be made for how this service, embedded in HIV clinics, can be better linked to primary care, social services and even the ACM.

Conclusions and next steps

There are a range of activities that could improve integration and coordination of care for older people living with HIV in Greater Manchester. Some of these opportunities go beyond HIV and relate to developing HSCP and ICS-wide systems and services, but others involve adjusting and adapting existing services and processes to remove barriers to integration.

The legislative shift to Integrated Care Systems is intended precisely to address barriers to integration and identify opportunities. There is a clear set of responsibilities for the HSCP, not least in systems leadership. The recommendations described here are the start of a blueprint for how to respond to the needs of an ageing population living with HIV that is relevant to leaders across the functions of the ICS.

Poor HIV knowledge and HIV-related stigma is an ongoing problem in general healthcare services. Encouraging formal links between these and HIV services will help to ensure they are fit for purpose, and can be trusted by people living with HIV to meet their needs as they age and to do so respectfully.

Older people living with HIV report different experiences. This cohort cannot be lumped together, and flexibility is needed to meet varied needs. However, all the people living with HIV who participated in this project expressed concern

over whether a system would be in place to respond to their needs as they got older. They were particularly worried about what would happen if they were less able to advocate for themselves and manage their own care. Given the ageing profile of the UK population living with HIV, this issue cannot be ignored in Greater Manchester or anywhere else.

Although there are aspects of HIV that make it unique, in terms of care needs and delivery it has many similarities with other health conditions. People ageing with HIV in Greater Manchester should be able to take advantage of the age-related programmes already rolled out in the area.

Greater Manchester is a Fast-Track City, and the mayoral commitment to the scheme's ambitions is as much about supporting people living with HIV as it is about ending new transmissions. To achieve this, any commitment to an Action Plan for Greater Manchester must be future-proofed against changing circumstances, including an ageing population living with HIV. There are already models being implemented in Greater Manchester that can be built upon and made universally available, as is explored in this paper. Greater Manchester could lead the way and set a clear example for the rest of the country of how to provide effective HIV care for an ageing population.

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We're the UK's HIV rights charity. We work to stop HIV from standing in the way of health, dignity and equality, and to end new HIV transmissions.

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