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# An examination of the contribution of specialist nursing to HIV service delivery: A short report.

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## **Introduction**

We report the results of the largest and most comprehensive study of the contribution of nurses in advanced practice roles to the delivery of HIV services in England.

## **Background.**

HIV care has changed radically in recent years and is now mainly directed towards chronic disease management.<sup>(1,2)</sup> 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 increasing 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). Three categories reflect 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. Category 1 covers patients who are newly diagnosed and those within 12 months of starting their first 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 co-morbidities that identify them as a special patient group.<sup>(3)</sup> The majority of patients fall into category 2 which is paid at a lower tariff.

Changes to commissioning due to the Health and Social Care Act 2012 have resulted in split commissioning for HIV. HIV treatment and care services are now commissioned as a specialist service by NHS England whilst responsibility for commissioning public health aspects of HIV work and sexual health services, within which HIV services were commonly situated, rests with local authorities.<sup>(4)</sup>

The HIV and AIDS UK Select Committee report 'No vaccine, No cure' recommended a greater role for the nursing workforce in the delivery of HIV services.<sup>(5)</sup> The extent to which this workforce is currently utilized and the potential for further expansion of roles and responsibilities is currently unknown.

The aim of our study was to undertake a detailed examination of specialist nursing roles in HIV services across the country to understand how they currently contribute to HIV care and the potential for maximising that contribution. Our initial intention was to look at advanced practice roles. However, it 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.

## Methodology

We used a multi-method qualitative sequential study design involving three stages

- Stage 1: 19 semi-structured interviews with representatives of key stakeholder groups: service providers, service commissioners and service users in order to detail current provision, challenges and opportunities for service delivery and the advanced nursing contribution.
- Stage 2a: 42 semi-structured interviews with nurse/physician pairs from 21 purposively selected HIV services (13% of total in England) to understand the range of ways in which services are organized and the contribution of specialist nursing.
- Stage 2b: 5 detailed case studies from site visits to purposively selected services from stage 2a. Multiple data collection methods including interviews, non-participant observation and documentary evidence were undertaken to understand in more detail the specialist nursing contribution.

Data were analysed using framework analysis <sup>(6)</sup>, a pragmatic approach to qualitative data analysis with a clearly defined analytical structure that contributes to the transparency and validity of the results. Analysis of data from each stage informed sampling, data collection and analysis decisions for subsequent stages. Findings are reported as a synthesis of all stages.

Research integrity was ensured by involvement throughout the project of: a patient public involvement group, a comprehensive project advisory group and an HIV specialist nursing reference group.

## Findings

### Challenges facing HIV services

- Changing health status of those living with HIV: access to effective anti-retroviral therapy (ARVs) has resulted in around 80% achieving stable HIV infection, good immune function and health.
- New demands on health and social care arising from an aging cohort of people living with HIV with increasing co-morbidities.

- Increasing numbers of vulnerable patients with complex psychosocial needs that are resource-intensive but not recognised as category 3 within the PbR HIV tariff.
- Changing sexual behaviours including the use of illicit drugs to enhance the experience (“Chem-sex”) and associated transmission of other sexually transmitted infections and viral hepatitis.
- Changes to service commissioning are profoundly affecting HIV care provision:
- Separate commissioning of HIV services and sexual health services is having significant adverse effects. Where sexual health services are tendered out to new providers, these 2 clinical services previously provided under the same roof and by the same medical and nursing staff are being separated.
- There is a lack of clarity in the HIV service specification around commissioning responsibilities for community based HIV nursing services.
- Concerns were expressed about the potential unintended consequences of over-reliance on the specialist nursing workforce that may negatively impact on specialist medical training in HIV and destabilise medical teams in some settings.
- HIV infection is now a long-term condition for most patients. The consensus opinion was that future HIV services would need to move increasingly towards a model of care that:
  - Offered greater flexibility and accessibility in the way that routine HIV care is delivered.
  - Provided greater integration of care between specialist HIV services and primary care.
  - Included specialist community nursing care input.

### **HIV service models**

- There is substantial variability between services in the structure and composition of the specialist nursing workforce in terms of: number of staff, role titles, and pay bands.
- Delivery models may place specialist nurses within acute hospital Trusts, partially in community settings or within separate community nursing teams. The figure below captures the range of different delivery models.

## Models of HIV Specialist Nursing Provision

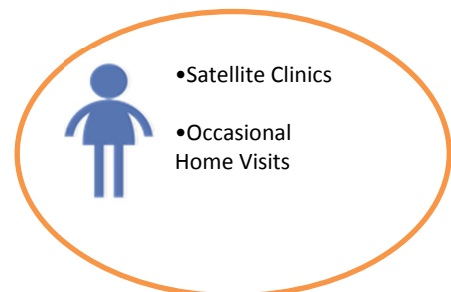
### 1. HIV specialist nurses employed by HIV services and working in hospital settings only

*Observed in high and low prevalence urban settings*



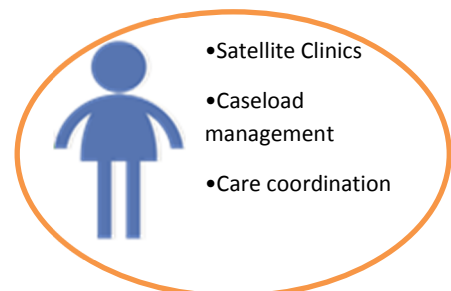
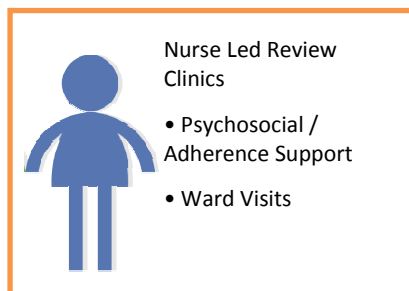
### 2. HIV specialist nurses employed by HIV services and working predominantly in a hospital setting with occasional community input

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



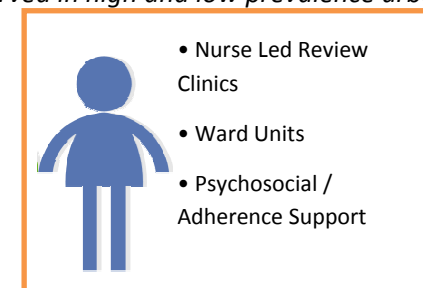
### 3. HIV specialist nurses employed by HIV services and working across hospital and community settings

*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*



## HIV specialist nursing workforce

- The HIV nursing workforce is highly experienced. 80% had worked in HIV for over 10 years and 33% for over 20 years.
- The majority (15/21) held the title of Clinical Nurse Specialist.
- The majority were graduates. One third held master's qualifications, two of whom had the advanced nurse practitioner qualification.
- 68% (13/19) of the hospital based specialist nurses had prescribing qualifications and 21% (4/19) had completed training in clinical assessment skills. There was a lack of consistency across the workforce between job titles, roles, pay bands and academic qualifications.

## HIV specialist nursing roles

- The main role of specialist nurses was in providing direct clinical care. Some had leadership responsibilities which enabled them to contribute to shaping the service.
- The roles and responsibilities of specialist nurses varied widely across England with the greatest differences between hospital and community based teams.
- Hospital based HIV specialist nursing roles were mainly involved in monitoring, supporting and promoting self-management across the HIV cohort.
- Community HIV specialist nurses mainly delivered community based care for patients with complex needs to support their retention in care and to co-ordinate care packages.
- All played a valuable role in supporting the engagement in care of those with complex psychosocial problems in order to reduce the likelihood of hospital admissions and onward transmission of infection.
- Community based HIV nurses were particularly effective in engaging hard to reach patients and facilitating re-engagement.
- In most HIV services nurse-led clinics were well established, primarily to manage patients who were stable and well. In several areas services had developed further to manage increasingly complex patients and provide services through alternative means including satellite clinics and virtual clinics.
- The development of nurse-led clinics increased capacity of services and enabled medical staff to be freed up to focus on more complex HIV care.
- Accredited training in clinical competencies (prescribing and clinical assessment) increased the efficiency of the service and enabled the nurses to expand their scope of practice to include the care of more complex patients.
- Multi-disciplinary team working ensured that specialist nurses had ready access to medical advice and supervision that enhanced their own learning and development as well as ensuring best clinical practice.
- Some of the activities the nurses were performing would have been more appropriately undertaken by staff on lower pay bands, e.g. blood taking, immunisations and booking appointments.
- In the full report we illustrate the varied role of specialist nurses in different settings using a series of 16 exemplars drawn primarily from the five case studies.
- In addition the full report provides examples of practice from across the dataset and maps them against the domains and elements of advanced nursing practice as identified by the Department of Health <sup>(7)</sup>.

### **Determining the specialist nursing contribution to services**

- The activities undertaken by the specialist nurses were shaped by the composition of the multi-disciplinary team (MDT) in which they worked.
- Current measures of effectiveness of care including clinical outcomes and patient experiences of care were deemed unsatisfactory because they relate to performance of the MDT rather than individuals within that team.
- Any measure of effectiveness would need to capture psychosocial well-being which is a key aspect of the specialist nurse role but this is complex and no existing tools were identified to capture this.
- It was suggested that nursing interventions that support adherence and retention in care may offer the greatest cost-benefit by preventing hospital admissions.

### **Ensuring a sustainable advanced nursing workforce**

- Some services faced retention and recruitment problems attributed in part to the lack of a recognised career pathway in HIV nursing.
- The current cohort of HIV specialist nurses contains a large number of nurses nearing retirement age.
- Succession planning is difficult due to small numbers of HIV specialist nurses working in any service and the lack of specific nursing qualifications in HIV care.
- Where HIV and sexual health services were co-located, specialist nurses commonly trained sexual health nurses to develop expertise in HIV. This career pathway into HIV nursing will be in jeopardy where sexual health and HIV services are separated as a consequence of commissioning arrangements.
- For the existing HIV nursing workforce, access to support for academic development was variable. Difficulties were greatest in securing adequate support to obtain Master's degrees.
- Continuing professional development needs were mainly addressed in-house through the MDT. Involvement in wider networks which is valuable for ensuring the quality of professional practice was commonly constrained by organisational and workload pressures.

### **Discussion points**

- The availability of HIV specialist nurses enables services to respond to increasing capacity demands and improve accessibility by delivering care in alternative settings and through the use of virtual clinics and consultations using multi-media technologies. Prescribing qualifications enable them to deliver services efficiently.
- Specialist nurses are perceived as valuable within the context of appropriately skill-mixed multi-disciplinary teams that enable patients to access staff with the right competencies for their specific needs.
- There is considerable scope to develop specialist nursing roles but consideration must be given to the potential unintended consequences of doing so in some settings.
- Community nursing provision offers a useful bridge between acute trust specialist services and community services. This supports delivery of care for those with complex psychosocial needs and could facilitate integration with primary care services.
- There was widespread recognition of the inadequacy of current measures as ways to evaluate the effectiveness of advanced nursing practice. Measures are needed to

capture the impact of nurse-led psychosocial support on patient well-being and quality of life.

- Recruitment, retention and retirement issues pose a substantial threat to sustainability and development of the specialist nursing workforce. Succession planning needs to be addressed as a matter of priority to ensure that existing expertise is not lost to the service.
- Recognition of the value of specialist nurses by the directorate and organisation is a prerequisite to protect and enhance these roles in times of austerity.

## **Recommendations**

- 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.
- Develop a career pathway for HIV nurses including a structured training programme for advanced nursing 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.
- 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 measures and tools that are sophisticated enough to evaluate the advanced nursing contribution to the effectiveness of HIV services.
- 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.



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