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how can we do it?

Findings from the BHIVA Primary Care Project

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Executive Summary

There are around 104,000 people living with HIV (PLHIV) in the UK and our clinical outcomes are among the best in the world. Almost half of those accessing care are now over 45 years and age-related comorbidities such as hyperlipidaemia and hypertension are common. For those whose HIV condition is well controlled, these comorbidities may have a more significant impact on morbidity and mortality than HIV itself. More than ever, we now need to focus on holistic management of healthcare needs, which addresses both HIV-related and non-HIV-related health conditions without losing the successes of HIV care. We believe that this can best be achieved by collaboration between primary and specialist care to provide a person-centred, rather than disease-specific, model of care across the life course. However, there is little evidence on how best we can achieve this.

To address this evidence gap, BHIVA commissioned a one-year programme of work with the overarching aim of informing commissioning and delivery of high-quality healthcare for PLHIV between primary and specialist care across the life course.

We hope that by describing contemporary care models for PLHIV across the UK, matching them with evidence measuring service quality, and then sharing the successful care model configurations, we will support community-based care for PLHIV through improved integration of care across both primary and specialist services.

Methods

Between August 2015 and June 2016 we engaged with health professionals, commissioners, service providers and service users to gain their perspectives on what consists of quality shared primary and specialist care for PLHIV in the UK.

We conducted a wide review of models of care identified in the medical literature. We then used interviews, online general practitioner (GP) and service-user surveys, and a service-user focus group to identify examples of best practice and case studies.

Main findings

The dynamic nature of HIV care, over time and over the very long life course has significant implications for the provision of high-quality healthcare within and between primary and specialist services. We describe three key areas: (i) clinical care; (ii) staff education and training; and (iii) excellence in commissioning. The need for continued research combined with robust evaluation, of what are often localised and pilot schemes, is pertinent to all the findings of this review.

Clinical care

In the context of the UK's excellent outcomes of HIV care and the 'lighter touch' specialist services now provided for clinically stable PLHIV, there is limited evidence of the effectiveness, efficiency and acceptability of moving to a shared model of care. The need for a more rigorous evaluation – including randomised controlled trials with health economic analysis – has never been stronger.

Models of care

Two models of care were identified in the literature:

- Shared-care models have an agreed protocol of responsibility between partners and are facilitated by networks to support the coordination of care.
- Collaborative-care models are more fluid and responsive. They rely on case-based management and structured care plans that are communicated to everyone involved in the individual's health and social care.

While both models were acceptable and feasible, the cases described in this report had evolved locally, through small networks of professionals and in response to specific care contexts. Leadership from local practitioners or commissioners was critical in their local development. Costs and thus sustainability of the models was not clear.

HIV as a chronic condition

Reduction in specialist review for stable patients and the perception that GPs are the gateway to health services that were previously open access is causing anxiety among PLHIV. HIV clinical nurse specialist (CNS) models demonstrated flexibility in meeting the different needs of local patient cohorts. Where the CNS have worked across the primary–secondary care interface, they have been instrumental in meeting the complex-patient needs of individual patients, training primary care staff as well as encouraging HIV-testing initiatives and reducing discriminatory practice. Such schemes could expand to support the navigation and transition between primary and secondary care; however, stability in the commissioning model for this CNS service would be needed since funding for these schemes is often short-term.

Communication

Effective, timely communication was felt to be key to development and maintaining effective models of sharing care. Shared electronic patient records and laboratory systems were thought to be ideal. As this is not yet feasible, guidance on best practice was sought.

Staff education and training

Practitioner knowledge was identified as key to the quality of care experienced by PLHIV in primary care. While best practice training courses were identified there were also multiple barriers to increasing practitioner knowledge of HIV, including the predominantly low caseload of the majority of GPs in the UK, which reduced the priority for HIV training, and the overall lack of funding or locum cover for training within primary care. Practices could be judged to be HIV-friendly if staff had attended training; for example using techniques combating stigma and encouraging the use of personal testimony, and widening anti-discriminatory policies.

Commissioning

Flexible, responsive healthcare that centres on the person living with HIV and not the healthcare-delivery system may be best placed to cope with the changing needs of PLHIV over the life course. Scaling-up of some of the promising models of joined-up commissioning described in this report with robust evaluation to determine whether wider implementation is appropriate.

Recommendations

The findings of this project have generated a set of recommendations to improve the quality of care for PLHIV in the UK across the life course.

Clinical care delivery

- Support and evaluate models of case-based management, including those supported by community nurse specialists, that support PLHIV navigate across social care, primary care and specialist services.
- Support and evaluate patient-centred approaches to care, including those supported by peer navigators, online care planning and patient-held records.
- Design and disseminate (e.g. through commissioning groups, CCG co-ordinating centres, health boards communication team, BHIVA website) a template for the different GP software systems detailing the requirement for appropriate medical services for PLHIV in primary care, including HIV testing prompts.
- Work with specialist commissioning partners and general practice to create a 'best practice' communication protocol between HIV services and primary care with flexibility for local adaptation.
- Continue to advocate for a shared e-patient record system nationally.

Staff development/training

Embed training, for example SHIP or STIF or DFSRH training courses, within the faculty of General Practice to standardise GP knowledge and skill in sexual health.

Support third-sector organisations in their anti-discrimination and awareness raising work, specifically:

1: to provide patient testimonies to all staff;

2: to design and deliver a national re-education campaign to de-stigmatise HIV and increase awareness of HIV among healthcare and the general population.

Commissioning

Review the commissioning structure for HIV services in England. If more support is being offered by primary care, including HIV testing, appropriate finances should follow.

Support, through responsive commissioning and financing, better integration of electronic patient records and collaborative care models.

Continue to commission care co-ordinators such as community nurse specialists to help complex patients navigate care.

Research and evaluation

Evaluate emergent models of patient-centred collaborative care across the various stages of the life course including ageing with HIV; this must include randomised controlled trials with HIV and non-HIV outcomes and robust health economic analysis that can then inform policy.

Evaluate models of person centered commissioning of care for HIV prevention and treatment.

1 Introduction

1.1 Historical context

In the early days of the HIV epidemic few treatment options could be offered. HIV testing was made available in 1985, and the national government campaign 'Don't die of ignorance' was launched 2 years later. Many people recollect the iconic tombstone image in their discussion of HIV in the UK 30 years later [1]. In the 1980s, community organisations became rapidly involved in promoting safer sex among gay men and have remained active in shaping services and providing a valuable support network for all people living with HIV (www.hivaware.org.uk/about/timeline-of-hiv). While men who have sex with men (MSM) continues to be the group most affected proportionately by HIV infection, with a higher prevalence in London, 52% of the estimated number of people living with HIV in the UK in 2014 acquired their HIV infection through heterosexual contact [2]. Black African heterosexual men and women are disproportionately represented in this group. Late diagnosis, where the immune system is compromised and treatment does not yield the optimum response, remains a significant problem among the heterosexual group with 55% newly diagnosed in a late stage of infection in 2014. Of these, 51% were black African. A complex social, economic and historical context contributes to late health-seeking behaviour in this group [3].

The timeline of the UK HIV epidemic highlights the partnership between clinicians and people living with HIV as they have learned together about the experience of living with HIV, the impact of the virus on the body, and the effect of medication combinations on both the virus and body systems. The active and vocal community organisations have acted as a quality check on a very successful service delivery model where 91% (76,462) of adults seen for HIV care in 2014 were on treatment and retained in care, with 95% achieving sustained HIV viral suppression the gold standard of successful management of HIV [4]. As a result of this context, HIV is now becoming classified as a long-term chronic condition [5-7].

This unique relationship was supported by the origin of HIV care. In many settings, particularly genitourinary medicine clinics, patient records are assigned a unique identifying number separate from the NHS number, keeping this record out of the mainstream NHS medical notes. As a result, specific consent is required from the patient for information to be shared with the GP. This anonymity aims to promote attendance, treatment and partner tracing for sexually transmitted infections that do not usually require long-term treatment. It was in this setting that many gay men were seeking healthcare in the 1980s. There was little communication with primary care or other specialities. As a result of the confidentiality system, people could, and often still do, travel out of their borough or to a larger city to access care. Furthermore, although disclosure of HIV status to GPs and non-HIV service providers is high and increasing, there remains a small but significant cohort of people whose GPs are unaware of their HIV diagnosis. A lack of disclosure is potentially a concern due to the risk of drug interactions between the ART prescribed by the specialist HIV service and medication for other conditions prescribed by the GP or other healthcare professionals. This is in addition to the loss of a link to access local support services. However, this confidentiality option is felt by some to be an essential requirement in the promotion of testing and retention in care among certain marginalised groups, as HIV infection remains highly stigmatised. Stigma in this context refers to prejudice, negative attitudes and abuse directed towards people living with HIV from both external sources and by the individuals themselves.

1.2 Commissioning of HIV services

HIV inpatient and outpatient services are provided under a 'specialist commissioning' model in England. The public health department of the local authority is responsible for HIV screening in primary care, sexual health services and HIV social care. Within this model, the Health and Social Care Act 2012 introduced greater sharing of responsibility for service provision among a variety of providers across the HIV pathway [8]. This increase in sharing has been recognised within the NHS contract for 'specialist HIV adult services' service specification. One of the objectives of the contract is to agree pathways defining responsibility for meeting the non-HIV needs of patients and to identify opportunities for shared care across the different care providers. This includes the involvement of primary care, mental health services, social care and peer support services [9]. The impacts of different funding processes in Scotland and Wales are referred to within the main body of the report.

In addition to the entry of new service providers into the care landscape, there have recently been some other significant changes to specialist HIV care configuration in response to advances in research and funding constraints. For example, non-HIV medical issues being seen in primary care; people are starting ART earlier; virologically stable patients are now offered less frequent review appointments and are often followed up virtually, through telephone and email clinics, supported by less frequent laboratory testing and home delivery of 6-monthly supplies of antiretroviral therapy. In a group of patients who learned the experience of HIV alongside their physicians, these changes and the perceived loss of control can create anxiety, especially as there remain many unknowns around the impact of ageing and HIV, and the long-term use of ART on the body.

2 Rationale

Historically a significant proportion of healthcare was provided in specialist settings. This was partly because the effects of HIV and its treatment were largely unknown [10,11]. An expectation persists among many service users of this accessible and re-assuring model of care [12]. However, the epidemiology of the HIV epidemic in 2016 is very different from that of the 1980s. Improved survival and new diagnoses at an older age, has led to a Public Health England report of all people accessing care in 2014; 48% were aged 45 or over [4]. Consequently, comorbidities associated with ageing such as high cholesterol (26%) and hypertension (16%) are becoming an issue [4]. Furthermore, 46% of people living with HIV had been diagnosed with depression at some stage of their life and 1 in 6 were currently taking antidepressant medications. These figures emphasise the need for increased involvement of non-HIV specialists in the non-HIV management of the stable people [13].

This changing landscape and the evolving health needs of people living with HIV is occurring in a context where specialist HIV services are providing the excellent HIV-related outcomes highlighted above. There is, therefore, a need to understand the different models of care that support the management of non-HIV and primary care aspects of HIV care in collaboration, or shared with, HIV specialist services, as well as the pattern of increasing the involvement of primary care and non-HIV specialists in the management of aspects of care for people who live with HIV. This will help us understand the strengths, weaknesses and quality of care provided by these emerging models of care. We aim to use these findings to inform recommendations that will support the development of flexible models of care that are responsive to the needs of people living with HIV at different stages of their HIV experience. Sharing these care-model configurations could support community-based care for people living with HIV through improved integration of care across the landscape of primary and specialist services.

2.1 Project aim

To inform commissioning and delivery of high-quality healthcare for people living with HIV between primary and specialist care across the life course

2.2 Project objectives

1. To conduct a scoping literature review of the models of care that support ‘sharing or collaborative’ care for people living with HIV across primary and secondary care in the UK.
2. Explore the emergent models of care for people living with HIV provided within primary care across the UK.
3. To describe the strengths and weaknesses of the different models of care in different contexts
4. To explore the relevance of the different models of care across the life course of the person living with HIV.

3 Conceptual model

To inform design of the data collection tools, we created a conceptual model following review of the literature surrounding the management of chronic disease (Figure 1). The aim of this model is to generate an understanding of the relationship and influence of different components of a shared or collaborative-care model across the life course of an individual with a chronic disease. This model, created for this study, is an empirically grounded conceptual tool that orientates the analysis of factors facilitating the delivery of quality shared care to people living with HIV. The model explicitly acknowledges that health and social care are both relevant to the well-being of a person with a chronic condition. However, the focus of this work was the co-ordination of care between specialist and primary care and so this was reflected in the study population and research methods used.

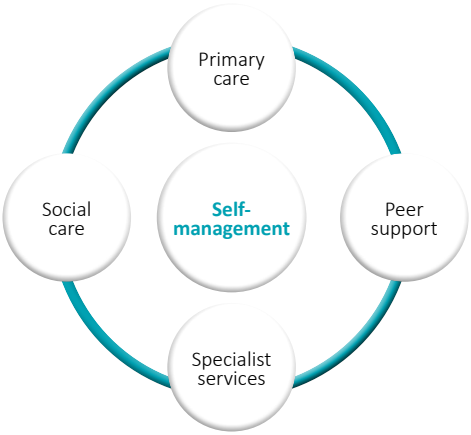


Figure 1. Conceptual model of chronic disease management

People living with a chronic condition are responsible for maintaining their own wellness for most the time with the support and input of medical, social care, peers, family and friends. The outer ring of this model contains the specialist services, revolving around the individual and their self-management. These services are connected to each other, reflecting channels of communication, with the support of the individual remaining central at all times. Models of care for people living with HIV reflect this configuration with different support services dominating at different stages of the individual's HIV journey. This project aims to track the factors facilitating the support process to provide quality care at every stage of the life course. This is especially pertinent considering the emerging experiences of ageing with HIV and the increasing involvement of primary care.

4 Methodology

This project will follow the principles of participant observation methodology [14]. This approach is appropriate for exploratory and descriptive studies when the phenomenon of investigation is observable within an everyday context. It will allow an understanding of the care-pathway landscape and potentially uncover new service configurations overlooked by previous reviews and studies. The methodology of participant observation aims to view meaning and interpretation from the insider's perspective. As this project has stated, different service contexts and service delivery perspectives have prompted different service responses to the provision of appropriate medical services for people living with HIV in primary care across the country. Thus, the insider's version of reality has consequences on the configuration and delivery of these models of care.

It is necessary to comprehend the language and culture used to communicate meanings within this world as insiders manage and negotiate meanings in different situations. As a result, the research team have remained open to continuous redefinition of the original research problem based on information collected in the field. This approach suits a case study design, as concepts and generalisations are formulated as interpretive theories [14]. This translates well into practical decision-making, as is required from this project.

5 Methods

This multi-perspective scoping project [15] aimed to describe current collaborative or shared models of healthcare between primary and specialist services to inform commissioning and high-quality delivery of care for people living with HIV across the life course. Different perspectives are essential to provide insight into complex systems and reveal the differing concerns of stakeholders. This approach allows a broad exploration of service and system dynamics, highlighting similarities and differences across groups. Exploring an issue from different angles can reveal hidden aspects while adding strength to other findings. According to the multi-perspective approach we decided to access a mix of health professionals including commissioners, service providers and service users to address the question of what facilitates quality shared primary and specialist care for people living with HIV in the UK.

We first considered specialist service providers, namely HIV consultants and clinical nurse specialists (CNS) to gain their experience of working with colleagues in primary care. Second, we identified the group of general practitioners in different areas of HIV prevalence to gain insight into configurations of collaborative care in other disease specialities, and examples of shared models of care with HIV services in their specific geographical and HIV-patient cohort contexts. It was acknowledged at the design stage that this group may be hard to reach, thus, both key informant interviews and an online survey were administered. Third, we identified the varied and highly valuable other service providers. These largely covered the third sector but included patient representatives from NHS sites. Finally, we decided to gather empirically grounded qualitative data from HIV-positive service users. They were chosen as a rich source of information because of their social and medical experience of living with HIV and insight into the reality of access and collaboration between different sections of the health service. An initial scoping review of the literature provided the context for this project, informing the conceptual model, data collection and analysis design. Key informant interviews were supplemented by two online surveys (GPs and service users) and a service user focus group discussion.

5.1 Scoping literature review

This review investigated published and grey literature describing models of care for people living with HIV with a particular focus on the involvement of primary care in a UK context. As the scoping study method identifies relevant literature regardless of the study design, an iterative approach was taken and search terms were constantly redefined as familiarity with the field of inquiry increased. Thus, search terms were reviewed and refined to ensure comprehensive coverage of the literature. The initial search term combination was ‘HIV, primary medical care, model, UK’. Experts in the field were consulted (DA, MS, SS, JkM) to ensure the use of appropriate terms, signposting to additional grey literature, pending publications and to validate findings from the main scoping review [16]. Since the aim of scoping the field of inquiry was to be as comprehensive as possible to meet the project objectives, evidence was sourced from electronic databases (EMBASE, MEDLINE, PubMed), grey literature, hand searching of reference lists, conference presentations and posters. Time span of the literature inclusion was impacted by two significant milestones in UK HIV care, namely the introduction of highly active antiretroviral therapy (HAART) in 1996 and the split in commissioning responsibilities in England owing to the 2012 Health and Social Care Act. Evidence from 1996 to 2016 was taken for this review but read within the context of the changing landscape of service commissioning in England. The final literature search took place in January 2016.

5.2 Key informant interviews

The in-depth telephone interviews were conducted from August 2015 to March 2016. Ethical approval for the interviews was obtained through the Health Research Authority (HRA) process, covering all NHS healthcare providers and clinical commissioning groups (CCGs) in England. Site-specific approval was granted from Research Wales and Research Scotland for recruits in these specific countries. No participants were available from Northern Ireland. Service user experience was obtained from community organisations through their dual role as a service provider and from data collected and shared with consent by a third sector provider.

Through the HRA permissions notification process, sites expressed interest to participate in the study and provided contact details of clinical providers or passed the researcher contact details to the relevant clinical team members. The study was also advertised on the BHIVA website and in the regular e-newsletter sent to GPs by their CCG co-ordinating centres. Two reminder emails were sent to respondents following delivery of the consent form and participant information sheet. Participants were screened based on their experience of collaborative care arrangements within primary care/specialist HIV services in different sites across the country, and those responding were then interviewed for this project.

Interviews were conducted over the telephone by the researcher (JM), facilitated by a topic guide reflecting the standard pathway of care for people living with HIV categorised as 'stable' (Appendix 1). The interviews lasted between 30 and 120 minutes, field notes were taken and analysed using QSR NVivo 10 software. Data were coded independently by JM, then used to identify concepts and categories. These were then discussed with the panel of experts (DA, MS, SS, JkM) in a consultation exercise to achieve consensus and future direction of inquiry. Concepts and categories were thus revisited and refined following each interview. Common, although context-specific, concepts recurred across the interviews with both urban and rural representation, thus it was felt by the research team that data saturation had been reached with this sample. This process facilitated the description of emergent models of care across the UK with representation from different geographical and service user contexts.

5.3 GP online survey

The GP online survey (Appendix 2) was developed to gather a wider range of GP experiences of caring for people with HIV in primary care. A survey link was publicised on the website of the British Journal of General Practitioners, sent to a selection of CCG co-ordinating centres across England for publication in their weekly e-bulletin for GPs, publicised on the BHIVA website, and through key informant interview contacts. The survey ran through the months of February and March 2016. Participation in the prize draw for a training grant incentive of £150 for a nationally recognised sexual health foundation course was available on inclusion of an email address at the end of the survey. As with any open survey, the respondents and their views were a snapshot of experience and not representative of GPs in the UK. Simple descriptive analysis was conducted using Microsoft Excel.

5.4 Service user online survey

The service user online survey was conducted in collaboration with a third-sector

organisation through the month of February 2016 (Appendix 3). It was designed to gather individuals' perceptions of their health, their experiences of primary care, and of the collaboration between primary care and specialist HIV services. The survey was publicised on the charity website, Facebook and Twitter accounts with the link shared through respondents' social networks and UK Community Advisory Boards (UK-CAB). As with any open survey, the respondents and their views were a snapshot of experience and not representative of the majority of people who are living with HIV in the UK. However, the results provide some useful insights into experiences of primary care. Results were analysed in Microsoft Excel and yielded descriptive statistics. A number of free-text options allowed for more in-depth response and a selection of these are included as quotes.

5.5 Service user focus group discussion

The service user focus group discussion was conducted in collaboration with the same third-sector organisation in February 2016. Participants were invited to participate through the organisation's website, they established an over-50's support group through social networks and on the UK-CAB community boards. The discussion followed a topic guide (Appendix 4) exploring experiences of primary care, designed in congruence with the long-answer questions on the GP online survey. The discussion was transcribed verbatim and analysed thematically [17] with results synthesised into the key informant interview (KII) findings.

6 Limitations

The principal limitation to this study was the short duration of the project. The projected timeline for completion was August 2015 to March 2016. The ethical approval process was completed in January 2016 following numerous setbacks, with permission to interview in Scotland and Wales granted at the very end of the project. This has resulted in a snapshot rather than a comprehensive mapping exercise of NHS-based care models across the country. However, both high- and low-prevalence sites were included. Owing to time and governance constraints, the varied and vital role of the third sector in care provision and co-ordination has been touched upon but not explored in depth.

The interview sample was conducted using a snowball approach while survey respondents were self-selecting. Despite the potentially polarised and biased responses, analysis revealed a spectrum of experiences. The majority of respondents were reluctant or unable to share financial details of care-model developments due to the, understandably, sensitive nature of this information in a climate of reducing and competing healthcare budgets. Evidence of care-model success was, therefore, insinuated from retention-in-care figures, proportion of the cohort achieving viral suppression, proportion of the cohort on ART and service user feedback where available.

7 Findings

7.1 Scoping review of the literature

The three databases yielded 83 records post deduplication, plus 54 records from manual searching and grey literature. The initial inclusion criteria were for articles to report models of care for adults living with HIV in the UK, with a focus on primary care involvement. The number of records returned was low (five). Search terms were then redefined to include models of care for all long-term conditions, with a focus on primary care. This added another 80 records for review. Following this search, examples of case-based management, transitional care and HIV testing in primary care were returned. These models were then searched specifically through the grey literature with some examples taken from non-UK countries where appropriate. This resulted in 59 records to fulfil the objectives of this project. The search strategy is presented in Figure 2. The search was not exhaustive but fulfilled its scoping aim to identify a variety of care models to inform the context of this project.

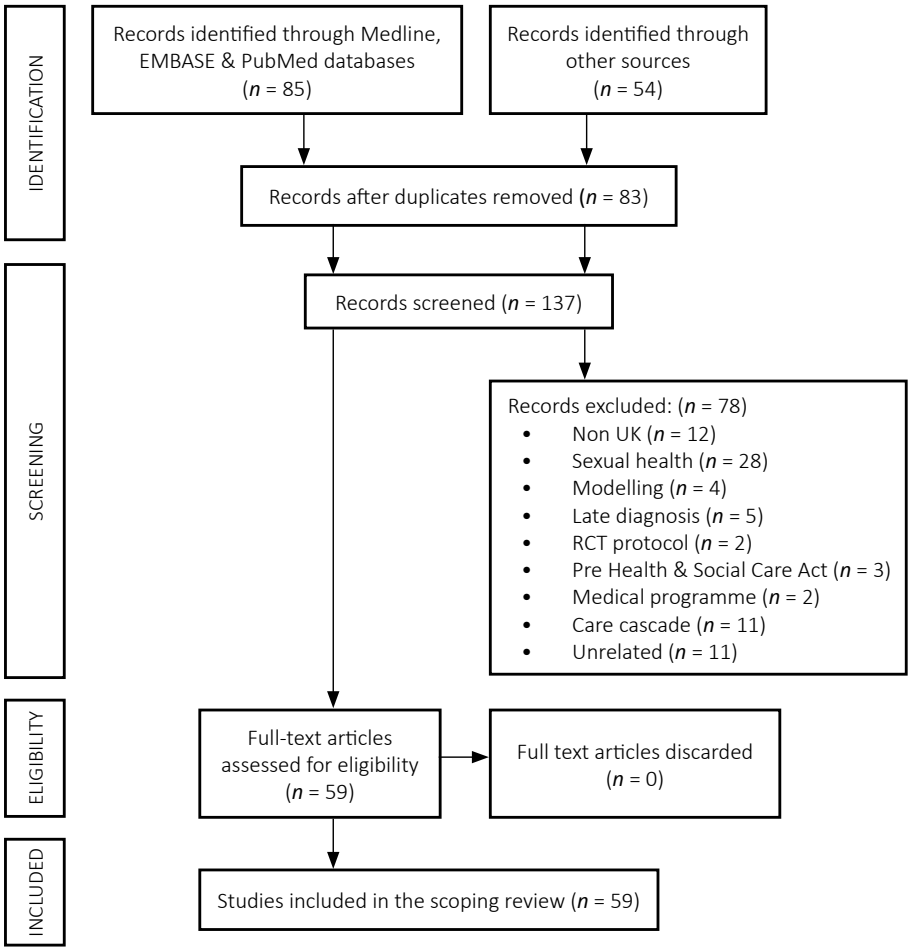


Figure 2. Search strategy for models of care for people living with HIV in the UK for scoping review

Models of care summarised in this review involve a link between specialist services and primary care. The aim of this project was to review models of care supporting the provision of non-HIV care for people living with HIV in primary care; however, more involved care-model arrangements can provide guidance for incremental development of the future care process. The different formats of these models are: (i) standard specialist model; (ii) shared care; and (iii) collaborative care.

7.1.1 Current standard specialist model

The current standard model for people living with HIV in the UK that are classified as virologically stable involves specialist follow-up 3–6 monthly in the specialist clinic. This includes checking the blood picture and reviewing results. Some sites have moved to home delivery of ART medication, requiring less frequent contact with specialist services. New guidelines from BHIVA advocate a reduction in follow-up frequency to 6 monthly. This could be in a nurse-led clinic, or through virtual contact, by telephone or email [18]. The frequency of viral load testing is recommended every 6 months. If a person has experienced a CD4 cell count >350 cells/mm^3 and viral load suppression on two occasions a year or more apart, the CD4 cell count is no longer routinely required. Other routine blood tests are recommended between 6 and 12 monthly as indicated [19]. Within the (often annual) specialist consultation, clinical, psychological and issues of well-being are addressed. Any non-HIV conditions identified in the consultation are referred back to primary care for diagnosis and management [10].

7.1.2 Shared care

The discussion regarding models of care and the role of specialist over generic services in the care of people living with HIV has been ongoing since the early days of HIV in the UK. A series of letters published by the British Medical Journal in 1994 described a pilot of moving HIV care into primary care with agreed shared-care protocols [20]. Shared care is defined in the literature as: 'The joint participation of primary care physicians and specialty care physicians in the planned delivery of care, informed by an enhanced information exchange over and above routine discharge and referral notices' [21]. There was a dispute on what the terms of shared care would be, with a suggestion that this move was before its time [22].

This discussion is even more pertinent now as ageing with HIV becomes a new clinical phenomenon. This has presented new issues as the discourse moves from early death to the uncertainty of living with a chronic disease. The 90 life-history interviews of people living with HIV by Rosenfeld *et al.* [23] revealed an atmosphere of navigating 'uncharted territory' and of experiencing an 'experiment in living'. This was related to the unknown effects of HIV and ageing, and the difficulty associated with distinguishing between the physical effects of ageing and those of HIV itself. This caused a lack of confidence in the self-management of symptoms and confusion and anxiety over when to seek medical advice and from whom. Living with HIV was described as a life of peaks and troughs with a constant underlying anxiety over whether another peak will be experienced or if this trough is the ultimate decline. These findings provide some explanation for the resistance from some people living with HIV to move their health seeking from the specialist HIV clinic to their GP as first port of call.

A systematic review by Mapp *et al.* [11] of models of shared HIV care and HIV in primary care revealed a variety of context-specific models that had grown out of patient or provider need. The shared-care models reviewed tended to have formal frameworks or agreed care protocols. They utilised professional networks to share knowledge and skills

among providers, or existing primary care specialist centres that had developed their specialist capacity internally. Facilitators of shared care from this review [11] included training for the health professionals involved in the shared-care arrangement, appropriate and timely communication between parties, formal division of roles and responsibilities, and the presence of small professional networks to co-ordinate care. Networked models of care in HIV tend to focus on the collaboration of different levels of HIV centres to ensure high standards of care, rather than a formal programme to support shared care. This network of HIV centres would have leadership, research and education provided for all interested practitioners by a large, central unit [24].

Challenges to the establishment of shared care in HIV from a primary care perspective were described by Newman *et al.* [25] as keeping up with knowledge, the need for a minimum caseload to maintain skills, lack of a formal framework or agreed care protocols and lack of shared IT systems. Factors important for the success of shared-care models were: leadership in the involved GP practices, treating HIV infection like any other chronic disease, good professional relationships and two-way communication between specialist services and GP practices. A cohort study by Page *et al.* in Switzerland [26] found significantly higher patient satisfaction in a GP shared-care model or where GPs were actively treating HIV patients in comparison to those cared for by the infectious disease specialists. Within the shared-care model there was no significant difference in median CD4 cell counts or ART adherence when compared with specialist services alone. This picture was reflected in the systematic review by Wong *et al.* [27], which looked specifically at outcome data related to the performance of primary care in diagnosis and management of HIV in primary care. They reported counselling, testing and treatment to have similar outcomes when compared to specialist services. However, the 'active ingredients' of the shared-care agreement facilitating these outcomes were not reported [28].

Training for health professionals involved in the shared-care agreement and appropriate and timely communication can facilitate quality care. An example of shared care in oncology demonstrates the inclusion of these components. The model comprises a 'knowledge package' transfer from the specialist to the GP [29]. It comprises a discharge summary, information on the disease and its treatment, general chemotherapy and radiotherapy information, general information on pain, nausea, vomiting and acute oncological conditions with contact details of specialists. This was found to significantly impact patient perception of co-operation between primary and specialist care. Patients reported receiving more care from their GP and feeling less in limbo. Intervention GPs had higher knowledge of the disease and treatment. Essential to the success of this project was an innovator, co-ordinating in both settings to ensure project acceptance and adherence.

An example from specialist drug services in north London illustrates how a shared-care model can be facilitated through a primary care training and specialist support initiative [30]. For most GPs in Brent and Harrow, addiction was a small part of their work. They expressed concern about dealing with challenging patients in isolation. Pre-training, 60% of the GPs agreed that they should provide general medical services for this patient population. Specialist drug teams were created to support GPs through team training, ongoing support sessions and audits of treatment. The shared-care arrangement came with financial reimbursements for the practice. This approach also helped service user concerns about the competence and attitude of GPs to provide treatment for them. Post GP training all participants agreed that they should provide general medical services for this cohort, with documented levels of an increased treatment activity, confidence and willingness to treat among those trained GPs. An evaluation of the model found successful points to be: training led by the primary care sector with peer exchange between GPs; an initial specialist assessment of patients with continuing availability of specialist support,

including pharmacists; financial recompense for the increased workload; and detailed guidance, protocols and roles. There was no cost-effectiveness data available for this model.

A similar approach of GP-facilitated training in Lothian was found to be successful in the involvement of large numbers of GPs in shared care with drug services. This was in contrast to a specialist model of community drug teams that tended towards treatment themselves rather than facilitating treatment by GPs. There is no published evidence in the UK of formalised shared-care models between specialist HIV services and primary care and none of these studies looked at either cost or cost effectiveness of the shared-care approach.

7.1.3 Collaborative care

The term collaborative care is often used interchangeably with integrated care. It originated in the specialty of mental health and describes the involvement of primary care and the patient in the promotion of their well-being [28]. This approach has become popular in the management of long-term conditions [31]. It moves the focus of care from the health service to the person with the condition, and advocates a case-based approach to care, which is responsive to the individual's need. This allows the model of care to evolve and change over the life course of both the condition and the person, supported by a case manager. The King's Fund reviewed quality of care experiences of people with a variety of long-term conditions in general practice. They compiled a list of important elements promoting quality in collaborative-care models [32]. Depression can be taken as a relevant example to this project due to the shared characteristics with HIV of stigma and the fluctuating nature of symptoms across the life course.

For people experiencing depression over extended periods, high-quality care involved being supported by a planned system of support rather than accessing care on an ad hoc basis. This supports the frequent request among people living with HIV for continuity in their health-provider relationships [33,34]. A successful framework combined case management, scheduled patient follow-up and closer working between primary and secondary care. Case management involved a single individual responsible for co-ordinating different components of care, monitoring of the condition, follow-up and some psychosocial input. This can be facilitated by a structured care-management plan shared with the patient. Case managers performed best if they had access to supervision from a specialist [35]. Scheduled follow-up of the patient was enhanced by a multi-professional approach between the GP and specialist services. Systematic identification of patients with depression through the use of screening among high-risk groups can facilitate provider knowledge and involvement in the care of people with depression. Closer working relationships between primary and secondary care supported patient education and promotion of self-management. This approach may not be suitable for everyone and some may find it intrusive. Different configurations of this model place greater focus on either the self-management or the co-ordination components of the model.

Treatment in chronic disease differs from an acute episode as therapy is life-long, thus treatments must be sustainable to be successful [36]. Patients and their families become the experts in managing symptoms, function and administration of therapy within their own environment as they hold the daily responsibility for care. To enable successful management, providers are charged with delivering the tools, motivation, knowledge and skills that patients need to become good chronic disease self managers [37]. Successful self-management depends on collaboration between the patient and their care providers. This motivation is dependent on issues of importance and confidence. Patients may understand the importance of taking ART but if they lack the confidence to manage the

side effects, remember dosing times and how to safely store the medication, their overall motivation will be weak. Conversely, some patients may have confidence but lack an understanding of the importance of taking the medication. The principal source of benefit in self-management programmes is a growth in confidence in the ability to cope with the condition.

A systematic review of nursing transitional-care models within a US context found a patient self-management focus to discharge planning and follow-up reduced readmissions at 6 months and a year [38]. It required a good connection between acute care providers and the primary care team. Such an approach has been modified for the UK primary care context using the House of Care metaphor [32]. It encourages adaptation of the chronic care model to the local context, using a partnership model, where patients are active in determining their own needs through personalised care planning with a GP or CNS [31]. The GP or CNS would act as the case manager, co-ordinating different services to meet the needs of the patient with a long-term condition. This approach is community based and aims to improve delivery of integrated care through the production and co-ordination of a personalised care plan.

Those few hours a year that the patient spends with a healthcare professional are often inadequate to support and inform, although the management of the long-term condition is still seen as the clinicians' responsibility [37]. Care planning, therefore, identifies needs, agrees goals, and creates action plans and a review timetable. It is a continuous process rather than a one-off event. Research has shown that when people are more active in self-management, they experience better health outcomes [39]. The Royal College of General Practitioners announced care planning as a quality marker of best practice with a programme to embed the process in primary care delivery. Competencies to deliver care planning are to be assessed in GP professional training. Care plans are usually implemented for people with complex health needs, such as the multiple comorbidities that may be experienced when ageing with HIV or psychosocial complexities that impact on the chronic condition.

In many parts of the UK, clinical nurse specialists are involved in the HIV care pathway, often taking this case management role, alongside the expansion of their caseload in a task-shifting agreement, from the medical team. There are no cost-effectiveness studies of the role of the HIV CNS in the UK. However, an economic evaluation of a community HIV CNS from a London site (Watson, publication pending), highlights significant financial and service capacity savings from the avoidance of hospital (re)admissions and speed up of discharge from their co-ordination, liaison, adherence and psychosocial support, advocacy and 'rescue work' activities. It is a complex exercise to monetise the diverse role of a community-based HIV CNS; however, using case studies of before and after CNS input, Watson demonstrates up to 75% cost savings following CNS input. The Royal College of Nursing [40] recommends that all patients with long-term conditions have access to a specialist nurse due to the care-quality improvements and cost-saving impact of their role. Evidence from rheumatology revealed cost savings through task shifting of £175,000 per year per nurse, while having access to the supportive and co-ordinating function of the CNS by telephone averted 60% of patients from requesting a GP appointment, thus saving £72,588 per year per nurse. Quality outcomes included psychological support, with help to develop coping strategies, symptom management, co-ordination of care and referral to other members of the multidisciplinary team (MDT) [41]. A less sophisticated analysis of a multiple sclerosis nurse specialist role revealed a cost saving of £54,000 per year per nurse by preventing 300 outpatient appointments and 40 emergency admissions [42].

From a quality perspective, a study from the Netherlands suggests an HIV CNS model to improve quality due to the increased patient contact and focus on adherence while freeing the consultant for new and complex case consultations. This is expected to reduce

healthcare costs [43]. An impact assessment from the National Association of Clinical Nurse Specialists in the USA found that clinical nurse specialists play an integral role in reducing costs and improving quality. Principally, this was achieved through their activities in care co-ordination, transition support, improving access to preventive care through early detection of those at risk of chronic disease, and promoting self-care [44].

7.2 Key informant interviews

In-depth interviews were conducted with 65 participants. This purposive sample consisted of 19 HIV specialist consultants, 13 GPs, seven HIV clinical nurse specialists, seven specialist and local authority commissioners, 10 third-sector providers, seven researchers working on related studies and two patient representatives from across the UK (Appendix 5). Findings from the service user focus group discussion (fgd) were synthesised with the in-depth interviews for greater coherence. The 2-hour focus group discussion included 10 women and three men with different experiences of living with HIV. Participants were predominantly of black African ethnicity, with black Caribbean, white European and white British representatives. Data analysis involved thematic analysis and peer review. Findings were discussed and themes created, reflecting the focus of different models of care for people living with HIV. The three principle themes identified in the data were: (i) enhancing communication; (ii) improving primary care practitioner knowledge; (iii) case-based management. Each theme was illustrated with examples of care models from practice in boxed case studies with a traffic light system indicating cost effectiveness, clinical outcome and patient satisfaction evaluation data for each model. Red indicated no evidence available; amber indicated evidence pending or internal evidence not in the public domain, with green indicating publicly available evidence.

7.2.1 Enhancing communication

Interview respondents for this project from primary and secondary care requested greater levels of ongoing communication from each other. Collaborative care works best when built on pre-existing clinical relationships and when there are good relations between primary and secondary care [32]. Some local-level interventions to facilitate this enhanced level of communication were uncovered by this project. These are adapted from other chronic disease models and applied in areas of high and low HIV prevalence. They follow a hierarchy of complexity, with decreasing frequency of use, as detailed in Figure 3.

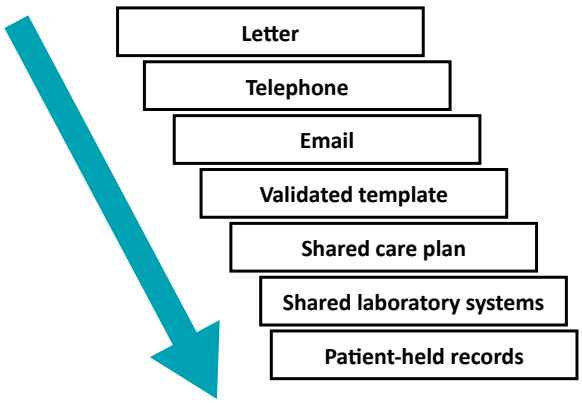


Figure 3. Hierarchy of communication complexity facilitating a shared care model

7.2.1.1 Current context

There is a 'commissioning for quality and innovation' (CQUIN) payment for secondary care HIV services to communicate yearly with primary care. However, GP respondents reported the receipt of variable levels of communication (GP1–6,8,9,12). In contrast, there is no incentive for primary care to communicate with specialist services or published audit of GP communication in HIV secondary care notes. GP interview respondents for this project, reported their communication with specialist HIV services to be restricted to instances of referral (GP1–11) or contact for a specific clinical concern (GP1-11) except in a minority of exceptional cases (GP6,12). Among the majority of participants, an enhanced information exchange did not take place; often a reliance on the patient to share information among those involved in their care was reported by GP respondents (GP1,3,4,9–11). As one GP respondent described:

> *My cohort is very articulate and directive, they tend to share information with me from their specialist. (GP4)*

This role was reflected in a less positive example from the service user fgd:

> *They send you to do it. My GP will say can you talk to your consultant or can you phone your clinic to ask about this… (TNfgd)*

This could be related to the historical organisation of care in England for people living with HIV where the specialist consultant would act as case manager and refer the patient to other specialists and services as indicated. As one fgd participant described:

> *…when we were being diagnosed, we used to have our services from the hospital. Everything. So the consultant would just refer you to service that you want. (TN fgd)*

This role has now moved to primary care, yet there remains a sense of belonging with the HIV service and their overarching position as one fgd participant described:

> *If the services have been put back to them to look after me, they should be able to communicate with my consultant (TN fgd)*

A GP respondent reported an adequate level of communication with specialist services to be the patient sharing their repeat prescription list (GP6). Unfortunately, this system was reported by HIV specialists to be unreliable, especially in light of the risk of drug-to-drug interactions of common medications with ART and the review of 'stable' patients occurring much less frequently than previously (C4,6,7,9,13–19). Furthermore, this approach did not account for the need to share test results for prescription, dosage or dispensing of medications. The financial and inconvenience cost in many areas for both services and service users of test duplication due to contractual arrangements (C16), the separation of GUM records, and this lack of information sharing between many primary and secondary care computer systems was highlighted by primary care and specialist service respondents (C4,6,10,12,14; GP3,4,6,8).

Moving this communication responsibility back to the healthcare team, GP8 reported that non-HIV secondary care specialities emailed the GP practice a week before the scheduled outpatient appointment requesting an updated past medical history and medication list. The GP would then return this information by email or fax. This is a well-established system that could be used by HIV services. Unfortunately, when this idea was shared with

an HIV consultant in the east of England, they reported doing this for all patients with a documented GP; however, they would rarely receive a response (C19). A lack of clinic administrative support to follow up the requests further constrained the potential success of this approach.

Postal communication was the most frequently cited method of sharing information with other care providers, followed by telephoning the on-call specialist team if there was a more urgent enquiry. A principal concern of specialist clinicians and GPs in relation to communication was potential drug interactions with ART. There was anecdotal reporting of a BHIVA initiative to standardise the contents of clinic letters to GPs to include the Liverpool Drug Interaction site address and specialist contacts for queries. However, comments have been made at its length and lack of user-friendly formatting (GP1). Furthermore, clinic letters to GPs are read, actioned and archived. There is rarely time to review such documents before a consultation, perhaps explaining why the interactions website address in the footnote is sometimes missed (GP3,8,9). The majority of GPs interviewed for this project preferred to pick up the telephone and have their drug query answered immediately, especially if they were unaware of the website. Where there is a specialist HIV pharmacy service available, this was often the first resource accessed. This is especially pertinent as some commonly prescribed drugs in primary care require dose modification rather than exclusion if the patient is on a specific ART regimen.

7.2.1.2 Alerts and templates

Primary care record systems are often different between practices and non-compatible with secondary care. Creating alerts, templates or notes on records is dependent on the system knowledge of the user. To highlight the need to check for potential interactions when prescribing, some GP respondents would list the ART on the prescription list as quantity zero or one (GP2,3,6,8,12). This also highlights that they have not been prescribed by the GP. However, if there is a lack of awareness about the potential for drug interactions, this system is not adequate. One GP respondent described restarting a patient's steroid inhaler that was discontinued after each visit to the hospital. It was never communicated in the discharge letter that this interacted with the patients ARV medication. The GP thought it was an error by the discharging physician who did not have expertise in asthma (GP12). As one respondent insightfully commented, 'you don't know what you don't know' (GP5).

> **Action Point**
>
> Creation of a drug interaction alert in the GP computer system activated when the patient record is opened.
> This must be acknowledged and cleared before the record can be entered

To prevent such a situation, an explanation for discontinuation of the medication in the discharge letter would be useful. A more robust system controlling for other GPs consulting with the patient and being alerted of the risk of drug interactions has been implemented by two GP respondents (GP6,8). An alert stating the risk of drug interaction comes on the screen whenever the patient record is opened. This needs to be acknowledged and cleared before the record can be entered.

The use of email communication between specialties appears to have evolved out of convenience, with greater use among a proportion of those interviewed. GP9 gave an example of email dialogue with a psychiatrist in a complex case requiring regular case discussion and service co-ordination. The use of this communication format requires local agreement, a commitment to check emails, or arrangement to have a generic email

that is always checked, such as that of the practice manager (C13) or duty doctor (GP8), to account for periods of absence. This is apparently a common approach used by other specialties and more efficient than the 'ping pong' of telephone communication or the lengthy delays experienced in postal communication (C9).

Augmenting these key communication pathways through the use of a computer template was suggested (GP3,8,9) as a step towards the shared-care level of enhanced information exchange necessary to facilitate the delivery of 'appropriate primary care services' [11]. These services consist of primary care-level interventions to support people living with HIV to live healthy lives. They incorporate a variety of health promotion and screening activities that are implemented more frequently or at an earlier age than among people who do not have HIV. A lack of knowledge of these nuanced needs among non-specialist healthcare practitioners could lead to missed opportunities in care (C6; GP8,9). The template method was recommended by three respondents (GP3,8,9) as a method of clarifying responsibility for interventions and documenting their completion. The template could be standardised across primary care and embedded in the different primary care software systems. An alert would be raised when there was an outstanding investigation, intervention or communication milestone.

Three GP software support centres were contacted in the course of this project (Vision, SystmOne, EMIS Web) and all were willing to support practices to create such templates for patient records if there was an absence of knowledge in-house. However, it requires a diligent GP or informed administrative staff member to action. A more robust approach could involve the creation of a BHIVA-validated template for 'stable' people living with HIV, made available for free download from the BHIVA website. This would include instructions on how to adapt it if greater responsibility was taken locally by some practitioners (GP3,5). Alternatively, if software account holders agree to participate, the help centre analyst can email the template to all software account holders across the country. The use of templates is common in other stable long-term conditions and is described as a lower-level intervention than care planning (GP3).

> **Action Point**
>
> Creation of a validated template for appropriate primary care services for a 'stable' person with HIV, available for free download from the BHIVA website, with instructions on how to adapt it if greater responsibility is taken by practitioners

7.2.1.3 Care planning

Personalised care planning is used as a tool to improve the delivery of integrated care for patients with long-term conditions [45]. It is community based and usually involves structured patient assessment, patient education and clinical monitoring components [46]. The co-ordinator of the care planning process could be the GP, community nurse or specialist practitioner [46]. Further discussion of the use of care plans is contained under the 'case management' theme (Section 7.2.3).

Care plans are not relevant for all people living with HIV. However, some service users have expressed concern about communication of advanced directives and resuscitation wishes in the absence of a capacity, family member or advocate. Within this context, greater use of the electronic patient record summary (ePtRS) could meet this communication gap. In a study in Scotland, the ePtRS is shared between GPs, out-of-hours services and secondary care [47]. This was felt to improve clinical management, empower clinicians, increase patient safety and reduce hospital admissions.

7.2.1.4 Advanced model of communication

Despite some local solutions to the identified communication problems, a comprehensive system of shared records between primary and secondary care was cited as the solution to patchy communication issues such as that used in antenatal care (Cons 4,7,9; GP1,4,5,6,8). The move to electronic patient records (ePR) in west Scotland is a significant step towards this aim. They use portal technology (Orion Health), allowing practitioners to view a shared record space (called SCIStore), which includes all laboratory and radiology results, correspondence, community nursing and social care records. Correspondence from the specialist service is messaged to any GP in the west of Scotland directly into their Docman system and is included in the normal document workflow. GPs refer patients to acute services electronically using SCI Gateway, which pulls agreed details from the primary care record. Across the whole of Scotland the emergency care summary includes details of recent and repeat prescriptions from primary care, and the key information summary is co-created between GPs and patients for those with complex care needs and is visible to acute care clinicians. All radiology images and reports are viewable across the whole of Scotland via the PACS system (C11).

Within an English context, use of the ePR was described by one GP, working in a rural and inner London practice, as being an efficient system outside London to communicate between the hospital and the GP but not in the city (GP9). Furthermore, this system was found not to work from GP to hospital. Other electronic systems are in use within specialist services (Climate) or systems are held and used by the patient (HIV i-Base, MyHIV) but neither connects all parties involved in care. One alternative to a comprehensive, connected electronic record system has been piloted that puts the patient as the co-ordinator of information flow between relevant contributors in their healthcare journey. The 'Patient Knows Best' (PKB) electronic patient-held record was piloted in 14 HIV services across the UK from 2013 to 2016. It allowed the sharing of communication about care to ensure specialist monitoring of the HIV patient, a record of primary care interventions and support of patient self-management in their HIV journey. Benefits were described as increased communication with patients, empowerment of patients in self-management, the sharing of blood results and clinic letters. Different sites have reported the prevention of admissions and a reduction in the number of phone calls received by the nursing team each day as they have a scheduled catchup with all PKB queries, 5–6pm each day (C14). In another site it has allowed a virtual clinic approach and remote management of the outreach community nursing team (C6). PKB has been used by an HIV service in southwest England, with favourable results, detailed in case study 1.

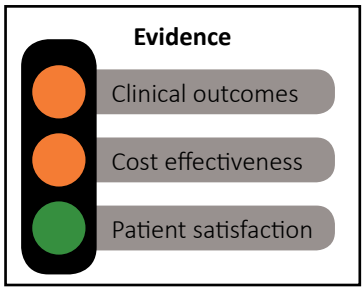
Case study 1: 'Patient Knows Best' electronic patient-held record

Plymouth Hospitals NHS Trust serves a population of around 450,000 across the southwest England peninsula. The cohort of HIV-positive patients registered at the specialist centre is around 340. Disclosure of HIV status by patients to their GP is approximately 85%, principally due to the rural nature of the population and concerns about confidentiality. As a result, some GPs across the region are generally not engaged in the primary care of patients who have HIV. Those who are, can telephone the specialist clinic for support or advice. Since there is no permanently staffed 'hotline', availability of appropriate staff can cause an inefficient use of time to try to return the call. There is an HIV network in the southwest and a peer-support network both in and outside the clinic setting.

Communication solution

Plymouth is a PKB pilot site. The system supports laboratory results, electronic GP letters, pre-ordering of prescriptions, appointment bookings and discussion threads. The specialist clinic created accounts for all patients with 50% choosing to activate them. They tended to be patients with good English across all age ranges, accessing their account on smart phones, personal and library computers. Uptake was clearly linked to clinician support and enthusiasm.

PKB has allowed sharing of the HIV care plan with patients and invited GPs. This facility is felt to reduce anxiety around the treatment of other conditions. The discussion thread allows swift answering of queries by the specialist between consultations. Sharing of laboratory results prevents test duplication and gives patients access to their results without the need to visit, phone or email the clinic; electronic GP letters meet the CQUIN target of sending clinic appointment updates within 5 days. PKB has also allowed the safe reduction of face-to-face time with stable patients and admin time regarding appointment changes and DNAs. (NOTE: GP email issue overcome by emailing PKB alert to the practice manager who would forward it on to the most appropriate GP)



However, the system is not without its challenges, as identified by some of the other trial sites (C6,7,11,13,14). The most frequently mentioned issue was the lack of laboratory integration at many of the PKB pilot sites due to hospital-side IT delays. In one site, the clinician manually inputs the blood results. This is an inefficient use of time (C14). Moreover, where there is laboratory integration, there is no interpretation linked to the blood results, or no automatic link that suggests what action should be taken if blood results are high or low (C11). GPs must log in separately to the PKB system as it is not yet integrated with their computer systems. If there are only a few HIV-positive patients in the practice, this is often not a priority. Despite high rates of disclosure to GPs, the system relies on patients to invite their GP. This is not happening in some of the pilot sites, as perhaps patients do not realise the benefit of GP involvement or have the confidence to initiate that involvement. Perhaps patients are also not aware that clinic letters are opened by admin in the surgery, scanned, filed, and not read by their named GP. There have been reports of the HIV consultant not wanting to use the technology, preferring the traditional system of their secretary sending letters to patients. Cost of the system after the funded pilot is an issue, but PKB are willing to negotiate with trusts. Negotiations are underway to make PKB available at population level, enrolling all primary care patients across a selection of London boroughs. This would significantly reduce cost and exclusivity of access.

7.2.2 Improving primary care practitioner knowledge

A Cochrane systematic review concluded patients cared for by clinicians with HIV training or expertise had better medical and social outcomes than patients under clinicians without training or expertise [48]. Among the GP respondents interviewed for this project, 46% had received specific training in HIV. One respondent noted:

I've never had specific HIV training, I have learned through experience. (GP4)

A lack of knowledge, especially in relation to drug interactions (GP3,4,7,8,9,10,11) and how to distinguish HIV from non-HIV symptoms (GP4,8,9) were cited by respondents as barriers to their increased involvement in the provision of appropriate primary care services to people living with HIV. This was underpinned by a perceived lack of time (GP1,5,8,9,10).

Aa variety of approaches was uncovered by this project to address the lack of HIV knowledge among primary care staff. The risk of drug interactions has been described in the previous section. In relation to distinguishing HIV from non-HIV symptoms, HIV consultants or CNS in many areas have conducted local, case study-based training sessions during their 'admin time'. These were often stimulated by 'look back' sessions on cases of late diagnosis (C9,10,15,16; CNS2,6). A checklist approach to improving HIV diagnosis in primary care takes an experiential approach by focusing on the late diagnosis trend across the country and presentation of patients at their GP with indicator symptoms. Sometimes these symptoms or clinical signs are non-specific, pointing to HIV infection only in retrospective case debriefing. Furthermore, HIV maintains a relatively low national prevalence, especially in non-urban areas and often does not enter the differential diagnosis of the GP and many other general physicians.

In many of my GP colleagues, HIV hasn't crossed their mind. (GP9)

As an aid to diagnosis, two GP respondents (GP3,8) suggested linking an 'offer HIV test' alert to certain codes and requests within the GP computer system that must be cleared on screen before the operator can re-enter the patient record. In the summer of 2016, this system was introduced in six high-prevalence GP practices in a north England city using SystmOne software. Two levels of alert have been set. The first asks if an HIV test has been considered, the second strongly recommends an HIV test. The second prompt is activated in the coding of certain conditions such as unexplained weight loss, chronic diarrhoea, unexplained bacterial pneumonia, lymphadenopathy, campylobacter/shigella/salmonella, hepatitis B and C, chronic herpes, chronic psoriasis, candidiasis, and seborrhoeic dermatitis. No evaluation data is yet available.

Within the east of Scotland, primary care was described as comfortably involved in the management of non-HIV medical care of people living with HIV (GP7). In the early days of the epidemic in this area, HIV was concentrated among the intravenous drug user (IVDU) population. For intravenous drug users, HIV diagnosis was often made in primary care, and therefore all their care, including their substance misuse support, remained in primary care with specialist support (GP7). This example supports primary care testing as a route to increasing practitioner confidence with people living with HIV.

7.2.2.1 HIV testing in primary care

High-quality care in long-term conditions requires early diagnosis [32]. National HIV surveillance data from Public Health England estimates 103,700 people to be living with HIV in the UK in 2014 [4]. Modelling work, informed by anonymous surveillance screening, estimates 18,100 of these people were unaware of their HIV infection [2]. HIV testing is the key to reducing transmission as people who do not know their status are three times more likely to pass on the infection than those who do know their status [49]. While reducing transmission, early diagnosis has significant health benefits for the individual through better management of the condition, and reduced financial costs to the health service. Being diagnosed late increases the risk of dying within the year by 10 times [4]. The cost of HIV care in the first year of diagnosis is twice as high among those diagnosed late. This is due to the significantly higher rates of morbidity linked to

late diagnosis. Furthermore, costs of HIV care remain around 50% higher each year after diagnosis if the diagnosis has been late [49].

The UK has the third highest number of people living with HIV in Europe with late diagnosis remaining a significant problem [50]. An average late diagnosis rate (CD4 cell count <350 cells/mm^3) in the UK of 40% in 2014 [4] hides regional disparities of up to 64%. Lack of up-to-date knowledge of the changing face of the HIV epidemic among healthcare practitioners in the UK has been blamed for impacting the consideration of HIV as a differential diagnosis in many contexts (C1–19; GP1–9,12,13; CNS1–7). It is not only the provision of testing and awareness of risk that exacerbates these figures. Perceived external stigma and self-stigma from an 'acquired' disease also impact on health-seeking behaviour in some sections of the population (GP2,6; CNS2,4). However, raising awareness of HIV through the provision of testing in primary care is a first step in changing primary care culture, normalising the disease and preventing its transmission (C1–19; CNS1–7; Com2,3,4–7; GP1–9, GP12–13; TS1,2,10).

With the reconfiguration of the NHS in England, where the majority of people living with HIV reside, commissioning responsibility has been split between NHS England, CCGs and local authorities. Consequently, HIV and sexual health services have become increasingly fragmented. Sexual health, HIV screening and prevention has become a public health responsibility under the local authority. In many areas across England, sexual health screening and prevention has been identified as an unmet population need. In some of these areas, HIV testing has been included under an enhanced sexual health screening contract between the local authority and primary care providers. This includes linking a payment to the practice per HIV test or per new HIV diagnosis (Com2,5,7). One local authority commissioner in south London borough has taken the provision of HIV testing, diagnosis and non-HIV medical management of people living with HIV from a public health perspective, creating a skilled primary care workforce competent in sexual health and increasingly in HIV. This bottom up approach is detailed in case study 2.

Case study 2: a public health approach to commissioning in southeast London

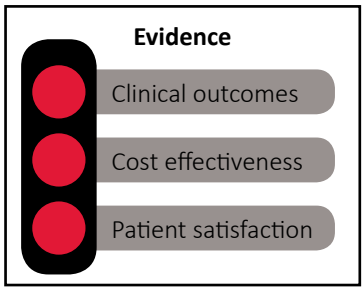
This London borough is in southeast London and has a resident population of 232,800 [51]. The recorded HIV prevalence in 2014 was 2.4/1000 overall, but some areas in the north of the borough have a prevalence rate of 10–20/1000 [52]. The late diagnosis rate is similar to the rest of the UK [52]. Due to regional borough boundaries there is no stand-alone GUM or sexual and reproductive health service within the borough; therefore, some primary care sites have developed a highly skilled workforce for the provision of long-acting reversible contraceptives (LARC). There is significant acceptability among the population for receiving contraceptive services from primary care.

Following an audit of the LARC service, a steering group was set up that included primary care practitioners, to work on an enhanced Sexual Health Service Specification. This was costed and sent to GPs to sign up. Of the 28 practices in the borough, 50% currently deliver the enhanced LARC service. Of these, 60% have received Sexual Health in Practice (SHIP) training and will be invited to take up the enhanced Sexual Health Service offer. The HIV component of the new contract focuses on reducing late diagnosis through the education offered by the SHIP training and a testing incentive. Previously an incentive model was followed that appears to be common around the country, of providing test kits for free with a £10 payment per HIV test performed by the practice.

Two new strategies have been developed:

1. *'opt out' HIV testing on an 'all bloods' basis with a GP practice in a high prevalence area. The local authority is responsible for financing HIV testing; thus they will pay for this serology. Previously, where HIV is indicated, serology testing would have been paid for by the CCG/NHSE. This testing approach is cheaper for the local authority than the point-of-care test by approximately £3 per test.*

2. *As part of the new enhanced services offer, any practice that is part of the scheme will be paid up to £500 per new HIV diagnosis – £250 per new diagnosis, with an additional £250 if that diagnosis is 'early' – in an effort to reduce the late HIV diagnosis rate.*



These new approaches have just been introduced to motivated GP practices with planned roll-out across the borough should they prove successful. This is in a context of an increased sexual health offer across the borough that includes: pharmacy, an increase in c-card outlets and free condom provision, and an online home sampling service. First evaluation figures are due at the end of summer 2016.

Such arrangements are dependent on local-level priorities. While identifying an increase in testing and awareness in some areas, this project has highlighted inconsistent provision of primary care HIV testing across the UK irrespective of local prevalence. This is despite the 2008 national BHIVA guidelines and NICE 2014 guidelines recommending all new registrants to a GP practice be offered testing in an area with HIV prevalence higher than 2/1000 [53].

Participants interviewed for this project reported testing as an 'opt-out' option in the new patient health check (GP2,6,8,9,12), others according to risk factors (GP1,3,5,7,8,10,11). Some practitioners did not feel they had enough time to offer a test (GP3,5,13). One respondent (GP5) commented how people often come with more than one problem, and asked,

> *Is it appropriate to add another one by talking about HIV in a testing context? (GP5)*

Respondents described how some colleagues avoid HIV testing as a result of their own prejudices,

> *It's a taboo subject. (GP8)*

In this context, they refer the patient to GUM services or other GPs/practice nurses in the practice (GP4,8,10). A lack of perceived expertise to deliver a positive result in the primary care setting was also a concern (GP3). In some sites, the CNS is able to support the GP in delivering a positive diagnosis and conducting the post-result discussion that the GP does not have time to cover in the allotted appointment slot. It was felt that the way the diagnosis was delivered impacted on the patients' perception of their future with the disease and engagement with care (CNS2,4,6). The newly diagnosed often undergo a lengthy consultation with the CNS as a first step into specialist services. This consultation builds a network of care for them and forges a strong relationship between the patient and service, impacting on their retention in care (CNS2; TS8,10). An alternative support system that includes primary care is evident in northwest England

(C16) and west Scotland (C11). All HIV-positive results are copied to the sexual health service, accompanied by the name of the requesting practitioner. A health adviser will then contact the practitioner to discuss the plan for delivery of the result and pathway into care for the patient, offering support as required.

Addressing the deficit in primary care knowledge on a deeper level, there are several nationally recognised courses, that focus on HIV and STI screening in the primary care context. Through this training, issues of lack of time, avoidance of drug–drug interactions and recognition of HIV-related complications are also addressed. One example described by participants in this study was the sexually transmitted infection foundation (STIF) education programme. This consists of an e-learning course followed by a core and plus training day, available in England and Wales. It targets primary care practitioners and specialists with an interest in sexual health. The intermediate and advanced levels are accredited by Greenwich University with clinic sessions to complete practical activities signed off in an assessed portfolio, leading to a diploma-level qualification. Sessions are organised and run through a GUM service from their budget. Delegates individually fund their place. Consequently, the impact of the course is less easy to evaluate as delegates are from around the country. However an evaluation in 2007 [54] did record an increase in chlamydia testing at 6 months post training. This model is in contrast to the SHIP training course (currently hosted by MEDFASH available in England and periodically in Wales) that is commissioned in a borough, with an assumption that a minimum number of trained staff across practices is required for behaviour change. The SHIP course also aims to address outdated knowledge that discriminates against people living with HIV and is still reported by service users from across the health service. This includes practitioners 'double gloving' to perform procedures (TS9) [1,55], putting someone with HIV last on the surgery list to enable a 'deep clean' of theatres after the procedure (TS10) and education about the prevalence of HIV among the heterosexual population. Personal testimony by a person living with HIV is a popular component of the course timetable. This approach represents a power shift to the people living with HIV, with them being in an equal or higher position of knowledge than the health professionals [1], and is important and successful in tackling stigma.

Participants working in the third sector and service users, both being groups that experience the reality of life with HIV in the UK, suggested that a national level campaign to re-educate the population would make a significant impact in the journey to normalising HIV. Many respondents to this project have commented on the interest of professionals in receiving update training about HIV, but lack of time and resources in an ever-stretched health and social care sector preclude its attendance (CNS1,2,3,4,6,7; R3,8,9; TS1,2,3,5,6,9,10).

Details of the SHIP course are contained in the following case study.

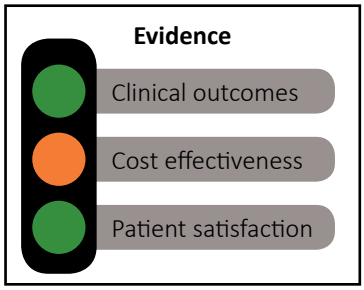
Case study 3: SHIP training for primary care

SHIP is a peer-led educational programme, supporting general practices to deliver sexual health services to their patients. The SHIP programme consists of two entry-level trainings for practice nurses (PN) (two afternoons) and GPs (one afternoon) followed by an 'HIV update' day for both practitioner groups together. They are interactive, locally specific sessions, designed to help GPs and PNs use sexual health risk-assessment skills and understand the key issues relating to HIV, STIs and contraception.

During observation of a SHIP HIV update for a mix of 15 GPs and PNs by the researcher, a shift in attitude was detected across the session.

Barriers to testing exposed many practitioners' own discomfort in talking about sexual health as the root of their avoidance of the topic. An additional provider-side barrier was fear of the patient's reaction if offered a test. Many practitioners expressed anxiety that they are perceived as judgemental. Role play and provision of suggested phrases to introduce the topic of HIV testing made some progress against the consultation attitudes or skills barrier. Commonly quoted barriers of time, knowledge, stigma and relevance to the consultation were firmly crossed off at the end of the session.

Participants have evaluated SHIP training sessions very favourably with an impact on behaviour change evident with increases in chlamydia and gonorrhoea screening, use of new swab screening techniques, and preliminary evidence of increased HIV testing rates in one high-prevalence borough of London [56-59]. A full cost-effectiveness evaluation is pending.



Some sites are approaching HIV testing through a move to point-of-care testing in pharmacies and home sampling. This involves the ordering of a kit online, which will be delivered to the home with instructions for use, where to return the sample and how the results will be delivered. Evaluations of these services are pending (south and southeast London Com6,7). Home testing, where the person collects the sample and interprets the result is currently only available through online purchase in the UK. Manufacturer evidence reports sales of 27,917 tests in the UK between April 2015 and February 2016. Sales have been concentrated in non-urban areas and among the MSM population (http://www.aidsmap.com/First-data-on-uptake-of-HIV-self-testing-in-the-UK/page/3052711/). There are concerns about links to the care pathway in this method of diagnosis yet offer a route to testing to those for whom geography, confidentiality or fear of stigma may act as barriers.

7.2.3 Case-based management

Interview respondents identified three different case managers within the context of models of care for people living with HIV: GPs; HIV CNS; and peer advocates.

7.2.3.1 GP

A King's Fund review of the management of long-term conditions identified the GP as being well placed to provide the co-ordinating role required in a collaborative care arrangement. This is due to their holistic view of the patient and their concerns (GP5,6) [32]. However, consensus opinion from specialist respondents for this project was that the majority of GPs lack the experience, time and inclination to take on routine non-HIV care of people living with HIV (C1,2,4,7,9,10–19; CNS4–6). This concern was reflected among long-term service users who have complained about difficulties in accessing appointments with a GP (JR, CS, DR, TN, WS fgd), time constraints (WN, PM, MS, JR fgd), being up to date with the patient's medical history (FP, MM, TN fgd, TS7,8,9,10), and GP knowledge of HIV and drug interactions (TN, DR, CS fgd TS7,8,9,10).

Four participants from the fgd described having a regularly reviewed care plan that involved the GP, specialist services, community services and their own input in relation to psychological and weight management issues (CN, DR, TN, WN fgd).

Because I was told I was obese and they arranged everything. Yeah with the dietitian like TN, the gym and all that and he [the GP] kept on checking on me.

The remaining participants in the fgd either did not know what a care plan was (MM fgd) or said they did not have one (CS, FP, MS, SC, WS fgd). Some respondents felt care planning was too involved for the 'stable' HIV cohort, who are the focus of this project (Com1; GP1,3,12).

Despite concerns about the service offered in some GP practices, this was not universal, with some descriptions of good communication and rapport.

…most of the GPs are also very good. There are a few that are not good but I know them now so I avoid them. (WN fgd)

Participants in the focus group discussion were asked if GPs should be paid more to provide better support to people living with HIV. They unanimously disagreed; however, the discussion did acknowledge that their care could be complex with multiple comorbidities and GPs could feel overwhelmed. This was described with examples that lead to mistakes. The group solution was:

…train us and go into the GP surgeries and do something about it. (MM fgd)

Empower the patients okay. To have more knowledge about their condition, whether that be HIV, whether that be diabetes. Let me tell you, the work load of the GP will lessen. (WS fgd)

The ideal model for me is…every GP surgery should have one…HIV knowledgeable doctor so that when I ring…they immediately link me to him…it would cut out a lot of problems. (MS fgd)

The majority of the focus group attendees wanted to access their GP in the HIV clinic. However, three participants were vocal about wanting to see their GP where they are but to have them educated:

The point of a GP is that it's local so that you can just walk there. (JR fgd)

I would like to see the frontline people at the GP services sort of educated, not just about HIV about various things… (WS fgd)

I think several practices should have an expert in HIV. (JR fgd)

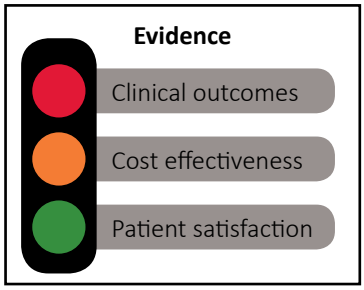
As one respondent succinctly commented, HIV can be classified as a long-term condition from a medical perspective, but the context surrounding the disease cannot. A future primary care model may comprise a GP lead in HIV but a transition phase is required, principally due to the impact of stigma within society, health professionals and individuals themselves (CNS4). The GP with a special interest (GPwSI) model is described as successful in the northwest of England context by a GPwSI in HIV (GP1). This model enhances patient care to a specialist level while taking a holistic approach to co-existing morbidities.

A commissioning model from southeast England aimed to address the lack of knowledge in primary care and service user lack of confidence. It involved a locally enhanced service (LES) agreement with primary care. This can be seen in case study 4.

Case study 4: southeast England specialist commissioning opportunity

Historically, service user concern over disclosure of their status to their GP as well as GP competence in issues of HIV resulted in non-HIV health seeking from specialist services. Consequently, specialist services were overwhelmed and access was compromised for other patients. A locally enhanced service (LES) for the provision of appropriate medical services for people living with HIV was agreed with interested primary care providers in the city. Conditions of the agreement included training for primary care staff with regular updates and a list of care requirements linked to the payment. This agreement provided reassurance to service users and supported their move to primary care for non-HIV medical care.

An informal quality feedback loop exists from the service users to the specialist commissioner. This is nurtured through the commissioner profile among the cohort, inviting direct feedback with any service provider issues. This profile is achieved through regular service visits, speaking with patient representatives and service users, and commenting on HIV issues in local literature. This feedback is important to maintaining service quality in the area.



Other sites have bid for an LES to take over primary care prescribing but were unsuccessful (GP1). There is a strong argument by some against introducing an LES incentive for primary care to fulfil their commissioned service responsibility for people living with HIV. It is stated in the GP contract with NHS England that essential services will be provided to those suffering chronic disease (section 8.1). However, with an expanding population with more complex healthcare needs, increasing patient expectation and a recruitment crisis in general practice, there is a generalised feeling among GPs of resources not matching patient need. Health service changes over the past 20 years have moved more responsibility away from secondary care into the community. This has often been without an associated increase in funding. The Royal College of General Practitioners describe how 90% of NHS care is provided through general practice with only 9% of the budget [60]. Among those already providing appropriate primary medical services for their patients who are living with HIV, resource constraints were not mentioned as a significant issue (GP2,6,7,8,12,13).

7.2.3.2 HIV clinical nurse specialist

Within the context of this project, different nursing models were found to have developed to meet the needs of the patient cohort according to caseload size and commissioning constraints. Care co-ordination for people living with HIV was felt to require a different approach to other chronic conditions such as diabetes (CNS1–7). Issues of self and social stigma originating from the 'acquired' component of the disease and perceived personal behaviour were found to impact significantly on every aspect of the disease experience. This is in contrast to the perception of diabetes as a physical failure in a body system through no direct action of the individual. Furthermore, HIV has been

described as a fluctuating condition (GP6) with side effects coming and going (TS10). This requires flexibility in access to care. Despite the diversity in service configuration, all CNS (employed in both the acute and community settings) interviewed for this project described a co-ordinating core to their role, joining up services across different settings and linking of professionals to establish packages of care for the patient (CNS1–7).The HIV CNS has been rated favourably in between the GP and HIV consultant on attitude, professional performance and viral load control among their patient cohort [61,62]. They are also seen as care co-ordinators by service users:

> *…if I need to be referred, we still have the HIV specialist nurse in my borough so if I want to talk to somebody, I call my specialist nurse first. (TN fgd)*

The use of personalised care plans to integrate service delivery is a particular tool of case management. This approach is used in the southeast England nursing care model for patients experiencing a requirement for extra support as in case study 5.

Case study 5: southeast England HIV CNS team

Commissioned by the CCG, HIV CNS see patients in their own homes. They know what services are available across the region and how to access them. There are clear pathways of referral into acute services.

This model is based on the House of Care concept with detailed care planning between the CNS and the client. Unlike the recommendations of managing long-term conditions from the King's Fund [32], this model has a set time frame agreed with the client. This supports the setting of goals and achievement of progress. Although the care planning follow-up comes to an end, the process can be recommenced at a future date if circumstances require. This process takes a holistic approach, looking at the full spectrum of client needs while maintaining a strong self-management and partnership planning focus. Following an initial assessment visit, the CNS provides ongoing support, information and liaison with other services, including third sector health trainers, psychology services and general practice. The care plan is reviewed every 4–6 months for up to 2 years.

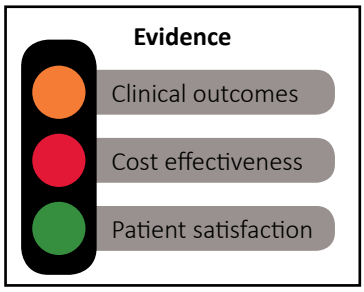
This nursing team links with non-HIV team meetings such as the 'frailty' meeting and those for the homeless to share information, pick up clients and work collaboratively across the service. There is a weekly multidisciplinary team meeting in the hospital hosted by the service where the CNS team/hospital/clinic and voluntary sector can become involved in both client referral and discharge planning.

Rural localities have lower disclosure rates to GPs, making the role of the CNS even more valuable as a source of knowledge and support. In this area, the team do fulfil a role in providing training for GPs, foster carers and care homes. A recent in-house audit measured that 86% of GPs wanted input from the CNS team for training.

One issue is how to measure the impact of the CNS service for the CCG to secure service funding. There is no standardised measurement tool, though the aim of keeping individuals out of hospital and promoting self-management in the cohort is frequently met, and complemented by favourable service user feedback.

Summary

This service model is based on care planning and self-management. The CNS provides the specialist assessment at the commencement of the process. They also provide ongoing review, support, guidance, advocacy and liaison with services. There are clear referral pathways and a nursing support network. Measurement of impact is an opportunity that needs to be developed to secure funding for the service.



A particular strength of the CNS as care co-ordinator was the confidence afforded to service users of the continuity and specialist back-up resource they offered. The role of the relationship between the patient and someone with specialist knowledge has been described as essential in facilitating adherence and stability of disease. One service user described moving clinics to remain under the care of the same practitioners. He explained that they knew his history and HIV journey and he didn't have to explain himself at every consultation (TS8). Furthermore, clinic staff have been described as 'family', creating a safe space for the respondent (TS10). He described his adherence improving as he got to know the staff as he didn't want to 'let them down'. Practitioners (C7,9,12,14,16; CNS1–7; GP1,2,12,13) also emphasised the relational element of care. As trust increases, so does disclosure of experiences and feelings that impact upon the individual's treatment. The potential loss of this continuity causes anxiety from both patients and providers (TS8–10). The CNS interviewed for this project credited their success to the human relationship element of care. In one area, the CNS described how patients transferred their care back to their home borough because of the continuity, specialist and local knowledge offered by the HIV CNS (CNS2).

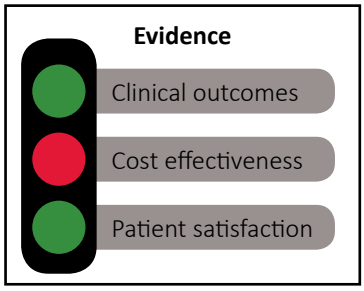
Case study 6: clinical nurse specialist southeast London

A service commissioned by the local authority as part of the integrated sexual health service in the borough. The caseload is currently approximately 250 but SOPHID data suggests that approximately 500 people are living with HIV in the borough. Co-commissioning by the local authority, CCG and NHS England would provide greater stability to the role. The service is detailed in the service specification and consists of a nurse-led review clinic within the acute GUM service of the 'stable' cohort with some 'complex' patients attending for support. More vulnerable patients can also be seen at home. All newly diagnosed patients are also seen in the nurse-led clinic as how that early stage is handled can impact on future attitude and adherence issues. Phone calls and queries from patients, families and other health and social care practitioners are common. The CNS fills the gaps on psychosocial, mental health and well-being issues with signposting to generic services.

This community-based role can follow the patient across organisational boundaries, bring aspects of care together and remove the information holding responsibility from the patient. The service supports primary care practitioners through the sexual health lead of each practice, promoting testing initiatives. This borough-wide profile encourages GP contact with the CNS for advice, information and support, for example in delivering a diagnosis, and pathways into care or troubleshooting.

Some GP sites have been SHIP-trained and are also taking on the new HIV testing initiative of payment per diagnosis.

It is felt by the CNS that lots of patients have a good relationship with their GP in the borough, especially as their sexual health and HIV expertise is increasing. Since the service users of this borough have not had access to some specialist HIV services such as psychology and specialist mental health provision, they have adapted well to the services offered. There has been some uncertainty of generic services, with examples of outdated advice and knowledge among some practitioners. However, the CNS remit allows teaching in areas where a need is identified, for example in mental health services or in a 'look back session' with primary care when there has been a late diagnosis.



Keys to success:

- *Profile of the CNS among primary care practitioners and patients*
- *Strategic involvement in development of borough primary care sexual health commissioning contract*
- *Commissioning of a service that can work across organisational boundaries, i.e. acute, community and primary care.*

People living with HIV are actively encouraged to consult their GP for non-HIV-related morbidity, and will be redirected to this provider by the specialist if deemed appropriate. This change in care configuration has left some service users feeling 'abandoned' (CNS4,7; TS8,9,10). However, in discussion of potential care models in the fgd, maintaining CNS input was received favourably:

If they bring HIV nurses to the clinic to sort of take care of us that could also improve the service. (MM fgd)

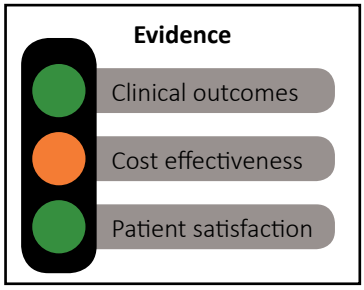
An example of such a nurse-led model can be seen for a stable cohort in south London.

Case study 7: nurse-led clinic, south London

The nurse-led clinic model is unique to south London. It comprises an HIV specialist nurse delivering nurse-led clinics in a primary care setting. The two locations of the clinic were chosen by their interest to host the service. These clinics are attended by over 100 stable category patients who voluntarily transferred their care from the specialist HIV clinic at the local hospital that treats a cohort of around 2500 patients with HIV.

The nurse delivers a comprehensive consultation covering issues such as mental health, counselling, wellman checks, and healthy living advice in addition to HIV monitoring. All primary care medical conditions are referred to the GP. Patient records are maintained through the Patient Knows Best electronic system. This system also enables remote clinical supervision and support for the nurse from the HIV consultant. Appointments are offered outside office hours and on Saturdays.

The initial set up plan had been to integrate the service with primary care but an identified skills gap has required workforce development input. Currently, the embedded CNS is used as an information resource by primary care practitioners. The clinic is also open to patients accessing care from other secondary providers although this option has not yet been exploited. Patient feedback of this model has been overwhelmingly positive. Some patients have commented that they surprised themselves how preferable it was to sit in a health centre waiting room in comparison to a clinic surrounded by HIV posters.



Remote management of patients with chronic disease, by phone or email, has been shown to reduce cost while improving adherence and health status [63]. This model has been used within an HIV context for stable patient review or non-attending patients with more complex needs. Complex needs can range from adherence issues, social and mental health problems to safe guarding and family support. Due to delays in referrals and a lack of responsiveness from mainstream services, some CNS describe touching base regularly with a core cohort of patients and averting emergencies by picking up problems before they become a crisis (CNS1,5). People with HIV can flow in and out of the 'stable' category; relationships break down; undisclosed mental health issues flare up; an older gay man discovers 'chemsex' and loses his job and his health deteriorates, but this is not reflected in their category classifying blood picture (CNS1).

A case example presented by a CNS (CNS 5) described a man who was classified as 'virologically stable' and who had experienced a violent attack. His state of psychological distress led him to discontinue his ART and seek a legal order from the magistrate to withdraw all treatment as he wished to end his life. Support and intervention from the CNS enabled this patient to seek sources of positivity and control in his life and revoke his end of treatment decision. He recommenced his ART. CNS and service users commented that HIV is not always an important or visible aspect of the patient identity until there is another life event. The negative experience of that life event is then emphasised by the fact that 'I've got HIV as well' (TS7). Psychosocial support in areas such as social isolation and fears around disclosure of status and discrimination can help individuals' live positively with HIV [64]. The majority of fgd participants accessed psychological support through the HIV clinic. This specialist input was preferred over generic services as one participant describes:

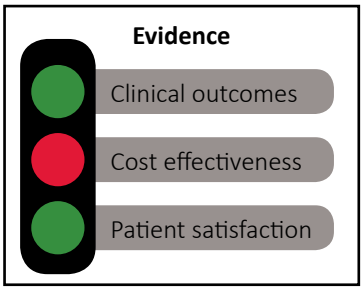
I ended up being sent to my GP for psychological support…I just found it ridiculously bad…they had no idea about HIV, where your problems are stemming from'. (JR fgd)

CNS models reviewed for this project also have a significant role in psychological care, especially in the support of vulnerable patients with complex needs. An example of a virtual clinic for patients with complex needs can be seen in a northwest England community HIV nursing team.

Case study 8: virtual clinic model

The virtual clinic is for patients who have not attended clinic for more than 12 months, which may be due to physical disability, social isolation, incarceration, challenging behaviour, psychological issues or financial constraints. The CNS and HIV consultant (ID or GUM) meet

monthly to discuss existing and potential patients. Each patient is reviewed; individualised care plans are formulated and agreed with the patient at home. Discussions and actions are documented in the patient record, HARS and community clinical system via an iPad during the virtual clinic. A joint CNS/consultant home visit is conducted annually to review the patient [65]. About 15 patients are active in this clinic; however, they generate a lot of activity and this system has proved excellent at keeping them engaged (CNS4).

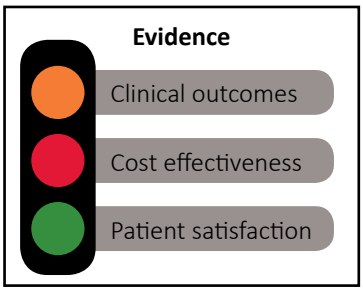


Within a region of north England, HIV services have been removed from the local sexual health provider. There is currently extreme concern over the future configuration of the community HIV service, which would previously co-ordinate care for those people living with HIV with complex needs (CNS6). CNS interviewed for this project requested a collaborative commissioning model to enable their work between acute and community settings. This model would also provide some stability to the role (CNS2,3,4,6).

Case study 9: 'open access service' and restrictions due to commissioning

The northwest England HIV CNS community team are based in a regular NHS community health centre providing a city-wide service, operational since 1993. Consequently, they are well known to primary care services. As they are integrated, they are well linked with generic services, facilitating referrals and educational input for practitioners, as needed. They are currently commissioned by the CCG and have about 100 patients in their caseload at any one time. Patients flow in and out of the caseload and remain for various durations. Sometimes a neighbouring CCG will spot purchase their service for individual patients, leading to a frustrating and inequitable service. Co- or collaborative commissioning with NHS England and the local authority would enable a pan-CCG model across the region as patients are more geographically dispersed than historically.

The caseload comprises psychosocially and medically 'complex' category patients, although they are available for the newly diagnosed and all people living with HIV who need information or support. The key to the community nursing team's success is their position in the community and the deeper level of support they can offer, which often is over long periods of time. This affords the flexibility to move between home and hospital depending on the needs of the patient.



7.2.3.3 Peer advocate

There is a medley of peer support models across the UK for people living with HIV. The range includes drop-in coffee and chat sessions, community-based support groups, peer support phone apps, online forums, social events, residential weekends, and in-clinic peer supporters. Psychological care is not only provided by peer supporters but it is a significant part of their role, as well as providing signposting and real-life experiences to the newly diagnosed. Within a healthcare context different terminology is used, such as 'peer navigator', 'peer advocate', 'peer support worker', and 'expert patient' to refer to

recruited individuals providing a support service from a similar social or illness experience background as the target intervention group. Usually they will receive some training in the role to offer a variety of support to others with this long-term condition [66]. A report on the in-clinic Peer Navigators project at the Homerton Hospital in London [67] recorded a 70% increased uptake of services, from benefits advice to immigration, following introduction of the Peers. Furthermore, there was a 76% reported increase in disclosure and talking to others about HIV.

Each model on the spectrum provides a service relevant for different sections of the HIV community at different times in their life. However, it is widely agreed, and endorsed by the Department of Health in the Five Year Forward [68] and the HIV CRG service specification [9], that peer support for people living with HIV is a valuable and essential part of the care package on offer. It provides a continuous emotional, social and practical support base rather than a service that only intervenes at times of crisis [69]. It supports both long-term care and adherence. A review of 524 studies was undertaken by National Voices [70] exploring the impact of peer support on service users. They revealed peer support to have the potential to improve health outcomes, behaviour, psychosocial outcomes, experience and service use, particularly in clients with long-term physical and mental health conditions. Being part of a community and not feeling isolated and alone with the diagnosis was reported as the principal benefit by respondents of this project (R9; TS3,5–10). These results are similar to those reported from case-management programmes [1,46].

Access to peer support appears to be fragmented across the country. However, work is in progress to link a peer supporter to every HIV clinic in the UK. This will be achieved by a third sector organisation facilitating the training and support of 1000 volunteer peer mentors. Over the course of the 4-year project, the impact of peer support on people's well-being and the cost effectiveness of the model will be evaluated (TS3). Defining national standards of HIV peer support is within the remit of the project. A community-based model can be seen in southwest England where a third sector organisation run by people living with HIV provides a range of support and awareness-raising functions for people living with HIV and the local community. This ranges from information and education around HIV and STIs, social events and drop-in sessions, counselling, aromatherapy and practical services such as meal clubs and washing facilities. This centre is also active in raising awareness among the local community and health professionals about the realities of living with HIV, tackling stigma, discrimination and misconceptions. This particular support centre relies on charity donations, which can affect the range of support it offers (TS10).

The format of the support seems to appeal to different populations with online, face-to-face and telephone support groups all having good results (TS8,9). Peer support was found to be most effective when organised around specific activities; they cite exercise and choir as examples, and those that focus on social support, education and physical support (Service User Online Survey). Other peer support approaches and target groups may be successful but there is no conclusive research evidence. Finding a peer support format that fits the service user needs can be a challenge, especially in rural or low prevalence areas (TS5,6).

The ability of peer support workers (PSW) to engage with clients on the same level through an understanding of the challenges of their situation is a core feature of their effectiveness and they act as a role model to show that living well is possible. An additional benefit of their role is their ability to bridge the client or provider gap. The value of peer support models for improving client access, uptake and engagement with health services and for adding value to the client experience is widely recognised. In an HIV treatment context, PSWs have described their role as integral because the treatment

process is so complex and challenging due to multidisciplinary involvement and issues of stigma among the client group (TS1–8) [66,71].

Generally, transition from the role of service user to PSW has been described as challenging, particularly with regard to where to draw the line between service provider and friend (TS3) [71-78]. It has been described as a hard place, occupying the middle ground between provider and service user [73]. The PSWs in Kemp *et al.* [75] recommended the provision of training in boundaries and ethics to overcome this danger, allowing them to manage the client relationship while keeping themselves 'safe' (R9). Balancing the volunteer PSW role and expectations of clients and health professionals with their own commitments was also described as challenging [71,75,79]. Within the Terence Higgins Trust (THT) 'MyHIV' peer support forum, the PSW can take time out of the role if they need a break (TS5). In other formats, clinical supervision is made available (TS3).

7.3 GP online survey

Survey respondents numbered 152 with 88% from primary care practices in London. The remaining 12% were from southwest England, southeast England, the Midlands and one from Scotland. Practice size ranged from a single GP to 21 (average 6.5) serving a caseload of between 2500 and 27,000 (average of 10,000). The average number of people living with HIV on the practice list was 35 with a range of 0–150 and 30 'unknowns'. This would give an average prevalence of 3.5/1000 if figures were felt to be reliable. Documented HIV prevalence in the respondents' areas ranged from 0.2 to 15.08 according to the Public Health England Local Authority prevalence figures [80], with 88% of the sample located in areas with a prevalence above the new patient screening threshold of 2/1000 [53].

7.3.1 HIV testing

7.3.1.1 Results of the GP survey

In response to the question about offering HIV testing in your GP practice, 96% (*n*=75/78) of the respondents answering this question replied in the affirmative. However, from this testing-cognisant sample (*n*=78), the majority of HIV testing was described as patient initiated (88%, 68 responses) followed by patients from high-risk groups (79%, 61 responses) and those with indicator conditions (74%, 57 responses). Free-text answers highlighted testing if there was clinical concern, a lack of response to treatment and during sexual health checks. Those respondents offering testing to new practice registrants were in the high-prevalence boroughs across London. They had experienced long-standing testing initiatives such as support from specialist services or inclusion of HIV testing in the sexual health contract between the local authority and CCGs with associated commissioned training. Within these sites, the HIV patient caseload averaged 30 people with a couple of respondents quoting over 80.

To further clarify guidance on HIV testing in primary care, respondents were asked about current testing guidelines in their practice. While less than 50% of the sample answered (*n*=68), the responses were generally proactive and included 'offer to new patients, at contraception checks, when relevant to symptoms, and according to risk'. The national testing guidelines from BHIVA and NICE were referred to by some respondents; however, the majority felt there was no specific policy or guidance in place and so they would be guided by clinical suspicion. Despite the perceived lack of specific guidance, time in the consultation to discuss testing was felt to be the most significant barrier (44%, 34/78). In

contrast, the remainder of the sample found time to be no barrier, suggesting different approaches to offering a test. Free text answers revealed some extremely proactive practices view an HIV test as routine and it is already widely offered and accepted. Another personally experienced barrier to testing was described as discomfort in the potential reaction of the patient when offered a test (19%, *n*=15) and in the delivery of a positive result (19%, *n*=15), with requests for a clear referral pathway (20%, *n*= 6).

Within this survey, respondents were asked whether they had received any training in HIV and how long ago this had been. Respondents described clinical suspicion as the principal guidance in offering an HIV test to a patient, thus the experience and relevance of training in the potential presentation of HIV in a patient is a requirement alongside an increase in primary care testing initiatives. The majority of respondents from this survey had received some form of training (63%, 84/134) with half the sample experiencing this more than 5 years ago (36/85). While this sample reflects a non-representatively high level of training in HIV, it is useful to see the range of training opportunities accessed by respondents. The source of the training is detailed in Figure 4.

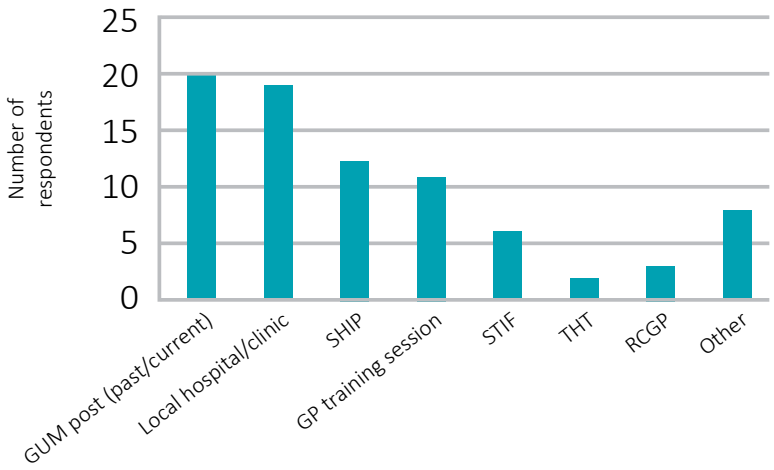


Figure 4. Source of training for respondents of the GP 'models of care' survey 2016

The majority of respondents had held, or currently held, a clinical position within infectious diseases or GUM services, which has acted as their principal source of training in HIV. Locally organised training included that facilitated by secondary care for GPs or by a GP with a special interest colleague. Overall training experiences were rated as useful, with the SHIP course most highly rated by respondents, followed by personal work experience in sexual health specialist services.

7.3.1.2 Deviation from guidelines

Only 43% (*n*=33) of respondents noted testing opportunistically or in a structured 'new patient health check' despite 88% (*n*=134) of the total sample practising in areas of high prevalence. There seemed to be a prevailing attitude among respondents that there was a need for lengthy pre-test counselling, adding time to a consultation or new patient health check that was just not available. Despite this, the majority of survey respondents referred to the new patient health check as the best opportunity to increase HIV testing in primary care with additional opportunistic testing. However, until testing is normalised

among patients and practitioners, this is not seen as a feasible option due to the aforementioned time and staffing constraints.

7.3.1.3 Implications

The high testing prevalence among respondents suggests there may be a responder bias to the survey. KIIs and the scoping literature review for this project intimate HIV testing in primary care to be much less common, even in the high-prevalence boroughs of London. Furthermore, the perception of a lengthy pre-test counselling requirement is in contradiction to progress in efforts to 'normalise' testing. Some respondents asked for training to 'normalise' the offering of an HIV test to a patient.

KIIs for this project have revealed clear referral pathways into specialist care across the country but results from this survey suggest this information has not been as widely absorbed by primary care as assumed.

7.3.2 Ageing with HIV

7.3.2.1 Results of the GP survey

As people living with HIV move into a discourse of ageing with HIV, a number of healthy well-being messages and screening activities are recommended to facilitate ageing well. These are appropriate for delivery in a primary care context and include annual 'flu vaccination, regular blood pressure checks, annual smear tests, dietary advice, psychological support and smoking cessation support. In five cases (3%, 5/66) an annual review was performed as is recommended in a chronic disease management model. These sites were in areas that have a known sexual health contract with the local authority with commissioned training or an incentivised enhanced service agreement. The stated cohort of HIV patients in each of these practices was not significantly different to the remaining sample, ranging from 10 to 110.

When asked if there was a mechanism to alert the clinician to a potential drug interaction, the majority of respondents described different alerts on the practice computer system (EMIS web, SystmOne, Vision, ScriptSwitch). This is only activated if the hospital prescribed medication is inputted into the record as 'tablets 1' to indicate a non-GP prescriber. The input of the ART must be done manually in response to an updated clinic letter and obviously depends on patient disclosure of HIV status to the GP. The drug interactions website of Liverpool University, which is detailed in the footer of clinic letters was also a popular resource for respondents.

7.3.2.2 Deviation from guidelines

Of those answering the question about what services they provide for people living with HIV (*n*=66), the majority stated 'general medical services' and 'nothing additional' with an occasional mention of annual 'flu vaccination. No mechanism to check for potential drug interactions was stated in 15% (10/68) of cases.

7.3.2.3 Implications

With ageing comes the experience of comorbidities such as hypertension and hypercholesterolaemia. The risk of drug interactions between the ART and medications for such common conditions prescribed in primary care is a major concern of respondents and stated as one of the key challenges in the provision of primary care services to people living with HIV.

7.3.3 Confidentiality

7.3.3.1 Results of the GP survey

Another challenge mentioned in the provision of primary care services to people living with HIV related to issues around stigma and confidentiality. Research has shown increased confidence among service users when there are confidentiality and anti-discrimination policies made visible in the practice waiting room [77]. Within this survey sample, 73% (83/113) of respondents declared the presence of a confidentiality policy in their practice waiting room. However an anti-discrimination policy was present in only 50% (55/110) of practices. In complement to the presence of visible policies was the attitude and reception of patients by support staff in the practice. When asked if support staff had received training in issues of confidentiality or anti-discrimination, there was a mixed response. Results are detailed in Figure 5.

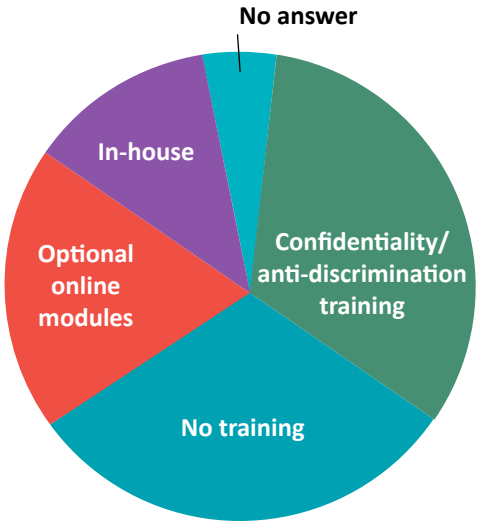


Figure 5. Training offered to GP support staff in respondents' practices

7.3.3.2 Implications

While information governance is a mandatory training requirement, confidentiality and anti-discrimination modules are optional. If time and encouragement are not given to complete these modules, it can be inferred from this sample that up to 50% (*n*=45/90) of respondents' support staff colleagues have received no training in these topics. Support staff interact with patients in the public space of reception and so play a vital role in implementing anti-discrimination and confidentiality policies.

7.3.4 Models of Care

7.3.4.1 Results of GP survey

In an attempt to garner primary care experience and opinion in overcoming some of the challenges of providing appropriate medical services to people living with HIV a variety of potential models of care with different forms of specialist support were presented to

the sample. These were adapted from the chronic disease literature and key informant interviews of this project with a request to participants to rank their usefulness for their particular HIV cohort. Unfortunately this does not allow for sensitivity in the analysis to ascertain the most favoured model in a particular context; however, it acts as a guide to further inquiry.

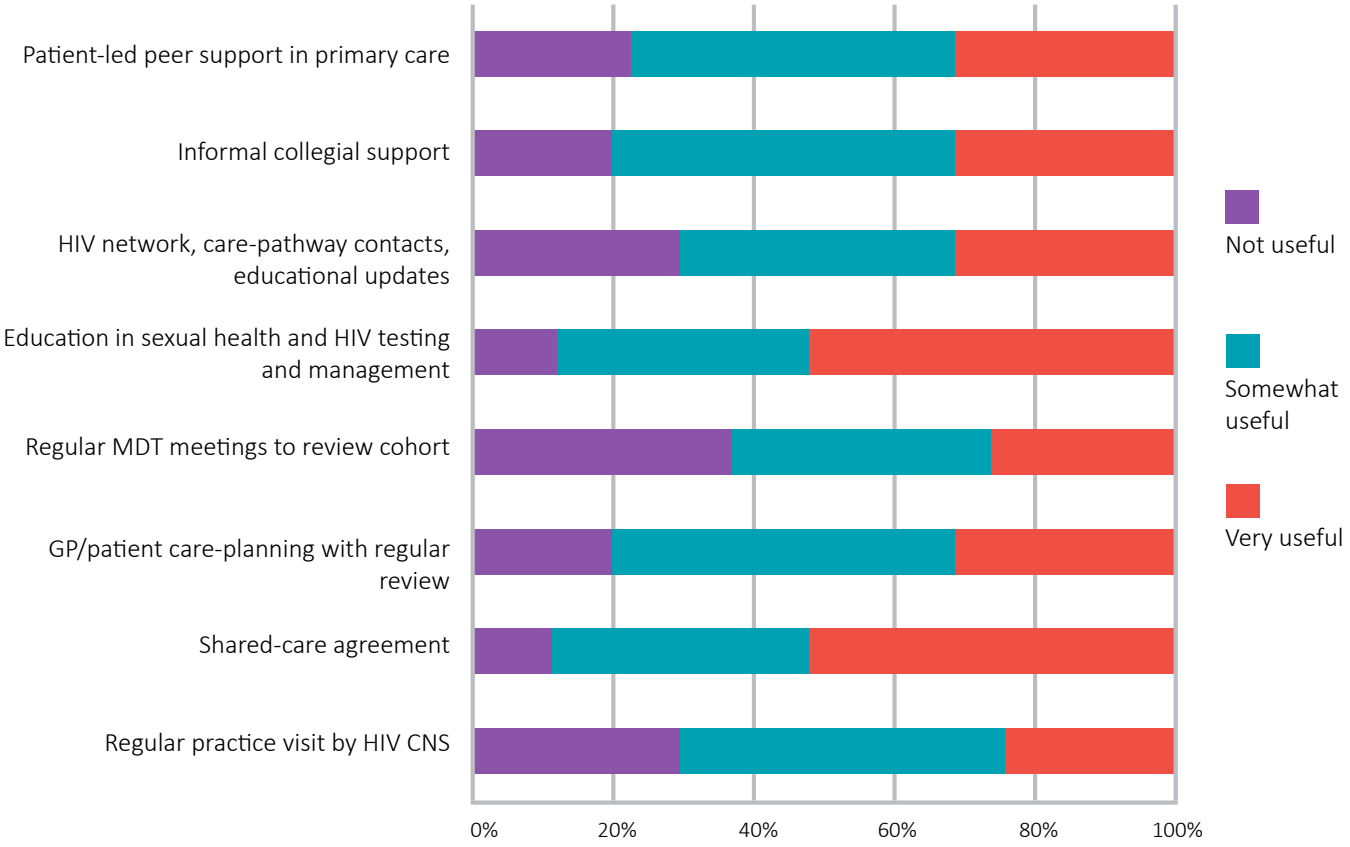


Figure 6. Usefulness of different models of care for respondents' HIV patient cohort

The most widely supported option (53%, 58/113 rating as 'very useful') was an educational update about testing and management in sexual health and HIV. This broad approach, including sexual health as well as the more specialist topic of HIV perhaps increases its appeal to primary care respondents.

The second most widely supported model (52%, 57/113 rating as 'very useful') was a shared-care agreement with yearly follow-up by an HIV specialist and sharing of a care plan with the GP. Shared care requires an enhanced level of communication, which was described as a key challenge in the provision of primary care services to people living with HIV in this survey. An awareness of the need to overcome stigma to support disclosure by the individual of their HIV diagnosis and thus enable communication between healthcare providers was expressed within the sample. Removing patients' ability to opt out of their GP knowing about their HIV diagnosis and care was felt to represent a fundamental step forward in normalising an HIV diagnosis and of providing safe medical care (respondents 17,54,60).

The majority of respondents reported annual communication from the specialist centre 50–75% (34/70) of the time with an average of three specialist centres quoted as being

involved in the care of these patients (121 respondents). There was an outlier quoted at 15. Although this figure is viewed with some scepticism, it certainly illustrates the involvement of a significant number of specialist centres with which the GP will be communicating. In contrast, communication from primary care to the specialist service was described as rare, or on referral only. Some respondents said they communicated with specialist services once a year with a minority in a more structured arrangement of monthly communication or even weekly multidisciplinary team meetings. Naturally communication arrangements depend on the complexity of the caseload and the commissioned structure of services. However, this survey suggests such frequent arrangements to be the exception. In the case of a clinical concern, communication pathways were clear as the specialist team would be contacted either by telephone, email or letter. Some respondents referred to use of the internet or contacting third sector organisations if appropriate. Evidence from the literature and the service user survey and focus group conducted for this project, revealed patients frequently being asked by the GP to get advice from their specialist team about a clinical issue. In contrast to this experience, only 4% (3/70) of the survey sample mentioned this route as a method of gaining information.

Other models that scored highly in the 'somewhat useful' category were peer support, informal collegial support and GP/patient care planning with regular review. These could reflect the needs of different members of the patient cohort, and the moves by the Royal College of General Practitioners to a collaborative care planning model promoting patient self-management support at its core. The 'very useful' scoring could reflect the most applicable model for the different needs or caseload size within the respondents' practice. For example, the regular MDT meetings to review the cohort received a mixed response. Furthermore, one respondent commented, 'we are already inundated with MDT meetings and HIV/sexual health education. I don't think any more of these are needed'. This suggests that this system is already in place where appropriate and not felt very useful in sites with smaller caseloads or patients with less comorbidity complexities. Although this project brief was to look specifically at models of care for people living with HIV, one survey respondent made an insightful comment about the implied continued exclusivity of HIV in the different model options. It was commented that perhaps we should be looking at appropriate models of care for all patients with blood-borne viruses. This is especially pertinent as people with hepatitis B and/or C share similar issues with respect to chronic disease management, stigma and siloed care.

7.3.4.2 Implications

Provision of an educational update about testing and management in sexual health and HIV could address a concern raised by some respondents regarding their lack of confidence ascribing patients' symptoms to HIV or non-HIV aetiology. This knowledge would inform appropriate referral to the specialist HIV team. Such an approach is an essential component in the move towards normalisation of HIV by positioning general medical care out of specialist services for patients who are stable and living well.

A shared-care agreement would need to be linked to a financial payment for the enhanced general medical services on offer to an HIV cohort, and would be formally commissioned. This could facilitate the time and space felt by many respondents to be missing in primary care for the provision of any services beyond what is offered currently. However, a respondent in the free text option described their experience of using care plans specified in the service agreement for their HIV cohort as a 'waste of time' (respondent 76). An alternative option was presented in the use of specifically designed templates for the primary care IT system that are linked to either QOF targets or conditions of the agreed service contract. The need to link to a robust quality control system was felt necessary to facilitate implementation (respondent 74). If a shared-care

protocol is to be developed between primary care and specialist HIV services, care needs to be taken to ensure that it facilitates communication and mutual support rather than being an exercise in 'form filling and shifting responsibility' (respondent 51). This may help address the frustration expressed by respondents at the fragmentation of communication and services, including some sites being unable to share blood results leading to the duplication of tests and unnecessary secondary care visits. The issue of time constraints in general practice was again mentioned in the free text section of this question by respondents, expressing the inability of primary care to take any more patients. However, this survey was looking at the best support model for the provision of appropriate general medical services in primary care for people living with HIV and not the devolution of any specialist services, although some respondents did express readiness to increase their involvement. Naturally, any enhanced service would need to be formally contracted and incentivised in the local context. Such nuances are outwith the scope of this project.

7.4 Service user online survey

In total, 167 respondents completed the online questionnaire. Where percentages are quoted, the total number of question respondents is detailed to contextualise the results. As with any open survey, the respondents and their views are a snapshot of experience and not representative of the majority of people who are living with HIV in the UK. Respondent characteristics are summarised in Table 1.

Participant characteristics		
Gender	Male	64%
(Total respondents=98/167)	Female	35%
Ethnicity	White British	54%
(Total respondents=100/167)	Black African	21%
	White other	13%
	Mixed	5%
	Black British	2%
Age	Range	26–72
(Total respondents=98/167)	Average	48
Years living with HIV	Range	1–33
(Total respondents=98/167)	Average	15
Orientation	Heterosexual	35%
(Total respondents=96/167)	MSM	53%
	Bi-sexual	9%
Location	London	32%
(Total respondents=85/167)	SW England	24%
	East Midlands	11%
	NW England	11%
	East England	8%
	NE England	5%
	SE England	7%
	Wales	1%
	Scotland	0

Table 1: Characteristics of survey respondents

In general questioning about respondents' view of their health and well-being, the majority related well-being with feeling happy with good mental and physical health. Being physically well enough to do what they wanted was rated the highest contributor to well-being followed by their family and having enough money to meet their needs. When given the opportunity to elaborate, the majority of free text responses focused on access to support networks, and being accepted and respected by others as a normal human being, highlighting the issues of stigma that surround living with HIV. Participation in social networks through work and an active social life incorporating music, dance and group trips gave both purpose and meaning in life. This was felt to contribute to positive self-esteem and individual well-being. Access to quality health and HIV support was only mentioned by seven of the 68 respondents answering this question, highlighting the more holistic concept of health shared by the majority. Factors preventing well-being were listed as financial (50% of respondents 54/109), confidence to do what I want (40% 44/109) and being physical well enough to do what I want (39% 43/109).

7.4.1 Experience of primary care

There was a range of comorbidities experienced among the sample, with a higher than national average of depression or anxiety [81]. This could reflect responder bias; however, there is evidence to show that people living with HIV are disproportionately affected by mental health problems [82]. Details of other health conditions affecting the sample are presented in Table 2.

Diagnosis	**Respondents** (99/176)
Depression/anxiety	48%
High cholesterol	28%
High blood pressure	18%
Gastric condition (reflux/ulcers)	15%
Hepatitis B	13%
Hepatitis C	13%
Osteoporosis	10%
Rheumatoid arthritis	10%

Table 2: Comorbidities experienced by the survey respondents

The survey sample, whose average age was 48, recorded a variety of comorbidities. However, only 47% of the sample recorded being registered with a GP. This figure should be viewed with caution as only 79/167 respondents answered this question. It cannot be assumed that the remaining 88 in the sample are not registered with a GP. There were varying perceptions of GP knowledge of the respondent's HIV, with the majority neither agreeing nor disagreeing with the statement 'My GP has a good understanding of HIV'. However, the free text section highlighted concern among respondents of GP knowledge in drug-to-drug interactions. A similar non-specific response was given to the statement 'my GP is able to manage my health condition', with some concerns around the GP not being up to date with the respondent's medical history.

Reassuringly, 68% of respondents felt their information to be confidential in the GP practice (70/103), with only 11% disagreeing (11/103). It seems that experiences of primary care are very context-dependent as 40% of respondents felt there was enough time to discuss their problem with the GP (41/103), while 36% felt there was not enough

time (37/103). Over half of the sample felt they were unable to see the same GP each time, while 30% were able to achieve this practitioner continuity (30/103). However, when asked to elaborate, only 8% of the sample felt that speaking to the same person when discussing their care to be the most important factor when accessing healthcare (8/104). Being listened to (32%, 31/104), and being seen as a whole person and not just a medical condition (18%, 18/104), were ranked as the most important factors. This was followed by non-judgemental care and having trust in the provider. Over half the sample felt comfortable talking about sexual health with their GP, with a perception from 42% (43/103) of the respondents that GPs are comfortable talking about sexual health with them despite some information to the contrary from the primary care literature [59]. Perhaps this survey sample has specifically selected their GPs based on their essential access criteria. Having treatments explained and being in control of choices were also mentioned as important factors alongside a desire for holistic care and the provider to have experience in HIV care. In a free-text section asking about positive aspects of primary care experience, GPs fulfilled many of these important factors and were credited by the sample for listening to them, knowing their medical history, being non-judgemental, and being interested in them. The most frequently cited strength of GP care was their locality, as being local was felt to be important.

7.4.2 Future care models

When asked to rank a variety of care models for the future of their HIV and other healthcare needs, the option with the top ranking was to have all care provided at the hospital alongside the HIV clinic. This could involve having a GP in the clinic. Second was continuation with how care is provided now, with the providers at different locations. A significant proportion of respondents liked the option of being in control of their medical records, who can view them, to be able to invite different care providers and view their own interpreted test results via a secure online system. Since the average length of time living with HIV of the survey respondents was 15 years, this preference for hospital based-care reflects the historical care configuration experience. The most popular model ranked as '2' by participants was the option of all care being provided at the GP with HIV and other specialists visiting the practice. Respondents may have had little or no experience of specialist services in a community context, yet this option was a popular alternative to clinic-based services (Figure 7).

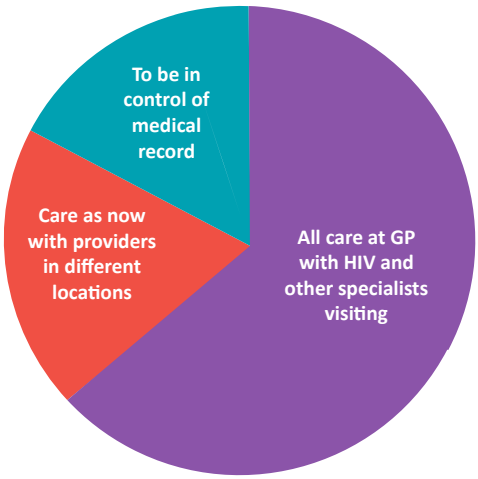


Figure 7. The most popular option, ranked 1, was to have all care provided at the hospital alongside the HIV clinic. The option ranked '2' is shown here where all care is provided at the GP with HIV and other specialists visiting.

Despite the interest in having the GP as the site of healthcare access and co-ordination, almost 60% (62/103) of respondents agreed with the statement 'I am mainly responsible for making sure my GP has to up to date information about my HIV'. A significant proportion of respondents was aware of their HIV specialist communicating with their GP (67%, 69/103) but communication from the GP to the HIV specialist was more mixed with one-third of the sample feeling that this was done, one-third not sure and one-third feeling there was no such communication. Communicating with the HIV team and other parts of the health system was felt to be an important factor in improving the care received from the GP. The overwhelming response when asked what could improve care received from the GP focused on better availability of appointments and being able to have longer appointments. Over half of respondents were unable to book an appointment at a time to suit them and there were complaints of up to 4 weeks' wait by some for non-urgent appointments.

8 Discussion

HIV has evolved into a chronic manageable condition, spanning the lifetime of an individual and resulting in evolving healthcare needs over time. While the evidence suggests that the best model of care would be one that is person-centred, responsive and based on a collaborative-care model, this review suggests that this is constrained by a multitude of factors. These include the historical context of HIV care provision, commissioning barriers; patient-level barriers such as stigma and trust; structural barriers such as electronic patient records that cannot communicate between care providers; and a lack of time, training, and resources among partners in primary care. The reduced time spent by stable people living with HIV in HIV clinical services advocates for adoption of the principles of collaborative care to appropriately support primary care clinicians to manage comorbidities of ageing and support HIV self-management out of the specialist setting.

The objectives of this project were as follows:

- To conduct a scoping literature review of the models of care that support 'sharing or collaborative' care for people living with HIV across primary and secondary care in the UK
- Explore the emergent models of care for people living with HIV provided within primary care across the UK
- To describe the strengths and weaknesses of the different models of care in different contexts
- To explore the relevance of the different models of care across the life course of the person living with HIV

The scoping literature review identified two models of care that incorporated both specialist HIV services and primary care. These were shared care and collaborative-care models. The majority of published data on shared- or collaborative-care models between specialist services and primary care referred to non-HIV services. Shared-care models, by definition, had an agreed protocol of responsibility between partners. This was facilitated by training of health professionals, appropriate and timely communication, and networks to support the co-ordination of care.

Collaborative-care models were more responsive to an individual patient's needs; however, they required the resources to support case-based management and communication of action plans to all health and social care providers. Factors promoting the quality of care experienced by the patient included a planned system of support, scheduled follow-ups and closer primary and secondary care working. The use of a care plan and case manager to administer these requirements was common. Incorporating screening for the condition under discussion was found to facilitate primary care involvement in the patient's care, even if they were not acting as case manager [32]. The original conceptual model of chronic disease management constructed from the literature to guide this project visually portrayed the patient at the centre, engaged in self-management, facilitated by an outer ring of support services. This project suggests that while this model has the flexibility and responsiveness for a very long-term condition such as HIV, it needs to be able to change focus allowing the prominence of different support services at different stages of the individual's HIV journey. Furthermore, there needs to be inclusion of a core foundation reflecting the communication, knowledge and training, and anti-stigma measures necessary to support the integration of the model components.

The key informant interview themes reflected and developed these core facilitating

factors, exposing both enhancement of communication and improvement of practitioner knowledge as significant contributors to the development of shared or collaborative-care models. Evidence of these models in practice for people living with HIV was low and dependent on the evolution of local models in response to specific care contexts. Leadership from local practitioners or commissioners was found to sustain these relations. It was clear from the KII that communication between primary care and specialist services was variable. The use of letter, telephone, direct communication with the patient themselves and, increasingly, email was common. Suggestions from practice to improve communication of general information regarding the role of primary care in the provision of appropriate medical services (including annual 'flu vaccination, annual cervical smears, hepatitis B vaccination, CHD screening etc.) identified low level interventions appropriate for national use. These consisted of a variety of alerts and templates to ensure the quality of patient care is standardised. It is possible to create such systems 'in-house' as many GPs have done already. However, a more robust system that could support GPs with low caseloads of patients with HIV or if access to update training is restricted, would be a standardised template and guidance on creating alerts freely accessible and disseminated appropriately.

Within the identified hierarchy of communication, the use of care plans in the management of multiple comorbidities was in evidence. However, experience of a connected record and laboratory system was identified as a key barrier to collaborative and shared-care models. Within eastern Scotland this has been achieved at health-board level, however in England it is available only through patient held e-records, and this was patchy requiring both time and financial resources to sustain. Experience of both systems is largely positive but requires significant financial commitment and are systems to aspire to rather than available for immediate implementation. This does not remove the need to continually advocate for shared record and laboratory systems across the NHS and remain abreast of developments in patient held e-record coverage.

Practitioner knowledge was identified as key to the quality of care experienced by people living with HIV in primary care. Impediments to increasing practitioner knowledge of HIV included the predominantly low HIV positive caseloads of the majority of GPs in the UK and the lack of funding or locum cover for training within primary care. As the incidence of HIV continues to rise and late diagnosis rates remain high across the country, a number of sites have identified HIV testing in primary care as a local population priority. HIV testing in primary care was found by this project to be variable across the country. Provider side barriers identified from the KII and the GP survey were time to offer a test, discomfort in delivering a positive result, practitioner prejudices regarding those at risk, and feeling uncomfortable talking about sexual health issues. Service user barriers included self-stigma and fear of practitioner stigma, especially in the local GP practice. Often sexual health or GUM services were preferred for the anonymity they offered. This context has resulted in a series of service side commissioned support measures including practitioner training and practice incentives for both testing and diagnosis.

On the back of the drive to increase primary care testing is a concomitant increase in the awareness of HIV among practitioners and familiarity with symptoms and issues related to HIV. Although there is no definitive evidence to support the assumption, this approach could positively impact practitioner attitude and improve their provision of appropriate medical services to people living with HIV as the practice becomes more 'HIV friendly'. From a service user perspective, anti-stigma work in targeted populations is ongoing. However, the rise in HIV diagnosis among white people over the age of 50 has revealed a need to re-educate the general population about the risks of HIV. Stigmatising out of date perceptions of who is at risk of HIV are still highly prevalent in the healthcare and general population.

It is important to note that the 'stable' classification upon which people living with HIV are categorised is based upon the stability of certain blood values. The recommended changes to the standard model of adult HIV care reduces the frequency of blood monitoring and specialist review in virologically 'stable' patients. This means some patients could have their viral load measured every 6 months and may only have their CD4 cell count measured if there is evidence of symptoms or treatment failure. This project reports anxiety around these changes, especially as ageing with HIV is new territory.

However, stability of an individual's HIV is more complex than a categorising blood picture and care models need to be flexible to reflect patient needs. The findings of this project describe HIV as a fluctuating condition in terms of physical symptoms and psychological perspective. Qualitative work by Nixon *et al*. [83] reveal people living with HIV view their stability in relation to physical and social factors. Those experiencing more symptoms preferred face-to-face consultation with an HIV specialist. Interviewees experiencing negative social identity and uncertainty about their future health had a stronger attachment to HIV services. Those experiencing fewer symptoms preferred virtual models of care such as telephone and email clinics. The HIV CNS models reviewed for this project demonstrate their flexibility in meeting the different needs of a local patient cohort, from case management in complex cases, through virtual clinic models to acting as an intermittent accessible specialist resource for the 'stable' cohort and primary care practitioners. Enabling the CNS to bridge the primary/secondary/social care divide has been instrumental in meeting patient needs as they consider the wider determinants of health such as quality of life issues, socialisation, peer support and psychosocial factors. Within this project they have also made a key contribution in the support of primary care testing initiatives and working with generic services in both secondary care and the community to update staff knowledge and reduce discriminatory practice. Stability in the commissioning model for this CNS service is urgently requested from respondents during this intermittent phase of transition to increase the appropriate involvement of primary care practitioners in the care of people living with HIV. This 'skilling up' of primary care practitioners could involve access to a GP with a special interest in HIV through the federated practice scheme, providing specialist knowledge alongside their skills in the management of comorbidities. However, this is currently available in only a few locations.

There is acceptance of the role of primary care among service users contributing to this project, with many examples of good quality care. Furthermore, there is the presence of willingness among respondents to work with practitioners to improve the context of care. GPs are now described as the gateway to health services that were previously experienced as open access. However, the lack of confidence among many service users and GPs themselves of differentiating HIV from non-HIV symptoms further increases anxiety and the reluctance for many GPs to get involved in the non-HIV medical care of people living with HIV. Primary care practitioners in this project have specifically requested swift access to specialist support or clear guidelines on when to refer a patient back to the HIV service, supporting a formalised care agreement delineating responsibility and support contacts.

9 Conclusion

The dynamic nature of HIV care, over time and over the very long life course has significant implications for the provision of high-quality healthcare within and between primary and specialist services. As the conceptual model from the original scoping review and the findings of this report illustrate, a person living with HIV experiences phases of needs across their lifetime. These phases are not linear and require different levels of input in terms of time and professional support. Trials of a variety of models has taken place across the country to meet the different and changing needs of people living with HIV in a primary care context and have been presented in this report as case studies. Clinical outcomes and patient satisfaction have been fairly well reported as detailed in the traffic light annotations to the case studies. However, there has been a conspicuous lack of cost-effectiveness data, constraining advocacy and decision making. The findings of this wide, but not exhaustive, scoping review of models of care in the UK for people living with HIV advocate for the implementation of an assortment of care models in response to changing needs. We describe three key areas: (i) clinical care; (ii) staff education and training; and (iii) excellence in commissioning. The need for continued research combined with robust evaluation of, what are often localised and pilot schemes, is pertinent to all the findings of this review. With this in mind, a series of incremental recommendations has been generated en route to the ideal of a shared or collaborative care agreement.

10 Recommendations

The findings of this project have generated an incremental set of recommendations to improve the quality of care for people living with HIV in the UK across the life course.

Clinical care delivery

- Support and evaluate models of case-based management, including those supported by community nurse specialists, that support people living with HIV and navigate across social care, primary care and specialist services.
- Support and evaluate patient centred approaches to care, including those supported by peer navigators, online care planning and patient held records.
- Design and disseminate (e.g. through commissioning groups, CCG co-ordinating centres, health boards communication teams, BHIVA website) a template for the different GP software systems detailing the requirement of appropriate medical services for PLHIV in primary care, including HIV testing prompts.
- Work with specialist commissioning partners and general practice to create a 'best practice' communication protocol between HIV services and primary care with flexibility for local adaptation.
- Continue to advocate for a shared e-patient record system nationally.

Staff development and training

- Embed training for example SHIP or STIF or DFSRH training courses within the faculty of general practice to standardise GP knowledge and skill in sexual health.
- Support third sector organisations in their anti-discrimination and awareness-raising work, specifically:

    1. to provide patient testimonies to all staff;

    2. to design and deliver a national re-education campaign to de-stigmatise HIV and increase awareness of HIV among healthcare and the general population.

Commissioning

- Review the commissioning structure for HIV services in England. If more support is being offered by primary care, including HIV testing, appropriate finances should follow.
- Support, through responsive commissioning and financing, better integration of electronic patient records and collaborative-care models.
- Continue to commission care co-ordinators such as community nurse specialists to help complex patients navigate care.

Research and evaluation

- Evaluate emergent models of patient-centred collaborative care across the various stages of the life course including ageing with HIV; this must include randomised control trials with HIV and non-HIV outcomes and robust health economic analysis, which can then inform policy.
- Evaluate models of person-centred commissioning of care for HIV prevention and treatment.

Glossary

AIDS	Acquired immune deficiency syndrome
ART	Antiretroviral therapy
BASHH	British Association for Sexual Health and HIV
BHIVA	British HIV Association
CCG	Clinical Commissioning Group
CNS	Clinical nurse specialist(s)
ePR	Electronic patient record
GUM	Genitourinary medicine
fgd	Focus group discussion
HAART	Highly active antiretroviral therapy
HIV	Human immunodeficiency virus
HRA	Health Research Authority
IV	Intravenous
IVDU	Intravenous drug user
KII	Key informant interview
LARC	Long-acting reversible contraception
MSM	Men who have sex with men
NHSE	National Health Service England
PLHIV	People living with HIV
PSW	Peer support worker
SHIP	Sexual health in practice
STI	Sexually transmitted infection
STIF	Sexually Transmitted Infection Foundation Course
THT	Terrence Higgins Trust
UK-CAB	UK Community Advisory Board

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There are around 104,000 people living with HIV in the UK and our clinical outcomes are among the best in the world. Almost half of those accessing care are now over 45 and age-related comorbidities such as hyperlipidaemia and hypertension are common. For those whose HIV condition is well controlled, these comorbidities may have a more significant impact on morbidity and mortality than HIV itself. More than ever, we now need to focus on holistic management of healthcare needs that addresses both HIV-related and non-HIV-related health conditions without losing the successes of HIV care. We believe that this can best be achieved by collaboration between primary and specialist care to provide a person-centred, rather than disease-specific, model of care across the life course. However, there is little evidence on how best we can achieve this.

To address this evidence gap, BHIVA commissioned a one-year programme of work with the overarching aim of informing commissioning and delivery of high-quality healthcare for people living with HIV between primary and specialist care across the life course.

We hope that by describing contemporary care models across the UK, matching them with evidence measuring service quality, and then sharing the successful care model configurations, we will support community-based care for people living with HIV through improved integration of care across both primary and specialist services.

British HIV Association
BHIVA