

# An examination of the contribution of specialist nursing to HIV service delivery

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## **Glossary of acronyms and abbreviations**

AIDS - Acquired immune deficiency syndrome

ANP - Advanced Nurse Practitioner

ARV - Antiretroviral therapy

BASSH - British Association of Sexual Health and HIV

BHIVA - British HIV Association

CCNS - Community Clinical Nurse Specialist

CCG - Clinical Commissioning Group

CNS - Clinical Nurse Specialist

CPN - Community Psychiatric Nurse

CRG - Clinical Reference Group

DNA - Did not attend

GUM - Genitourinary Medicine

HA - Health Adviser

HIV - Human immunodeficiency virus

ID - Infectious Diseases

MDT - Multidisciplinary team

NAM - National Aids Manual

NHIVNA - National HIV Nurses Association

NHSE – National Health Service England

PbR - Payment by Results

PLWHIV - People living with HIV

PEP - Post exposure prophylaxis

PEPSE - Post exposure prophylaxis following sexual exposure

PKB - Patient Knows Best

PN - Partner notification

PPI – Patient and public involvement

THT - Terence Higgins Trust

# **Chapter 1: Introduction to the study**

## **1.1 Introduction**

The report presents the findings of a national project to examine the contribution of specialist nursing to the delivery of HIV services in England. The study was undertaken in response to the urgent need to review the models of HIV care delivery and adapt them to address the changing health needs of those living with HIV care within the current financial constraints of the NHS. It arose from a recognition that maximising the nursing contribution was essential to enable services to respond to those challenges and an acknowledgement that there is a lack of understanding about what specialist HIV nursing roles currently consist of. This report addresses that knowledge gap and contributes to the wider debate about development of HIV services.

## **1.2 Background**

### **1.2.1 HIV services**

The health outcomes of those living with HIV in the UK have improved dramatically as a result of major advances in anti-retroviral therapy. HIV is now considered a complex chronic medical condition and care is directed towards managing antiretroviral treatment and HIV associated co-morbidities<sup>(1,2)</sup>. The numbers who are living with HIV are increasing as is the proportion of those with infection taking antiretroviral therapy. The costs of care are therefore escalating. There is an urgent need to review the current models of HIV care delivery and adapt them to address the changing health needs of those living with HIV and the financial constraints within HIV services.

Changes to the funding of HIV care took effect in 2013 with the introduction of a pathway system of Payment by Results (PbR) that reflects the different levels of complexity and cost associated with caring for patients who are medically stable in comparison with those who have complex co-morbidities. The HIV outpatient currency is divided into three categories: category 1 covers newly diagnosed and newly on antiretroviral therapy (ARV); category 2 covers those who are stable with respect to their HIV infection either on or off treatment; and category 3 covers those with specific complexities that identify them as a special patient group. The majority of patients fall into category 2<sup>(3)</sup>.

The changes to commissioning arrangements for health provision in England, which were introduced as a result of the Health and Social Care Act 2012, have had a major impact on

HIV services. HIV treatment and care services are now commissioned as a specialist service by NHS England whilst public health aspects of HIV work including HIV testing and prevention activities are commissioned separately and the responsibility for this sits with local authorities. Sexual health services, within which HIV services are commonly situated, are also commissioned by local authorities<sup>(3,4)</sup>. In addition to these split commissioning arrangements, uncertainties have arisen around the commissioning arrangements for community specialist HIV nursing services. The HIV service specification includes specialist nursing provision in the document, however community specialist nursing is only included in parenthesis<sup>(5)</sup> and it is uncertain therefore whether commissioning responsibilities lie with specialist commissioning or clinical commissioning groups (CCGS) who commission community services.

The HIV and AIDS UK Select Committee report 'No vaccine no cure: HIV and AIDS in the United Kingdom' identified the need for fundamental changes to how services are organised and for improvements within the existing model of care. They made a number of recommendations for improving existing services including a greater role for the nursing workforce in the delivery of services<sup>(6)</sup>. The revised funding arrangements serve as a powerful catalyst for services to respond to the recommendations of the committee including developing and expanding the contribution that specialist nurses can offer to HIV care.

### **1.2.2 Advanced nursing practice**

Whilst specialism in nursing has been evident since the 1900s, speciality nursing differs from advanced practice nursing which is a relatively new development in the history of the profession<sup>(7)</sup>. Advanced Nursing roles began to appear in the United Kingdom (UK) during the 1980's across a range of primary and secondary healthcare settings as a response to the challenges of healthcare systems and the need to optimise the contribution of all health professionals<sup>(8)</sup>. Multiple titles emerged for what could be described as advanced practice roles<sup>(9)</sup> and there is considerable ambiguity among health providers and the public about what those titles mean in terms of role expectations and scope of practice<sup>(8)</sup>. The extent to which those roles actually reflect advanced practice is often unclear and it is suggested that misuse of terminology and inconsistent role titling serve as barriers to realising the full potential of these roles<sup>(10)</sup>.

In recognition of the inconsistent way in which the term 'advanced level practice' was applied to different roles and the resultant confusion about the scope and competence required at this level of practice, the Department of Health published a position statement describing the

level of practice expected of nurses working at advanced level<sup>(11)</sup>. The statement defines nurses working at advanced level as expert practice leaders in providing direct care to patients and the population. It goes on to describe a generic benchmark for advanced nursing practice that applies to all those working at an advanced level and comprises 28 elements clustered under 4 themes: clinical / direct care practice; leadership and collaborative practice; improving quality and developing practice; and developing self and others. The nurse working at an advanced level is expected to demonstrate expertise in all of these elements. The statement highlights that there is an expectation that advanced nurse practitioners should be qualified to master's level and develop their practice through extensive clinical/practice experience.

### **1.2.3 Nursing roles in HIV**

Specialist HIV nursing roles developed originally in the 1990's in response to need. In the community setting, roles were created from the early 1990's onwards to provide care at home for patients who were critically ill with AIDS related conditions and to provide ongoing support for their significant others and for professionals involved in their care. In the hospital setting, posts were largely created from the late 1990's onwards to address issues of adherence as combination therapies were becoming available, supporting patients with the associated large pill burdens and side effects and providing ongoing psychosocial care. In the subsequent years, the specifics of the role in both settings have evolved substantially in response to changes in HIV care and development of nursing roles. HIV nurses have key roles to play in HIV care and advanced nursing practice can potentially make an important contribution to the delivery of patient centred, cost-effective HIV care. However a recent scoping review identified that there is substantial variability in HIV specialist roles across the country and a lack of understanding about the ways in which the workforce is currently utilized and their current roles and responsibilities. Additionally, there is a lack of information about role effectiveness and no assessment of cost effectiveness on HIV specialist nurses with a particular paucity of information from a UK context<sup>(12)</sup>.

This project sought to undertake a detailed examination of HIV services across the country to understand how advanced nursing practice currently contributes to HIV care and the potential for maximising their contribution. Our initial intention was to look at advanced practice roles. However, it soon became evident that nurses were employed in a range of specialist clinical roles although few of them were employed specifically as advanced practitioners. We therefore widened the brief of the study to include HIV nurses working in specialist roles.

## **1.3 Aims and objectives**

### ***Overall project aim;***

To develop evidence based recommendations for multidisciplinary team HIV service delivery that maximises the contribution of nurses working in advanced practice roles in order to enhance clinical outcomes and standards of care.

### ***Project objectives;***

- To detail the potential for developing HIV service provision that maximises the contribution of nurses in advanced practice and the major considerations that would impact on realisation of that potential from a variety of stakeholder perspectives.
- To map national HIV service provision in order to detail variability and establish the contribution of the nurses working in advanced practice roles and collect information about how they demonstrate effectiveness.
- To build detailed insights into the contribution of nurses working in advanced practice roles and identify lessons about successful role development and implementation.
- To develop recommendations to inform service development that maximises the contribution of nurses working in advanced practice roles to deliver effective care which improves patient experience, access and outcomes.

## Chapter 2: Methodology and method

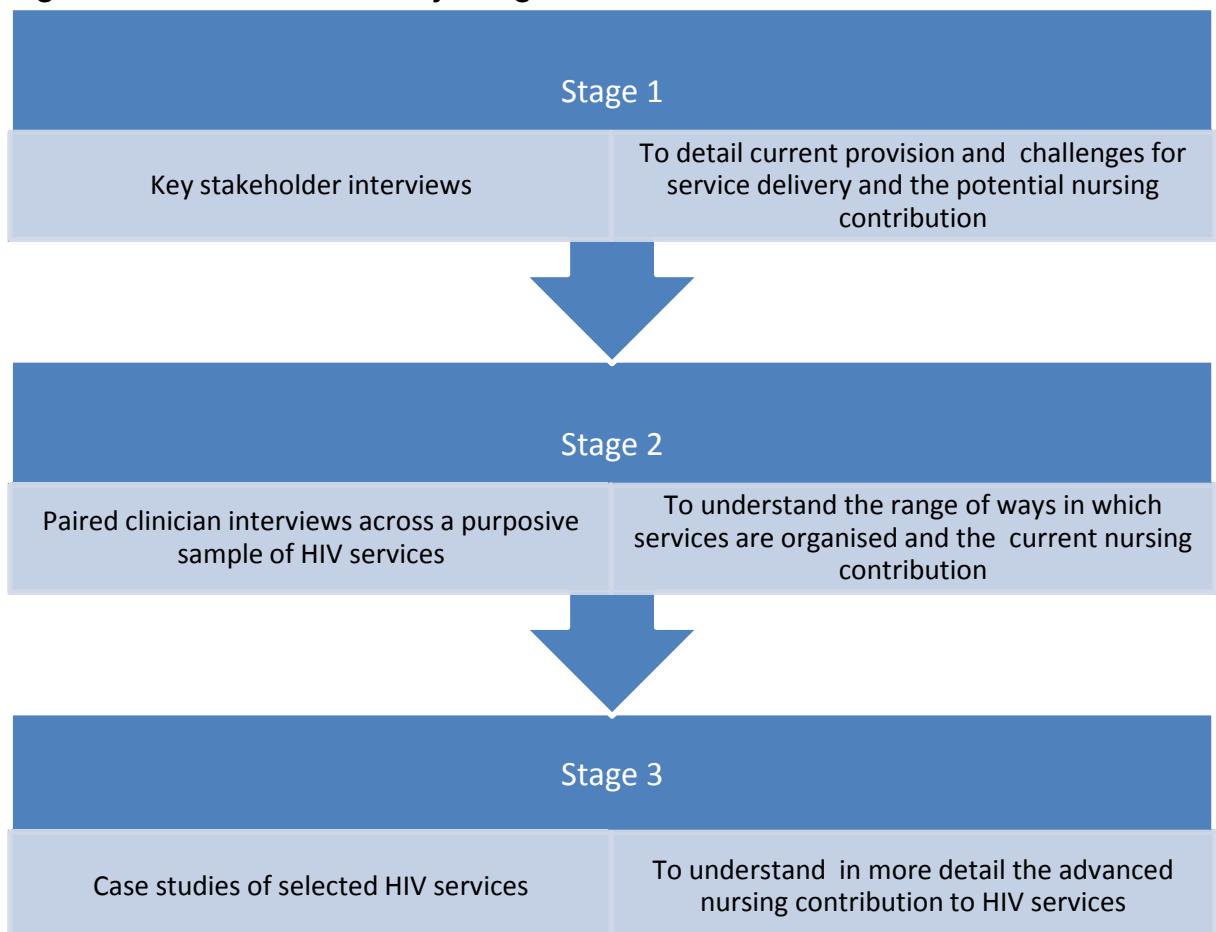
### 2.1 Introduction

In this chapter we detail the methodology and the methods used for the study. Initially, we present an overview of the whole study and the specific objectives they were designed to achieve. We then go onto describe the methods for recruitment, sampling and data collection for each of the stages in turn including ethics and governance issues. Finally, we detail the method of data analysis for the whole project.

### 2.2 Study design

The overall study design was a multi-method qualitative approach involving three stages. We adopted a sequential approach throughout in which the sampling, data collection and analysis processes for each stage were informed by the stages that preceded them. Figure 1 below provides an overview of the stages and the specific objectives they were designed to achieve.

**Figure 1: Overview of the study design**



## **2.3 Stage 1 - Key stakeholder interviews**

### **2.3.1 Sampling and recruitment**

A purposive sample of stakeholders were recruited to the study on the basis of their specialist knowledge and their ability to offer both national and local level insights into strategic and operational aspects of HIV service provision. The three stakeholder groups were service commissioners, service providers and service users. The majority of the participants were identified at the outset of the project by the project team with assistance from the project advisory group, mainly on the basis of their position and their roles on national bodies for example the NHSE HIV Clinical Reference Group (CRG) or national organisations including the British Association for Sexual Health and HIV (BASSH), British HIV Association (BHIVA), Terence Higgins Trust (THT) and Positively UK. A smaller proportion was identified using a snowball approach, during interviews with other stage 1 participants. All prospective participants were contacted, provided with information about the study including a project summary, participant information sheet and consent form, and then invited to participate. All service providers and service users identified were successfully contacted and agreed to participate. Three commissioners were identified but only one was recruited to the study because we failed to establish contact with the other two.

### **2.3.2 Data collection**

Data were collected by means of individual semi-structured interviews. An interview guide was developed and then modified for use with each stakeholder group to ensure that it captured the specific perspective of that group. Interviews collected data on the following areas:

- The current contract and commissioning arrangements for HIV delivery
- How geographical, demographic and organisational factors impact on the ways in which the service is currently organised and delivered
- The current advanced nursing contribution to HIV service provision
- The potential for maximising the advanced nursing contribution in order to maximise service efficiency and positive patient outcomes
- The major considerations that might impact on realisation of achieving the potential contribution of advanced nursing roles to HIV provision
- How the contribution that advanced nursing roles make to HIV can be determined

Interviews were undertaken with 19 participants representing five stakeholder groups as detailed in table 1.

**Table 1. Stage 1 participants**

<b>Stakeholder group</b>	<b>Participants</b>
Service user	4
Medical practitioners	8
Nursing practitioners	5
Service manager	1
Service commissioner	1

Interviews were conducted either face-to-face or by telephone by a member of the research team (HP or GB). They were digitally recorded and fully transcribed. Written consent was obtained for face to face interviews and verbal recorded consent for telephone interviews. Interviews lasted an average of 39 minutes and ranged in length from 15-70 minutes. Data collection was completed over a five week month period, April - May 2014.

## **2.4 Stage 2 - Paired clinician interviews across HIV services**

### **2.4.1 Sampling and recruitment**

A purposive sampling approach was used. Our overall aim which directed selection of site for recruitment purposes was twofold: firstly to capture maximum variability across a range of characteristics and secondly to include sites that were recognised for their excellence and innovation in advanced nursing practice. To achieve this we undertook the following processes.

1. Determination of a broad sampling frame on the basis of specific organisational and demographic criteria (table 2).
2. Discussion with members of the advisory group and those involved in stage 1 interviews to identify an initial set of potential sites.
3. Using HPA data (2011), areas of high and low prevalence across the country were identified and then plotted onto a map of England to provide a visual representation. This was then used to inform sampling decisions around geographical criteria.
4. Details of 160 HIV services across the country were compiled using the NAM aidsmap website (NAM) “find an HIV service” database. We then used the information from the processes detailed above and drew up a list of potential sites. Sites were deemed potentially eligible if the NAM aidsmap information indicated that they had a specialist HIV nurse. That nurse was then contacted for information related to the nursing-specific criteria, to outline the project and to determine their

willingness to be involved. Those interested to participate were asked to nominate an HIV physician they worked closely with and to ascertain whether that physician would be willing to be interviewed. Sites were eliminated if we failed to establish contact after several attempts or if either member of staff declined to participate.

5. This resulted in a study sample of nineteen sites each of which included at least one specialist HIV nurse. After discussion with the advisory group, an additional two sites were subsequently added where the role of an HIV specialist nurse was being fulfilled by someone who did not carry that specific title on the basis that it was the role rather than the title which was the issue of concern.
6. For all 21 sites, a formal letter of invitation, protocol, participant information sheet and lay summary were sent to the CNS and physician involved.

**Table 2. Sampling frame for stage 2**

<b>Criteria</b>	<b>To include</b>
<b>Demographic criteria</b>	Sites across the country
	Metropolitan - Urban - Semi-rural
	High and low HIV prevalence areas
<b>Organisational criteria</b>	Large, medium and small services and cohort size
	All types of service location - HIV specific, GUM based, ID based
	Acute and community based NHS Trusts
<b>Nursing specific criteria</b>	Hospital and community based nursing services
	All types of nursing workforce size and structure - from single specialist nurse to substantial structured workforce.

#### 2.4.2 Data collection

Data were collected by means of individual semi-structured interviews using an interview guide which covered the following areas:

- An overview of the demographic profile of the HIV population served by the service.
- The structure and configuration of the HIV specialist service.
- Details of the advanced nursing role and responsibilities.
- Preparation, development opportunities, clinical support and supervision for those working in advanced nursing roles.
- Workload management and role determination within the multidisciplinary team, degrees of accountability and professional autonomy.
- Impact of the advanced nursing role on patient outcomes, service access and acceptability including details of audit or service evaluation conducted.

- Unanticipated implications or outcomes of the role.

All interviews were conducted by telephone and digitally recorded. A participant information sheet and consent form was sent to the participant prior to interview. Verbal consent was obtained and recorded at the beginning of the interview. All interviews were conducted by a member of the research team. Where possible, the nurse was interviewed prior to the physician and pairs of interviews were conducted by the same interviewer. Data were collected September 2014 - May 2015. Interviews lasted between 30-60 minutes.

#### **2.4.3 Summary of participants**

We interviewed one nurse and one physician from a total of twenty one services (13% of services in England). In one service we interviewed two practitioners who were collectively fulfilling an HIV specialist role (one was a nurse and the other was a health adviser who did not hold any professional qualification). In one service we interviewed two physicians because the specialist nurse worked across sexual health and ID in the same service. A total of 44 interviews were conducted (21 nurses, 1 health adviser, 22 consultant physicians).

The majority of the specialist nurses (18/21) were employed to work in HIV services. The remaining three were employed in Community NHS Trusts to work alongside and in close collaboration with HIV services. In two of those cases, the community specialist nurses worked with a single HIV service whilst in the other case, s/he worked with two separate HIV services and held honorary contracts for those services.

The specialist nurses worked in HIV services located in high and low prevalence areas (7 and 14 respectively), semi-rural, urban and metropolitan areas (6, 11 and 4 respectively) and a range of different service settings: standalone HIV services (4), Sexual health/GUM services (14) and Infectious diseases units (2). One nurse worked in a service provided in both ID and sexual health within one NHS Trust. The majority of services (13/21) employed one or two specialist nurses. The size of the HIV cohort ranged from 80 to 6,000. There was some relationship between the size of the cohort and the size of the nursing team but this was not consistent, for example there was a single specialist nurse in one service with a cohort of 1000 and a team of two working with a cohort of less than 200.

All those working in standalone HIV services and ID services had a role that only included HIV work. Half of those who worked in a sexual health based service had a combined role that included both HIV and sexual health.

## **2.5 Stage 3 - Case studies from selected HIV services**

### **2.5.1 Sampling and recruitment**

Case study sites were purposively selected from those that contributed to stage 2 and on the basis of the data collected at that stage. The case was defined as the advanced practitioner and the purpose of the site visit was to gain greater insight into the nature of that role and the service in which it had developed. This determined the two criteria on which sites were selected: firstly that each site individually indicated excellent and innovative advanced nursing practice, secondly, that the sites collectively reflected contrasting examples of how the advanced practice role was operating in a range of different contexts and conditions. To this end, the sample included practitioners who were working in hospital and community based services, in areas of high and low HIV prevalence and in urban, metropolitan and (semi) rural geographical locations. Additionally, as we were interested to explore development of the role, we aimed to include sites where the current role had been operating for many years and was very well established and sites where it was a more recent development.

We contacted the specialist nurse in each of the potential sites and explained why we wanted to include them as a case study. We explained that a site visit would involve some or all of the following: interviews with members of the multidisciplinary team (MDT) they worked within, scrutiny of service documents including policies, proformas and job descriptions, non-participant observations of service meetings and an exit interview with them to clarify any issues that had arisen over the course of the visit. In all cases, they and their service accepted the invitation and agreed to host a site visit of two days. Following governance approvals, site visits were organised for mutually convenient dates that offered the most comprehensive range of data collection opportunities.

### **2.5.2 Data collection**

Data were collected over a two day period for each site by two members of the research team. The specialist nurse served as gatekeeper in terms of identifying who it would be most helpful to interview and setting up the interviews. Individual semi-structured interviews were held with up to seven members of the multidisciplinary team. Interviews used a topic guide that covered the range of topics covered in stage 2. Their purpose was to gain a more detailed insight into the contribution of the specialist nurse to the service from a range of perspectives. Non participant observation was undertaken in a range of different meetings including MDT treatment meetings, virtual ward rounds, pre-clinic discussions and community MDT meetings in order to capture the involvement of the specialist nurse in any advanced clinical decision making, planning of care and development of services. These

were captured in field notes. Additionally any relevant documentation including care pathways, job descriptions, nursing competences, and service guidelines were reviewed or collected to help provide a more detailed insight of the service. At the end of the visit, an exit interview was conducted with the specialist nurse. Written consent was obtained for each of the individual interviews. For meetings, the specialist nurse gained verbal agreement for us to attend from all participants prior to the site visit. All visits were completed February - March 2015.

**Table 3. Summary of study sites**

	Geographical Area	Service Type	Cohort Size	Prevalence	Cohort Type (Mixed, MSM, Black African)
<b>Site A</b>	Semi-rural	SH//Community	300	Low	Mixed
<b>Site B</b>	Urban	Large S/H unit	1800	High	Mixed
<b>Site C</b>	Urban	Integrated sexual health & HIV service	1000	Low	Mixed
<b>Site D</b>	Urban	Community Healthcare Trust	2230	High	MSM
<b>Site E</b>	Metropolitan	Large HIV Unit	6000	High	MSM

## 2.6 Data analysis

All interview data were digitally recorded and fully transcribed by a commercial company. Framework analysis was used as the data analysis approach. NVIVO 10 was used to organise and manage the process<sup>(13)</sup>. Framework analysis is a pragmatic approach to qualitative data analysis involving a systematic process of sifting, charting and sorting the material into key issues and themes. This allows the integration of a priori issues into the emerging data analysis and provides a clearly defined analytical structure that contributes to the transparency and validity of the results. We followed the five data management steps for data analysis: familiarisation, constructing an initial thematic framework, index and sorting, reviewing data extracts and data summary and display<sup>(13)</sup>. We began the process when stage 1 data collection was complete and continued throughout stages 2 and 3 of the project with data collection and analysis taking place concurrently. Initially we familiarised ourselves with the data by listening to the interviews, reading the transcripts and making notes. Through group discussions we identified and agreed a preliminary thematic framework that captured the rich detail of the data and addressed the broad objectives of the study.

Indexing involved working systematically through the dataset to identify and label segments of the text using the thematic coding system. In order to ensure consistency and validity, we agreed brief descriptors for each of the themes and involved two members of the team in indexing each transcript. Data summary involved populating the thematic framework with summaries that captured the key points in the coded sections of data and provided a display format for the entire dataset in each of the stages. Regular 'Time out' days where we discussed the data and offered critical reflections provided important opportunities to ensure that we used the theoretical and clinical expertise and insights of all members of the research team.

## **2.7 Ethics and governance**

Ethical approval of the study was granted by Sheffield Hallam University Faculty Ethics committee. Governance approvals were secured from all study sites for data collection in stages 2 and 3.

## **2.8 Data storage and management**

Interviews were transferred to a password protected computer as soon as possible after they had taken place and deleted from the recording equipment. All transcripts were stored on a secure site on a University computer and accessible only by members of the project team. A secure password protected data stick was used for backup.

## **2.9 Research integrity**

PPI was provided by members of the established South Yorkshire HIV Network's Lay Expert Advisory Panel (LEAP). Membership of LEAP is limited to HIV service users, partners or carers for people living with HIV (PLWHIV) or lay people in communities disproportionately affected by HIV. Most members are currently HIV service users within Sheffield Teaching Hospitals NHS Trust and attending specialist HIV services in either Genitourinary Medicine/Sexual Health or Infectious Diseases or both. They were consulted during the early stages of the study design, commented on the protocol and advised on the study materials including the participant information leaflet, consent form, and stage 1 interview guide. Additionally, a member of LEAP was recruited to the project advisory group and offered valuable insights throughout the project.

A project advisory group was established and met three times over the course of the project. Members consisted of senior academic and clinical medical and nursing staff, a service manager and a service user. They advised on all aspects of the project particularly sampling

and recruitment, offered critical comment on findings as they emerged and advised on dissemination strategies.

Yorkshire and Humber HIV CNS Nurse forum served as a reference group for the project. Members of the research team attended their meetings three times over the course of the project. In the first two meetings preliminary findings from stage 1 and 2 were presented for discussion and sense checking. At the third meeting, we conducted a workshop to test and validate the conceptual framework that was developed as part of the data analysis.

Accuracy of the information provided in the exemplars was assured by sending them to the relevant specialist nurse for comment and approval.

## **2.10 Overview of the findings**

The findings are reported in the following four chapters. In each chapter we draw on data from all stages of the study in variable proportions. The first findings chapter draws primarily from stage 1 of the study to examine the challenges facing HIV services and the ways in which they need to respond to those challenges. The next chapter reports on the specialist nurses involved in stage 2 of the study. The following chapter details the specialist nursing roles and the activities that make up that role, focusing initially on their contribution to clinical and direct care and then on to their leadership and service development activities. We then report on the challenges associated with measuring their contribution to care and the attempts that are being made to address those challenges. The last findings chapter focuses on sustainability and examines what is being done to develop and maintain an HIV specialist workforce.

We were concerned to report on the variability across the services but also to provide more detailed information about some of the ways in which advanced HIV nursing was exemplified. To do this we have developed a series of exemplars that focus on specific examples of advanced nursing practice, the context within which they have developed and the contribution they offer to the service. The majority of them were drawn from stage 3 study sites. We make reference to them in the main body of the findings chapters and present them as a portfolio of advanced practice in appendix 2. Additionally, the practice examples contained in the case studies have been mapped against the 28 elements of advanced practice identified in the DOH positional paper <sup>(11)</sup> to produce a matrix which is presented in appendix 3.

## **2.11 Reporting conventions**

Throughout the study we have adopted the following conventions.

We refer to all the nurses who participated in stage 2 as 'specialist nurses' rather than by their specific titles in the interests of anonymity and clarity. The study set out to identify the variability in roles and responsibilities. Not all specialist nurses may have been practising at advanced level and therefore it would have been inappropriate to use the term advanced practice throughout the report. The exemplars in appendix 2 and the matrix in appendix 3 detail examples of advanced HIV nursing practice from the study.

We refer to all medical participants as physicians. All stage 1 participants are identified as such and also by profession as follows: N = nurse, Ph = Physician, M = manager, C = commissioner, SU = service user. Those from the same profession have been numbered sequentially. e.g. a quote from one of the nurse participants might be attributed as: stage 1 N1

All stage 2 participants are referred to by number (1-22) and by profession (N or Ph). Those with the same number work in the same service

Those who only participated in stage 3 are referred to by stage and by profession.

The case-study sites used in stage 3 are referred to by letter (A - E).

We use the gender neutral pronouns's/he', 'they' and 'their' to refer to all participants throughout the report.

We refer to 'Sexual Health' services rather than 'GUM' services since many are integrated with contraceptive services. We distinguish between HIV and Sexual Health services.

## **Chapter 3: The challenges facing HIV service and proposed responses**

### **3.1 Introduction**

In this chapter we outline the challenges facing HIV services and the ways in which it was proposed they needed to develop to ensure that they can continue to meet the needs of the HIV population.

### **3.2. Financial pressures**

There was general agreement among participants that two major considerations were impacting on HIV services and creating substantial challenges for the delivery of care. The first of these was the financial challenge and the need to deliver care in a more cost effective way. The numbers of patients accessing HIV services continues to increase. Patients are offered antiretroviral treatment earlier in the course of their infection and remain on it life-long. As PLWHIV now have a near normal life expectancy, it is clear that the costs associated with ARVs has risen substantially over the last decade. As PLWHIV move into older age, services will need to provide care for increasingly complex patient cohorts without a similar increase in funding or in workforce capacity. Commissioners and providers agreed that using the nursing resource to greater effect was essential if services were to meet the demand. As one of the physicians explained:

*'It [the advanced nursing workforce] is a hugely untapped resource ... I don't think we are going to manage the increasing size of the cohort without tapping that resource.'* (stage 1, Ph 6).

The extent to which these pressures were currently impacting on services appeared to be variable with some indication from the data that large services in high prevalence areas were facing the greatest challenges. In those areas, a substantial proportion of care was already being delivered by nurses. As one of the physicians working in a large metropolitan HIV service explained: *'In my service, 70% of patients don't see a consultant when they attend.'* (stage 1, Ph8). This contrasts with the situation described by a physician working in a low prevalence area with a small HIV cohort where HIV workload pressures were less acute and the service priority was more about maintaining adequate medical expertise:

*'We don't have that many patients, if the nurses were seeing the patients routinely that we're seeing, then one of us [consultants] would probably have to stop doing HIV, and that would affect how we manage our inpatients.'* (stage 1, Ph 5).

Overall, the introduction of the revised pay tariff system serves as a powerful driver for a more substantial role for the nursing workforce in the delivery of HIV care because it offers a valuable and potentially cost effective alternative to consultant delivered care for the majority of patients. As one of the physicians stated:

*'The new tariff is being calculated on consultants only seeing people who have a medical need .... there is no part of that tariff which is going to allow anyone to see a consultant for twenty minutes unless they have a reason to do so.' (stage 1, Ph 8)*

However, they also emphasised the importance of determining how that nursing workforce is used and considering key issues such as the grading and skill-mix in relation to workload allocation and particularly ensuring that advanced skills are used appropriately, as an HIV network manager explained:

*'How do we capitalise on the role that nurses take in the management of HIV patients in a way that helps us manage the finances and make the best use of advanced nursing roles .... there's nothing worse than having an absolutely advanced and skilled workforce and then not using them to their capacity.' (stage 1, M 1).*

### **3.3 The changing needs of the HIV population**

The second driver for change, discussed in detail by the participants was the emerging healthcare needs of that population as a result of: the changing demographic profile of the HIV population and the changing sexual behaviours among the MSM population. The demographic profile of the HIV population has broadly polarised into two distinct groups. At one end of the scale is the majority population who are stable and well with few health problems, and an undetectable viral load. The size of this population is increasing as a result of new cases of infection, improved early diagnosis and effective treatment. At the other end of the scale is a smaller but also increasing population who may not meet the PbR category 3 but who have complex care needs that make substantial demands on the service. This sub population includes those with late diagnoses, those who have been living with HIV for many years and who have an increasing number of complex co-morbidities as a result of growing old with HIV, and those who are particularly vulnerable and have multiple psychosocial and medical problems.

These two populations have different healthcare needs and present a different set of challenges to the current organisation and delivery of care and indicate the direction in which services need to develop.

The participants reported that changing sexual behaviour among MSM involving 'club drugs' to enhance sexual performance and pleasure ('chemsex') was increasingly common in some

areas among MSM of all ages and backgrounds. The use of drugs such as GHB, GBL, ketamine, mephedrone, MCAT and crystal meth which typically involve unprotected sex and/or needle sharing with multiple partners, increase the associated risk of transmission of HIV, viral hepatitis, syphilis and gonorrhoea, all of which have increased significantly among MSM in recent years. The indications were that regular use of club drugs, which were often injected, had become problematic for some, leading to mental health problems, self-neglect and/or disengagement with HIV services. For example one participant described how some '*older.....functioning professional*' HIV patients who had been injecting would avoid attending clinic for blood tests because '*someone's going to notice the state of their arms.*' (N 5)

### 3.4 The consequences of changes to commissioning

Changes to the commissioning arrangements for services that were introduced as a result of the Health and Social Care Act 2012 have produced consequences that have had a major impact on some HIV services. Two major areas of concern were identified by the participants. Firstly the separate commissioning arrangements for HIV and sexual health services, the tendering processes that have resulted from this and the fragmentation of services that has resulted from separation of the two services. They reported that these factors had begun to impact on the provision of the HIV service and on the ability of that service to adequately address the sexual health needs of their population.

The majority of HIV services across the country developed from and are located within sexual health services. In those services, most of the medical and nursing workforces have a dual role that includes providing both HIV and sexual health services. In some services the HIV specialist nurse has a combined role and in other services they are employed solely for HIV work. A number of local authorities who are now the commissioners for sexual health services have already put those services out to tender and many others are set to do so. Transfer of the sexual health contract to another provider was considered to present a major threat to the continued provision of the HIV service because the two services are linked and one physician explained: '*It's the same people who are providing HIV that are providing the STI services.*' (stage 1, Ph 5) The possibility of tendering was causing considerable uncertainties and destabilising the workforce as one of the participants explained: '*Everybody's quite concerned about the future, generally in sexual health and HIV care, in our area [we] foresee quite a lot of changes ahead but we don't really know what those are.*' (stage 3, nurse)

Where sexual health contracts are transferred, the HIV service may either be disbanded with transfer of patients to a neighbouring service or continue as a standalone service. One participant offered insights into the impact of the latter situation. When the sexual health contract was won by a neighbouring community NHS Trust, all the staff were transferred under Transfer of Undertaking and Protection of Employment (TUPE) arrangements with the exception of the two HIV specialist nurses who worked for the HIV service and therefore did not qualify. The HIV contract had remained with the acute NHS Trust who had bought back consultant time to run the service. However, there was no longer any staffing infrastructure for the service because, '*all the other nurses who used to do some HIV care as part of their job no longer do that because they've been transferred.*' The two nurses worked primarily in the community '*doing outreach work looking after hard to reach patients and those patients with significant issues to help them engage in care and keep them safe.*' (stage 1, Ph 1)

The separation of the two services was causing substantial problems, particularly around providing sexual health services for HIV patients. HIV services were no longer able to undertake sexual health screens or colposcopy when patients attended the service and it was not clear how risk reduction work was being undertaken given that there was no longer anyone in the HIV service who had expertise provided by sexual health advisers. Separation of the services had also resulted in severe financial problems for the HIV service. In this situation, decisions had been taken to deploy the existing specialist nursing resource in the community because as the physician explained: '*the cost effective way of managing these patients appropriately is to ... keep them out of hospital, keep them well.*' Given the current financial situation for the service, there was little likelihood of developing the service and expanding the nursing workforce even though clinicians were clear that this would offer substantial benefits because '*we could deliver the service more efficiently and probably better if we had more dedicated trained nurse practitioners.*' (stage, Ph 1)

The second area of concern was the fragmentation of commissioning arrangements for HIV services and the uncertainties that this had produced around the commissioning of specialist HIV community services. New commissioning arrangements and specifically the split between specialist commissioning and Clinical Commissioning Groups (CCGs) posed a substantial threat to community based HIV services, both community specialist nursing teams and voluntary sector organisations. The remit of specialist commissioning for HIV services covers inpatient and outpatient treatment and care but this does not specifically extend to include community or voluntary sector services. As a consequence, anything outside the HIV service specification is subject to local interpretation. When the service specification was developed, community HIV nurses were included but in brackets. This reflected a previous lack of clarity about where they sat within service organisations but had

resulted in a situation whereby neither specialist commissioning groups nor CCGs had clear responsibilities for commissioning these services. This situation was threatening the continued existence of specialist community HIV teams in those areas where they existed and was likely to reduce the possibility of developing them in those areas where an unmet need had been identified.

### **3.5. Developing the service**

There was consensus agreement that the way in which HIV services are delivered needed to change and that services needed to develop towards a more community based provision in line with national policy to manage long term conditions in the community. The participants identified three broad models of care that need to develop to meet the health needs of the whole HIV population. The three models were: 1) one that offers greater flexibility and accessibility in the way that routine HIV care is delivered, 2) one that provides more integrated care between primary care and specialist HIV services and 3) one that provides community based specialist nursing care. They suggested a substantial role for advanced nursing within each of these three models of care.

#### ***1. A service model that offers greater flexibility and accessibility in the way that routine HIV care is delivered***

There was general agreement from commissioners and providers that the way in which HIV care is delivered to the majority of patients needs to change, that it needs to move to a model of care that fits better into patients' lives and offers greater flexibility in terms of when, where and how services are delivered in order to support long term engagement in care. In order to achieve this, it was proposed that services would move towards delivering more routine care in community based settings. There were different interpretations as to what that might mean. Some suggested that it would lead to the expectation that GPs have a greater role in the delivery of HIV care. As one explained: *the talk that exists around community delivery ... is the talk of GPs, if we're not going to do it in the hospital then let's get the GPs to do it (stage 1, N 3).* However, a range of stakeholder viewpoints identified that this was unlikely to be feasible or acceptable in the majority of cases for several compelling reasons. Most GP practices have very few HIV patients on their caseload and as one of the participants explained '*GPs do not want to touch HIV for various reasons.*' (N 7) The consensus opinion was that the majority of GPs lack the experience, expertise and inclination to take on routine management of HIV care.

The service users expressed considerable concerns about any such proposed move. They had all been living with HIV for many years and were highly appreciative of the high quality and expert care they had received from the HIV service. The idea that their HIV care might

be managed by GPs was a source of anxiety because they too felt that GPs lacked the necessary expertise. Their experiences suggest difficulties in engaging effectively with primary care, ongoing problems securing regular supplies of medication, concerns about levels of expertise and understanding and a general lack of confidence in increasing GP involvement.

Concerns about stigma and confidentiality continue to determine the extent to which patients are willing to share their HIV diagnosis with their GP. Although some participants suggested that this was no longer acceptable because of the substantial medical risks associated with withholding an HIV diagnosis from a GP, a proportion of patients continue to do so, particularly in rural areas. As one of the physicians explained:

*'Our push has been to try and get patients to see their GPs with GP related things ... but there's a certain cohort who won't ... there's just huge concerns about confidentiality' (stage 1, Ph 5)*

A more realistic approach proposed by most stakeholders was one that mirrors that adopted in sexual health services: a move from '*what is currently a medically led workforce to become a nursing workforce.*' (stage 1, Ph 3) In this structure, specialist HIV nurses would be largely responsible for delivering community-based HIV care, using a range of different settings and approaches including GP practices and community sexual health clinics. There was an indication that this was happening to some degree although it was recognised that there was substantial work to be done. The data offered some insights into these developments. Two services that were both based in rural locations and covered large geographical areas, had developed nurse-led outreach clinics based in community clinics (exemplar 1 provides more detail about one of these). A similar approach had been adopted in another small service based in a sexual health clinic where the HIV cohort was effectively being managed by the specialist nurse with medical input provided by a consultant from the regional HIV service.

Additionally, a funded project had been established to provide nurse delivered routine care within a GP practice. The One Clinic project had involved relocating HIV care from a secondary to primary care setting and offering a more integrated package of care that incorporated aspects of the practice nurse role into HIV consultations. It offered flexibility in appointment times and was initially limited to stable well patients although the criteria had been expanded over the course of the project as the specialist nurse became more experienced and confident in the role. A primary aim of the project was to determine the cost effectiveness of delivering HIV care in a primary care. However, it produced other important

information, including insights into which groups of patients appeared to benefit most from this delivery model. As the lead physician for the project explained: '*this model is potentially more beneficial to people who are not stable well, particularly those people who are disengaging with care, because they don't like to come to the HIV clinic.*' (stage 1, Ph 6)

## ***2. An integrated model of care between primary care and specialist HIV services***

A pressing requirement identified by many participants was the need to move towards a more integrated pathway of care for all patients, greater involvement of primary care and more effective collaboration between primary and specialist services. This is particularly important given the increasing number of patients who are ageing with HIV and developing multiple co-morbidities as a result. One physician for example reported that in their service, 20% of the cohort was over 60 years old. A number of questions were identified in relation to this ageing population, for example: how can we ensure that stable elderly patients are able to access the community services they are entitled to, how are comorbidities best managed, who is best placed to provide care for this population and how can we ensure that the care provided is cohesive and joined up.

There was consensus agreement that effective engagement with primary care was a key requirement but that substantial work was required and considerable barriers needed to be overcome in order to make progress in this area. One respondent suggested that '*my experience of primary care is that they actually know very little or relatively little about HIV*' (stage 1, N 5) and another explained that whilst '*we're quite good at one-way communication ... in terms of writing letters to GPs ... we don't get any information back, and there's not really great dual management.*'(stage 1, Ph 6) Service users similarly indicated that their GPs were reluctant to engage with their HIV. As one explained:

*'I know my GPs are aware of what is happening here, through letters and whatever, but whenever my HIV is brought up they just kind of nod ... I think they're happy to leave it in the hands of the specialists here, and they don't want to intervene or interfere really.'* (stage 1, SU 3)

It was suggested that specialist nurses have a key role to play in addressing those barriers and working with primary care to develop integrated care. As one of the physicians explained:

*'I see the role of the specialist nurse as part of education with primary care, to actually integrate this ageing population of patients who have actually done extremely well into the primary care setup system.'* (stage 1, Ph 4)

There were limited indications of activities in this area. The One Clinic described previously offered one approach for developing closer working relationships between HIV services and primary care. Another approach was through the use of electronic patient - held medical record that were being used by several services and commonly managed by the specialist nurse. In one service for example where this was happening, the system was being used primarily as a communication tool with patients but there was also a specific intention to use this system as a means of communicating with GPs. Over 90% of the patients using the system had agreed for GP contact and comprehensive information was uploaded to the record including care plans, links to interaction websites, all the patient blood results and GP letters. A third example came from case study site A. The specialist nurse worked in a low prevalence area in a rural setting and had a role that spanned both hospital and community settings. S/he invested substantial effort into developing a relationship with the GP practice for all the patients in the caseload in order to address issues of confidentiality that are an ongoing concern for patients in that area and to establish effective communication between the services (see exemplar 2 for details).

### ***3. A model of nursing care that provides community based specialist input.***

A substantial proportion of the participants identified the importance of having services that offered some community nursing provision, with nurses who are able to undertake home visits and work alongside other community services to support patients who are highly vulnerable with complex care needs and have difficulty remaining engaged with care. The majority of services involved in stage two of the study offered some degree of community provision however there was considerable variability in terms of how it was structured and what it consisted of. It ranged from a dedicated community nursing team in some areas to very occasional home visits by a hospital based specialist nurse. Two services had no community nursing provision. Appendix 1 provides a pictorial representation of the different types of provision.

The current situation seems to have arisen largely as a consequence of historic developments. Where services have not adapted sufficiently to meet the changing needs of the HIV population and are no longer fit for purpose, they are unlikely to survive. A recent example of this was reported in the data. In one urban area, community nursing roles had been recently lost because *'it was felt the role was not really that successful and wasn't really that necessary.'* (stage 1, N3) By contrast, the two specialist community HIV nursing services included in this study were characterised by development and highly innovative approaches that ensured they met the care needs of their population. A number of features were evident in both services that appear to have contributed to their continued existence and their effectiveness (exemplar 3).

The current situation where there is very patchy provision of specialist community HIV nursing is unlikely to reflect need. This was clearly illustrated by the situation in one area where different commissioning arrangements for the HIV service and the community HIV nursing service had resulted in a postcode lottery for patients in that service. As one participant explained:

*'Obviously the acute sector provides the medical care, and yet their footprint is much bigger than ours, so often they'll try and refer people to us, but we can't see them because we're not funded for it.'* (stage 3, N 4)

Those working in areas with substantial community provision were clear of its value. In particular they identified the contribution it offered to improved health outcomes for patients and cost saving benefits to the service. Public health data which is routinely collected in one area appears to support this position and indicates reduced hospital admissions and shorter hospital episodes where patients have access to this provision (14). The uncertainties concerning commissioning of community nursing services were identified as a matter of considerable concern. Participants emphasised the urgent need to address this situation and the importance of clear guidance from the CRG to direct commissioning around who should be paying for community nursing. They suggested that such guidance should clarify which items on the service specification the service is being commissioned against.

### **3.6 Summary**

HIV services are facing substantial challenges. The financial pressures that have served as a key driver to development of specialist nursing roles in some services are set to impact across all service and increase in the light of changes to funding structures. Changes to commissioning and specifically separate commissioning arrangements for HIV, sexual health and community services have impacted on the delivery of services. Within this context, services are faced with the challenge of providing accessible and appropriate high quality services to a population with two distinct groups: the stable well and those with complex comorbidities who are growing old with HIV. In order to do so, stakeholders were clear of the need for services to move towards community-delivered care with service delivery models that offer greater flexibility and accessibility for the delivery of routine care, greater integration between HIV services and primary care services and community based specialist nursing input for those with the most complex care needs.

## **Chapter 4: The specialist nursing workforce**

### **4.1 Introduction**

In this chapter we focus on the specialist nursing workforce. We report on their clinical and academic experience and qualifications and their status. We then go onto consider how their professional development needs were met and the barriers and facilitators that had impacted on that development.

### **4.2 Professional qualifications**

The 21 nurses interviewed in stage 2 were all registered adult nurses and one was also registered in mental health. Three held community qualifications; two in district nursing and the other in health visiting. One interviewee who was employed as a sexual health adviser did not hold a professional qualification.

### **4.3 Role titles and pay bandings**

Tables 4 and 5 indicate the substantial variability across services in terms of the role titles and pay bands. Two services had staff working in a role broadly comparable to that of an HIV specialist nurse but no-one in that service with that title. Only one nurse carried the explicit title of Advanced Practitioner, a role that had been specifically created in one Trust in response to a review of nursing roles.

We interviewed a senior specialist nurse in each service and table 5 therefore indicates that Trusts had taken different approaches to remuneration. In some Trusts, those with the post of CNS were employed on a band 6, in others they were all employed on a band 7. One Trust employed two CNSs on a band 8. In some cases there were differential bandings within a team who all held the title of CNS. In the majority of cases, the difference in pay band was attributed to managerial responsibilities rather than any differences in clinical roles. One Trust had taken a different approach to role titles and pay banding and differentiated between band 8 Advanced Nurse Practitioners and band 7 Nurse Practitioners.

**Table 4: Role titles of participants**

<b>Job title</b>	<b>Numbers</b>
Advanced Nurse Practitioner	1
Senior HIV Clinical Nurse Specialist / Lead Nurse	3
HIV Clinical Nurse Specialist	15
Health Adviser	3

**Table 5: Pay bands on which participants were employed.**

Pay band	Number of nurses
8a	2
7	18
6	2

As tables 6-8 indicate, the specialist nurses were highly experienced. A substantial proportion had been working in HIV for many years and most had additional experience that was highly relevant to the role. The most commonly cited route into the role was a career path starting in sexual health services and a gradual progression through to HIV work within that service. A smaller number reported a career pathway that had begun in an HIV service and progressed within that service. In several services this pattern was also reflected across the whole of their specialist nursing workforce, with some teams indicating that all their specialist nurses had over 20 years of experience in HIV care.

**Table 6: Length of time working in HIV**

Years in HIV nursing	Numbers
1-5	5
6-10	6
11-15	4
16-20	5
>20	2

**Table 7: Length of time working in current role**

Years in HIV care	Numbers
1-5	1
6-10	4
11-15	5
15-20	5
>20	7

**Table 8: Previous relevant roles**

Previous relevant roles	Numbers
Health Adviser	5
GUM nurse	4
ID nurse	3
HIV in-patient nurse	1
HIV community nurse	1
Homeless Healthcare team	1
District nurse	2
Counselling, mental health, drugs and alcohol	1
Critical care	3
Community Drug and alcohol team	1
Senior nurse manager	1

#### 4.4 Academic and clinical qualifications

The nurses' highest academic qualifications are presented in table 9. Just over one third (8/21) held a master's level qualification in a relevant area. For those studying more recently and those contemplating doing so, the most likely programme was the Master's in Advanced Nursing Practice. Three reported that they had completed a Master's degree in Advanced Nursing Practice (the recommended qualification for ANPs), one was part-way through the programme and another had a place organised and was due to commence. There was a lack of consistent alignment between pay banding and level of qualification: not all those with a master's qualification were on a band 7 and not everyone on a band 7 was qualified to master's level. Additionally of the three with a specific master's qualification in advanced practice, two were employed on a band 7 and the other on a band 8.

**Table 9: The highest academic qualifications of the CNS**

Highest qualification	Numbers
Diploma	6
Bachelor degree	9
Master's degree	8

Most of the nurses had completed some HIV specific education. The only specific course identified was the ENB (English National Board) 934, a module that had been available across the country with academic credit rating at diploma or degree level. As the ENB was abolished in 2002, these modules have not been available for the past thirteen years. Others had completed a range of HIV degree level modules offered by individual universities or had acquired specialist HIV knowledge in other ways, for example by taking an HIV focus in a public health degree.

The most common recently completed training was in non-medical prescribing. A little over half of all the nurses (13/21) and 13/19 of those who worked in hospital-based HIV services had qualified as non-medical prescribers. Among the prescribers, four had also completed training in clinical assessment skills, two of whom had gone onto complete the full ANP qualification and one was in the process of doing so.

#### **4.5 Professional development**

The specialist nurses reported that most of their professional development took place in practice, through a range of clinical opportunities. Much of this was ongoing and provided through informal means, through individual support, and advice from other members of the multidisciplinary team and through multidisciplinary team meetings although they also attended seminars, particularly in the larger teaching hospitals. Physicians were identified as a particularly important source of support. The majority of the participants described well established and highly supportive relationships with the medical consultants they worked with and 'open door policies' that ensured they were clinically well supported. In several cases, they also had formalised clinical supervision arrangements. In most cases, these had been established in relation to specific training, for example prescribing, or where their role had developed in a specific way. For example, N2 met regularly with Ph2 when s/he first came into post and N8 had a similar arrangement with Ph8 when s/he assumed responsibility for the PEP service and the stable patient work. These structures facilitated development and in all cases, the frequency of meetings decreased over time as their expertise and confidence developed. In some of the larger HIV services, formalised supervisory arrangements and regular meetings were an integral part of the service structure. In one they were being used particularly effectively by linking them to the Quality Improvement Programme, identifying an issue and developing actions. As the physician explained, this approach '*formalises it into something that then counts for [the nurse] and counts for the service.*' (Ph 7) The specialist nurses working in teaching hospitals had regular access to lectures and seminars and these were commonly made available to those working in smaller services within their network.

The importance of the specialist nurses having access to an adequate clinical network for professional support as services become increasingly nurse-led was identified as a key issue by several of the participants. Concerns were expressed about the extent to which this currently existed and the difficulties that some specialist nurses had in accessing that network. The indications were that this was variable across the country. N3 and N12 who both ran largely nurse-led services and N16 who worked in the community all reported working closely with the larger services in their network and regular access to training

opportunities although the opportunity to attend regularly was restricted by workload demands. Several of the study participants were responsible for leading regional networks in their area and organising regular meetings whilst others reported less active roles and in some cases infrequent attendance, often because of workplace commitments. A lack of organisational support for the nurses to attend network meetings impacts negatively on individual services and others in the area because it becomes difficult to maintain an active network in those circumstances. Electronic communications and video-conferences offer the means to address many of these problems but interestingly, we identified only one instance where this was happening. In that situation, weekly regional multidisciplinary meetings were supported by online facilities and could be remotely accessed. For N3, who delivered a largely nurse-led HIV service, this was extremely valuable because as s/he explained:

*'[travel time] has been a barrier in the past ... I've got a huge caseload and I've got to drive an hour to [the meeting], [now] I can just set it up on the computer so that's a huge advantage.'* (N 3)

A similar picture emerged with regards to attendance at conferences and academic outputs. The majority reported regularly attending and in several cases contributing to national and international nursing and medical conferences. Some had also published academic papers and supported junior colleagues to produce outputs. Organisational funding and support for conference attendance was available to a variable degree. Those who did not have an HIV job title identified specific difficulties in obtaining organisational support to attend HIV conferences because they were not seen as relevant to their role which suggests the importance of having a title that accurately reflects the role. A lack of funding represented a major barrier to attendance at conferences and all other professional development events that incurred costs.

#### **4.6 Academic development**

Several identified the lack of HIV specific educational provision and specifically the lack of a nursing HIV qualification as a particular problem. As one explained, '*There are not even modules anywhere that you can do. Or even if you've got a module it doesn't give you a qualification in HIV.*' (N 3) A specific qualification was considered important because of the opportunity it afforded the nurses to acquire and demonstrate a higher level of HIV specific knowledge that was important for clinical credibility and professional recognition. Several made comparison with the medical diploma in HIV and suggested that this qualification should be available to the specialist HIV nursing workforce but more commonly they proposed a postgraduate qualification in HIV nursing that would be nationally recognised. One of the participants summarised this viewpoint:

*'I would love there to be a more formal qualification for nurses. In fact I'd like to be able to do the diploma or maybe some sort of equivalent. Because ... I don't think there's enough formal training as a recognised qualification for HIV nurses.' (N 16)*

The most commonly reported recent training undertaken by the specialist nurses was non-medical prescribing. Organisational support and funding seemed to be readily available and several indicated that they had been encouraged to undertake the training. As one explained: '*the nurse prescribing was quite easy because that's just a pot of money.*' (N18) A little over half of them (13/21) had qualified as prescribers and there was a general opinion among the nurses and doctors that this was highly valuable to the service. All those who held a non-medical prescribing qualification regularly prescribed as part of their role and considered that it had enhanced their role substantially, enabling them to work much more efficiently, to practice more autonomously and to offer a better quality of service to their patients.

There were a variety of reasons why some had not qualified as prescribers. A small number indicated some reluctance to extend their role in this way. Others recognised the value to the service although individually, they felt too near end of their own career to do the training. As one explained '*for any of the new nurses coming through now, prescribing is something that we will be really encouraging them to do, wanting them to do, because I think it is the future.*' (N13) Those in the specialist community teams adopted a different position. They saw little opportunity for using such a qualification in their role therefore had not followed this route because they felt it would not currently enhance the work they were doing or benefit their patients.

Among the prescribers, four had also completed training in clinical assessment skills, two of whom had gone onto complete the full ANP qualification and one was in the process of doing so. Three of the four reported that this training had enabled them to expand their scope of practice and that they were using their skills to manage care for more clinically complex patients. The fourth had not had opportunity to expand the role in the same way and consequently had not been able to maintain the skills acquired. As s/he explained: '*I have done ... the course ... and I can listen to chests ... but I wouldn't do it because I don't feel I do it often enough to warrant being competent really because most people I see are well and stable.*' (N 18) This situation highlights the importance of ensuring that training opportunities and role development opportunities are aligned to ensure that services benefit from the investment.

The nurses reported a variable level of organisational support for obtaining a master's qualification. Some had been well supported with funding and study time whilst others had struggled. Participants identified an overall shortage of funding which was a significant barrier to development of the workforce. As one of the physicians identified: '*nursing education has a very poor budget and so it's really difficult for people to look at expanding their skill base.*' (Stage 1, P7) The impact on this was evident in the study. The ability to secure any study time and the staffing workplace implications reduced the inclination of the nurses to invest in their own education where funding was not available and to embark on a programme when funding was available. Even when funding had been secured and study time was nominally available, the small workforce made it difficult to progress. One had delayed from enrolling on an externally funded programme because sickness within the nursing team made it difficult to take study time. A lack of study time had also impacted adversely on timely completion. One participant had received funding but no study time other than the taught days for the programme requiring them '*to work for really long days to try and get a day off [for study].*' (N16) S/he took five years to complete the master's programme.

#### **4.7 Summary**

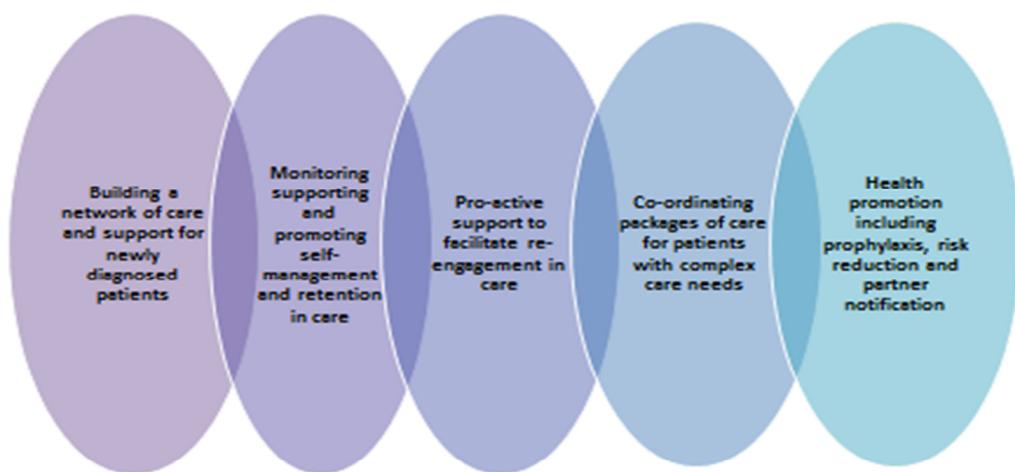
In summary, the participants were a highly experienced workforce and many were in the later stages of their career. As well as qualification and expertise in HIV care, many had considerable experience in sexual health and health advising which provided them with a wider knowledge base and skillset. Most were graduates and one third was qualified to master's level. There was substantial variability in role titles and in pay banding which did not reflect the level of academic qualification. In terms of recent qualifications, there was a clear trend towards non-medical prescribing and to a lesser degree clinical assessment skills qualifications with a minority going on to achieve the master's in advanced practice. Support for academic and professional development was variable. Service demands often impacted adversely on the attendance for professional training events.

## Chapter 5: The clinical roles of specialist HIV nursing

### 5.1 Introduction

In this chapter we report on the specialist nursing roles. The major component of the specialist nursing role is clinical and direct care and this is the focus of this chapter. There was substantial variability in terms of the types of care activities the participants were involved in. In order to reflect this variability in a coherent way, we analysed the data in terms of the overall purpose of those activities and identified five categories or 'aspects of care' which are presented in figure 2.

**Figure 2: Aspects of care**



Each of these aspects of care is considered in turn in the five sections of this chapter. Within each section we report on the ways in which the nursing roles have developed and the factors that have influenced that development.

### 5.2 Building a network of care for newly diagnosed patients

The majority of the nursing participants were involved with HIV patients from the point at which they were diagnosed and engaged with the service. For those with late diagnosis associated with hospital admission, this involved a member of the specialist nursing team visiting patients on the ward to provide initial support and '*ensure that they are linked in into outpatient services.*' (*Ph9*) For those attending out-patients, the initial appointment with the

service was often a lengthy consultation with the specialist nurse who then served as a source of immediate and easily accessible means of ongoing contact for the patient. In both situations, there was substantial nursing input in that initial period, in terms of extended consultations and ongoing support. This input served three main purposes. Firstly, educational input covering aspects such as HIV prognosis and disease management including potential treatment options, secondly clinical assessment including medical history and baseline bloods on the basis of which treatment judgements were made and thirdly psychosocial assessment, support and signposting to other agencies as required.

*'S/he is seeing the newly diagnosed patients, where s/he is telling them about HIV, assessing them, as well as looking to them from the clinical point of view. S/he can decide if this is routine or they need to be looked at [by a physician] tomorrow or maybe today ... s/he has got this clinical sense, and s/he makes that decision.' (Ph13)*

Several participants identified the importance of this early involvement because specialist nurses are particularly skilled in addressing the psychosocial issues and allaying initial anxieties about the diagnosis and the prognosis. As one explained, *'often when they're first diagnosed they still think that they're not going to live very long and they're frightened. So we spend a lot of time with them initially.'* (N13) The nursing team was well placed to serve as a first point of contact with the service at a time when ready access to clinicians is of key importance. In recognition of this, one participant had led an initiative in the service to change procedures so that a specialist nurse was involved with patients from the point at which they entered the service. As s/he explained:

*'We're much more accessible and it's at the time when they probably need more support so .... we're changing the system completely here, we're going to see them as soon as they're diagnosed and be able to follow them through and see them much more frequently.'* (N7)

That early contact with the patient provided the basis of a long term relationship between the patient and the service and was considered important for long term retention in care. The specialist community teams were also involved with some patients from the outset, primarily those who presented as inpatients with late diagnoses and/or with complex social problems. Referrals into the community team during hospitalisation enabled them to begin to build relationships prior to discharge and to provide community based care after discharge. The community teams emphasised the value of all patients being aware of their service and what it offered. Whilst it was accepted that some patients might never need to access their service, and others might not need them for many years, the importance of gaining their consent to the community team being involved in their care if this became necessary at some point was seen as critically important. As one participant explained:

*'What's tending to be happening is someone will get to crisis point, they'll want us to see them but they haven't got consent. And we can't visit them because of the problems with confidentiality and they may not have told their family. We can't go out and visit someone unless we've got consent. So we are trying to get that done in the initial assessment, that they ask when they're well, if it was necessary would you be happy to have input from the community nurses?' (stage 3 participant)*

### **5.3 Monitoring supporting and promoting self-management and retention in care**

A major part of the role for all the specialist nurses was directed towards supporting patients to self-manage their condition, to continue with treatment regimes and to remain fully engaged with the HIV service. This work involved a range of activities that included periodic monitoring and review of their health status, educational input and advice to support adherence around treatments, psychological care and support, and response to problems and concerns.

Much of this work was done through regular outpatient clinics. However a substantial number of activities were also done outside clinics appointments by both hospital and community nurses. The work they did in the clinics and outside the clinics will be considered separately.

#### **5.3.1 Clinic work**

All the hospital based specialist nurses were involved in running the routine outpatient clinics and they saw patients in those clinics for a variety of reasons. These included providing psychosocial care and support and educational input, often in relation to specific issues such as starting or switching treatment or in relation to specific concerns including adherence issues. In many services, they were responsible for the annual sexual health screening and health reviews as recommended within the BHIVA guidelines (15). In most services they ran nurse-led clinics for routine follow up reviews. In many areas these had developed considerably with the nurses managing a growing cohort of patients, using advanced clinical skills to deal with increasingly complex medical problems and operating in an increasingly autonomous way providing services in different settings and using different approaches.

#### **5.3.2 Nurse-led clinics**

Nurse-led clinics that were operating had developed along similar lines. Historically nurse consultations had a supportive function, following on from a medical consultation to provide what might be considered the nursing dimension: educational input, psychosocial care and support or for an annual sexual health review. In a small number of cases, this approach continued. As a physician from one service explained: *'we did want [the specialist nurse] to*

*have his/her own dedicated clinics, but it's just we've found the greater need has been more the supporting role.'* (Ph17) In another service, a lack of space had prevented development of the nurse-led clinic because they did not have enough consulting rooms to run a medical and nursing clinic concurrently. In most services however, nurse-led clinics had developed and in some, particularly the larger ones in urban areas, they were very well established and had been running for many years.

Over two thirds of the participants ran nurse-led clinics and in most cases, the specialist nursing workforce in their service was responsible for running four to five clinic sessions per week which accounted for a substantial proportion of the clinical appointments. For example, one service, with a cohort of approximately 200 patients, offered four nurse and two medical run clinics per week. In another, which served a cohort of approximately 300, the nurse ran five clinics per week and provided the only HIV specific lists in the service: medical consultants saw HIV patients as part of combined HIV/GUM clinic lists.

The organisation of the clinics varied to some degree but a common approach taken when nurse-led clinics were established was for them to run alongside medical clinics. Clinic lists were determined at a pre-clinic meeting with the nurses seeing those that required a nursing dimension and/or stable patients attending for regular reviews. This was beneficial because it enabled patients to be easily referred from one professional to the other and provided the specialist nurse with ready access to medical support. In some areas this remained broadly the arrangement.

The following two examples typify this arrangement. One participant explained that they had: '*nurse-led clinics where we see well-established people on therapy that have maybe had an undetectable viral load for at least two years' and 'another clinic where we just see people that have seen the consultants and they may need a bit more input.'* (N21). Another described a similar set-up in which '*we have nurse-led clinics every day. [The] stable asymptomatic patients who come in ... a lot of them are six monthly ... [and] we also obviously see patients in the clinic that come from the doctor who they want to start on treatment.'* (N13). Within this arrangement, there was often an expectation that patients have a medical review every twelve months effectively meaning that those on six monthly recall alternated between a medical and nursing consultation. As one physician explained: '*given that we are the named consultant for that individual, we're sticking with seeing them annually ... I suppose then we keep that relationship a little bit.'* (Ph14)

It was recognised that nurse consultations were distinctly different from medical ones because they took a more explicitly psychosocial perspective and a more holistic approach. They were often more comprehensive. One of the consultants summarised the situation: '*There are several clinics where they [the specialist nurses] see patients as we would, but they are more of a one-stop shop - bloods, STI screen etc. - everything at one time so more holistic and convenient*' (Ph7)

### 5.3.3 Factors influencing development of the nurse-led clinics

#### ***Medical staffing levels***

In many of the services, it was evident that the scope of the nurse-led clinics had developed substantially and the nurses were dealing with greater complexity and managing patients in a more comprehensive way. Additionally, there was a clear trend away from annual medical review of all patients reflecting the suggestion from some physicians that it was '*artificial*' to impose a 12 month medical review and that '*there isn't really a role for a doctor with the very stable wells.*' (stage 1, Ph6)

In most cases, this development had occurred incrementally, in response to a lack of medical cover. One participant was supposed to '*see stable patients on treatment and stable patients off treatment.*' However, a lack of doctors had meant that s/he '*ended up seeing various types of patients and it just continues like that.*' (N15). Another was also supposed to run clinics for a caseload of asymptomatic patients but found that '*anything ends up coming into that [clinic]. So that will be involving managing patients who are on and off treatment, starting new regimes and changing regimes.*'(N3) In that service, which was run by the specialist nurse with medical input once a week, logistical constraints meant that s/he had a much more substantial role than that originally envisaged. As the consultant explained:

*'There are some patients [who can't attend when I run my weekly clinic] who I have never seen ....I have only ever heard of them virtually because [the specialist nurse] manages them' [Also] I did say I would like at least to see a patient a year, but I've realised that it's impossible because I can't fit everyone into a Tuesday morning.'* (Ph3)

#### ***Prescribing***

Most of those who were running nurse-led clinics had qualified as non-medical prescribers and were using their skills on a daily basis for repeat prescribing of ARVs. This offered a number of clear benefits to the service. It enabled the nurses to autonomously manage episodes of care, it increased the efficiency of their clinics, it increased the smooth running of the service and it improved the patient experience. Some nurses also made more complex treatment decisions, instigating processes for either starting or changes treatments. The policies and shared decision making processes in their services provided a robust

structure within which this could operate. One participant explained how '*nobody ... can initiate or switch without bringing the case to the MDT*' (N10) and another outlined a similar situation in which the service had a two tiered system for starting patients on treatment and within this system, all experienced prescribers were able to initiate treatment for some patients. As the participant explained:

*'There's a team discussion for really complex but if it's a straightforward start we can refer to what we call the treatment advice tab and we just take them and then we initiate.'* (N7)

### ***Skill-mix***

The availability of an adequate staffing skill-mix was a key factor that determined the ability of the specialist nurse to practice at an advanced level in the clinics, to increase their expertise and improve the service. Where there was a lack of resourcing and appropriate skill-mix in services, the nurse inevitably spent a substantial amount of time doing jobs more appropriate for someone on lower pay band. For example, a participant who worked in one small HIV service reported that they spent much of their time doing routine work such as venepuncture and organising medication supplies because: '*there's no admin so we're the secretary, a receptionist, a healthcare support worker and a specialist nurse.*' (N11). In another larger service, where the nursing workforce consisted of band 6 and 7 nurses, they had an organisational structure that involved the band 6s rotating continuously between sexual health and HIV. As a consequence, the nurses did not have the opportunity to develop sufficient expertise to function as a band 6 HIV nurse which impacted adversely on the role of the band 7s:

*'The band 6s are acting like GU band 6s rather than HIV. So we tend to do everything ... we do treatment advice, we do treatment switches, we do all the adherence work, we tend to take the complex like lots to follow up, whereas I think in other centres some of the 6s could take some of that.'* (N7)

In one service they had taken a systematic approach to this problem. In case study site B, an initial skill mix review undertaken by the newly appointed specialist nurse demonstrated that the nursing team were spending 50% of their time on activities that could more appropriately be done by someone else. This enabled them to make a successful case for increased resource and reallocation of the workload which in turn had enabled them to introduce several service developments including establishing nurse-led clinics (see case study 4)

### **5.3.4 Examples of improving services through nurse-led clinics**

In several areas, the nurse-led clinics had developed substantially and they had made a significant contribution to service improvement through: increased capacity, increased accessibility and improved service provision. The following five examples outlined here and presented in more detail in exemplars contained in appendix 2 illustrate the ways in which they had done so.

#### ***A one-stop clinic***

In case-study site B, the senior specialist nurse was appointed to the service as part of a reconfiguration of the nursing team. The service did not provide nurse-led clinics. The nurse-led one-stop clinic was established shortly after s/he came into post and had made a substantial contribution to the service by addressing capacity issues and improving service efficiency and acceptability by streamlining procedures and reducing the number of required appointments (exemplar 5).

#### ***Holistic care for a complex caseload***

In case-study site E, nurse-led clinics were well established. They had developed substantially over several years with the more experienced nurses working at an increasingly advanced level of practice. The study participant ran three clinics per week for a defined caseload of approximately 300 patients. The caseload mix reflected that of the cohort in terms of medical complexity but was skewed towards patients with a greater degree of psychosocial complexity because they were preferentially referred to the specialist nurses in recognition of their expertise (exemplar 6).

#### ***A virtual clinic***

One participant worked in a metropolitan HIV service. S/he had developed and ran a stable patient service for a caseload of 300 patients which represented one third of the cohort. S/he then developed and established the virtual clinic. Through this means s/he managed care for a small but growing sub-cohort of the caseload who were highly stable according to set criteria and who elected to self-manage their condition with reduced direct contact with the service (exemplar 7).

#### ***A satellite clinic***

In case study site A, the specialist nurse worked in a semi-rural low prevalence area with a large geographical footprint. S/he had developed and ran a weekly satellite clinic which was

based in a community clinic. S/he managed all the patients in that clinic with limited medical input and remote access to medical support (exemplar1).

#### ***An over 50's clinic***

The specific health needs associated with an ageing HIV population had become increasingly evident in case study site E. In response, the nurse and a medical colleague collaboratively developed the over 50's clinic. The clinic which was well established offered patients a comprehensive biomedical, neurocognitive and psychosocial assessments and appropriate management through clinical referral pathways (exemplar 8).

#### **5.3.5 Work outside the clinics**

All nurse participants were involved in a range of activities outside the routine clinics, to ensure smooth running of the service. These included: managing medication supplies, chasing up results, reviewing results, organising follow up tests, repeat prescriptions and letters to other services. The specific activities varied between services and were influenced to a degree by the size and the organisation of the service and the size and composition of the multidisciplinary team.

#### ***Service administration***

The availability of administrative support was a key factor and in those services where there was a lack of support, the participants reported spending a substantial amount of time on administrative tasks. Most of those who ran clinics and regularly communicated with primary care had secretarial support for letter writing. In some cases this was formalised using templates and dictation systems, in other case it was more ad hoc. An example taken from case study site A demonstrates the importance of having adequate administrative support in order to effectively run outreach clinics. In that service, the specialist nurse was well supported by the administrator who was responsible for the organisational management of the clinic including appointments and a number of systems including one for ordering repeat prescriptions that helped to ensure a smooth and efficient service (exemplar1).

#### ***Ongoing support for all patients***

The specialist nurse was most commonly the first point of contact with the service for all patients and they dealt with a range of queries and problems. In most services, and particularly those with limited medical input over the course of the week, they were the first point of contact for unscheduled attendances. They triaged the patients, and made clinical

judgements that involved either dealing with the problems themselves or referring to another clinician. Those with clinical assessment skills were particularly well equipped for this work.

In addition, several spent a substantial proportion of time dealing with patient queries and concerns by telephone and email, contacting them with blood results and providing ongoing support related to a wide range of issues related to treatments and specific medical, psychological or social concerns. Clinicians were clear on the value of this aspect of the role because it meant that many problems could often be '*nipped in the bud*'. In some services, much of this activity went unreported whilst other services had taken measures to log this activity. Services were increasingly using electronic patient held records for ongoing communication with patients and in some areas the specialist nurses played a lead role in managing the system. In one service for example, it was used to give blood results, to check up on patients after they had started treatment and to deal with ongoing queries and concerns. The system they had developed whereby the consultant was copied into communications provided ongoing supervision. As the physician explained: it meant that we could:

*'Sit on the sidelines and see the issues as they evolve, or advise as issues develop. [The specialist nurse] is managing those issues as they arise much more autonomously now.'* (Ph 14)

#### ***Targeted community work***

Most of the services had a small minority of patients who necessitated community based care in order for them to stay engaged with treatment and the service. Those in prison were one specific group. One CNS worked with several prisons providing ongoing educational and psychosocial input around issues such as diagnosis, results, treatment, and risk reduction. Another visited a prison weekly and as s/he explained:

*'I manage all the HIV care there. The consultant would go in but [has not needed to do so].'* (N12)

The other group who received community-based care were those for whom remote management of care was the only option available. The availability of this facility was dependent on some community provision and it therefore varied between services. The number of patients in any cohort that were cared for in this way was small. One service cared for two patients remotely and another cared for one. The problems that prevented these patients from attending were substantial and included a range of mental health problems such as agoraphobia.

Community specialist nurses were ideally placed to support retention in care by working with patients in the community. In some cases, they worked with patients on short term interventions designed to re-establish social stability. As a member of one of the teams explained:

*'We still come in and do the quick wins, ....do some support, have some ideas, link them to online self-help things, ....local gardening courses... Over-50s walking clubs..., so we think outside of HIV.'* (stage 3, Service manager)

More commonly however, this aspect of the role involved working with a small number of patients, often providing ongoing care and support and working with patients and their carers in their own homes or in residential care facilities. The trust relationships they developed with patients and carers over long periods of time and the detailed knowledge they had of people's lives meant they were able to identify early warning indicators of likely disengagement and escalate the healthcare response (exemplar 9). Their role in the community also enabled them to manage a small proportion of patients remotely. As one participant explained:

*'Those who for one reason or another, either can't go to hospital, because it's not physically possible for them to do that. Or they're so chaotic that they'll just annihilate the waiting room.... So we'll feedback periodically to the consultant how they're doing, but we'll do the disease progression monitoring bloods at home, and then all their results just go on into their case notes. So that's good, it makes people that otherwise wouldn't take medication adhere and also be less infectious to others.'* (N4)

In some cases, the problems were so great, the patients required ongoing sustained input. The community specialist nurses visited them several times per week over many months or years and remotely managed their HIV in ways that would not have been possible for those with a hospital based role. The care they provided was delivered within a clear structure of short term goal setting directed towards the overall objective of self-management. This was highly resource intensive, but examples from case study sites C indicate the value of this provision. In that site, sustained high intensive input with two patients both of whom had highly complex physical, psychological and social problems had resulted in taking them from a state of high dependency to a position where they were physically stable, with undetectable viral loads and were self-managing their condition (exemplar 9).

## **5.4 Pro-active support to facilitate re-engagement in care**

All the specialist nurses were involved in managing non-attendance and to a variable degree with a range of activities targeted towards re-engaging patients with the HIV service. There

was consensus that there are two categories of non-attendance: those that occurred for simple reasons, for example, forgetting an appointment, and those with more complex reasons, where non-attendance suggested underlying problems and indicated that patients had either disengaged from the service or were at risk of doing so.

Managing the simple non-attendances was a straightforward but time consuming activity. In the absence of adequate administrative support the responsibility generally fell to the nursing participants and several reported spending substantial proportions of time on this activity, making phone calls, rebooking appointments or organising for this to happen.

A greater concern was the smaller proportion of patients with complex needs where non-attendance triggered concerns in staff because it was seen as an indicator for disengagement with care. The specialist nurses were all involved to a variable degree in trying to establish and maintain contact with these patients, to keep them engaged with the care and prevent them becoming ill which could result in prolonged hospital admissions.

In small and medium sized services, where actual numbers were smaller and patients were very well known to the service, the general approach was for the specialist nurse to try to contact patients directly, by phone or letter or indirectly through other services such as primary care. However they recognised the limitations of this approach and in those services with little or no community provision, hospital based services struggled to make contact with patients. As one of the participants explained, '*it's very difficult if they're not coming in ... there's only so much you can do.*' (N16). The problem appeared to be greater in the larger urban services where the actual numbers involved were larger and the population was more mobile.

In three large services that had no community provision, the specialist nurses had been instrumental in developing initiatives to tackle the problem. In the first example, a clinic was set up for '*those patients that are constantly DNAing and have complex social issues .... drug problems.*' (N9) Patients were referred to the clinic when they did turn up at the service and the nurses then started to work with them and build relationships with keyworkers and outside agencies in order to try and re-engage them fully into care. Although there had not been large numbers of referrals in the six months since establishing the clinic, initial results were encouraging. In the second example, the specialist nurse had taken a strategic lead on an initiative to systematically identify and re-engage those who were lost to follow up from their service. As part of this initiative, they had worked with the voluntary sector to appoint a community worker who could establish contact with this group of patients and facilitate their

re-engagement in care (exemplar 10). In the third service, the DNA policy had been revised which streamlined the process of managing the service response to non-attendance. Simple DNAs were distinguished from complex ones by all clinicians at the end of their clinic and the simple ones were dealt by the service administrator. Complex DNAs were entered onto the complex database, a system developed by the specialist nurse to identify those with multiple psychosocial problems who required higher levels of ongoing support from the nursing team to enable them to remain engaged with care (exemplar 11).

Those services where the specialist nurses had a combined hospital and community remit or where there was a community specialist nursing team were much better placed for re-engagement work and were considered highly effective in this role. The caseload management system used in some services meant that they worked with the patients across the hospital and community setting and had detailed insights into their social circumstances. They also worked hard to establish relationships with other care providers, particularly primary care providers. The community specialist teams were able to make contact with patients in the community, identify the issues, and work with them with the objective of re-engaging with the hospital services. They were also integrated into community networks which made them particularly effective in liaison with other health and voluntary sector agencies. Their flexible working patterns enabled them to be persistent in trying to making contact and responsive in terms of how and where they worked with patients. This was identified as particularly valuable in the light of hospital policies to discharge patients from the service after three consecutive non-attendances and they anticipated an increasing number of referrals as a consequence.

Where separate community nursing provision existed, the hospital and community staff worked closely together. Regular meetings between the teams which involved either nursing staff or a wider multidisciplinary team provided a structure for formalised communications. One participant explained:

*'We get together [every month] to go through everyone who's met our trigger criteria for lost to the service, and we go through each person one by one. We review, we decide what we're going to do, we allocate tasks to people, responsibilities, and then we review that the month after.' (N8).*

These meetings were important in enabling both teams to gain a wider and more comprehensive understanding of the issues and to identify creative ways in which to collaboratively support re-engagement (exemplars 12 & 13).

## **5.5 Co-ordinating packages of care for patients with complex care needs**

The specialist nurses played a key role in working with those patients with complex needs, a group largely made up of those diagnosed late and the chronically infected with multiple comorbidities who had been living with HIV for decades. Their role involved co-ordinating care across different settings and in partnership with a range of other agencies to establish packages of care. The extent to which this role was developed varied between services. The hospital-based nurses had established networks with a range of health and social care services and with voluntary sector organisations and referred into those services. The indications were that a reduction in these services was impacting negatively on vulnerable HIV patients. One HIV service for example that had substantial numbers of asylum seekers and homeless patients in their cohort, struggled to refer those patients to social services because they did not meet the required criteria and as a consequence the nursing team had had to skill themselves to better support patients in accessing social care packages they needed. As the participant explained:

*'We've had to do a lot over the last six months, the nurses, finding out really a lot more about where we can send people to food banks, where we can send people for benefits advice, where we can send them for housing, where the hostels are.' (N2)*

Those with a specific community remit had a much more central role in working with patients and a range of other agencies to co-ordinate and manage care packages. One of the physicians explained that they were key in working with:

*'incredibly complex patients in the community who are not accessing care .... bringing those people back in to services, or providing those services in an outreach way.' (Ph 5)*

The amount of input to individual patients was highly variable, largely patient led, often long term and in some cases very intense. As one participant explained, *'you could have one complex case that could take up all your week's work really, if there's a safeguarding and other things going on with it.'* (N 5)

Participants were clear on the value of the community nursing provision to the patients and the HIV service. As one of the physicians explained:

*'[The nurse] keeps these people engaged ... works with them to [prioritise issues] ... engage with clinicians to make sure things are done in an coordinated way and no one's doing everything twice .... There are patients who I could not manage without the [community specialist nurse].'* (Ph 5)

More details on this aspect of the role are provided in exemplars 2 and 14.

## **5.6 Health promotion including prophylaxis, risk reduction and partner notification**

A range of specific elements can be identified under the broad heading of health promotion: partner notification, risk reduction, post-exposure prophylaxis and regular sexual health screening.

Sexual risk reduction/ condom use was addressed by most nursing participants and incorporated in the annual review although patients requiring ongoing work would be referred to a health adviser. For some, risk reduction was mainly undertaken when working in a community setting where a health adviser was not available, such as prisons or home visits. In the majority of cases, the specialist nurses undertook the annual patient reviews including sexual health screens either within routine follow-up appointments or as separate consultations.

### ***Partner notification***

Although health advisers have primary responsibility for partner notification (PN), the majority of the specialist nurses had some involvement in the process, supporting the view that '*everybody's got a role in partner notification*' (N12). Several had dual nursing/ Health Adviser roles, and others had previous experience which equipped them to '*dip in and out*' (N11) of PN, particularly when a health adviser was not available. Examples of involvement included taking partner details during a ward visit, following up PN outcomes or enquiring about new partners during nurse reviews and discussing disclosure. One physician described how the established trusting relationship with a patient made it possible for the nurses to manage partner testing effectively in a community setting:

*'What's helpful ....is the outreach work and identifying at risk people ....seeing families and thinking about have all the people in this family been tested. Understanding, as relationships shift, as people meet new people .....that's been very helpful.....in clinical settings it's easy to miss some of that.....You're getting family units tested and sexual partner tested - offering a safe space for that.'* (Ph4)

### ***PEP/PEPSE***

The extent to which provision and management of PEP falls within the remit of the HIV service was a matter of some contention given that it is a preventative service, for those who do not have HIV. Most of the specialist nurses reported some involvement in this activity and in some cases this was substantial. One physician explained that:

*'With the PEPSE I hardly see them ....s/he [the specialist nurse] is responsible for the PEPSE and PEP assessing and initiating, because s/he is working closely with the*

*pharmacist ..... [Also] s/he's one of the authors for the local, the county-wide PEPSE guidelines [physician].'* (Ph 13)

Those services that had reviewed the provision of PEP had reached different conclusions about how this should be delivered. In one service, PEP management had been transferred from the HIV team to the sexual health team following a workload review, to reduce pressure on the HIV nursing team. In another, they had taken the opposite stance and moved to a nurse-led provision where the HIV specialist nurse had taken on full responsibility for PEP across the trust, in an attempt to improve audit outcomes. The HIV nurse , who felt '*in a good position*' to set up this up, managed everyone on PEP or PEPSE within the trust, including those who were commenced on treatment by the Accident and Emergency department or Occupational Health as well as by Sexual Health. Initially PEP clinics were run separately from HIV clinics, but these had been subsequently merged so that patients could attend any of the four nurse-led HIV clinics run per week. Training and support was provided by senior doctors and development of the role was clearly evident. As the specialist nurse explained, the role was developed incrementally, from a position where: '*it was very highly supervised at the beginning, from a consultant*' to one where '*the only input is when I've got a query that there's something that I think might be beyond my level of competence.*' (N 8)

#### ***HIV testing***

Several clinicians emphasised the importance of having someone to take a lead role around HIV testing activities and this was reflected in the workload of a substantial proportion of the specialist nurses. Some reported having responsibility for testing the children of HIV positive parents. In one service the specialist nurse had worked with the community children's health team and hospital outpatients to strengthen child testing referral pathways. Others reported taking a lead role in initiatives targeted at other groups of health professionals or specific community outreach activities, working in collaboration with a range of other health and voluntary sector organisations. One community specialist nurse had a role that specifically included health promotion enabling them to be involved in a range of testing initiatives. S/he worked with a voluntary sector organisation to offer an ongoing HIV testing service to a range of marginalised and hard to reach groups. S/he had taken a lead role in HIV testing activities locally and nationally as s/he explained:

*'I originally helped to write the NICE guidelines around testing black Africans and gay men, and so it [the development of a local testing service] was an ideal opportunity to put what was discussed at NICE into practice here really, and maybe try and influence some of the commissioning decisions around that.'* (N 4)

## **5.7 Summary**

The findings indicate that the clinical roles have evolved in response to the needs of the service. The hospital based specialist nurses had roles that spanned all five aspects of care but that were largely concerned with aspect two: monitoring, supporting and promoting self-management in care. The role had largely developed in terms of providing nurse-led clinics. Prescribing qualifications in this context were highly valuable and enabled the nurses to run clinics efficiently. The specialist nurses were working at different levels. The majority managed stable well patients whilst a minority used advanced practice skills to manage mixed caseloads of medically and psychosocially complex patients with minimal medical input. The extent to which the nurses were able to develop and function at an advanced level was partly dependent on the skill-mix in the team including adequate administrative and healthcare assistant staff to enable appropriate task allocation.

The community based specialist nursing role also included all aspects of care and was focused on a small caseload of patients with complex physical and psychosocial needs. Their community based approach to care meant that they were particularly well placed to work with patients at risk of disengaging from treatment and support their retention in care and to work effectively across multiple agencies to co-ordinate packages of care.

## **Chapter 6: A responsive and sustainable service**

### **6.1 Introduction**

In this chapter we focus on the context within which specialist roles have developed and factors that impact on continued development. Initially, we consider the ways in which key interrelationships within the MDT service impacted on their role. We then report on how some services have enabled specialist nurses to develop more substantial leadership roles and the ways in which those services have benefitted from such developments. In the third section, we examine the extent to which services have sought to determine the specialist nursing contribution to their service and the challenges that participants identified in determining that contribution. In the final section, we consider sustainability of the specialist nursing workforce, the challenges that services faced in terms of recruitment and retention of staff and the ways in which they had responded to those challenges.

### **6.2 Roles within the workforce**

There was considerable variability in terms of the size and the composition of the MDT within which the specialist nurses worked. Some included HIV social workers although in several places the role had disappeared or been restricted to provision of social care packages. The majority included some psychology provision and some of the larger services also included a dietitian. Most but not all services included pharmacists and in some cases also pharmacy technicians.

The interrelationship between the nursing and medical roles and the ways in which the specialist nursing role had developed and expanded in response to changes in the workload and the medical resource has already been explored in some detail in chapter 5. However, there were other key interrelationships which similarly impacted on the role. In some cases these were related to changes to the composition of the MDT and the loss of roles. As previously detailed in section 5.5, a loss of social work resource available to deal with referrals from staff in study site B meant that the specialist nurses had had to increase their own knowledge and expertise in order to provide their patients with the information and support they needed.

In other cases, they were related to the shared expertise within the MDTs and the ways in which these enhanced the service, not only in referrals within the service to ensure high quality care but also in the ways in which one group served as a valuable resource for colleagues thereby increasing knowledge and skills within the team. The benefits to the specialist nurses of close interprofessional relationships with psychologists has already been

identified in exemplars 8 and 14 (appendix 2). Similarly there were close interconnections between the roles of the health advisers and the specialist nurses. A close working relationship and overlap of roles with the health advisers (HAs) was frequently mentioned, particularly in relation to providing psychosocial support. In a third of services, the same staff were responsible for both roles: three with the job title of 'health adviser' also undertook HIV specialist nursing duties, and three with the job title of 'HIV CNS' also managed partner notification (PN), risk reduction and child testing. In one service the HA team had been recently disbanded and duties transferred to the specialist nurses, although there were plans to re-introduce a specialist team with a similar remit to HAs. Both HIV services based in ID had support from the neighbouring sexual health based health advisers with PN, although often this was managed in-house, as one participant explained: '*Sometimes I would use [the health advisers] to help me with some difficult partner notification, otherwise I would keep it with myself and my patients, and we would do it.*' (N 19)

Where both HIV specialist nurse and HA posts existed in the same service there was evidence of mutual flexibility and support. One participant explained that '*If we have a new diagnosis and I'm not around then s/he would maybe see them instead... so we sort of share that*' (N 18). Some described ad hoc input to PN by taking partner details or checking progress if the health advisers were not available. In one service, the nurses had incorporated routine PN review into nurse appointments to improve PN outcomes for the service in line with national standards. The health adviser perspective was also valued in pre-clinic team meetings where '*it is quite a multidisciplinary approach really, because there's usually somebody in that meeting who knows particularly more complex patients and has something to input.*' (N 6)

Another key relationship was that between the pharmacist and the specialist nurse. Specialist pharmacist input was largely around treatment decisions and drug interactions which was provided through regular MDT meetings and ongoing advice. The nurses worked closely with the pharmacists who were a highly valued source of specialist knowledge and advice. Those who were non-medical prescribers particularly identified the value of access to advice around treatment decisions and drug interactions.

In some services, the pharmacists were involved in direct patient care. In some cases this had resulted in adjusting the boundaries of nursing practice. In one service for example, the pharmacist had assumed a greater responsibility around treatment management and support, a role previously fulfilled by the specialist nurse. Services benefitted from complementary nature of the roles drawing on the psychosocial expertise of the specialist nurse and the pharmacological expertise of the pharmacist. This was evident in study site B.

The pharmacist was a relatively recent addition to the team and had a role that they described as specifically related to '*dosing and drug interactions*' and medication reviews '*for those on a lot of medicines and very complex drug histories.*' This pharmacological expertise was highly valued by the specialist nurse who benefitted from ready access to a '*really useful resource for ... any medication interactions.*' (N 2) The pharmacist was similarly clear about the specific expertise of the specialist nurse as one explained:

*[The specialist nurse] can definitely manage complex patients and complicated situations a lot better than I think I do ... and always knows when to refer.... from my point of view it's been a massive learning curve to see the variety of roles that the nurse specialists undertake .... I think they really recognise the fact that if you don't have the basics sorted then you're never going to get your health sorted.' (stage 3 participant)*

### 6.3 Leadership and service development

A substantial proportion of the specialist nurses had a lead role in their service and had been instrumental in identifying and developing a range of initiatives to improve service delivery. Some of these specific initiatives have been previously identified in chapter 5 and exemplars 5,7 and 8. Additionally, in two services the specialist nurses had acquired specific qualifications in order to offer New-Fill as a nurse- led provision for their service. In another, the specialist nurse had identified the need for a gym-based exercise clinic to tackle the increased cardiovascular risk in the HIV population and secured funding and support to introduce this initiative.

The leadership roles of the specialist nurses and the benefits they offered were most clearly evident in those services where they held clearly influential positions within the managerial structure of the service. Study site B for example held away-days where all senior members of the MDT each presented ideas for developing the service. The one-stop clinic (exemplar 5) had been presented at that forum with good effect: as a senior consultant explained, it was '*one of the ideas from that day that is nearest to fruition.*' (Ph 2) In study site A, the specialist nurse had been proactive in the strategic development of HIV services across the local network in response to changes in commissioning arrangements for in-patient care. This had included involvement in a piece of work to demonstrate that the network was able to meet all the HIV service specifications and developing referral pathways within the network to clarify service roles and responsibilities and improve seamless service delivery (exemplar15). In study site E, the specialist nurse had recently been appointed as joint Clinical Director with the Medical Clinical Director. This collaborative structure had enabled interprofessional working at the highest level. The different perspectives offered tangible

benefit to the service in terms of the issues that were identified and the innovative solutions that were developed to address those issues (exemplar 10).

The specialist community nursing services were characterised by a clear sense of purpose and a strategic approach to developing and improving the service. The degree of autonomy they had as a nursing service enabled them to be highly responsive to the changing requirements of service users, providers and commissioners. In study site C, the team had developed and introduced a range of initiatives to take the service forward. These included developing specific services such as chronic pain management workshops and targeted HIV testing initiatives in response to the changing demographics of the population. They had also introduced structures and processes to improve the efficiency and effectiveness of the service and on a more fundamental level, restructured the entire service to make it more innovative and sustainable (exemplar 16).

## 6.4 Measuring effectiveness

Although all the nurses were involved in a range of service evaluation and audit activities, few reported any activities that had sought to capture their specific contribution to service provision or determine the effectiveness of that contribution. The consensus opinion from nurses and physicians was that to do so was both complex and problematic and various problems were identified with the current types of information routinely collected by services provided some indication, these were necessarily very limited for a variety of reasons.

Patient satisfaction data was identified as one important source of information because as one of the physicians identified: '*the standardised satisfaction assessment survey is probably the only and the best predictor of quality of the service over a large number of patients.*' (stage 1, Ph2) Within these surveys, which were routinely undertaken, it was acknowledged that the specialist nurses always performed well, often scoring higher than other professional groups. Several physicians identified that '*nurses always come out on top in the annual patient satisfaction survey*' (stage 1, Ph 8) and that they do '*exceptionally well in terms of psychological support.*' (Ph 6) The nurses however expressed reservations about the discriminatory value of this type of data. As one participant explained: '*the fact that somebody likes me is nice, but it's not saying that I've done a better job than anybody else.*' (N 6)

Colleague satisfaction was also suggested as a valuable indicator by the physicians. The extent to which this data was routinely collected was not clear. In some services, the nurses collected 360 degree feedback which fed into their annual appraisal although this did not

appear to be standard practice and in some cases, as with patient satisfaction data, the data related to the nursing workforce rather than any individuals within that workforce.

In many services, the specialist nurses played a key role in providing some aspects of care that were often routinely monitored against agreed service outcomes, in particular annual sexual health screens, child testing and PEP services. In a small number of cases, these were the sole responsibility of the specialist nurse and therefore provided specific information related to the role. More commonly however, in keeping with the majority of other service elements, these activities were not the sole domain of one single professional group and audit outcomes therefore reflected service performance rather than that of individual groups within that service.

The participants most commonly identified current clinical outcomes, for example undetectable viral load, as the most readily available indication of effectiveness. However serious reservations were identified about the value of using the data for this purpose. One concern related to the inadequacy of using service outcomes to measure the discrete contribution of one professional group because they most commonly related to the whole team. This was less of an issue where individual specialist nurses were responsible for managing a caseload of patients, for example through an e-clinic. In those circumstances, auditing clinical outcomes in that caseload provided important information about how well the nurse had performed clinically as one of the participants explained: '*how many of those patients have had viral load blips, how were they managed, what other abnormalities were in their bloods ... were they managed appropriately.*' (stage 1, N3) Together with patient satisfaction surveys, these data sources provided information on the quality of the service, however as s/he went on to identify:

*'It doesn't really measure what is it's [the e-clinics] impact, what does it add to a service?'*  
(Stage 1, N3)

Another concern was the lack of sufficient discriminatory power of these clinical indicators. As several participants identified, these outcomes will be achievable in the vast majority of patients as a consequence of the drug treatments that are now available. Consequently, they are not a good marker of the quality of care provided by services. They will be particularly poor indicators of the quality of the nursing contribution within a service given that in the majority of cases, the nursing workload will be skewed towards providing care for those who are socially or psychologically complex because that is where the nurse's skills are most valuable. Simply measuring viral loads gives no indication of the quality of care that has been required to achieve undetectable levels.

This indicates the importance of ensuring that any tools used to measure effectiveness are able to adequately reflect the caseload and capture the nuances of the psychological care and support provided in order to be valid and meaningful. As one of the physicians explained, current measures do not do this:

*[His/her] patients are necessarily much more complicated... It can boil down to what's the new to follow up [ratio], what's the DNA [rate], what's the viral load, but that's not going to do [the specialist nurse] justice I don't think.' (Ph6)*

A substantial proportion of the participants, particularly the key stakeholders from stage 1 were of the opinion that the work that the specialist nurses did with psychosocially complex patients to keep them well, keep them engaged in care and keep them out of hospital was likely to be where they made the most effective contribution to the service. As one explained:

*'It's about showing that those interventions [with] these patients who are ... just a bit chaotic prevent admissions and even failures. It's about showing that the work of the [specialist nurse] reduces people coming to hospital, even to A&E.' (Stage 1, Ph 6)*

There were no indications that the hospital-based teams were doing any significant work to capture the effectiveness of this activity although one service was planning to do so: in study site B the specialist nursing team had started work to capture data on a range of activities that indicated the nursing input to psychosocially complex patients with the intention of measuring successful re-engagement with care in those patients. The proposal in that service was to use the BHIVA standards for retention in care as a key performance indicator.

One community service was involved in a national programme of work to develop community indicators that identified the outcomes they were working towards and therefore how their service might be judged. Engagement was one key outcome for them and getting patients '*to a point of self-care*' was another. These were providing the basis for development of this piece of work with the expectation of moving from the current position where the service specification was around a specified number of contacts per month to one which was: '*measuring outcomes for patients or having a set of standards in place.*' As one participant explained:

*'Maybe an agreed percentage of patients who should remain engaged with services.... We've looked at about five or six statements so far around getting people engaged in care, getting a reduction in viral load and an increasing CD4 count, just so that we know that we can actually prove that what we're doing for patients is I guess the right thing.' (N 4)*

That service worked collaboratively with the HIV and AIDS monitoring unit at the local university using public health data collected at a regional level to indicate the value of a community HIV nursing service and were proactive in sharing this information with commissioners. The data enabled comparison of areas with and without a specialist community nursing service and indicated a lower number of hospital admissions, shorter hospital stays and fewer late HIV diagnoses in the area with a community nursing team as compared to neighbouring areas in the region with comparable demographics (14).

## **6.5 Developing and maintaining an advanced nursing workforce**

If HIV services move increasingly towards a nurse-delivered service, ensuring that the nursing workforce is maintained and expanded will be essential. Addressing sustainability was identified as a priority area and an issue of key concern by all the participants. Collectively they expressed considerable reservations about the current ability of services to maintain an experienced nursing workforce. In large services and metropolitan areas where there are greater employment opportunities, problems were largely around recruiting and retaining staff. One participant reported difficulties in recruiting to an HIV clinical lead nurse position in their service and another highlighted problems with rapid turnover of staff seeking higher pay grades and the impact of this on services in terms of training needs and quality of provision. Adequate development opportunities and a clear career pathway were identified as essential in order to attract and retain high quality staff and maintain a skilled nursing workforce.

A more widespread problem affecting HIV services across the country was the need to replace the substantial proportion of highly experienced HIV specialist nurses who would retire from the service in the near future. As reported in chapter 4, several of those who contributed to this study expected to retire in the next five years and the majority in the next ten years. Succession planning was a key concern for some services and participants expressed serious doubts about their ability to replace the specialist nurses with sufficiently qualified and experienced staff. As one explained:

*'They [the specialist nurses] will be retiring soon and it is a concern about what the future is. Probably [sexual health] nurses will take over but we will lose the experience, [it will be] very difficult to replace that.' (Ph 21)*

The extent to which services were working to address this problem through staff development was very variable. The larger services had a structured HIV specific nursing workforce that included pay bands 5-8 and were well placed to train and develop staff.

However, as previously indicated, they identified problems with retaining the workforce and the cost and resource implications associated with having to repeatedly train the replacement workforce. Where sexual health services and HIV services were co-located, it was common for part of the sexual health nursing workforce to be involved in delivering the HIV service and in this context, the HIV specialist nurse was well placed to train and develop more junior staff. The effectiveness of this approach was dependent on the staffing structure. Some services had a rotational system in place with band 6 staff rotating between sexual health and HIV and in others they worked between the two services on an ad hoc basis. Both approaches were seen as problematic. It was felt that using the workforce in this way did not acknowledge the nature of HIV and the need to develop specialist expertise. Also that it thwarted any attempts to develop an HIV nursing workforce. Two participants explained the problem:

*'I think the management at the moment sees GU and HIV as very similar, and I personally think it's extremely different [because HIV is] a chronic disease. With nurses floating between the two services you don't get the band 6s really experienced in HIV.'* (N 7)

and

*'There is no natural progression, I want a full-time band 6 ... like a junior [HIV specialist nurse] who could work up that way. But they decided that actually they would take the band 6 nurses and just rotate them ... there isn't any progression there for who's going to replace us ... we'll be replaced as a band 6 and the HIV expertise won't be there.'* (N 20)

A more effective approach adopted in other services was for a proportion of the sexual health nursing workforce to have a combined role that included HIV and to input to both services on an ongoing basis. Three participants described a team structure in their service where they were able to work with enthusiastic junior staff supporting their development. They identified two factors that were important for that development: the first was an appropriate skill-mix within the teams to ensure that the staff were not spending disproportionate amounts of time engaged in tasks more appropriate for a healthcare assistant; secondly, the need for a formalised training and development structure. Although there is an HIV nursing competency framework ([www.NHIVNA.org](http://www.NHIVNA.org)) and several reported using this to good effect for training purposes, the lack of access to HIV specific training and qualifications was considered a substantial barrier to development. As one of the participants explained:

*'The difficulty is we need to upskill all the nurses but how do we do that without the qualifications that back it up?'* (N 3)

In a substantial number of services, the HIV nursing workforce was limited to a single or a small team of specialist nurses. In this situation, there was no clear route through which to

develop staff in order to replace the existing workforce. The situation that had occurred in one service underlines the importance of having structures in place for ongoing training and development of a nursing workforce. When both the specialist nurses resigned in a short space of time, the service was left with no HIV nursing workforce. The impact of this on the service was substantial because as the physician explained: '*things just aren't happening the way they used to be .... they kept a machine running more smoothly.*' (Ph 19) The service had needed to draw on sexual health nursing staff in order to provide nursing support for medical clinics. The indications were that these nurses had no specific training or experience in HIV and no access to specialist nursing support either within their own service or within the wider HIV network. In this situation, the service was faced with the task of re-establishing a specialist nursing workforce from scratch, a task that was particularly challenging given the lack of nationally recognised qualifications and the lack of a recognised training pathway.

In two cases, the specialist nursing teams had been highly proactive in addressing this problem, identifying resources and creating training posts within their service. In the first, some additional resource related to a research project had been secured and this had enabled the specialist nurses to start training a band 5 and a band 6 nurse to manage stable HIV patients because as one of them explained: '*where are people going to get their experience from if they don't start?*' (N10) The second example came from a community specialist nursing team. The team had restructured themselves in the previous two years, expanded the team and introduced a tiered nursing structure by employing two band 6 nurses, both with general community experience. Advance planning is essential to maintain a skilled workforce as the participant explained:

*'In order to hand over what we've developed to other people, they need to be in post a length of time in order to develop the skillset and also the knowledge base and the attitude as well to dealing with patients, because it's a very different client group to what a district nurse would normally see.'* (N 4)

The community specialist nurse mentored both band 6s and had a structured approach to training which included joint home visits with peer review, feedback from patients, and regular caseload discussion.

As detailed in Chapter 3, stakeholders identified the need for an overall move towards a more community based HIV provision and that in order to meet the health needs of the whole HIV population it should: 1) offer greater flexibility and accessibility in the way that routine HIV care is delivered 2) ensure greater integration of care between primary care and specialist HIV services and 3) provide community based specialist HIV nursing input. In line

with these proposed developments, participants identified key questions about what the sustainable workforce should look like: '*what are we training people to do?*' In response to such questions, one nurse participant suggested the need for a nursing workforce that could: '*flow between inpatient and outpatients in the community.*' (stage 1, N 4) Another similarly proposed one in which '*advanced nursing practice and community nursing practice were aligned*' in a workforce who had '*the skills and the knowledge to manage patients in the community.*' (Stage 1, N 3)

Participants proposed that one way to achieve this was through establishing hospital and community roles within the HIV nursing team and rotating staff between those roles. It was suggested that these offered substantial benefits because they were '*more efficient ... more beneficial to nurses, and [more beneficial to] the patients.*' (Stage 3 participant) In study site B, this was the solution they had identified and were actively pursuing in order to address the problems previously identified around a lack of community provision in their service.

## Summary

HIV care is a team endeavour and all the nursing participants worked closely with other members of the MDT and benefitted from expertise within the team. Their own role was flexible in response to changes in the team by either assuming or relinquishing specific activities. In the context of an MDT it is difficult to determine the contribution of any one individual to care delivery because the most readily available measures, clinical outcomes and patient experiences of care, usually reflect the impact of the MDT and the service as a whole. Additionally, psychosocial care which is a significant aspect of the specialist nursing role is complex and difficult to measure. A dominant viewpoint is that retention in care and re-engagement of patients lost to follow up are areas where nursing interventions could have greatest cost benefit. The development of community care indicators reflects this viewpoint. Whilst the main role of the specialist nurses was concerned with direct and clinical care, in a substantial proportion of cases, their contribution to the service had extended beyond this and services were benefitting from the service improvements they had been instrumental in developing and implementing.

A strategic approach to workforce development was seen as a matter of priority to ensure that the specialist nursing workforce is sustainable and able to make a maximal contribution to high quality effective HIV services. Some services had taken a pro-active approach to this but the current lack of HIV-specific educational opportunities and the lack of a clear career pathway made this difficult and might be expected to have an ongoing impact on the situation.

## **Chapter 7: Conclusion and Recommendations**

### **7.1 Conclusion**

This study is the most comprehensive examination of the role of HIV specialist nurses in England to date. It indicates substantial variability within the workforce. Collectively they work in hospital and community settings, have a range of job titles and are employed on different pay bands. The most common role title that services employed was Clinical Nurse Specialist but this has translated into very different roles across the country. The variability between roles was most apparent between hospital and community based teams reflecting their different origins and different scope of practice. In broad terms, those working in hospital based HIV services were mainly involved in monitoring, supporting and promoting self-management across the HIV cohort whereas community based teams were primarily involved in supporting engagement in care and co-ordination of care for a small number of patients with complex medical and psychosocial needs.

The study identified substantial variation in the amount of community HIV nursing provision that exists between services. This impacts on the ability of services to support engagement in care and to co-ordinate the care of patients with complex medical and psychosocial needs. Although the proportion of patients who require this level of care will vary between services, the indication from several services was of unmet need. Community delivered care is resource intensive but the indications are that a nursing workforce with the specialist skills and expertise to work in the community and to deliver community based care to those with identified need may produce substantial cost saving through reduced hospital admissions and improved health outcomes.

It is evident from this study that the HIV specialist nursing role has developed substantially in recent years. In many services the specialist nursing workforce were using advanced clinical skills to deliver a substantial proportion of HIV care and this has enabled those services to effectively manage increased capacity demands and provide high quality and appropriate care. These developments have been supported by investment in training and robust supervisory structures that supported their clinical practice. Where the nurses have been enabled to develop a more expansive and advanced nursing role, services have benefitted from the wider contribution they have made in terms of shaping and developing care provision.

The financial pressures that have served as a key driver for developing the nursing workforce are set to increase and to impact across all services. The extent to which individual services might justify developing the nursing role will vary and be determined by a

range of factors including cohort size and medical workforce capacity. The findings from this study which detail development of nursing roles across a range of settings can inform workforce development decisions and support services in responding to the challenge of delivering high quality and appropriate care within increasing financial and organisational constraints.

Although the nurses in this study were routinely involved in a range of quality monitoring activities including patient satisfaction surveys and service audits, the extent to which these provided any meaningful indication of the effectiveness of their role was limited. Notwithstanding the difficulty of isolating the contribution of one professional group within a multi-disciplinary team care model, there is greater scope for specialist nurses to assess their clinical effectiveness by monitoring and evaluating aspects of their care, particularly nurse-led services.

The findings from the study identified a range of issues associated with recruitment and retention including the impending retirement of a substantial proportion of highly experienced specialist nurses. Sexual health nursing or health advising is a natural career pathway into HIV and helps to ensure an HIV nursing workforce with health protection and risk reduction skills. The split commissioning arrangements for HIV and Sexual Health pose a substantial risk to this career pathway. A pro-active approach to succession planning and a clear career pathway for HIV nursing is required in order to ensure a sustainable specialist nursing workforce.

## 7.2 Recommendations

### *Recommendations for practice*

- Ensure there is organisational support for the ongoing professional development of HIV nurses through mentoring and clinical supervision, access to educational meetings and support to seek relevant clinical / academic qualifications.
- Explore the potential for developing and using forthcoming national Patient Related Outcome Measures (PROMs) and Patient Related Experience Measures (PREMs) to capture the wider impact of advanced nursing on HIV care.
- Develop a career pathway for HIV nurses including a structured training programme for advanced nursing practice.

*Recommendations for research*

- Examine the unintended consequences of separating HIV and sexual health commissioning on the sustainability of the HIV nursing workforce, given that most HIV nurses come from a background of sexual health nursing or health advising.
- Evaluate the models of community based HIV provision. This is of particular relevance for patients with complex psychosocial issues and poor retention in care and for managing those with multiple co-morbidities.
- Develop and validate measures and tools that are sophisticated enough to evaluate the advanced nursing contribution to the effectiveness of HIV services.

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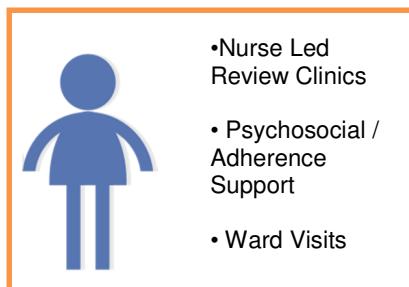
## **Appendices**



## Appendix 1: Models of HIV Specialist Nursing provision

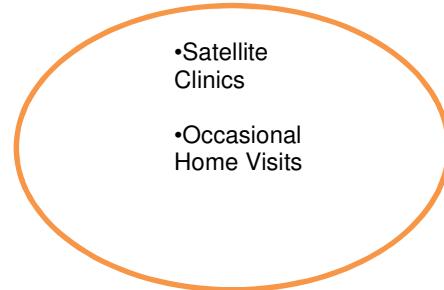
### 1. HIV specialist nurses employed by HIV services and working in hospital settings only

*Observed in high and low prevalence urban settings*



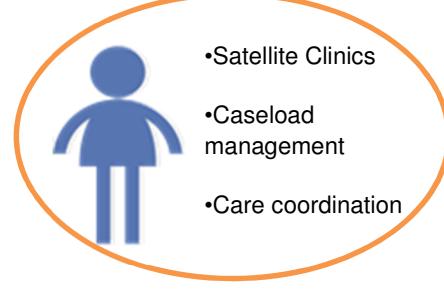
### 2. HIV specialist nurses employed by HIV services and working predominantly in a hospital setting with occasional community input

*Observed in high prevalence metropolitan and low prevalence urban and rural settings*



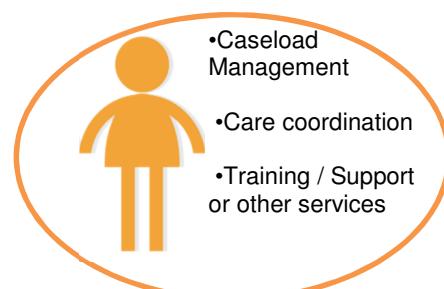
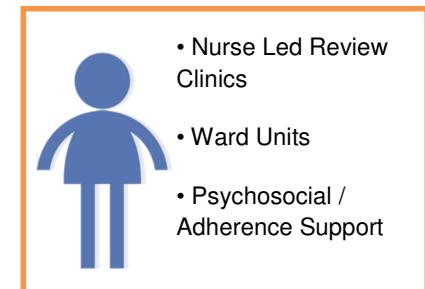
### 3. HIV specialist nurses employed by HIV services and working across hospital and community settings

*Observed in low prevalence rural setting*



### 4. Two separate HIV specialist nursing teams: one employed by HIV services and working in a hospital setting and one employed by community services and working in community settings

*Observed in high and low prevalence urban settings*





## **Appendix 2: Exemplars of Advanced Nursing Practice**

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### **Exemplar 1 - Nurse-led outreach clinic**

Site A comprised of a hub and two satellite services providing HIV care for 300 patients across a large rural geographical area. The specialist nurse ran a weekly outreach clinic and was the sole practitioner managing the clinic list for three out of four weeks. On the fourth week a consultant was available to see complex patients, transfers and annual reviews.

The specialist nurse combined nursing and medical approaches to provide a seamless episode of holistic care for a wide range of patients: '*new diagnoses, fairly complex patients, and whatever comes through the door*'. A nursing consultation typically covered a health assessment, sexual history; adherence support, HIV/ARV monitoring; ARV prescribing; well-being / psychosocial review, risk reduction and partner discussion. After consultations the nurse regularly engaged in liaising with other agencies including GPs, social workers, a dietician, district nurses and the voluntary sector to advocate for the patient and co-ordinate aspects of care. The specialist nurse was able to focus on providing advanced level care because there was adequate support in running the clinic, including a health care assistant to do observations and phlebotomy. S/he was clear of the value of not multi-tasking during consultations: '*... I'm not busy faffing doing bloods.....someone starts telling you something that's really quite important. And you're focused on getting the right bottle next.*'

The service also had strong administrative support from a medical secretary who was described as "*pivotal to our whole service working*". Her role involved managing all appointment bookings and maintaining a confidential database recording patient tests, results and medication that could be accessed by HIV clinicians from all locations across the service. A sexual health nurse was available at the end of the satellite session for patients requiring a STI screen. This supportive infrastructure enabled the specialist nurse to concentrate on holistic assessment and non-medical prescribing, with maximum benefit for the patient and the service. Clinical support was available by telephone from a physician who expressed confidence in the nurse's capability and professional boundaries: '*s/he's a very safe pair of hands and if s/he needs help, s/he will call for help, and the help is there.*'

## Exemplar 2 - Working collaboratively across settings

In site A, patients were cared for across settings throughout their HIV journey, under a caseload management system. As the specialist nurse explained: '*we follow them through from clinic to home to hospital, we don't have any distinction between inpatient care or clinical care or community care, if a patient is on your caseload it's your patient.*' The specialist nurse had the flexibility to deliver care in a variety of settings including a sexual health service, an outreach clinic or the patient's home depending upon circumstances. Collaborative relationships had been built up with colleagues within all settings to ensure optimal care delivery for the HIV patient, whose needs were often complex. The physician reflected on the specialist nurse's ability to advocate and co-ordinate care on behalf of one patient: '*that strong link that she had across GPs and the hospital in [his area] and across the [HIV] services here kept him going until he died of something different.*'

The specialist nurse emphasized the importance of developing a close working relationship with GPs to ensure best care for patients who may present in crisis when HIV specialists were not available. To develop such relationships, the community based remit enabled them to visit the GP of a newly diagnosed patient to introduce themselves, discuss the patient's care, confidentiality and methods of communication. On occasion, s/he also organized a joint visit with the GP '*so the patient knows the GP is aware, supportive and has access to specialists.* The benefits of investing time *liaising with people and keeping communication open* was demonstrated when a patient discharged himself from another hospital following admission for a fall: the discharge summary was only sent to the GP, who then liaised with the HIV service.

### **Exemplar 3 - Characteristics of effective community services**

The community-based services in the study shared several characteristics which appeared to have contributed to their survival and success compared to others which were decommissioned in many areas.

Close links with other professionals and agencies which were essential to facilitate referrals and collaborative management had developed through a range of meetings, joint projects and training events.

Regular community nurse-led meetings with other services/ agencies involved in HIV care were set up to discuss referrals, share information and insights about patients' care needs and circumstances, and plan joint interventions. Attendance at virtual ward rounds were an opportunity to promote awareness of the community nursing service, offer support with discharge planning and meet other members of the MDT.

Contractual arrangements, such as honorary contracts, allowing the community nurse access to acute care settings to see patients, find results or speak with staff was also felt to be useful in one service: '*S/he still has links in the hospital and I think that that actually really does help when you're going on to other wards and finding routes in and navigating your way through the system.*' (Senior nurse)

Collaborative projects between services allowed close working relationships to develop, breaking down boundaries and increasing co-operation. Examples include joint workshops with the voluntary sector for service users and a point of care testing pilot study involving the hospital, the community nurses and the voluntary sector.

Providing training and/or ad hoc support on HIV management to other professionals, agencies and carers enabled others to deliver good quality care, and was a good opportunity to build the partnerships necessary to co-ordinate care effectively. Examples include responding to a GP request for support in giving a positive result and providing training for nursing home, district nurses and health visitors.

Effective management of the workload was facilitated by regular team meetings to review workloads and allocate new referrals according to capacity. A caseload management system to provide structure and focus through goal setting, care planning and regular review through to discharge. Clinical supervision was provided to band 6 nurses by an experienced senior colleague including regular caseload review and occasional joint visits to observe practice.

We observed several examples of strong nursing leadership in community teams, where senior nurses had a background in HIV nursing and the autonomy to shape the service in accordance with nursing values. Equally essential was an appetite for innovation, a good relationship with the local commissioner and the strategic vision to align service developments with changing needs of service users and emerging political priorities:

*'we've all got our fingers on the pulse about what might be happening at a national level, and I think it helps to be ahead of the game'. (Senior nurse)*

Feedback from patients was sought via satisfaction surveys and/or meetings with service user groups.

#### Exemplar 4 - Skill mix and workload review

Case study site B was located in a sexual health service with an HIV cohort of approximately 1750, a substantial proportion of whom were highly vulnerable with multiple social and medical problems. The specialist nursing team structure comprising four specialist nurses (one band 7 Senior CNS and three band 6 CNSs) had been recently established when the specialist nurse (the band 7 senior CNS) was appointed. At that time, the nurses were struggling to cope with an excessive workload, a lack of organisational structures and lack of resource leading to clinical risk. As the specialist nurse explained: '*we were just two band 6s having to run a whole service on our own.... . It was safe-ish but we were absolutely exhausted..... There were 300 patients on recall that had never been actioned because they just didn't have the time to do that.*'

Since her appointment, the specialist nurse had been instrumental in bringing about substantial change, effectively transforming the role and providing significant improvement to the service. An initial audit of the nursing workload indicated that 50% of the work they did was routine and could be done by a healthcare worker. Additional administrative and healthcare resource had enabled much of this work to be re-allocated and the systems s/he had developed had provided greater role clarity and streamlined activities around specific aspects of the work. This is illustrated by developments around non-attendance. Prior to the development '*We had a DNA process but I think it just ticked along rather than .... going to appropriate levels.*' Focusing on causes of non-attendance to distinguish between those that can be managed routinely and those that require more intensive input has transformed this aspect of the service. As the specialist nurse explained:

*We've got a new DNA policy, and what we're doing now is we're trying to separate people.... we have a DNA proforma ... [all the clinicians] review the notes and then they take either a standard recall, which is done by the admin worker, or a complex recall, which is done by us.*

## Exemplar 5 - Developing a one stop clinic

Case study B illustrates the introduction of nurse-led clinics, the immediate benefits they offered and the plans to rapidly expand this provision. Prior to the development of the one stop clinic, all regular reviews were conducted by physicians, and patients were required to make two attendances, an initial appointment with a healthcare assistance for bloods and three weeks later a physician consultation for review of results and prescription of medication. Additionally, patients might also have had a nurse consultation for an annual health review. The service had been struggling with a large cohort and '*we constantly felt like we're running out of appointment slots.*'

The one stop clinic increased efficiency of the service and reduced the burden of appointments for medically non-complex patients. The initiative had been proposed by the specialist nurse and the clinic developed over a six month period during which s/he trained as a non-medical prescriber and developed the structure and supporting paperwork in conjunction with one of the medical team. Patients attended for a single comprehensive consultation covering: medical review, an update on partner notification, sexual health screening, cytology if indicated and psychological review. Blood samples were taken as part of the consultation. The results were reviewed a week later and emailed to the patient, and a repeat prescription issued at this point.

The benefits to the service were clearly evident. One member of the medical team emphasised that '*it has definitely improved the patient experience*' and another explained that: *there's more flexibility for the patients... and it also relieves the burden on us a lot. I know it's certainly something that I feel confident that they [the specialist nursing team] could do very well.*'

This had resulted in a shared vision for the service that is two-fold: to expand nurse-led provision by training the band 6 nurses to deal with non-complex patients and to expand the role of band 7 to deal with greater medical complexity. Plans were in place for both of these. The band 6 nurses were due to train as non-medical prescribers and to start running clinics themselves. As the specialist nurse explained : '*what they [the medical staff] are saying now is the nurses can just take over and do that, and this is the way we should be going, we shouldn't be bringing people back for two appointments when they're stable, we [the nurses] should be able to manage it.*' Additionally, the band 7 was scheduled to undertake training

in clinical assessment skills that will enable him/her to deal with a greater range of patients and practice more autonomously.

## Exemplar 6 - Managing a caseload

The specialist nurse started running review clinics several years ago when the service introduced nurse-led clinics in response to the shortage of medical resources available to see patients coming for routine follow-up. Their role in those clinics was split between managing patients who were stable and doing well on treatment and working to keep those with more complex needs engaged in care. Over the next six years, s/he had acquired advanced practitioner qualifications and considerable clinical experience and was “*able to see clinically more complex patients as well as the antiretroviral complex patients and the stable antiretroviral patients*”. S/he ran regular clinics with 20 minute consultations; comparable with those of other staff. S/he worked as an independent autonomous practitioner managing a mixed caseload of approximately 300 patients, which consisted of: ‘*70% clinically stable who require routine six monthly follow-up and 30% who are clinically unstable, either not taking treatment or not taking it well; and who need more frequent follow up for psychosocial support.*’

In that role, s/he provided high quality comprehensive care that effectively combined advanced level clinical management with a nursing dimension. S/he reviewed resistance results, undertook physical examinations, prescribed ARVs, initiated treatment decisions and referred patients to other specialities, for example renal, neurology and the pain management service. Safe practice was ensured by a clear sense of professional boundaries, ready access to a consultant supervisor and a service infrastructure which required that all decisions about changes to treatment to be made collectively within a weekly multidisciplinary meeting. The specialist nurse drew on the expertise of others during case discussion at virtual ward rounds and pre-clinic meetings, as s/he explained: ‘*I meet with my team ... a consultant, a registrar, a research nurse and health adviser....it's quite a multidisciplinary approach...because there's usually someone in that meeting who knows particularly more complex patients and has some input.*’

The nursing dimension was evident in terms of expertise in caring for those who are not complex in terms of the HIV categories, but are complicated in that ‘*a lot of emotional energy goes into supporting them.*’. New patients with complex psychosocial needs were likely to be preferentially referred to the specialist nurse clinics. A holistic approach was also evident in the comprehensive nature of the consultations. As s/he explained: ‘*anyone who comes to see me will leave with at least being offered a sexual health screen, If they're of a certain age, I'll probably just do all the over 50s checks ..... so they avoid coming back*’

*unnecessarily [for another appointment]. And they will have had quite a comprehensive review going through all of the things that I consider to be standard in any consultation.'*

## Exemplar 7 - Developing a virtual clinic

The specialist nurse in one service had the responsibility for managing stable patients. The service took approximately two years to set up and become established and for the specialist nurse to complete non-medical prescribing and clinical assessment skills training. Patients were initially referred into the service on the basis of inclusion and exclusion criteria and were required to have an annual medical review. Over time the criteria have become more relaxed and their remit has expanded. As the nurse explained:

*'I have a cohort of around about 300 patients that I will see almost always by myself, exclusively seen by me, around about 300 patients, which is obviously a third of the cohort. Not all of these meet the original criteria. I've got some people that have got hepatitis and people that have got hypertension and high cholesterol, but most of those things I'm okay to manage.'*

S/he also led on the virtual clinic service for those who were stable. This consisted of a booked appointment for the E-clinic or the T-clinic (email or telephone/text) in which results were reviewed and communicated to the patient and drugs were ordered for delivery. Patients attended to have bloods taken a week prior to the appointment at a time convenient to them. Six monthly virtual appointments were alternated with annual face to face appointments where s/he undertook a comprehensive review.

The specialist nurse was developing the service further, training other staff to run the virtual clinics in a supervised capacity and has developed protocols to support this.

S/he was well supported clinically and had developed substantially in the role. S/he met weekly with a senior consultant for supervisory purposes. Initially, they discussed every case, but now only difficult cases identified by the nurse.

### Exemplar 8 - The over 50's clinic

The over 50's clinic was established several years ago in study site E. It was a collaborative initiative between the specialist nurse and one of the physicians which emerged in response to the identified needs of the increasing cohort who had been living with HIV for many years and were growing old. As s/he explained, '*we've got a reasonable cohort of 70 plus and a few 80 plus year old patients.*' Both practitioners ran the service and undertook the embedded clinical research which was making a substantial contribution to knowledge in this emerging area of HIV.

The clinic benefited from the shared nursing and medical perspectives to provide a holistic service, with biomedical and psychosocial components. Many of the patients had moved to a large city many years ago and were now growing old on their own with no partners or family. The social isolation was causing substantial psychosocial problems as the nurse explained:

*'when you just ask that question, say how is life in general...many people are either retiring or facing retirement...we're seeing some 50, 60 plus year olds who are coming out of relationships and getting into the whole chem sex scene, because they want to, they don't want to get old on their own, they want to keep their link to the young scene as much as they can, and that's the only way that they can do it currently.'*

The clinic was ran weekly and patients were referred into the service through the general HIV clinic. They were allocated to one of the practitioners according to availability: '*we ... just divvy them out to whoever's got spaces.*' Patients generally attended twice for assessment and a range of biomedical, neurocognitive and psychological tests. As the physician explained '*they're normally assessed at baseline, and then they're assessed at the follow-up visit with the results of any sort of specialist investigations that have been done.*'

All the clinicians running the clinic referred patients to a wide range of services according to clinical referral pathways and commonly also directed them to peer support service with whom they worked closely. Collaboration with psychology and psychiatry to develop a neurocognitive screening tool and pathway had resulted in a close working relationship which had been particularly beneficial for the specialist nurses own clinical development. As s/he explained:

*'One of the main things they taught me was yes, you're doing all these questionnaire based things, but actually you need to really prepare patients for what the upshot of that will be if*

*they do score poorly. Because it might be that people who had no idea, could be facing a query dementia diagnosis.'*

### Exemplar 9 - Retention in care

In study site C, the specialist community team had a specific role working with selected vulnerable patients to keep them engaged in care. They had developed relationships with many of the most vulnerable patients by working with them in the community over a long period time. These enabled them to work with patients and keep them retained in care because '*we have a relationship where they trust us and usually we could get them to hospital if we felt they needed it.*'

They also had detailed insights of those patient's psychological state and social circumstances. This was invaluable because it enabled them to identify early-warning signs that a patient might disengage and to respond proactively, putting appropriate care and support in place to avert disengagement. As they explained:

*'If you know that they're starting to drink more for example, you can see them spiralling into somewhere where they don't need to be going in terms of their alcohol use. So we'd obviously get the alcohol team in then, get that intervention in quicker. If the patient stops ringing or the engagement is starting to fall off, then we go more full on in terms of trying to engage with them. So maybe more home visits...So its overseeing how they're living would give you those triggers as to when things are going to go wrong for them.'*

The community nursing team had close working relationships with the hospital team and remotely managed a small number of patients. These included those with severe problems which required sustained involvement over a prolonged period of time with patients and their carers. Two examples provide insight into the way advanced community nursing care enabled retention in care and progression from a state of total dependency to one of self-management.

Patient A was diagnosed very late with multiple AIDS defining conditions. When he was stable with an undetectable viral load he was discharged from hospital. He was physically disabled, immobile, unable to communicate, needed PEG feeding and initially required input from an extensive multiprofessional team. Patient B had learning difficulties; he had failed to engage with services for many years and was failing physically.

In both cases, the team provided HIV nursing care input visiting several times per week. They provided ongoing and educational input and psychosocial care for the patients and their relatives, helping them to come to terms with an HIV diagnosis, to understand, engage with and effectively manage treatment. They also liaised with other agencies and advocated

on their behalf including addressing breaches of confidentiality by carers. Labour intensive interventions such as secondary dispensing, (filling the patient's dosette box) were undertaken as interim measures with a clear objective of building confidence and developing the knowledge, skills and motivation to enable self- management. In both cases, they had been highly successful. Patient A's viral load remained undetectable and his mother now managed his treatment with periodic support from the nursing team. Patient B had also become undetectable and now managed his treatment with substantially reduced support. As the specialist nurse explained, the result is that '*we've gone from somebody who was almost written off to somebody that .....comes to clinic once every three months and is perfectly well.*'

## **Exemplar 10 – Leadership in service**

Study site E which served a large HIV population is characterised by a history of strong nursing leadership which had been clearly beneficial to the service. The nursing contribution was well established and highly developed. These factors had been influential in enabling the specialist nurse to develop substantially to the position where s/he now had a senior leadership role within the service and a wider influence on the development of HIV care at national and international level.

The specialist nurse had been instrumental in leading service development and research initiatives over several years, for example the over 50's clinic (described in more detail elsewhere) and had a clear leadership role within the nursing team supporting their clinical practice and professional development. S/he sat on the directorate research committee and is actively involved in developing research capacity within the nursing team. S/he also played a significant role in education and development of the wider workforce on an ongoing basis and through more formal educational programmes.

S/he had been recently appointed as joint clinical director and now shares responsibility for leading the service with a senior medical consultant. The insights that both had developed into each other's role had produced tangible benefits to the service, for example in the ways that staffing levels and capacity issues were dealt with and the innovative approaches to service improvement. Recent work on managing lost to follow offers one example. The problem came to the attention of the nurse when s/he assumed the role as clinical lead because '*I suddenly started getting sent these emails about people who hadn't been seen in the service for more than eight months.*' Further enquiry indicated that there was no robust system in place for managing the situation and this had resulted in an initiative led by the medical director and involved the nursing team. It included a recently established clinic, ran by the nurse practitioner under the leadership of the specialist nurse, which had a small number of significant successes in re-engaging patients in care and a shared initiative with the voluntary sector to establish a post for a follow up worker based in the community.

### Exemplar 11 - Developments to support re-engagement in care

In case study B, when the specialist nurse came into post, there had been an ongoing concern within the service and particularly within the nursing team about those patients they were struggling to engage with: '*about the patients that we were worried about, that we couldn't get into clinic, we had no way of getting them and nobody was helping us with that.*' In response, s/he developed the complex patient database: a system for identifying and managing those who are vulnerable and in need of more intensive care and support. This sub-cohort had multiple social problems: '*not so much about adherence, it's about drug misuse, alcohol misuse, homelessness... ...they need to be on medication, [but] there isn't anywhere for them, so they don't take it.*'

Other recent service developments that s/he had taken a lead role on support this work. Firstly, work around DNA policy and protocols to distinguish between simple DNAs and those where non-attendance was an indicator of more complex problems. Those in the latter group were added to a database to quantify what was happening to them and to determine when and what additional support could be provided. Linking the DNA processes with the complex database ensured that these vulnerable patients were followed up. Secondly, the workload audit s/he conducted and the subsequent work to review and re-allocate workload had enabled the specialist nursing resource to be redirected towards work that required their specialist input. This ensured their expertise and experience was used in a more focused way to support and care for this group of patients, developing networks with other agencies, working collaboratively across statutory and voluntary sectors around issues such as safeguarding. In the absence of a community nursing service the specialist nurse liaised with other agencies, including CPNs, the HIV voluntary sector and a local housing project that were able to visit people at home to help with budgeting or accommodation.

This work was particularly challenging and time consuming. The nursing resource was both stretched to capacity and constrained to working in the hospital setting. As the specialist nurse explained '*we've got 70 patients on the complex database, and what we were doing is putting them on, but then not having the resources here to follow any of this up.*' These difficulties were compounded by a lack of social support: '*there is a HIV social worker ... he covers the whole area ... we can refer to him ... but unless somebody is eligible for a social care package, he will not take any more referrals.*'

S/he had identified a clear need for a community outreach team who could work with patients in the community, do home visits, re-engage them back into care and support them through difficult times. Developing this provision had become a service priority, with a proposal to extend the role of the clinic HIV specialist nurse to include a community remit. As one of the consultants explained: '*where I would like to see the role going is developing community delivery..... I know one person can't do everything, and obviously that would be a role for the team to take forward but, I think s/he's got the skills and the ability to do that. And I think our patients and our team would benefit from that.*'

## Exemplar 12 - Re-engagement in care

In site C, a large part of the community specialist nurse's role was to address re-engagement in care. Patients who had defaulted from the clinics and were a cause of concern were referred to the community team who went to considerable lengths to engage with them. Their community location and working practices enabled them to be highly persistent and flexible in establishing and maintaining contact with a clear objective of keeping them well. As the specialist nurse explained: '*if they'll let us go in once a week at home we will. They can come here, we can meet them at the voluntary sector, we can meet them in [a café] ... whatever does it for them we'll do. We get there in the end with them. And that will prevent an ICU bed, hospital admission on a specialist unit somewhere down the line.*' This work had clear value in the light of the service policy to discharge patients after three non-attendances.

The specialist nurse was clear of the value of engaging with patients in the community: '*seeing them in a completely different situation than you are in a clinic setting, completely different, seeing how they really live.*' This holistic perspective enabled them to gain a clearer sense of the issues that prevented attendance, advocate on their behalf and instigate appropriate care responses in conjunction with other agencies and the hospital HIV service.

The monthly nurses meeting that involved the community and hospital specialist nursing teams were an effective vehicle for managing the process. At that meeting, they discussed patients who were a specific cause of concern. Cases to be discussed were submitted prior to the meeting by both teams and then presented by that team. Meetings provided opportunity to update each other and resulted in an action plan with an agreed set of actions for each team. In some cases this involved the community team trying to establish contact with someone who was lost to follow up, in other cases the hospital staff streamlined services to make clinic attendance more likely and more effective. For example, they negotiated a 'fast-track' appointment for one patient who had DNA'd 50 appointments, was highly anxious about attending, had limited time and mobility problems. They also co-ordinated staff from across three services so that an HIV review, a sexual health review and a psychology review could all take place during the one appointment.

### Exemplar 13 - Supporting engagement in care

The community specialist nurse in site D played a key role in supporting attendance and re-engaging those who had fallen out of care by working closely with patients to understand their difficulties and mobilise appropriate support. The HIV lead consultant described the role as '*an absolutely pivotal part of the jigsaw for the socially vulnerable individual, largely with mental health problems*' who were a significant proportion of the local cohort.

Prompt interventions to nip problems in the bud were regarded as cost-effective to prevent a patient disengaging from care and spiralling into crisis, requiring (expensive) hospital admission. The public health cost benefits of supporting engagement to reduce infectiousness were also particularly pertinent to site D, where the trend towards 'chemsex' among MSM increased the risk of onward transmission.

Patients in need of support were usually referred via the weekly community multidisciplinary meeting, the virtual ward round or the 'new patient' clinic. This was attended weekly to meet newly diagnosed patients needing community support with psychosocial problems including housing, benefits, domestic violence, mental health. For some patients, barriers to engagement were complex, requiring the specialist nurse to '*work with people slowly over time, unpicking the problems, finding out what the key thing is to be able to move a situation forward*' For others, a brief intervention with creative solutions might be all that was required. As the service manager explained: '*we still come in and do the quick wins, ....do some support, have some ideas, link them to online self-help things, ....local gardening courses... Over-50s walking clubs..., so we think outside of HIV.*'

Patients who had disengaged from the service were discussed in a weekly 'lost to follow-up' meeting between the community specialist nurse and a senior nurse from the HIV unit. These patients typically had more complex problems which required time and skill to unravel before barriers to attendance could be understood.

Once needs had been assessed and goals agreed, the specialist nurse might liaise with others to provide additional help/ advice, or to advocate on behalf of the patient: '*being able to support people to come to the clinic, being able to advocate on behalf of the patients and say well actually ..... they find this difficult about coming to the clinic and being able to then come and talk to us about that and we can address that.*' (Senior HIV nurse)

Ethical considerations were also addressed in an observed discussion with the senior nurse about whether/ when it was ethical to withdraw efforts from patients who declined to engage with services. They concluded that '*patients are allowed to make decisions we don't agree with*' and autonomy should be respected providing the patient '*has capacity*' to make an informed decision. As the senior nurse explained: '[the specialist nurse's] approach *is very respectful of patient's individual wishes and that she will back off if that's the right thing to do.*'

## Exemplar 14 - Complex care management

The vital role HIV community nurses play in managing and coordinating the care of sick patients was highlighted by the HIV lead at site D who explained: '*Where I worked before ...[HIV community nursing] services did not exist...these patients largely died quite quickly.*'

Despite the potential of ARVs to keep people well, into old age, the need for community HIV nursing has not diminished. Complex caseloads include those who are diagnosed late, admitted to hospital with AIDS defining illnesses, and those who are unable to manage adherence to ARVs and / or have multiple age or HIV related co-morbidities.

Most complex care referrals came from the weekly virtual 'grand round' where inpatients close to or recently discharged from hospital are discussed. Others came via the Community multidisciplinary meeting, chaired by the community specialist nurse for all services involved in HIV care to exchange referrals and updates, and to work together for the benefit of patients.

The community specialist nurse had an honorary contract with both inpatient and out-patient services across the statutory and voluntary HIV sector, so was able to visit patients in any care setting, access test results, write in the care record, and communicate with staff:

*'S/he has a presence in the clinic.....s/he will work alongside whichever nurse is involved in that patient at the time. Also, obviously, with named doctors, s/he will also come and seek them out and talk to them. So s/he's got a visual presence, and I think it makes a difference.'* (Senior HIV Nurse)

A caseload management system based on a Chronic Conditions model provided structure and focus, clarifying the boundaries of practice and responsibility. Emphasis was on holistic, collaborative, goal oriented and time- limited interventions. This involved a full needs assessment to identify problems and agree goals, developing a joint care plan and co-ordinating a package of care to restore independence wherever possible.

As a care coordinator, the specialist nurse maintained and promoted communication between services, advocating on the patient's behalf, organising and chairing case conferences if required, drawing on her wider knowledge of community services. Initiative and tenacity were evident:

*'S/he involves everyone who she feels is important to the patient.... S/he will pull people together. S/he'll email them, telephone them. S/he's proactive, s/he's dynamic, she's enthusiastic, determined, .....and keeps going to make sure she's done the best she can.'*  
*(Service manager)*

The specialist nurse was proactive in seeking input from other professionals to improve patient care and develop professional practice. For example, when coordinating the care of an immobile bariatric patient, s/he sought guidance from the HIV psychologist through a joint home visit followed by supervision to develop skills in supporting behaviour change by 'coming alongside' the patient.

The specialist nurse provided support and training in the care of HIV patients to other health care workers, including hospital specialties, nursing homes, district nurses and health visitors.

Additionally, s/he demonstrated a proactive response to changing needs of the population. In response to a local increase in homelessness, s/he had started working more closely with homeless services: attending meeting with the aim of developing a care policy that would support better collaborative working practices.

## Exemplar 15 - Regional service planning

The specialist nurse in site A had played a key role in the strategic development of HIV services across the local network, advocating strongly for the contribution of advanced nurses in caseload management.

When HIV services were redesigned locally, the specialist nurse took the initiative, with directorate management support, to work with the service planning manager for the Infectious Diseases unit to complete the required 'Derogation Form' for the Department of Health. The purpose of this was to demonstrate that the network was able to meet all the HIV service specifications required to be a service provider. Requirements include access to: HIV specialist in-patient, outpatient and emergency care, HIV treatment, monitoring and adherence support, STI screening, partner notification and health promotion, collaborative management of co-morbidities, and liaison with social and psychological care to meet holistic care needs. During discussions s/he advocated for the Caseload Management Model<sup>1</sup> used by site A, whereby patient care is co-ordinated by a specialist nurse as a key worker across in-patient, out-patient and community settings, working closely with other carers to provide a seamless, holistic package of care.

The specialist nurse also took the lead on developing a referral pathway for the network to clarify that patients admitted to the Infectious Diseases hub would be discharged back to the care of the referring service on discharge. Achieving agreement from all services in the context of conflicting interests required high level negotiation skills.

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<sup>1</sup> Shilpa Ross, Natasha Curry, Nick Goodwin (2011) *Case Management. What it is and how it can best be implemented*. The King's Fund

## **Exemplar 16 - A proactive response to change**

The specialist HIV community nursing team in study site C had a dual remit. They worked with individual patients with complex physical and psychosocial needs to support re-engagement, adherence and self-management. They also had a public health role around community based HIV testing. They were highly responsive to the changing needs of HIV patients, other service providers and commissioners and had introduced a range of initiatives to improve and develop the service.

The team took a strategic approach to succession planning and introduced skill mix into the workforce as part of a service restructure. Expanding the workforce to include two band 6's enabled them to improve the service because they could be more innovative. As one of the team explained '*we can actually do different things to engage with the patients, particularly those that are problematic.*' They revised their caseload management system to improve effectiveness and efficiency. The band 6 nurses managed most patients in the 'short term' caseload under supervision of the senior specialist nurse. Senior staff provided more input to those on the 'corporate caseload' who required longer term input. Care plans were restructured in line with the BHIVA standards for PLWHIV 2013<sup>i</sup>, and were completed and reviewed after each contact. Caseloads and care plans were regularly reviewed by the ANP with the aim of discharging patients who no longer needed support.

The HIV nurses' meeting was introduced to enhance collaborative working between community and hospital services. Regular meetings were established with an agreed case list supplied by staff from both services. Cases for discussion included referrals to the community service, those who had disengaged from care or were at risk of doing so. Discussions were formalised through documentation and action plans were agreed for each case.

The ANP collaborated with social services and the voluntary sector to introduce a range of community based initiatives, many with a social focus that aimed to challenge the stigma of HV and increase social engagement of those living with HIV. S/he was also instrumental in developing and facilitating an innovative peer support chronic pain management group that received national recognition.

The service started community HIV testing programmes in response to changing demographics and identified high risk populations and this was subsequently formally incorporated into commissioning of the service. With increasing emphasis on early diagnosis the specialist nurse had been proactive in developing testing initiatives targeted towards at

risk populations. S/he set up a pilot study in collaboration with local stakeholders in HIV to deliver point of care HIV testing in a community drop-in centre for MSM and sex workers. Conclusions from this pilot study aligned with NICE HIV testing guidelines, 2011. Future plans included testing initiatives to reach newly arrived migrants at risk, such as the Roma community.

## **Appendix 3: Mapping practice against the domains and elements of Advanced Nursing Practice**

<b>DH Advanced Nursing Practice domains and elements</b>	<b>Examples from the ANCHIVS study</b> ( Exemplar or page number in full report for more details)
<b>1 Clinical/direct care practice</b>	
1.1 Practise autonomously and are self-directed	Nurse- led HIV outpatient clinics (exemplars 1,6,5) Virtual HIV clinics for results management (exemplar 7) Nurse – led PEP service (p 51) Nurse-led New-Fill injection service (p 55) Caseload management and care co-ordination (exemplars 2,9,14,16)
1.2 Assess individuals, families and populations holistically using a range of different assessment methods, some of which may not be usually exercised by nurses such as physical examination, ordering and interpreting diagnostic tests or advanced health needs assessment	Sexual history taking, physical assessments, ordering / interpreting tests for booked and walk – in patients in nurse-led clinics (exemplars 1,5,6)  Assessing the health, social and psychological needs of patients in order to plan and co-ordinate care in a community setting. (exemplars 2,12,13,14)  Use of population surveillance data to identify local need and explore the impact of gaps in service provision (exemplar 16)
1.3 Have a health promotion and prevention orientation, and comprehensively assess patients for risk factors and early signs of illness	Annual review incorporating sexual and medical history; screening for STIs cardiovascular, bone, neurocognitive, renal or psychological impairment; referral for investigation / support if indicated. (exemplars 1,8)  Being alert to signs that patients might be in difficulty and mobilising support to prevent disengagement with services. (exemplars 9, 13)  Facilitating partner notification / and risk reduction counselling (p 50)  Leading on HIV testing initiatives in community settings. (exemplar 16)  Introducing a gym-based exercise clinic to tackle increased cardiovascular risk. (p 55)

1.4 Draw on a diverse range of knowledge in their decision-making to determine evidence-based therapeutic interventions (which will usually include prescribing medication and actively monitoring the effectiveness of therapeutic interventions)	<p>Prescribing and monitoring anti-retrovirals. (exemplars 1, 5, 6)</p> <p>Nurse-led New-Fill injection service (p 55)</p>
1.5 Plan and manage complete episodes of care, working in partnership with others, and delegating and referring as appropriate to optimise health outcomes and resource use, as well as providing direct support to patients and clients	<p>Managing an HIV caseload in an outpatient unit, working closely with psychologists and psychiatrist to develop screening tools to identify cognitive impairment, anxiety and depression, and to provide appropriate psychological care/ referral. (exemplar 8)</p> <p>Managing a caseload and co-ordinating care across multiple agencies in a community setting. (exemplars 2,9,12,14,16)</p>
1.6 Use their professional judgement in managing complex and unpredictable care events and capture the learning from these experiences to improve patient care and service delivery	<p>Managing a caseload and/or co-ordinating care across agencies, sharing learning through discussion at multi-disciplinary meetings to improve care and services. (exemplars 6,12,14,16)</p> <p>Developing a complex patient database to improve the management of patients with multiple medical and psychosocial needs, ensuring prompt and appropriate interventions, referrals and liaison with other agencies. (exemplar 11)</p>
1.7 Draw upon an appropriate range of multi-agency and inter-professional resources in their practice	<p>Attending multi-disciplinary team meetings to discuss cases, exchange referrals, co-ordinate care and critically reflect on patient management. (exemplars 6,12 14,16 )</p> <p>Liaising with GPs of newly diagnosed patients to offer support and establish a collaborative working relationship (exemplar 2)</p> <p>Working closely with voluntary agencies to provide a range of practical and psychosocial support for patients (exemplars 11, 16)</p>
1.8 Appropriately define the boundaries of their practice	<p>Initiating a skill mix review to renegotiate the role of the HIV CNS, devolving responsibility for phlebotomy to HCAs, DNA management to admin staff and PEP to GUM nurses. (exemplars 4,1)</p> <p>Clarifying ANP roles and responsibilities during case discussion or service planning meetings. (exemplars 6,7,15,)</p> <p>Complying with prescribing protocols (exemplar 6)</p>

	<p>Using a structured approach to care planning based on a model of care to clarify boundaries of practice (exemplars 3,14,16)</p>
<b>2. Leadership and collaborative practice</b>	
2.1 Identify and implement systems to promote their contribution and demonstrate the impact of advanced level nursing to the healthcare team and the wider health and social care sector	<p>Developing nurse-led services (exemplars 1,5,7, 10)</p> <p>Setting up meetings with staff from other services and agencies to promote the role of community nurses, share intelligence, exchange referrals and feedback on outcomes. (exemplars 3, 14,16)</p> <p>Initiating a skill mix review and restructuring the service to maximise the impact of ANP contribution (exemplars 4, 5).</p> <p>Working collaboratively with the HIV &amp; AIDS monitoring unit at a local university to evaluate the impact of the HIV community nursing team and sharing findings with commissioners. (p 58)</p>
2.2 Provide consultancy services to their own and other professions on therapeutic interventions, practice and service development	<p>Be responsive and proactive in providing guidance to other professionals, eg GPs, on the management of HIV patients. (exemplars 2, 14).</p> <p>Contribute to multi-agency case conferences or multi-disciplinary discussions. (exemplars 6, 14, 16)</p> <p>Bring an ANP perspective to the strategic planning and service development process. (exemplar 15)</p>
2.3 Are resilient and determined and demonstrate leadership in contexts that are unfamiliar, complex and unpredictable	<p>Proactively seek involvement in service planning at regional level and advocate for the potential contribution of HIV specialist nurses across the region, despite encountering resistance. (exemplar 15)</p> <p>Sharing the clinical lead for a large HIV service (exemplar 10)</p> <p>Coordinating care from multiple agencies across settings to meet complex medical and psychosocial needs. (exemplars 2, 14)</p>
2.4 Engage stakeholders and use high-level negotiating and influencing skills to develop and improve practice	<p>Negotiating with colleagues to change to the skill mix and re-design services to include a nurse-led one-stop-shop. (exemplars 4, 5)</p>

	<p>Leading on the development of a regional care pathway for patients requiring in-patient care, negotiating agreement despite conflicts of interest between services. (exemplar 15)</p> <p>Liaising with commissioners regarding evidence that patients in areas with community nursing service had fewer and shorter hospital admissions than areas without such provision. (p 58)</p>
2.5 Work across professional, organisational and system boundaries and proactively develop and sustain new partnerships and networks to influence and improve health, outcomes and healthcare delivery systems	<p>Liaising with personnel in the newly appointed regional in-patient hub to develop working relationships that can facilitate best possible patient care and transition between hospital and home. (exemplar 15)</p> <p>Working with the voluntary sector to deliver HIV Point of Care testing and health workshops for HIV patients (exemplar 16)</p> <p>Working closely with colleagues in psychology and psychiatry to develop screening tools for cognitive impairment, anxiety and depression, and to set up referral pathways for those needing further investigation / support. (exemplar 8)</p> <p>Working collaboratively with Community Children's Health team to set up a robust system for managing the testing of children at risk of HIV. (p 51)</p>
2.6 Develop practices and roles that are appropriate to patient and service need through understanding the implications of and applying epidemiological, demographic, social, political and professional trends and developments	<p>Responding to the changing health and social needs of an aging population by setting up a specialist service for over 50s, with additional monitoring for age-related morbidities. (exemplar 8).</p> <p>Taking the initiative to work more closely with homeless services by attending meetings and developing a care policy, in response to a local increase in numbers of homeless HIV positive patients. (exemplar 14)</p> <p>Identifying the need for community-based HIV nursing and proposing a service model involving Clinic/ community rotations. (exemplar 11)</p>
2.7 Identify the need for change, proactively generate practice innovations and lead new practice and service redesign solutions to better meet the needs of patients and the service	<p>Reducing inconvenience to patients by introducing a one-stop-shop with all medical and nursing care provided during one appointment and with results by email or phone. (exemplars 5,7)</p> <p>Setting up a service to identify and address the specific health and social</p>

	<p>needs of an aging cohort. (exemplar 8)</p> <p>Changing the skill mix of the team to improve cost-effectiveness and efficiency by providing ancillary staff to take blood, filter phone calls, manage appointment booking and organise repeat prescriptions, freeing up nurses to focus on advanced nursing duties. (exemplar 4)</p> <p>Piloting a nurse-led stable patient clinic in a GP surgery, with an extended health screening role for the HIV specialist nurse. ( p 26)</p> <p>Introducing a gym-based exercise clinic to tackle increased cardiovascular risk (p. 55)</p> <p>Piloting an 'Assertive Inreach' clinic for patients lost to follow-up, with longer appointment slots to address barriers to regular attendance. (p 47)</p> <p>Setting up an HIV Point of Care testing (POCT) service in a voluntary sector drop-in centre. (exemplar 16)</p>
<b>3 Improving quality and developing practice</b>	
3.1 Are proactively involved in developing strategies and undertaking activities that monitor and improve the quality of healthcare and the effectiveness of their own and others' practice	<p>Initiating a workload management review to identify risks and inefficiencies, and developing new systems to improve safety, accessibility and effectiveness. (exemplars 4, 5, 11)</p> <p>Approaching the HIV psychology service to set up regular team meetings with community nurses and provide one to one clinical supervision, to improve the management and care of patients with mental health problems. (exemplar 14)</p> <p>Providing mentorship for junior colleagues, including care plan review, caseload discussion and feedback on observed client consultations. (exemplar 3)</p>
3.2 Strive constantly to improve practice and health outcomes so that they are consistent with or better than national and international standards through initiating, facilitating and leading change at individual, team, organisational and system levels	<p>Taking responsibility for HIV service planning and evaluation as joint HIV Lead, representing the service at Trust level meetings. (exemplar 10)</p> <p>Redesigning and managing a PEP service in response to audit findings that highlighted failure to meet national standards. (p 51)</p>

	<p>Working with the health adviser team to improve partner notification outcomes in line with national standards by including PN review in nurse consultations. (p 54)</p>
3.3 Continually evaluate and audit the practice of self and others at individual and systems levels, selecting and applying valid and reliable approaches and methods which are appropriate to needs and context, and acting on the findings	<p>Working collaboratively with a local university Public Health department to evaluate the impact of the community HIV nursing team, communicating findings to commissioners across the region. (p 58)</p> <p>Monitoring a complex patient database to ensure care is timely and comprehensive, alerting others to gaps in service provision. (exemplar 11)</p> <p>Seeking service user feedback from annual patient satisfaction surveys and developing an action plan for service improvement, to be submitted to the Trust board. (exemplar 3)</p>
3.4 Continually assess and monitor risk in their own and others' practice and challenge others about wider risk factors	<p>Critically evaluating the quality of care patients receive from other services, and advocating on their behalf if necessary. (exemplar 13)</p> <p>Raising awareness of risks associated with the lack of a community HIV nursing service. (exemplar 11)</p> <p>Evaluate the impact of a community nursing service on rates of hospital admissions and raise concerns with commissioners in neighbouring boroughs regarding the risk of having no community nursing provision. (p 58)</p>
3.5 Critically appraise and synthesise the outcomes of relevant research, evaluations and audits and apply the information when seeking to improve practice	<p>Setting up an over 50s clinic to meet the needs of older HIV patients and gather data to fill gaps identified by current research. (exemplar 8)</p> <p>Identifying appropriate models of care from the literature and implementing these locally to improve case management. (exemplars 2, 14)</p> <p>Working with the health adviser team to improve partner notification outcomes in line with national standards by including PN review in nurse consultations. (p 54)</p>

3.6 Plan and seize opportunities to generate and apply new knowledge to their own and others' practice in structured ways which are capable of evaluation	<p>Piloting an 'Assertive In-reach' clinic for patients who have defaulted from care, with longer appointment slots to build rapport and address barriers to attendance, in order to assess whether a hospital-based facility is effective in re-engaging patients. (p 47)</p> <p>Introducing the 'Patient Knows Best' (PKB) system for sharing test results with patients who can then choose to make these available to other clinicians ( eg GP) involved in their care. (p 27)</p> <p>Setting up a complex patient database to monitor and evaluate care (exemplar 11)</p> <p>Setting up a virtual clinic to allow patients more convenient access to results / information / advice. (exemplar 7)</p>
3.7 Alert appropriate individuals and organisations to gaps in evidence and/or practice knowledge and, as either a principal investigator or in collaboration with others, support and conduct research that is likely to enhance practice	<p>Setting up an Over 50s clinic to meet the needs of older HIV patients and gather data to fill gaps identified by current research. (exemplar 8)</p> <p>Evaluating outreach nurse-led care delivered in a GP practice by an HIV CNS. (p 26)</p>
3.8 Use financial acumen in patient/client, team, organisational and system level decision-making and demonstrate appropriate strategies to enhance quality, productivity and value	<p>Introducing lower grades of staff such as healthcare assistants to support specialist nurses, there by improve cost-efficiency. (exemplars 1, 4)</p> <p>Alerting commissioners to the potential long term cost benefits of a community HIV nursing team to reduce hospital admissions. (p 58)</p>
<b>4 Developing self and others</b>	
4.1 Actively seek and participate in peer review of their own practice	<p>Approaching a psychologist to provide clinical supervision for her management of patients with mental health problems. (exemplar 14)</p> <p>Seeking clinical supervision from a medical consultant and/or nursing supervision from a senior nurse within the Trust. (exemplars 5, 6)</p>
4.2 Enable patients/clients to learn by designing and coordinating the implementation of plans appropriate to their preferred approach to learning, motivation and developmental stage	<p>Providing health workshops – eg on pain management in a community setting, in collaboration with the voluntary sector. (exemplar 16)</p>

	<p>Teaching and supporting patients one to one in their own home to manage their dosette box (exemplar 9)</p> <p>Using a 'coming alongside' motivational interviewing approach to help patients find ways to change entrenched behaviours. (exemplar 14)</p>
4.3 Develop robust governance systems by contributing to the development and implementation of evidence-based protocols, documentation processes, standards, policies and clinical guidelines through interpreting and synthesising information from a variety of sources and promoting their use in practice	<p>Using BHIVA Standards of Care for PLWHIV (2013)to underpin the structure of care plans (exemplar 12)</p> <p>Introducing a caseload management system based on <i>An integrated model and framework for action for Chronic Conditions in Wales, 2007</i> (exemplar 14)</p> <p>Advocating the use of the King's Fund Caseload Management Model across the region to ensure good standards of HIV nursing care. (exemplar 15)</p>
4.4 Work in collaboration with others to plan and deliver interventions to meet the learning and development needs of their own and other professions	<p>Providing other workers with practical guidance on managing patients with HIV, including GPs, health visitors, district nurses and care home staff. (exemplars 2, 14)</p> <p>Developing a training programme and provide mentorship for nurses entering HIV care. (exemplars 10,16)</p> <p>Accessing further training and / or attending educational meetings and/or facilitating access to learning opportunities for junior members of the team. (exemplars 3,5)</p>
4.5 Advocate and contribute to the development of an organisational culture that supports continuous learning and development, evidence-based practice and succession planning	<p>Supporting other HIV CNSs to access the non-medical prescribing course. (exemplar 5)</p> <p>Creating training posts to develop sexual health nurses with an interest in HIV nursing to prepare a potential future workforce. (p 61)</p> <p>Reviewing banding and reconfiguring the team to fund additional trainee posts as part of succession planning. (exemplar 16)</p>

<p>4.6 Have high-level communication skills and contribute to the wider development of those working in their area of practice by publicising and disseminating their work through presentations at conferences and articles in the professional press</p>	<p>Organizing regional educational meetings for HIV CNSs to learn, network, and discuss complex case management. (p 34)</p> <p>Presenting work /facilitate workshops/ chair sessions at national or international conferences (exemplars 10,16)</p> <p>Publishing articles in HIV/nursing journals (p 34)</p>
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<sup>i</sup> British HIV Association Standards of care for people living with HIV 2013



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