

# Providing coordinated care for people living with HIV



## 1 Introduction

Health and care in the UK is intended to focus on 'person-centred' care. That requires a holistic approach, which effectively integrates and coordinates the various elements of an individual's care. This is especially important for people who experience 'multimorbidity', defined as having two or more long-term health conditions.<sup>1</sup> In practice, supporting people living with multimorbidity often requires responding to a number of different healthcare needs (or 'comorbidities') with potentially interacting symptoms and treatments, as well as non-clinical complexity, such as poverty, insecure housing, need for social care, or uncertain migration status. Poorly integrated care can cause the inconvenience and unnecessary cost of increased treatment burden, but also risks clinically suboptimal, or even potentially dangerous treatment.

Managing multimorbidity is a significant concern for people living with HIV and for those who treat and care for them. According to data from the Positive Voices survey, 72% of people diagnosed with HIV have at least one other long-term health condition, with the most prevalent being high cholesterol, hypertension and diabetes (all known precursors of cardiovascular disease, for which people with HIV have double the risk<sup>2</sup>), arthritis, peripheral neuropathy, and kidney disease. In addition, 46% of people receiving HIV treatment report a social or welfare need, with two-thirds (62%) of this need going unmet.

People living with HIV, especially long-term survivors, tend to experience multimorbidity at an earlier age than the general population.<sup>3</sup> 42% of people diagnosed with HIV need advice on how to manage their long-term health conditions, and one-third of this need remains unmet.<sup>4</sup> However the risk of having a long-term condition increases with age and, as the cohort of people living with HIV in the UK ages,<sup>5</sup> needs related to multimorbidity are likely to increase.

Generally, multimorbidity is identified and managed through the GP. However, in some circumstances – where a person has cancer or mental illness for example – the GP's role is as a member of the healthcare team rather than its coordinator. Historically, HIV services in the UK have been pivotal in ensuring coordinated care provision across their patients' comorbidities and wider complexity, and it is still likely that multimorbidity and complexity will be first recognised by HIV services. Legislative reform in 2012 and subsequent developments have reconfigured commissioning models, with HIV clinics no longer funded to provide or coordinate non-HIV care and ensuing fragmentation of care for people living with HIV.<sup>6</sup>

However, a set of policy responses to multimorbidity and complexity lean towards re-integrating service provision in new ways.<sup>7</sup> In order to identify how some of these new strategies and guidelines might play out in practice, NAT reviewed key documentation and interviewed 14 people living with HIV plus a range of comorbidities and other complexity, and 14 clinical and non-clinical service providers.

This briefing provides first hand evidence of the outcomes of poorly integrated and coordinated care, and it shows how emerging models are aiming to respond to that fragmentation by providing integrated healthcare at the system level complemented by care that is coordinated around the individual. Rather than prescribe exactly what care models should be commissioned, we conclude by deriving principles for integrated, coordinated care that should be tailored to meet the needs of specific cohorts.

<sup>1</sup> NICE, 2016 *Multimorbidity: clinical assessment and management*. NICE guideline [NG56]

<sup>2</sup> Shah ASV, Stelzle D, Lee KK, Alam S, Clifford S, Longnecker TC *et al.* 'Global Burden of Atherosclerotic Cardiovascular Disease in People Living with the Human Immunodeficiency Virus: A Systematic Review and Meta-Analysis'. *Circulation*. 2018 Jul 2.

<sup>3</sup> Terrence Higgins Trust, 2017, *Uncharted Territory: A report into the first generation growing older with HIV*.

<sup>4</sup> NAT, Positively UK, Public Health England & Watipa, 2018, *Changing Perceptions: Talking about HIV and our needs*.

<sup>5</sup> By 2023, more than half the people living with HIV in the UK will be over 50. See Terrence Higgins Trust, 2017, *Uncharted Territory*, *op. cit.*

<sup>6</sup> BHIVA, 2017, *Shared Care: how can we do it? Findings from the BHIVA Primary Care Project*; The Kings Fund, 2013, *The future of HIV services in England: Shaping the response to changing needs*; NAT, 2016, *HIV in the future NHS What next for people living with HIV in England?*; All Party Parliamentary Group on HIV/AIDS, 2016, *The HIV Puzzle: Piecing together HIV care since the Health and Social Care Act*.

<sup>7</sup> These include generic, cross-condition provisions as well as HIV-specific measures. See, for example, NHS England, 2019, *Universal Personalised Care: Implementing the Comprehensive Model*; NICE, 2016, *Multimorbidity*, *op. cit.*; BHIVA, 2018, *Standards of Care for People Living with HIV*.

## 2 The impact of poorly integrated care: responses from people living with HIV

People living with HIV plus comorbidities or other complexity described the difficulties and harms that arise from fragmented care provision:

- Managing multiple appointments with various consultants and other providers, sometimes on the same day in different places, means that attending for healthcare becomes expensive and all-consuming.
- Having the same tests, especially blood tests, repeated a few days apart by different providers is invasive and unnecessary.
- Uncertainty undermines confidence in the healthcare being provided. This was reported in relation to inconsistent, contradictory advice and treatment decisions, and to being bounced backwards and forwards between different doctors due to uncertainty of clinical responsibility.

### Personal experience

One person told us that they were adhering to their ART regimen, but they had stopped going to some medical appointments because they couldn't cope with the conflicting advice.

- Being asked to repeat complex histories to multiple healthcare providers makes people feel like their case is not understood holistically across the healthcare system, and is also especially troubling in the context of fear of stigma. This is exacerbated by insufficient continuity of care among GPs and other health providers (although, with one exception, respondents specifically reported that this was not the case for their HIV care).
- Needing to act as the communication link between healthcare providers leads to concerns that clinicians are not having necessary discussions and do not have the appropriate information to enable them to make the right decisions (e.g. around drug interaction or decisions about care).
- There is a lack of confidence that other healthcare providers understand HIV adequately and, although reported far less, some people also expressed concern that HIV consultants did not properly understand their comorbidities.
- Not being able to get good information about all their comorbidities or about how those conditions and their treatments may interact disempowers people, and makes it harder for people to be involved in decisions about their own care.

### Personal experience

A person with a strong desire to manage their own health in a holistic way told us about the difficulties in getting their consultants to communicate with each other and in gaining access to their medical notes.

- People report not being able to access other necessary services either at all, or sufficiently quickly, following referrals and signposting.
- There is inadequate support for managing multiple long-term conditions, and uncertainty about who to ask or where to go to find that support.
- Self-management is hindered by difficulty with administrative arrangements, such as not being able to re-arrange appointments or coordinate multiple appointments.

### Personal experience

One person reported that an appointment for tests was rearranged by the provider, but they weren't able to convince administrative staff that the follow up appointment also needed to be moved after the tests. Rather than fail to attend, the person went to the appointment – a waste of time and money for themselves and for the NHS.

### 3 The impact of poorly integrated care: responses from service providers

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HIV clinicians and other affiliated healthcare professionals described the improvements that could result from better coordination and integration of healthcare services:

- Confidence that the system is providing the best quality care for patients, including knowing that those with comorbidities are having all their conditions properly cared for. Some clinicians expressed the concern that poor integration of care may have led, or at least contributed, to patient deaths.

#### Personal experience

A clinician reported how a patient with good adherence and stable HIV died after disengaging from care for heart and renal problems. The person was engaging with HIV care, but it wasn't within the HIV consultant's purview to manage the wider elements of their patient's care.

- Certainty around responsibilities for all elements of a person's treatment and care, including certainty of remuneration for services provided, would also mean clinicians could avoid unnecessary inefficiency, confusion, and negotiation with their Trusts.
- Efficient and easy access to treatment and care. This could include sharing specified responsibilities, reducing appointment and testing burdens on people living with HIV and increasing efficiency within the system.

#### Personal experience

One clinician suggested that basic HIV-related tests could be administered by other secondary or primary providers if people with stable HIV were being seen for management of other conditions. Results would have to be made available to the HIV consultant in a timely manner. One vital caveat is that planning not to see their HIV consultant must be a shared decision between the person living with HIV and their healthcare providers, and must always be revocable by the patient.

- Recognition of the value and volume of care coordination activity that is already happening, and the need for more consistent provision of that care coordination work.
- Encouragement for people with stable HIV to be seen in nurse-led clinics where they can be easily referred into wider support as required, while also freeing up consultants' time to manage clinically complex cases.
- An information sharing system that allows quick and effective communication and collaborative decision-making, to avoid uncertainty and delays in decision-making, and to instil confidence that the right treatment and care decisions are being made.
- New technologies that could save time and money for people living with HIV and the healthcare system (e.g. via virtual joint appointments) should be explored.
- The provision of sufficient services to enable referrals and facilitate management of complexity needs to be addressed. Especially mentioned were the inadequate provision of drug and alcohol services, mental health services and social care.

## 4 Identifying complexity

Considerable attention has been devoted to improving identification of multimorbidity in primary care.<sup>8</sup> Identification of people living with HIV and multimorbidity may be more likely to occur in the HIV service. However, the current definition of complexity used in HIV surveillance data,<sup>9</sup> which triggers intensive monitoring, further attention of a multidisciplinary team (MDT), and specialist clinics, is tied to very specific criteria such as treatment for TB, viral liver disease, cancer or persistent viraemia. These do not map closely onto the list of comorbidities experienced by people living with HIV, which means that many people living with HIV may be dealing with significant complexity that is not being recognised or generating an appropriate response.

In terms of triggering identification of multimorbidity and wider complexity, BHIVA guidelines call for the investigation and monitoring of a range of needs deriving from complications attached to HIV status or use of ART such as renal and liver function, osteopenia, diabetes, cardiovascular risk, colorectal and breast cancers, mental health difficulties, social care and welfare requirements, and immigration status.<sup>10</sup> Beyond these, and reported multimorbidity, there are other markers which could indicate that attention around integration and coordination of care is required, such as age of the patient, late diagnosis, and time of diagnosis plus ART regime experienced.<sup>11</sup>

There are also specific groups of people who tend to be the most marginalised in terms of service provision, for whom care integration and coordination may be particularly important but especially inaccessible. These include migrants (especially those with no recourse to public funds), trans people, people held in prisons and other closed settings, the homeless, sex workers, and people who inject drugs. People in these groups may be the most likely candidates for care coordination but, for various reasons related to stigma, lack of adequate knowledge among healthcare providers and fear of the consequences of accessing services, may feel that standard provision does not meet their needs.

Mechanisms that identify multimorbidity and complexity, however they manifest, must be built into healthcare systems to ensure that all people living with HIV receive services appropriate to their individual experience.

## 5 How can integrated care be delivered for people living with HIV and wider complexity?

Some people living with HIV reported to us that they were keen to coordinate their own care and need little by way of support, but that difficulties arise when they are faced with a poorly integrated system. The overarching message derived from the interviews we conducted is that for the coordination of an individual's care to be as effective as possible it needs to be layered onto an already appropriately integrated system of health and care. Integrated care models can take the form of either shared or collaborative care arrangements.<sup>12</sup>

### 5.1 Approaches to shared care

'Shared care' involves formal frameworks with agreed care protocols based on knowledge-sharing networks, training for healthcare professionals, effective communication, formal division of responsibilities, and networks to provide coordinated care.<sup>13</sup>

#### Joint clinics

**Definition:** The joint clinic centres mainly on direct interaction between different components of secondary care. It provides a 'one-stop shop' for people with specific comorbidities, thereby reducing the treatment burden on the person living with HIV, offering cost-savings by reducing the number of appointments that an individual attends, and also ensuring that the person is treated holistically rather than singly for the comorbidities they present with. In this model, the GP should be kept informed of developments but is not involved in the coordination of provision.

<sup>8</sup> See, for example, NICE, 2016, *Multimorbidity*, *op. cit.*

<sup>9</sup> Clinics use the HIV and AIDS Reporting System (HARS) to report patient data to Public Health England for monitoring and surveillance purposes.

<sup>10</sup> BHIVA, 2019, *Guidelines for the routine investigation and monitoring of adult HIV-1-positive individuals 2016* (2019 interim update)

<sup>11</sup> It is likely that complexity will increase with time since diagnosis, broadly classifiable as the eras before ART (diagnosis pre 1996), complex ART (1996-2004), fixed dose combinations (2004-2014) and post-START trial with guidelines for immediate treatment on diagnosis (2015 onwards).

<sup>12</sup> BHIVA, 2017, *Shared Care*, *op. cit.*

<sup>13</sup> BHIVA, 2017, *Shared Care*, *op. cit.*

**Experiences:** Joint clinics are based on an understanding of the needs of the local patient cohort. For example, the Silver clinic in Brighton is a joint HIV/geriatric clinic that responds to the high proportion of ageing MSM living in the area. One clinician estimated that a single appointment in the frailty clinic can replace five separate single-issue appointments. Another example is the collaboration between the HIV and ante-natal clinic at Homerton conducted by a senior nurse, supported by a social care coordinator. This service is an example of continuity of care across the life-course for a specific patient group.

### Personal experience

“What’s to stop us saying why do you need the HIV doctor and the neurologist in the same place at the same time once a month? Can we not be more flexible, particularly with digital technology, to allow the same standards of care more flexibly?”

HIV Consultant

**Potential barriers:** Joint clinics can respond to common needs and comorbidities in high prevalence areas but, because they are only likely to be viable with sufficient demand, they do not cater for less common comorbidities or for low prevalence areas. In these circumstances, some of the clinicians we spoke to suggested that virtual joint appointments could provide a more individualised model of integrated care.

### Recommendations:

- Providers and commissioners should collaborate to identify where joint clinics could provide an efficient response to local need.

## Well-connected clinics

**Definition:** The well-connected clinic has good referral pathways and links to other hospital specialties accessed by the patient. It can be particularly effective when services are co-located in the same hospital.

**Experiences:** One person living with HIV reported managing to transfer the secondary care for all their different health conditions into Chelsea and Westminster hospital, resulting in better communication between healthcare providers and improved care coordination. However, a different interviewee reported far poorer integration even though their consultants were also all co-located.

**Potential barriers:** Currently, GPs, rather than the HIV clinic, are usually expected to make referrals for patients living with HIV to other specialties, even in the same hospital. HIV clinicians are only supposed to make referrals without GP intervention for cancer or where the need is HIV-related. Clinicians told us that the involvement of the GP in referral making was an unnecessary inefficiency within the system that can cause delays and potential loss of information. However, in some areas commissioning arrangements have changed to allow direct referrals between secondary care providers.

This model relies on good referral pathways and networks. However, there is no HIV-specific model for what this might look like. Without formal linkages centred around effective communication and protocols to determine responsibilities, even co-located services may not realise the advantages of being ‘well-connected’.

### Recommendations:

- NHS commissioners should allow for and encourage direct referrals between secondary care providers, with mechanisms to inform GPs built in.
- To ensure clarity of expectations for providers and people living with HIV, BHIVA and NHS England Specialised Commissioning should collaborate to provide guidance on what constitutes good referral networks and pathways, with concrete examples of effectiveness and impact.

### 5.2 The collaborative care model

**Definition:** ‘Collaborative care’ provides a patient-centred, rather than system-led, model. It involves an individualised, responsive case-based approach, centred around a care plan developed with patient involvement and communicated to all relevant providers, and a named person with responsibility for coordination of care, monitoring and follow-up.<sup>14</sup> In theory, the coordination role could sit anywhere across the team of collaborators.

Collaborative care may be especially valuable for people with significant complexity, whether clinical or non-clinical, whose care is often already being managed by a multidisciplinary team, and for older people living with HIV.

There is considerable debate over the future role of GPs in collaborating around HIV and HIV-related care provision.<sup>15</sup> At minimum, the GP is likely to be one of the collaborators, but GP provision of care may be more appropriate in some cases than others. For example, one model has been identified where GPs provide both appropriate primary care and specialised HIV care opportunistically to socially vulnerable people who do not attend the HIV clinic consistently.<sup>16</sup>

A less-intensive form of collaborative care for more stable patients would involve the person living with HIV attending the service they felt was most relevant to their current needs. The monitoring and testing interventions required across their long-term conditions could be delivered within that one service. Face-to-face interventions at the HIV clinic would still be available, but only if required. Monitoring services could even be delivered by the GP or elsewhere in the community at the patient’s convenience, for example in HIV support services.

#### Personal experience

“Does it need me to do the FRAX score? Does the patient need to come to my unit to do the viral load? If we’re more creative than the diabetologist, the cardiologist and I can list what we need, and if the patient wants to they can be empowered to get these things done at their convenience, within time windows... if they don’t want to come to clinic they don’t have to.”

HIV consultant

**Experiences:** In Liverpool, a Community Nurse Specialist (CNS) team has joined up with a GP to provide care across a range of complexities in people’s homes for those who are unable to attend clinic appointments. Kings College Hospital in London has a GP service embedded within the HIV clinic.

**Potential barriers:** Collaborative care is perhaps the most resource intensive model suggested here but, in practice, may make cost savings by being preventive for people with high levels of need, and also by deploying the most appropriate provider (e.g. a CNS instead of a consultant). It is the least tested of the emergent care models, but also potentially the most transformative.

To work, this system needs to have a standard monitoring regime across all relevant disciplines, and good collaboration between and among clinicians and wider support services. BHIVA guidelines already make recommendations that could be built on, around communication between the HIV service, other healthcare professionals and the person living with HIV.<sup>17</sup>

Collaboration between primary and secondary care providers in the delivery of care for people living with HIV has remained underdeveloped as, historically, routine care has often been provided in the HIV clinic. If GPs are expected to take on a larger role they must receive adequate training and have access to expert advice.

Collaborative care depends on effective information sharing technology to ensure clarity around required interventions, prompt sharing of results, and easy communication between the care team and the person living with HIV. These components are not universally available, and systems are not all compatible.

<sup>14</sup> BHIVA, 2017, *Shared Care*, *op. cit.*; NHS England, 2016, *Personalised Care & Support Planning Handbook - Core Information*

<sup>15</sup> See BHIVA, 2017, *Shared Care*, *op. cit.*

<sup>16</sup> Hutchinson J, Sutcliffe LJ, Williams AJ, Estcourt CS, 2016, ‘Developing new models of shared primary and specialist HIV care in the UK: a survey of current practice’ *Int J STD AIDS* 27(8), 617-624

<sup>17</sup> BHIVA, 2018, *Standards of Care*, *op. cit.*

### Recommendations:

- Recommendations made in BHIVA Standards and their primary care project ('Shared Care') should be synthesised into a model of collaborative care that can be adapted locally.
- Existing networks that underpin joint clinics and well-connected clinics should consider whether also developing collaborative care models could provide effective care for some of their patient cohort.
- Where appropriate, existing 'HIV Champion' models should be expanded to ensure GPs have appropriate knowledge to allow for continuity of care for people living with HIV within primary care.
- NHS England must urgently address the barrier of incompatible information sharing systems. To achieve a functional and sustainable solution this must be dealt with at a national level with input from the range of healthcare providers.

### 5.3 Combining models of integration

Ultimately, some models will be better suited than others to certain individuals and cohorts. Commissioning decisions should reflect local demand, but it is likely that a combination of joint clinics and well-connected clinics across secondary care providers, and collaborative care models flexible enough to incorporate HIV services, other consultants, GPs, social care, mental health, drug and alcohol and third sector support services will be needed to provide adequately integrated care that meets the need of the current and future population living with HIV.

## 6 Who should coordinate care for people living with HIV?

Ensuring that all elements of care wrap around the individual in a way that meets their specific needs requires active coordination of clinical and non-clinical service provision. This is what we describe as 'care coordination'. In addition, people living with HIV often need support in overcoming barriers to access the multiple health, social care and voluntary sector services they may need. This is what we describe as 'care navigation'.

Generic, more administrative, care navigator roles are often held by non-clinical support staff in primary care,<sup>18</sup> whereas care coordinator roles may require clinical expertise or at least direct access to the clinical team.<sup>19</sup> However, there is no consistent definition for either role, and different functions will often be delivered by the same person.<sup>20</sup> In fact, one clinician suggested to us that it is usually preferable for a single person to fulfil both functions simply to avoid the need for a further layer of coordination.

In terms of entitlement to care coordination and care navigation support, BHIVA standards echo NHS provisions<sup>21</sup> by specifying that a care coordinator "should be utilised for people living with HIV with higher levels of need"<sup>22</sup> and that among older people living with HIV "consideration should be made for the use of designated care coordinators where possible for those experiencing complex care issues".<sup>23</sup>

### 6.1 People living with HIV coordinating their own care

The need for support with care coordination can derive from an individual's level of complexity and their capacity to respond to it, or from a lack of systemic integration of the health and care services they need.

It is well recognised in the literature, and was confirmed during our interviews, that people make the best coordinators of their own care. Care is inherently tailored to the person's aims and preferences when they play a significant part in decision making.<sup>24</sup>

<sup>18</sup> NHS England, Royal College of General Practitioners & Health Education England, 2016, *General Practice Forward View*

<sup>19</sup> NICE, 2016, *Social care for older people with multiple long-term conditions* [QS132]; NICE, 2015 *Older people with social care needs and multiple long-term conditions* [NG22]. *Tailored resource: The named care coordinator role from the perspective of older people*

<sup>20</sup> Health Education England, 2016, *Care Navigation: A Competency Framework*

<sup>21</sup> See, for example, NICE, 2016, *Social care for older people*, *op. cit.*; NICE, 2015, *Older people with social care needs*, *op. cit.*; NHS England, *Care for people with mental health problems (Care Programme Approach)*

<sup>22</sup> Standard 4c, BHIVA, 2018, *Standards of Care*, *op. cit.*

<sup>23</sup> Standard 7c, BHIVA, 2018, *Standards of Care*, *op. cit.*

<sup>24</sup> National Voices, 2014, *Person centred care 2020: Calls and contributions from health and social care charities*

However, some people living with HIV that we interviewed were concerned that they did not have sufficient knowledge or capacity to fully coordinate their own care, and wanted support. They expressed different levels and types of need, ranging from signposting and logistical support to a far more active advocacy and coordinating role. People must be empowered to be involved in their own care, but must not be penalised if they are not willing or able to do so. Everyone deserves well-coordinated care.

### Personal experience

“The ideal care coordinator is the patient, so it’s facilitating the patient and aiding the patient to coordinate their own care. But it might be a step too far for lots of patients. They shouldn’t be pushed into it. It’s only if they want to do it.”

HIV Consultant

Those of our interviewees living with HIV who wanted to coordinate their own care reported being frustrated by a poorly integrated, hard to navigate system, administrative and logistical difficulties, difficulty in accessing good information, and not having a point of contact who could resolve problems that arise. These barriers prevent them from using healthcare more efficiently, which would benefit themselves, service providers and the wider system.

People living with multimorbidity and complexity require greater investment in their care. But, as one HIV consultant told us, for a person whose HIV is stable that might simply mean ensuring easy access to administrative staff and using Electronic Patient Records (ePR) so that key clinical and administrative data is in one place and accessible by the person and all their healthcare professionals.

## 6.2 Who should provide care coordination support?

For the most part, GPs in the UK refer people into secondary care and maintain oversight responsibility for comorbidities when people are discharged back into their care. Under these circumstances, the GP may be the best person to coordinate care for many people with long-term conditions.<sup>25</sup> However, GPs have generally not been involved in coordinating care for people living with HIV. Instead, as described below, people in different roles have taken on some responsibility for providing that support.

### The HIV consultant

#### Advantages:

- Well placed to consider an individual’s complexity and their need for care coordination.
- Good clinical knowledge of how HIV relates to other comorbidities, potential treatment contradictions and drug interactions.
- Provide continuity of care.

#### Perspectives of people living with HIV:

- The HIV consultant is like a friend, and the only person with whom they really feel comfortable sharing the full detail of their experience of living with HIV.
- Most trusted to know whether their medical concerns were HIV-related or if they needed referral elsewhere.

#### Barriers and limitations:

- The most expensive option.
- Infrequency of appointments, especially for formally stable patients, may be insufficient to identify and respond to care coordination related needs.
- May not be suitable if the person’s complexity is a result of social rather than clinical need.

<sup>25</sup> The King’s Fund, 2010, *Managing people with long-term conditions*

### Recommendations:

- HIV consultants should identify the need for care coordination in all patients based on their assessments according to BHIVA guidelines.<sup>26</sup>
- They should, with patient consent, inform the other relevant care and clinical professionals of a person's need for care coordination.
- They should ensure a care coordinator is identified, where required. Where appropriate, the HIV consultant should be willing and sufficiently resourced to take on this role.

## The HIV clinical nurse specialist (CNS) or Community CNS

### Advantages:

- Geared towards providing a holistic approach and ideally suited to identify patients who may need coordination support, especially around non-clinical complexity.<sup>27</sup>
- Where most existing care coordination work sits (as with other health conditions)<sup>28</sup>, including medication optimisation, care optimisation, symptom management, screening for comorbidity, supporting continuity of care across providers, and emotional and social support.<sup>29</sup>
- Especially relevant where medical need intersects with significant social difficulties. Identifiable in specific cohorts or in settings where people are admitted to hospital for respite, rehabilitation or longer-term care.
- The Community CNS is especially engaged in complex case management and supporting self-management among those who are unable to access the HIV clinic or who have disengaged from that service. They liaise with all other services and provide some support with accessing services related to housing, welfare, and so forth.<sup>30</sup>
- Manages comorbidity at lower cost than an HIV consultant, with a wider set of skills around social complexity. A 'costs avoidance' analysis indicates value derived from preventing drug wastage, hospital admissions, ambulance call-outs and GP visits.<sup>31</sup>

### Perspectives of people living with HIV:

- There is significant trust in this relationship, such as in an example of recovery from alcohol dependency (which stemmed from difficulties with accepting an HIV diagnosis) which was dependent on the empathy, dedication of time and persistence of the CNS.
- At Mildmay Hospital in London, each person living with HIV has a key worker who can coordinate referrals and work to resolve issues around housing, benefits, access to nutrition and so forth, before the person living with HIV is discharged from in-patient care.

### Barriers and limitations:

- Works best when it involves frequent, in-person interactions, ongoing follow-up and monitoring, transition care, and the application of behaviour change principles, which are all time-intensive.<sup>32</sup>
- Huge variation in roles and not operating in all clinics, even in high prevalence areas.<sup>33</sup>
- Inconsistent awareness of specialist nursing services among people living with HIV.

### Recommendations:

- Providers and commissioners must recognise the important role the CNS plays in coordinating care for people living with HIV and include adequate CNS resource in their staffing plans.
- The adult HIV service specification should include more specific responsibilities for care coordination and should recognise the role of CNS staff in providing this care.

<sup>26</sup> BHIVA, 2019, *Guidelines*, *op. cit.*

<sup>27</sup> For a practical example of the value of the CNS role incorporating clinical and non-clinical functions, see Hudson, AP *et al.* 'Qualitative insights of patients and carers under the care of nurse navigators' *Collegian: The Australian Journal of Nursing Practice, Scholarship and Research*, 26(1): 110-117

<sup>28</sup> See, for example, Royal College of Nursing, 2005, *Developing integrated health and social care services for long-term conditions: Report from a symposium examining the interface between community matrons and specialist nurses for Parkinson's disease and multiple sclerosis.*

<sup>29</sup> Watson S, 2018, 'HIV complex care and care coordination: the nurse's role' *HIV Nursing* 18(2): 38-46

<sup>30</sup> Watson S, Bamford A, Barsley-Masina N, Jelliman P, and Tillet S (2018) *Providing a model of HIV community nursing.*

<sup>31</sup> For further detail, see Watson S, *et al.*, 2018, *Providing a model*, *Ibid.*

<sup>32</sup> Conway A, O'Donnell C, & Yates P, 2017, 'The Effectiveness of the Nurse Care Coordinator Role on Patient-Reported and Health Service Outcomes: A Systematic Review'. *Evaluation & the Health Professions*, 42(3): 263-296

<sup>33</sup> Watson S, *et al.*, 2018, *Providing a model*, *op. cit.*

### The embedded social care coordinator

#### Advantages:

- Links people up with social care, HIV support services, social services and external agencies (e.g. solicitors for migration advocacy) and, crucially, also follows up after those referrals and feeds incoming information back into the Multidisciplinary Team (MDT).
- Can easily access information from the MDT and feed information back in, being embedded in the clinic.
- Meets the needs of a particular cohort. The HIV clinic at the Homerton Hospital in London is the only service with an embedded social care coordinator, who supports a high proportion of migrants and people with needs for social care and other social services.
- Have greater capacity than those engaged in clinical work to develop expertise in managing complex external systems such as social care.
- More cost-efficient than utilising nurses for non-clinical work.

#### Personal experience

“For some of the people I’m working with, HIV isn’t that much of an issue for them. They’re more concerned about where they’re going to stay, are immigration going to grant them leave to remain... it’s all that other stuff that can quite quickly go wrong which will impact on their ability to self-manage and look after themselves.”

Social care coordinator

#### Perspectives of people living with HIV:

- Value having a single point of contact. People will also raise clinical matters because of the level of trust that has been developed.
- Makes it easier for clinicians to ask their patients about matters such as benefits, housing, accommodation, and so forth.

#### Personal experience

“If you’re a clinician asking someone about suicidal ideation or if they’ve got enough food in the house, you’ve got to have an answer if they demonstrate a need.”

Social care coordinator

#### Barriers and limitations:

- Limitations to interactions with some clinical staff, particularly those outside the HIV service.
- Case management is dependent on accessible, specialist services to refer people into. Provision of drug and alcohol and mental health services is inadequate, and HIV support services are dwindling. Inadequate service provision is a particular problem for anyone attempting to coordinate care that sits at the interface of clinical and non-clinical needs and outcomes. While this causes difficulties in London, for those in some parts of the country it can be almost impossible.

#### Recommendations:

- NHS commissioners must recognise the important role a social care coordinator can play in coordinating care for certain patient groups and include the role in the adult HIV service specification.
- Providers and commissioners should consider the value of having a social care coordinator to take on some non-clinical responsibilities currently conducted by CNSs, especially in clinics with a patient cohort that has considerable non-clinical need.

## Multidisciplinary teams

In practice, the HIV clinician, the CNS, and (where present) the social care coordinator will collaborate on care provision, contributing different skills and functions to the MDT. Similarly, the care coordination function may well be shared across staff in the HIV clinic, depending on the requirements of the person living with HIV.

In some settings an occupational therapist may also provide care coordination support as part of the multidisciplinary team. This may be especially relevant when people are being transferred out of in-patient care, for example from services for rehabilitative care such as those provided by Mildmay.

## The GP service

### Advantages:

- May suit those whose HIV is more stable and who attend the HIV service infrequently, as care coordination can centre around other health conditions.
- Link workers (or social prescribers) are usually accessed through GP surgeries and are increasingly provided by Primary Care Networks. They provide personalised support for people to identify meaningful health and wellness goals and link into community services, and reduce demand for clinical services for people living with multimorbidity.<sup>34</sup> Care navigation support can effectively complement the clinical offer from the GP.

### Perspectives of people living with HIV:

- Convenience of accessing care and support locally without having to travel further away to the clinic.
- Doubts about the capacity of GPs, and difficulties with getting appointments and securing continuity of care.
- Some strongly felt control of their care should remain in HIV clinics, primarily due to trust, access to specialist knowledge, and concerns about stigma.
- Others would find it acceptable to increase the GP's involvement in their care and one person reported a strong relationship with their primary care services and a preference for their care to be coordinated through their GP.
- A strong understanding of the needs of people living with HIV does not need to be limited to GPs in high prevalence, urban areas. Interviewees from low prevalence, rural areas, at some distance from their specialist care, discussed successfully 'upskilling' their GPs out of necessity, and consequent good experiences of care coordination within primary care.

### Barriers and limitations:

- Two-way communication between HIV services and GPs is often poor.
- Disagreement on whether, with better identification and management, primary care can respond to the demand arising from increased frailty and comorbidities.<sup>35</sup>
- Debates on the capacity of GPs to undertake routine HIV-related care is sometimes unhelpfully conflated with those around their role in coordinating care for people with multimorbidity, leaving the feasibility of GP involvement in coordination underexplored.
- None of the people living with HIV that we interviewed had experience of link worker services. However, some healthcare providers expressed concern that their output only involves a unidirectional flow of information, without follow up with the patient and feed-in to clinical service provision to allow coordination of clinical and non-clinical provision.

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<sup>34</sup> Moffatt S, Steer M, Lawson S, *et al* (2017) 'Link Worker social prescribing to improve health and well-being for people with long-term conditions: qualitative study of service user perceptions' *BMJ Open* 2017(7)

<sup>35</sup> Reeves D, Pye S, Ashcroft D *et. al.*, 2018, 'The challenge of ageing populations and patient frailty: can primary care adapt?' *BMJ* 362(8165): 234-236. And see the responses to this article.

### Recommendations:

- BHIVA should continue to work with primary care providers and NHS specialised commissioning to establish and pilot practical models of care coordination, including protocols for effective information sharing systems.
- GP practices with significant numbers of patients living with HIV should consider developing the HIV Champion role to ensure continuity of care for, and confidence among people living with HIV. GP practices without HIV Champions should consider facilitating easy access to named GPs, possibly through the Primary Care Network.
- HIV clinics and Primary Care Networks should explore how link workers could be used to support care coordination for people living with HIV.

## HIV support services

### Advantages:

- Provide trusted advice around long-term condition management and peer support.
- A nationwide training project means that many peer supporters are trained according to national standards.<sup>36</sup>
- Peer support proven to improve uptake of services, understanding of treatment, and confidence (among other outcomes)<sup>37</sup> which all increase the individual's capacity to be involved in the coordination of their healthcare.
- Peer support networks and wider HIV support services embedded in clinics facilitate easy access to support at relatively low cost.
- Providing services that support condition self-management helps individuals while also decreasing demand on clinical and social services.
- BHIVA standards of care and the adult HIV service specification recognise that peer support for people living with HIV is essential.

### Perspectives of people living with HIV:

- Seen as important, both as providers of information and support for long-term condition management and managing complexity, and as providers of information and practical assistance around non-clinical needs.
- Trusted as advocates and as non-judgemental spaces.

### Barriers and limitations:

- Generally an ancillary service supporting care coordination. Limited capacity for engaging directly in care coordination.
- Significant funding cuts<sup>38</sup> have led to reduced provision of services available for supporting people living with HIV.

### Recommendations:

- Clinical Commissioning Groups (CCGs) and emerging structures such as Integrated Care Systems (ICSs), with responsibilities around long-term condition management, must recognise that this involves taking the lead role in commissioning specialist HIV support services.
- National level bodies with responsibility for health policy including the Department of Health, NHS England, and Public Health England must hold CCGs and ICSs to account on their responsibility for ensuring provision of HIV support services.
- Commissioners and providers should collaborate to establish how best to provide HIV support services locally, and consider whether embedding support services in the clinic would be the most effective method of delivery.

<sup>36</sup> See Positively UK's Project 100 project <https://positivelyuk.org/project-100-2/> and the National Standards for Peer Support in HIV <http://hivpeersupport.com/>

<sup>37</sup> Anderson A, Anderson J, Fadojutimi M, Reeves I, Wills, M (2015) 'Peer navigators: can patient-led support contribute to clinical and well-being outcomes?' *HIV Med*, 16 (Supplement 2): 62

<sup>38</sup> NAT, 2017, *HIV Support Services: The state of the nations*

## Administrative support

### Advantages:

- Some people living with HIV who are strongly engaged in their own long-term condition management need only to have easy access to good clerical support along with an administrative system that can meet individual needs, to be able to coordinate their own care effectively.

### Personal experience

“Communications are vital, but they aren’t a panacea that will solve this. It needs people to look at the way they are providing healthcare and thinking that the system needs to be transformed into a much more patient-centric, patient run system, rather than the paternalistic doctor based system we have now”.

HIV consultant

### Perspectives of people living with HIV:

- Often faced difficulties in scheduling appointments and accessing information about their treatment and care.

### Barriers and limitations:

- Multiple administrative systems operating in the NHS and associated care mean HIV services cannot ensure administrative collaboration across all secondary and primary care providers.
- There is considerable variation in administrative flexibility. Difficulties in securing administrative support for condition self-management generally appears to be a matter of accepted protocols.

### Recommendations:

- Until compatible information systems can be delivered across all health and care services, healthcare providers should ensure that their administrative and information systems meet the needs of people living with HIV.

## 6.3 Making care coordination models work

To be effective, both integration and coordination of care must be available in a way that works for people living with HIV. Variation in needs and experiences of care means that any system will need to be flexible enough to allow for patient choice. Ideally, people living with HIV would choose their care coordinator, in discussion with appropriate healthcare providers.

It will also need adequate resourcing. Much of this work is fulfilled by the CNS role and therefore it is vital that this role is properly funded, but the possibility of other roles such as the social care coordinator should also be considered in commissioning models.

Services must be sufficient for referrals to result in prompt response to need. People living with HIV and healthcare providers that we interviewed especially mentioned inadequate and declining provision of mental health services, drug and alcohol services, social care and specialist HIV support services.

There are specific tools to make care coordination work, including case management plans and tools for measuring patient-reported outcomes. Vital to all these is effective communication between healthcare and ancillary professionals and the person living with HIV. There are various electronic patient record systems (ePRs).<sup>39</sup> One person living with HIV who we interviewed especially advocated for adoption of the ‘Patient Knows Best’ system which integrates records of primary and secondary care, test results, letters, and so forth. It enables people living with HIV to access and share those records, and also facilitates communication between the person living with HIV and their healthcare providers. Key to successful use of ePRs is to ensure that people living with HIV can determine who has access to their information.

<sup>39</sup> The INTUIT project (<https://intuitproject.org/>) based at Northumbria University is currently working to co-create new tools for information sharing.

Synchronising ePRs with multiple existing information technology systems for primary care reporting, lab results and so forth is difficult. These problems must be swiftly resolved to facilitate care coordination and patient involvement.

### Recommendations:

- The Adult HIV service specification should strengthen existing obligations for liaison with providers of non-HIV services, to state more specifically the need for care coordination work and to assign responsibility to the HIV service of ensuring that a care coordinator is identified for all people living with HIV who need one.

## 7 Conclusion

### Personal experience

“People living with HIV aren’t separating things into this is the diabetic doctor, this is the cardiologist... they have a series of issues and concerns and health problems and if there was a holistic way of addressing those in a more connected way and with less onus on multiple visits, multiple investigations, why can things not be joined up so instead of four doctors they see one or two doctors who then communicate and join things up?”

HIV consultant

Given variability of need and the requirement for flexibility, it is not possible to prescribe a system that suits everyone. This document discusses a range of options that can be drawn on when deciding how to meet locally-specific needs, and makes recommendations for how these models can be most effectively implemented.

Additionally, the following set of principles should underpin how integrated, coordinated care is provided for people living with HIV:

1. Healthcare must involve a holistic approach that encompasses non-clinical (e.g. social care, social services, counselling, drug and alcohol services) as well as clinical needs. This requires new ways of thinking to ensure integration between different elements of secondary care, primary and secondary care, physical and mental health, and health and social care.
2. Healthcare providers must recognise that the principle of ‘patient-centred care’ requires a fundamental change in how knowledge is shared, decisions are made, and outcomes are evaluated.
3. In order to provide a system that meets patient need, commissioning has to follow the patient. When a person living with HIV can access the right provider, in the right place, at the right time, efficiencies can be realised by avoiding fragmentation and duplication of care provision. But there must be flexibility in commissioning and remuneration to allow providers to offer that flexibility of care.
4. Locally specific combinations of models for integrated care provision should be arranged according to the needs of the patient cohort. Systems must be flexible enough to meet the range of needs and preferences among people living with HIV and be able to adapt as people move through the life course. They should be able to respond to the needs of those with uncommon comorbidities or especially complex needs as well as the comorbidities that occur more frequently among people living with HIV.
5. Healthcare should be available within an integrated system of service provision, with an overlaying system of care coordination (or care navigation) for those who need it. However, care coordination work cannot wait until properly integrated service provision is in place.
6. There must be adequate provision of services for people to be referred into (e.g. drug and alcohol, counselling, support services) in order that people can receive the care they need and increasing complexity can be avoided.
7. All healthcare providers must think about how to integrate care (e.g. maintain good communication and interaction with other providers, develop models of collaborative provision).
8. The person living with HIV is the best coordinator of their own care. People will usually need some level of support to navigate the healthcare system.

9. The person who is best placed to act as the named care coordinator should be determined by the person living with HIV, in conjunction with their MDT and other providers.
10. Care coordination must consider non-clinical as well as clinical needs. This may mean the coordinator role sits within an MDT rather than with a single person.
11. Integration and coordination of care is not only required for patients officially classified as 'complex'.
12. New technologies that could provide a more efficient, integrated healthcare system should be considered.
13. Care planning is integral to care coordination. It must involve shared decision making between multidisciplinary teams and the person living with HIV.
14. A system of information sharing must be in place that allows care providers and care users to efficiently provide and access information while respecting confidentiality.
15. A more easily navigable administrative system with accessible contact points would better support people living with HIV to coordinate their own care.

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