NATIONAL AIDS TRUST

Securing rights
Stopping HIV

Improving care for people ageing with HIV in **Newcastle**

JUNE 2021

Introduction

Given that the cohort of people living with HIV in the UK is ageing[1], the provision of integrated, coordinated care for older people living with HIV will become an increasingly pressing issue.

Positive Voices (2017) 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.

FIGURE 1:

Prevalence of common comorbidities among people over 50 living with HIV in the North East (2017)[4]
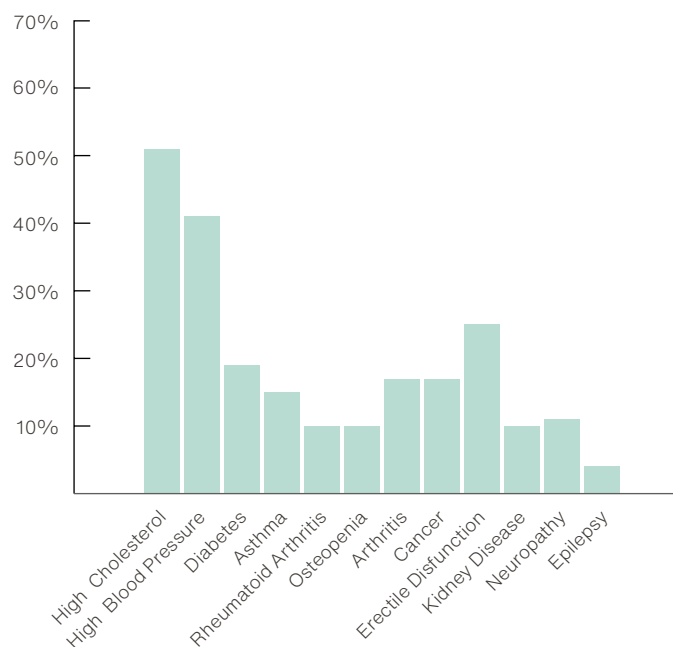
[1]By 2023, more than half the people living with HIV in the UK will be over 50. See Terrence Higgins Trust, 2017, *Uncharted Territory: A report into the first generation growing older with HIV.*
https://www.tht.org.uk/sites/default/files/2018-03/uncharted_territory_final_low-res.pdf

[2]Public Health England, 2020, *Positive Voices: The National Survey of People Living with HIV. Findings from the 2017 survey.*
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/857922/PHE_positive_voices_report_2019.pdf

[3]See National AIDS Trust, 2020, *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

[4]Personal communication Adamma Aghaizu, Positive Voices Team, PHE.

This report builds on previous work by National AIDS Trust (NAT) on providing integrated and coordinated care[5], 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.

This project is an example of that local work, intended to recognise existing good practice and support action to improve the response to the needs of people living with HIV over 50 in Newcastle. It draws from workshops and face to face interviews conducted with 12 people living with HIV, aged 39 – 69 (most were over 50), who access care in the Newcastle area (referred to as 'participants' throughout this report). The participants included people of Black African and white ethnicities, and people who are gay and heterosexual. They were recruited with the support of Blue Sky Trust.

The health conditions (apart from HIV) of the participants included: cardiovascular disease, high blood pressure, high cholesterol, pulmonary embolism and pulmonary hypertension, bronchiectasis, renal and liver failure, diabetes, sickle cell, ulcers, osteoporosis, neurological complications, Kaposi's sarcoma neuropathy, hepatitis C, asthma, allergies, eye problems, dermatology, psoriasis, sciatica, amputation, dyslexia, addiction, mental health issues, post-traumatic stress disorder, anxiety and audio hallucinations**.**

As well as care from the GP and HIV clinic, the participants also access care from: cardiology, diabetology, hepatology, neurology, physiotherapy, psychologists, dermatology, orthopaedic clinic, social care, AA Narcotics, social care, social services, welfare support, the local HIV support service (Blue Sky Trust), Thrive, and the Patient Participation Team.

We held a roundtable of health and care providers, commissioners 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 Newcastle.

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 Newcastle healthcare system. But we aim to support conversations that have already started in parts of the system around responding to ongoing need among people who are ageing with HIV.

[5] National AIDS Trust, 2020, op. cit.

Findings

1. Integration of care

1.1 Holistic / shared healthcare provision

Participants generally reported a lack of coordination between primary care and their HIV service. One participant commented how they had to attend two different places in the same week for separate blood tests ordered by their GP and their HIV clinician, despite attempting to bring the tests together into a single appointment.

However, those with multiple and complex long-term needs reported better collaborative care between the GP and the HIV clinic. Inpatient care was commonly recognised as being well integrated.

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"On the ward everything was set up very efficiently. The HIV consultant, my GP, the psychologist and social services were all very connected… until I got better. It's broken apart since I was discharged".

Participants generally commented that when their care was integrated, it was largely due to efforts within the HIV clinic. The clinic was reported as arranging x-rays and treatment for issues such as chest infections, as well as referrals to other specialisms like neurology.

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"My doctors are all connected. The HIV doctor refers me to the other consultants [including cardiologist and diabetologist] that I need"

The HIV clinic is seen by some as being very aware of the need for psychosocial support and as a result it makes regular referrals to Blue Sky Trust. Conversely, one participant said their GP had never heard of Blue Sky Trust and some people had found the service by chance years after diagnosis, having never had it mentioned to them by any of their healthcare providers.

Case study

One participant used to have a specialist HIV social worker who they felt communicated well with the HIV clinic, supporting integration of their clinical care with their wider needs. They now have access to a generic social worker who is not connected into the HIV service and does not provide support with integrating care needs. Without that additional role, they feel that their care is not well integrated.

1.2 GP understanding of HIV and stigma among non-HIV care providers

Participants expressed doubt that their healthcare could be properly integrated because other healthcare providers, including their GP, lacked an understanding of HIV and related stigma.

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"My GP isn't interested in my HIV"

There is a feeling among some participants who had previously lived outside the area that there is more stigma in the North East than in other parts of the country, and that this extends to healthcare settings.

In terms of receiving general healthcare from their GP, many expressed concern about the lack of continuity of care from their GP practice. This makes it difficult to develop a strong, trusted relationship with their GP. The need to repeat their history is particularly problematic given short appointment times and potential apprehension about stigma. Some also said that access to their GP is too slow for time-sensitive issues. Confidence in GPs has also been affected by the impact of COVID-19 on GP access.

Generally, participants reported feeling that GPs assume all medical issues are HIV-related and routinely send them back to the HIV clinic as a result. Many said they use the specialist HIV nurse at the Royal Victoria Infirmary (RVI), instead of their GP, for routine healthcare needs.

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"They always think that it's to do with your HIV and tell you to go to the clinic"

1.3 Polypharmacy and contraindications

Some participants who are taking multiple medications expressed concern that their healthcare providers did not seem to know what other medications they were taking. They were particularly concerned that providers appeared reliant on the patient's recall of medications as they do not always remember the details of their treatments, and they could find this harder as they get older.

There was also concern about the lack of regular review of medications, including for contraindications. For example, one person had been on some medications for over 10 years and had been prescribed further treatments in the meantime but had never had a review.

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"The GP always asks me what medications I'm taking and how much I'm taking. They should know that."

Case studies

One participant reported that a nurse at their GP surgery had loudly discussed why they needed a flu vaccination in a full waiting room (all people living with HIV are advised to receive the annual flu vaccine). This affected their confidence that this and other general practices understand the impact of HIV and HIV stigma.

One participant recounted that their blood sample had been labelled 'toxic' and they had experienced double gloving at their GP surgery. This undermined their confidence in attending the GP clinic

1.4 Responding to the needs of the whole person

Participants described how their broader life situation affected their access to treatment and care. One participant said that during a period when they had a very chaotic lifestyle due to addiction, having a drop-in clinic available was very effective in enabling them to access care.

Integrating non-clinical or statutory support into individual care plans, based on the circumstances of the individual, was also highlighted as important. For another person, who is reliant on their faith community for support, communication between their social worker, psychologist and pastor has been highly beneficial. Access to church is in their care plan. Others prefer not to have HIV discussed with people in other parts of their life.

Late diagnosis may impact a person's confidence in the healthcare system, affecting how they subsequently engage with it. One person commented that they had largely disengaged from non-HIV services, especially from primary care, following their late diagnosis.

There also appears to be inconsistency in implementation of policy or offering of services to people. The possibility of a frailty review, which is recognised by NICE as a key step in responding to the needs of people experiencing frailty, usually indicated by a combination of age and multimorbidity,[6] had never been raised with one participant who was close to 70 and struggling with their physical and mental health.

Opportunities for and barriers to integration of care

It would be useful to decide locally on a preferred model for the delivery of integrated care that is agreed and understood by GPs, HIV clinicians and people living with HIV. Currently, there are clear signs that, at least in some cases, GPs are not delivering routine primary care for people living with HIV. This could be for several reasons including GP levels of HIV-related knowledge, preferences of people living with HIV, and legacies from previous models of HIV clinic-led care.

Even with agreement on roles, appropriate information systems and education are important to facilitate integrated care (see section 2).

In terms of ongoing concerns around polypharmacy and contraindications, it would be useful to adapt existing IT systems to trigger automatic alerts to warn GPs of contraindications in newly prescribed medicines. The development of an Integrated Care System (ICS) in Newcastle offers the opportunity for this type of work to be implemented across the region.

The importance of services outside of what we may commonly think of as health and social care should also be considered. Being enabled to access support networks and services in a way which works for the individual is vital to maintaining wellbeing and could even prevent or delay need for more resource-intensive health and social care interventions down the line. Services such as Blue Sky Trust, community groups and churches as well as monitoring someone's frailty from an early stage, could all be components of this.

There is also the need to think about building flexibility into services so that they can meet specific needs of individuals. For example, those with difficulty accessing the HIV clinics may prefer having telephone access (as has been widely rolled out during COVID-19). Others may require or prefer face to face appointments. It is not always possible to exercise access choices across different services which can lead to inefficiencies and frustrations for the patient. Building the need for flexibility, coordination and communication into services (beyond HIV) is vital to overcoming this and there is a real opportunity as ICSs develop. An example could be allowing a person to incorporate blood tests and even appointments for multiple services into one visit. Choice and adaptability are critical to all services and should be considered as part of good integrated service design by, for example, ensuring that different service models are compatible with one another and are not designed totally in isolation.

[6] See, for example, NICE, *Improving care and support for people with frailty* https://stpsupport.nice.org.uk/frailty/index.html

Recommendations on integrated care

01 HIV clinicians and local CCGs or Primary Care Networks (which could be led by GP HIV champions) should agree a model for delivery of integrated care in consultation with people living with HIV.

02 The ICS should work with system designers, or follow models from elsewhere in the UK, to implement GP software that can flag contraindications.

03 The ICS should consider its role in supporting and publicising initiatives across the region that provide lower-level support to prevent or delay longer term, higher level health and care needs.

2. Information sharing

2.1 Communication between healthcare providers

Participants had mixed experiences of information sharing between their healthcare providers. One person described communication as 'pretty good'. Others feel it is poor, claiming that 'it's all in silos' and a number expressed concerns that they have to carry information between providers themselves. Some reported that results of blood tests taken at the hospital often cannot be seen by their GP and that this causes delays to their care.

There was a common worry among participants around whether communication systems would be effective enough if, as they aged, they lost capacity to pass information effectively between providers. This would be even more challenging if they experienced more comorbidities and increasing numbers of providers were involved in their care. This personal responsibility for information sharing is borne out of necessity rather than choice and therefore is not necessarily empowering.

2.2 Patient understanding of information sharing

Some participants were concerned that they do not know what health-related information is recorded and expressed a preference for improved access to their healthcare data. There was also a great deal of uncertainty about what information is shared, and with whom. Further clarity on this would support confidence and feelings of empowerment and control.

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"My GP doesn't communicate with my HIV clinic. The HIV clinic doesn't communicate with the drug service."

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"What will it be like if I'm not capable of giving the right information."

Case study

One participant reported that blood tests done at the hospital found a staph infection, but it took two weeks for the results to get to the GP. As a result of the delay, the infection went untreated, and they developed cellulitis

Opportunities for and barriers to information sharing

The HIV clinic at the RVI now shares notes electronically with GPs which should reduce delays in any treatment for people living with HIV that is being delivered in primary care as GPs have access to up-to-date information from the clinic. However, it is clear that information flows from the GP to the clinic are not up and running in the same way.

There is the potential for passing HIV-related information to other secondary care providers where agreed and appropriate. However it is unclear whether GPs pass on relevant information provided by the clinic. A solution could be to facilitate direct communications between secondary care providers as standard.

The NHS is gradually maturing towards integration of IT systems, albeit on a local (often Trust-level) basis, which presents possible solutions for sharing information between secondary care providers, but also raises challenges around control and confidentiality. Currently, those seen for care in the New Croft Centre Sexual Health Clinic will only have records shared when they give consent, whereas those receiving treatment in the Infectious Diseases department at the RVI will have their information shared as part of their hospital record.

Some people living with HIV do not want other healthcare providers to know about their HIV status. There are a number of reasons for this, including past experiences of stigma and discrimination in healthcare settings and lack of confidence around confidentiality. Some are concerned about the sheer number of people who may have access to their information in a Trust or specific staff in local services, for example the GP's receptionist, having access to that information. Sometimes people who work in the GP or hospital Trust where they receive care are concerned that their HIV status could be seen by people who know them. These concerns must be taken seriously by data managers and system designers, otherwise it risks people choosing not to engage with care or feeling coerced into sharing information. IT system design also needs to consider patient access to information about their own care.

People living with HIV need to be better informed about what information is shared about them. Given concerns that a considerable amount of health-related information accumulates around people, especially as they age and as they experience more comorbidities there is a further challenge of how to support people to manage and understand this wealth of information. This could be built into care coordination or specialist support service provision.

Recommendations on information sharing

01 Information systems that support effective communication between health and care providers must be in place. Providers across the area should be making plans for technological or administrative changes that support this with their existing systems.

02 IT system designers must work with healthcare providers and people living with HIV to respond to concerns around confidentiality and facilitate patient access to data and control over data sharing. The North East and North Cumbria ICS should play a strong role in advocating for patient rights to confidentiality and data access.

03 Healthcare providers should, routinely, discuss with people living with HIV who their information is being shared with, and how they can access it.

04 Commissioners and those providing care coordination or care navigation support should recognise their role in supporting people living with HIV to access, manage and understand their health data.

3. Access to key services

3.1 Social care services

Participants who use social care were concerned about the quality and reliability of provision. There is no sense that their clinical and social care is integrated and social care roles with specialist knowledge of HIV no longer exist as they used to. 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 Access to mental health services

Participants who use mental health services reported a strong connection between the services they used and their HIV clinic. They expressed the value of being able to access psychiatric and mental health services in the same hospital as their HIV clinic, given stigma around mental ill-health and the preference for not having their mental health needs widely discussed.

3.3 Value of HIV support services

The participants strongly value Blue Sky Trust.[7] Those with complex health needs, expressed a particularly strong reliance on the service despite it not being a healthcare service in itself. One participant also uses Thrive and the Patient Participation Team.

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"If I lost that support service, with my life I would feel very isolated. They may not give clinical advice, but you know that they're there. How are you going to get the information to access the right services if that support isn't there?"

Peer support services received particular mention, with one participant noting that peer support was not available for their other healthcare needs.

There has been increased pressure on HIV support services like Blue Sky Trust to do more with less in recent years, particularly with financial pressures on local authorities. One person mentioned that they would like to be able to use Blue Sky Trust more, but that there are not as many services available as there used to be. For example, they would like to have a dedicated service for older LGBT people.

Some want Blue Sky Trust to be more involved in their care provision, for example having a more formal care coordination role and links with clinics as well as facilitating drop-ins with HIV specialist nurses in the trusted space of the support service.

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"I ask Blue Sky Trust about everything. They answer all my questions about vaccinations, they signpost me to services, just everything really."

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"Blue Sky Trust has a holistic view. They signpost you to services because they understand what you need."

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[7]For transparency purposes, it is important to note that the workshop participants and interviewees were recruited by Blue Sky Trust.

Opportunities for and barriers to access to key services

Currently there are practical barriers to providing key services, in terms of guaranteeing availability of quality services, and being able to access them.

Provision of necessary services is inconsistent, such that access to adequate social care seems to be much harder in Newcastle than access to appropriate mental health services. This results in some people living with HIV getting their needs met while others do not. Locating mental health provision in the RVI and developing strong links between the HIV and mental health services has been an effective and trusted way of delivering mental health support.

While co-location has been beneficial for mental health provision, that will not necessarily be the appropriate solution for other services. It is important to establish what works best regarding service delivery and how good links and referral pathways can be established.

There is also inconsistency of referral into non-clinical services. For example, some people living with HIV are made aware of Blue Sky Trust's services while others have found them by chance. This sadly indicates that there may be further people in the area who need this service but who are unaware it exists. It is vital to establish clear care pathways and awareness of such services

among healthcare providers. However, service provision is ultimately down to commissioning decisions. Commissioners should consider whether there is a more integrated model of working between clinical and non-clinical services that will enable both to better meet the needs of those they support.

Key services have a preventive function. For example, providing appropriate social care reduces hospital admissions; triaging people into group counselling and peer support services reduces the need for more intensive mental health support; and care navigation support from Blue Sky Trust enables people living with HIV to access clinical care appropriately.

Sometimes it has been difficult to make budgets available for these services because the costs and benefits fall in different areas. For example, providing social care from local authority budgets reaps economic benefits in secondary care paid for from NHS budgets. Integration of budgets under the ICS has the potential to overcome this, to allow the recognition of the economic (as well as social) value of providing key services, and to realise economies of scale. At a time when budgets are especially tight, the ICS has a crucial role here.

Recommendations on access to key services

01 Local authority and NHS commissioners should collaborate, with leadership from the ICS, to support streamlined care pathways for key services, and facilitate provision of cost-saving preventive interventions.

02 Senior social care officials must be involved in discussions about integrated care delivery for people living with HIV and should improve communication with HIV clinics. Specialist social worker roles should be considered as a possible route to facilitate this.

4. Care coordination

4.1 Value of having a care coordinator

The participants reported different levels of interest in managing their own care. However, even the most activated had concerns about their capacity to manage their own care in the future, and whether there would be something in place to support them when they needed it.

Some people reported being heavily reliant on friends and family for support and expressed concern that they would not know what to do if that support was no longer available.

> "I coordinate myself. I'm well supported and I'm more in control if I'm doing it myself. But what about when I can't look after myself?"

Participants 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.

> "Especially as I'm getting older, it would be really useful to have one person who knows everything about me."

4.2 Flexibility regarding who acts as the care coordinator

Most participants said that their GP is not currently coordinating their care, but that it should be their role. However, some suggested that the GP appointment is too short and felt that GPs have insufficient HIV-related knowledge to coordinate their care.

Blue Sky Trust clearly plays a key role in supporting coordination, even if informally, and in empowering people to coordinate care themselves. Some said that Blue Sky Trust supports them to deal with their full range of concerns – from clinical to immigration – and enables them to manage their own care.

One person suggested that their specialist social worker had been crucial in supporting their self-management. However, they had been replaced with a general social worker who does not have the same level of understanding about HIV, is not connected into the HIV clinic and is therefore unable to provide the same level of service (see also, case study in section 1.1.).

> "When I had a specialist social worker, they were my first point of contact for everything. That worked really well."

Another person was hoping that a community support worker, who is being arranged for them by the local authority, would be able to support their care coordination.

> "Blue Sky Trust are great for this. They support me to coordinate my own care. But it's not really within their remit. I'm hoping I might get this from the community support worker."

Many participants expressed a preference for care coordination to come from within the HIV clinic. They indicated that their specialist HIV nurse at the RVI is very good and is already providing care coordination and navigation.

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"The [HIV nurse] knows you as a whole person. They give you peace of mind because you're talking to someone with knowledge. They know your results. They know about your other health conditions. But it's not all clinical, they know about your wellbeing too."

Opportunities for and barriers to care coordination

In Newcastle, ad hoc care coordination is already provided by a range of health and care providers, including clinicians, Blue Sky Trust and social workers. However, this role is performed at the edges of these provider's remits, stretching already thin capacities.

Rather than trying to implement a system-based reformulation of care coordination, the solution in Newcastle could be to acknowledge the value of existing work and commission services accordingly. This should be done in consultation with those already providing these services to ensure it reflects the volume of work being undertaken in response to complex need.

A larger-scale strategy that could be implemented in parallel, or as an alternative, is to provide new care coordinator roles, that can work with all health and care providers. In this case, service design should be based on population need, as determined by the health and frailty profile of the area, rather than being HIV specific. However, the service design process should include opinions

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.

from people living with HIV. To work for people living with HIV, care coordinators would need some specialist HIV knowledge and links to HIV clinics.

Some other areas have already developed models of care that could offer a useful template for coordinated care for people ageing with HIV in Newcastle. For example, in one part of Manchester, HIV clinical nurse specialists are referring their patients with high frailty scores into multidisciplinary Active Case Management teams. The clinical nurse specialists become part of the team, ensuring that HIV care is appropriately linked into the overall response.

There is little indication that primary care is providing care coordination services for people living with HIV, nor that it is currently well placed to do so. Given the general expectations for primary care to have this oversight role, it is important to consider how primary care can best be involved in care coordination for people living with HIV.

Recommendations on care coordination

01 The ICS should consider the best strategies for responding to care coordination need for people ageing with HIV in Newcastle. This must include consideration of how existing service commissioning may be adapted to accommodate the care coordination function.

02 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.

Conclusions and next steps

This work shows that there are a range of activities that could be deployed to improve integration and coordination of care for older people living with HIV in Newcastle, and that key services and information sharing systems need to be in place for integration and coordination to happen effectively.

Older people living with HIV report a range of very different experiences, and this cohort must not be lumped together. However, all the people we spoke to expressed concern over what would happen if they became less able to advocate for themselves. Given the ageing profile of the UK population living with HIV, this issue cannot be ignored in Newcastle or around the country.

In places like Newcastle, where HIV does not have the same profile that it has in the larger urban centres and economies of scale will be less achievable, it is important that expectations are based on practicable, locally relevant solutions. Still, people ageing with HIV in Newcastle deserve the same standard of care that is expected across the country and the components parts are there to make this happen.

Good practice should be replicated and made available for everyone in the area rather than being tied to specific hospitals and the potential of clinical nurse specialists and services like Blue Sky Trust should be maximised.

The legislative shift to ICSs is intended precisely to respond to the need for integration and coordination and there are responsibilities here for the ICS, not least in terms of system leadership. The recommendations described here are the start of a plan for how to respond to the needs of an ageing population living with HIV in Newcastle.

> Given the ageing profile of the UK population living with HIV, this issue cannot be ignored in Newcastle or around the country.

NATIONAL AIDS TRUST

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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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