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WHAT DO WE DO? AN EXAMINATION OF HIV SPECIALIST NURSING ROLES ACROSS ENGLAND.

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Background - current HIV situation

- Changes in commissioning and funding of services are having a direct impact on service delivery - more for less
- Current tendering of some GUM services are leading to fragmentation of services and instability of the workforce
- The HIV population is changing
  - majority are long term stable
  - increasing ageing population with complex co-morbidities

Background - HIV nursing

- Changes in commissioning and funding serve as powerful drivers to expanding the advanced nursing contribution to HIV care
- In a national survey of NHIVNA members, the majority reported functioning at advanced practice level in some aspects of their role (Barker, 2014)
- However, the extent to which the nursing contribution is currently utilized and the potential for expansion of that contribution, particularly at the level of advanced practice is unknown
- A recent scoping review identified an overall 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 (Tunnicliffe et al, 2013)

What is Advanced Nursing Practice?

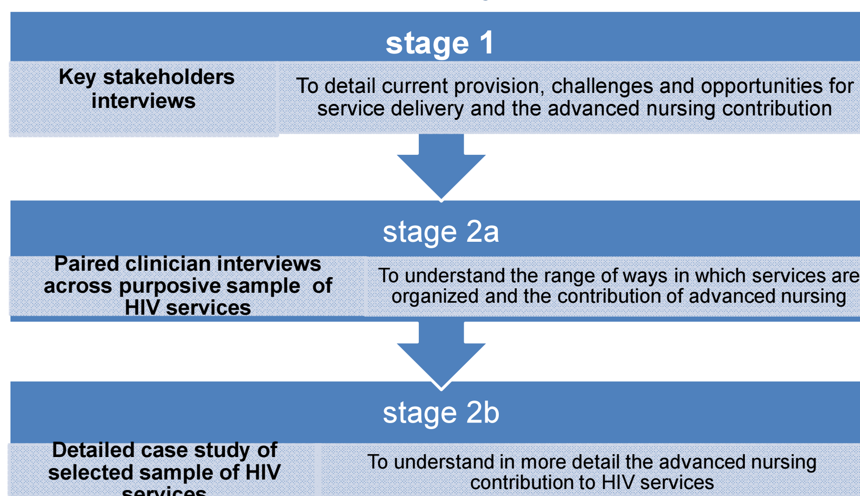
- Dept of Health - Advanced Level Nursing: A Position Statement (2010) identifies 4 domains of advanced nursing practice:
  - Clinical/direct care practice
  - Leadership and collaborative practice
  - Improving quality and developing practice
  - Developing self and others
- *'All four domains and their associated [28] elements must be demonstrable within the nurse's current role.'*

Study aim: To examine how advanced nursing practice currently contributes to HIV care and the potential for maximising that contribution.

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
- 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

Overview of the study



Stage 1 sampling and data collection

- Semi structured interviews with 19 representatives from key organisations representing commissioners, providers and recipients of HIV care
- Purpose - capture the views of key individuals with specialist knowledge and ability to offer national and local insights into strategic and operational aspects of provision.

Stage 2a sampling and data collection

- Sampling approach
  - Initial advisory group input
  - Mapping of HIV prevalence across England (from HPA data)
  - Identified potential services from NAM service directory ensuring geographical spread
  - Screening phone call to potential sites to ensure CNS workforce and gauge interest in participating
  - Recruitment of 44 participants from 21 study sites
  - Research governance approvals from all participating sites.
- Data collection
  - Semi-structured telephone interviews with a nurse from each service and a nominated medical colleague
  - Digital recording and full transcription
- Framework analysis

Stage 2b sampling and data collection

- Sampling approach
  - Purposive selection of sites involved in stage 2a to ensure maximum variation in roles, setting, caseload
  - Indication of nurses working at an advanced level
- Data collection
  - 2 day site visits
  - Interviews with members of MDT
  - Non-participant observation of meetings
  - Examination of service documents

Findings

- An overview of the nurses and their services
- Examine aspects of the HIV CNS role and their value to the service
- Consider the requirements for developing and maintaining the workforce

Overview of the nurses in stage 2a

- Length of experience
  - Majority >10yrs in HIV, ¼ 20 years experience
- Qualifications
  - Majority were graduates
  - 8 qualified to masters level with 3/8 qualified as Advanced Practitioner
  - 13/22 non-medical prescribers
  - Most had completed some HIV specific education, most commonly ENB courses
- Job title
  - Majority were Clinical Nurse Specialists (CNS), one Advanced Nurse Practitioner (ANP), three Health Advisors (HA)
- Pay banding
  - Majority band 7, two band 8, minority band 6.

Overview of the HIV services in 2a

- Service types - HIV units, sexual health services, Infectious diseases Units, community services
- Prevalence - 7 high, 14 low
- Cohort size - < 100 - > 6,000
- Geographical locations - 6 semi-rural, 11 urban, 4 metropolitan

Overview of the HIV workforce

- Huge variability in the CNS : cohort ratio, approximately 1:75 - 1:1500
- Considerable variability in the HIV nursing team structures - from single CNS practitioners to tiered team structure (bands 5-8)
- Variability in the composition of the multi-disciplinary team
  - Administrative support
  - Health care assistants
  - Specialist pharmacist
  - Health advisors
  - Social workers
  - Psychologists
  - Voluntary sector

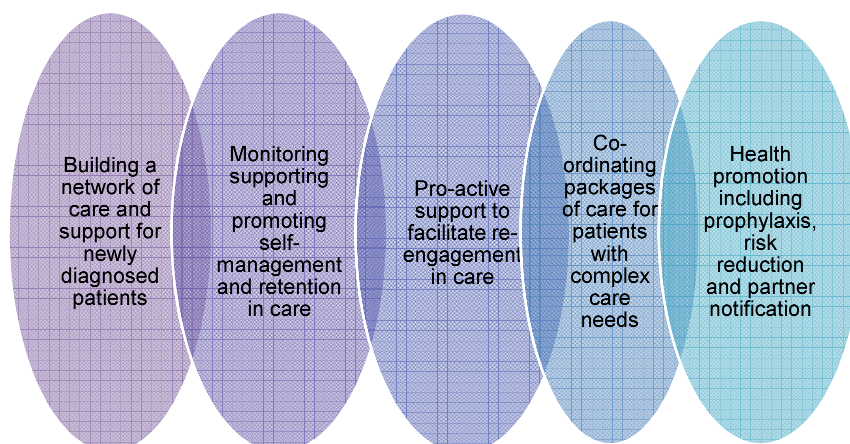
Overview of the data

- Considerable variability in terms of what constituted the role
- Evolved over time in response to:
  - Changes in HIV
  - Perceived service need
  - Expertise of the nurse
- Variability in levels of clinical practice - e.g. degree of autonomous practice /clinical decision making
- Key influences include:
  - Doctor:Patient ratio
  - Composition of the Multi-disciplinary team
  - Working relationships
  - Degree of support and supervision
  - Access to education and training
  - Workload and capacity issues

Categorising the data

- The majority of the data detailed the clinical aspects of care.
- We used these descriptions to develop a framework in order to:
  - map the commonality and variability in the way that the CNS role is realised within and between services
  - consider what constitutes advanced clinical/direct care practice within each of the aspects of care

Categorising HIV nursing - aspects of the role



Categorising the data

- Individual CNS roles may focus on specific aspects of care or span across the whole range
- One or more aspects of care may be addressed within any clinical encounter
- Incorporating the domains of advanced practice provides a matrix structure within which all aspects of the role can be captured and advanced practice can be articulated

Performing the role at an ANP level

	New patient work	Self management work	Re-engagement work	Care co-ordination work	Health promotion work
Clinical/direct care practice					
Leadership & collaborative practice					
Improving quality & developing practice					
Developing self & others					

Building a network of care and support for newly diagnosed patients

- The majority of the CNS's were involved with patients from the point of initial diagnosis
- Building a relationship with the service
- Activities include: educational, psychosocial and clinical assessment, signposting
- Influenced by the availability and role of the health advisor
- Significant time allocation reflects its importance

- *We'll see newly diagnosed patients …they come in to see the nurses first, so we can assess them. We can do all their baseline screening; we can spend time with them. As you know 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 (CNS)*
- *She is seeing the newly diagnosed patients, where she is telling them about HIV, assessing them, as well as looking to them from the clinical point of view. She can decide if this is routine or they need to be looked at tomorrow or maybe today .. she has got this clinical sense, and she makes that decision (Physician)*

Monitoring supporting and promoting self-management and retention in care

- Substantial part of clinical work, particularly for a hospital-based CNS
- Most CNS were running clinics for regular reviews and monitoring
- An area of care where prescribing and clinical assessment skills are particularly valuable

Nurse run clinics - 'substitution' model

- Primarily for medically stable patients but much wider remit in many cases
- Biomedical focus - with an added nursing dimension
- Operating in high and low prevalence areas, particularly where shortage of medical cover
- Expanding area of practice
- Offers scope for alternative approaches to providing care - virtual clinics, outreach provision etc.
- Prescribing and clinical assessment skills required for maximum benefit

- *So when I first came into this role I was meant to be seeing stable patients on treatment, and stable patients off treatment. And it's just never worked like that ... so it's just a case that I ended up seeing various types of patients, and it just continues like that (CNS)*
- *Yeah, so I manage all the HIV care there [in prison service]. The consultant would go in but he's never needed to in the five or six years we've been providing it (CNS)*
- *I have my own caseload of patients which is supposed to be an asymptomatic clinic or stable patient clinic but anything ends up coming into that as is often the case. So that will be involving managing patients who are on and off treatment, starting new regimes and changing regimes. I'm a nurse prescriber so I will prescribe drugs as well (CNS)*

The wider components of care

- *I tend to do a lot of prescriptions and monitoring of results and phone calls of results (CNS)*
- *We also have a nurse recall list, which we run every day for patients who have abnormal results or anything to call them back to (CNS)*
- *The CNS has a much more hands-on communication on a sort of day-to-day basis with the patients …..managing issues as they arise (CNS)*
- *The vast majority of my work is providing psychological support for patients, so looking at adjustment to disease, HIV diagnosis, looking at thinking about starting treatment, disease education, treatment education and ongoing support around symptom management…. addressing complex adherence issues (CNS)*

Value of advanced practice

- *I could do these clinics without having to wait 20 minutes in the corridor for someone to prescribe a drug for me, for the patients I had (CNS)*
- *I've done a master's on advanced practice. So I've been able to see people, examine them, diagnose, treat, prescribe, and request investigations, and interpret some but not x-rays (CNS)*
- *I saw a man …..said to the consultant I would like to start him on treatment. He said yes, I think that's absolutely fine, check with the pharmacist, the three of us did it together via email correspondence* (CNS)

Value of advanced practice

- *These patients who are … just a bit chaotic. We know these are the people who will suddenly turn up to clinics, saying they stopped their drugs two months ago …. It's an early warning … we won't just wait for them to call: we'll keep checking on them …to try and get an idea of what and how are their problems. It's about showing that those interventions prevent admissions and even failures…. that the work of the CNS reduces people coming to hospital, even to A&E (Physician)*

Pro-active support to facilitate re-engagement in care

- Most of the CNS's were involved in managing non-attendance and supporting re-engagement in those at risk
- Nurse developed structures and processes to identify and track those at risk of disengaging from care
- Range of mechanisms through which to access patients determined by the availability of a community resource
  - Refer to community team
  - Undertake community visits
  - Liaise through community organisations
  - Opportunistic targeted input when attend clinic

This is essential work …

- *The nice thing about being in a community trust, I can still do home visits...so if needed go and see people at home or bring somebody in...if that's the only way somebody can come in we do it (CNS)*
- *We have a significant problem with patients who drop in, drop out of the service, who are diagnosed and we never see them again, and then what happens of course is that group of patients they turn up somewhere two years later when they're sick and ill and have prolonged inpatient admissions. We use the CNS role to try and address this in terms of trying to get them to engage with the service. (Physician)*

But services struggle to do this work if no community HIV nursing provision

- *Some patients we have had real problems … they just genuinely seem to be lost to follow up. So we do as much as we can [phone calls, texts, letters, liaise with GP] but you do always get some patients that just disappear (CNS)*
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- *We developed a complex patient database …patients that need more intensive care and support. And so we've got 70 patients on the complex database, we're putting them on, but then not having the resources to follow any of this up ….. We need a community outreach team, to be able to go out, re-engage them back into care and support them through those difficult times, but we just haven't got that (CNS)*

Co-ordinating packages of care for patients with complex care needs

- Largely the domain of those with community remit.
- Characterised by:
  - Sustained periods of involvement - intense and over prolonged periods of time
  - Caseload management system

Prolonged and purposeful engagement

- *People with complex needs…for example a guy that we visit weekly now, he was diagnosed two years ago with a CD4 count of 4, with PML as well, but is still here and is doing astonishingly well. He went home with a hospital bed, district nurses were going in and carers were going in every day, and we were going in twice a week to support him and his mum. Now [the input] is just us going in once a week, and he goes to hospital for physio. He's in the process of learning to walk again and he can eat and everything (community CNS).*

Value to the patient and service

- *Wherever I've worked before, where these services did not exist …these patients largely died quite quickly. It's the CNS who keep these people engaged, work with them to decide what issues need to be addressed, in which order, engage with clinicians to try and make sure things are done in an coordinated way and no one's doing everything twice (Physician)*

Health promotion including prophylaxis, risk reduction and partner notification

- **Partner notification**

- Approximately one third were involved in some aspects of and a small number had overall responsibility

- *Sometimes I would use [the health advisors] with some difficult PN, otherwise keep it with myself and my patients (CNS)*

Health promotion including prophylaxis, risk reduction and partner notification

Risk reduction

- Acknowledged as important part of the role

- *With a long-term condition, [doctors] get to a point where they know somebody too well. So they feel slightly odd asking people oh and by the way I know I haven't asked you for five years but are you having sex with anybody else, and, if you are, are you using condoms? And to me that's ridiculous, because you just ask them, don't you? ….There isn't that digging for further information, which to be honest for me is a nurse's bread and butter, quite frankly (CNS)*

- However, competing priorities could undermine capacity to do so

- *Health promotion, education, … smoking are all part of the package but … it's not the first thing … I've got a protocol in my head of all the things I should cover … but it's all patient lead. So it's not the first thing that comes into my head (CNS)*

Health promotion including prophylaxis, risk reduction and partner notification

Post-exposure prophylaxis (PEP)

- There is some debate about commissioning and delivery of PEP services.
- However, PEP fell within the remit of the majority of the CNS and where they instigated HIV CNS initiatives

- *We did an audit of the PEP clinic and found we didn't meet the auditable outcomes, like the BASHH/BHIVA PEP guidelines. So we agreed to try it as a nurse-led service, and I was in a good position to do that. So, after initiation .. all PEP follow-up and PEPSE, so occupational as well as sexual, comes to me in the clinic (CNS)*

Where is the nursing contribution is best directed?

….It [the specialist nursing workforce] is a hugely untapped resource … I don't think we are going to manage appropriately the size of the cohort without tapping that resource…. I don't see any reason why advanced nurses shouldn't be completely managing everybody who's stable well.'

advanced practitioners should flow between inpatients and outpatients in the community. They should be the ones working managing complex problems, co-ordinating packages of care, reducing loss to follow up, safeguarding stuff

Because I think it's the integration of care and sort of connecting community services, hospital services, connecting partners and children and that sort of thing, which is where I would see the main role for a nurse specialist

the cost effective way of managing these patients is to keep them out of hospital, keep them well …..that's where we feel we can most cost effectively and gainfully employ this meagre CNS resource

What is required to develop and maintain an advanced HIV nursing workforce?

- Education and training
- Certification and accreditation?
- Succession planning?
- Resource allocation?
- Ongoing professional development?
- Supportive nursing management structure?
- Skill mix that supports advanced practice?
- Standards for practice?
- Evidence impact?

Conclusions

- The CNS role varies substantially between services, largely as a result of incremental development and individual service need.
- Categorising the aspects of the role offers a structure within which to articulate individual nursing workloads and inform workforce reviews
- The CNS workforce do make an advanced nursing contribution to HIV care but there is substantial potential to develop and expand that contribution
- There are substantial challenges that will need to be addressed in order to capitalise on that potential and establish a sustainable advanced HIV nursing workforce across the country.

Thank you

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