HIV Nursing: The Fight for a Future

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<th>Speaker Name</th>
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<td>Shaun Watson</td>
<td>I have undertaken non-promotional paid work for Gilead and Gilead’s Outcome Services and Support Team. I undertake unpaid work for NHIVNA which is supported by Gilead, Viiv, MSD and Pfizer. I am a member of the Clinical Reference Group.</td>
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Being a nurse isn’t about grades, it’s about being who we are. No book can teach you how to **cry with a patient**. No class can teach you how to tell their family that their parents have died or are dying. No professor can teach you how to find dignity in giving someone a bed bath. A nurse is not about the pills or the charting. It’s about being able to **love people** when they are at their weakest moments.
Defining Nursing

Nursing is experienced at some time by almost everybody. It is done by millions of nurses across the world, yet it is still difficult to describe and is poorly understood.

The use of clinical judgement in the provision of care to enable people to improve, maintain, or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability, until death.
Record numbers of EU nurses quit NHS

Staffing crisis worsens as workers fear being unwelcome after Brexit
Brexit: Number of EU nurses applying to work in UK plummets by 96%, show figures
New nurse registrants from the EU

Total number of EU nurse registrants in the UK, January 2016–April 2017

The Health Foundation © 2017

Source: Nursing and Midwifery Council.
And I Could Bang on About....

- Privatisations and the selling off of the NHS
- Revalidation
- NMC fees
- Study Leave
- Financing of study and conferences
- Home/work balance
- Staff shortages, sickness level, re-banding of roles
- Lack of Emotional Support
- Vanishing Clinical Supervision...etc, etc, etc!
We Are in a Bit of Mess!
And Now This.....

Jeremy Hunt hints at lifting of nurses' pay cap

Health secretary Jeremy Hunt has signalled that the 1% annual limit on nurses' pay may be lifted.

Nurses say Hunt's pay rise for NHS staff is 'insulting' due to cuts

'There shouldn't have to be these horrific events for us to be valued by the Government'
The plans include an education framework that details outcome-focused standards for healthcare institutions and placement partners. The framework focuses on five areas: learning culture, educational governance and quality, student learning and empowerment, educators, and curricula and assessment.

Suggests replacing mentors with 2 new roles:
A pool of practice supervisors: defined as ‘any registered health and social care professional who facilitates and supports students with their practice learning where appropriate’. Practice assessors: nurses who will confirm student learning on a placement but not take an active role in training.

The consultation runs until 12 September. Go to nmc.org.uk for details.
Nurses do great things every day. But in extreme circumstances, a few nurses shine more than others. They do things above and beyond. These are the nurses who selflessly rise above their own expectations and who provide the care that can only be called heroic.

Jocelyn Cerrudo Sese
Nurse died running towards danger to help other victims on London Bridge

London fire: 'It's my duty to help', says nurse who rushed to burning building

Simone Williams volunteered to help victims who were in the west London block as it was engulfed in flames.

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The Changing Face of HIV

• In the 1980’s HIV and AIDS were effective death sentences with people living between 3-5 years, requiring frequent hospitalisation for periods of acute infection and specialised terminal care.

• In the 1990’s and 2000’s HIV was an illness of adherence with strict rules around timing & diet, there was a rebirth but with severe, debilitating side-effects from complicated ART.

• To today where HIV is defined as a ‘manageable, long term condition’ with little talk of AIDS but now with the added complications of an ageing population and long-term ART use.
Profile of HIV Caseload in England

- **New patients**
  - Newly diagnosed/started ART within past 2 years

- **Stable patients**
  - On ART, undetectable, no ongoing health concerns

- **Complex patients**
  - Cancer
  - Pregnancy
  - AIDS
  - Chronic liver disease
  - End organ disease
  - Viral hepatitis
  - TB
  - Additional social care or psychiatric needs

- **Representing 68,607 patients receiving HIV care in England in 2016.**

What’s Happening Within HIV

Support agencies are losing funding and closing down (Birmingham, Bristol, London)

Although there is online support this won’t reach those who can’t or don’t access online support.

This could lead to increased social isolation, self neglect and increasing complexities that will need to be managed...by us!
What Do We Do?

Care, Compassion, Courage, Communication, Commitment and Competence

- HIV testing and screening
- Monitoring and maintenance
- Management of complex needs
- Results and prescribing
- Vigilance and rescue work
Remember: Nurses are like icebergs. At any one time you are only seeing about 1/5 of what they are actually doing.
Advanced HIV Nursing

• The nurse is an experienced practitioner providing comprehensive care beyond the standard scope of practice and across a wider domain, possessing considerable skills and knowledge in the field of HIV. The nurse practicing at this level demonstrates expert problem solving and sophisticated clinical decision making skills working autonomously within the context of a wider multidisciplinary team. Nurses working at this advanced level will be able to manage a caseload of patients with differing and complex physical, social, psychological, cultural and spiritual needs; from HIV diagnosis through to commencing medication and managing treatments and care.”
The purpose of the research study was to make recommendations to those in national and local leadership roles on how HIV services should develop over the next 5–10 years.

The investigators looked at the current situation for HIV services and the challenges and opportunities that they face.

They studied four areas in England as examples of urban and rural, low and high prevalence areas, undertaking focus groups with people living with HIV and interviewing around 100 people in local and national HIV services.
Figure 1 Increasing number and age of people living with HIV in the UK

Number of people

Per cent

2008 observed
2013 observed
2019 estimated
2023 estimated
2028 estimated

0 10 20 30 40 50 60 70 80 90 100

61,000 81,500 94,000 103,300 112,700

<15 15-24 25-34 35-49 50-59 60-69 70+

Source: Yin et al 2015
England has an outstanding record of achievements in HIV prevention, treatment and care.

It performs well on the 90:90:90 targets set by UNAIDS and achieves clinical and virological outcomes of care that are among the best in the world (Kirwan et al 2016).

HIV services in England are at a transition point which is characterized by:

- Changing needs
- Changing roles and responsibilities
- Changing policy environment

• In the 1980s and early 1990s HIV services were provided within highly specialized centres and funded separately to the rest of the NHS. Towards the end of the 1990s, commissioning responsibilities were devolved from the centre to PCTs.

• In 2012 the Health and Social Care Act created a new and complex model for the commissioning and provision of HIV prevention and care splitting responsibilities for commissioning across the HIV care pathway.
Who Does What?

• NHS England is responsible for commissioning HIV treatment to a national service specification through its specialised commissioning programme.

• Local authorities are responsible for HIV testing and prevention as part of their public health functions. Local authorities are also responsible for commissioning broader sexual health services to prevent, diagnose and treat sexually transmitted infections (STIs).

• CCGs are responsible for HIV testing and diagnosis within other treatment episodes that they fund. They are also responsible for commissioning the treatment of most other co-morbidities (such as hypertension) that are experienced by people living with HIV.
And There’s More

- Responsibility for commissioning some other HIV services such as peer support and counselling is not set out in law, so is discretionary and for local determination. These services are generally commissioned by local authorities and, in a few cases, by CCGs.

- **Arrangements for Community HIV clinical nurse specialists** are also determined locally and are usually commissioned by CCG’s.


Figure 2 Responsibilities for commissioning HIV care in England

Prevention
- Prevention
- Use of ART

Testing and entry into care
- Home sampling and testing
- Sexual health clinic testing
- Primary care testing
- Testing in hospital
- HIV treatment
- Antenatal screening
- Treatment in prisons

Ongoing treatment and care
- STI treatment
- Drug and alcohol treatment
- HIV support services
- HIV treatment
- Clinical nurse specialists
- Co-morbidities
- Primary care
- Treatment in prisons

Legend:
- Local authorities
- Local authorities or CCGs
- CCGs
- NHS England specialised commissioning
- NHS England or CCGs
- NHS England screening commissioning
- NHS England justice health commissioning
And All This Has Lead to...

- **Fragmentation of HIV services** – for example a person with HIV and another STI may need to access two separate services.

- **Increasing financial pressures** – for example lack of funding for prevention strategies.

- **Weakening role of national bodies** - for example there is a need for national oversight in preventing the spread of a potentially life-limiting communicable disease that has high treatment costs.
Findings

• Excellent quality of care
• Poor feedback for engagement with GP’s and Non-HIV specialists ‘passed from pillar to post’
• Stigma remains an issue particularly in non-HIV specialist settings
• Future models of care – most areas identified a need to change
• Reduced co-ordination of planning with mental health and with drug and alcohol services.
• Some places had developed aspects of ‘shared care’ (specialists and GPs working more closely together) and these pioneers might have lessons that could be applied more widely in HIV care.
Findings

• Despite the increase in the number of older people living with HIV, none of the study areas were planning for how HIV care would be co-ordinated with social care, for example, in care homes.

• Especially outside London, individual GP practices see very few people with HIV, and GPs’ involvement in HIV care is limited as a result. Nonetheless, primary care has an essential role in developing shared care.

• A consistent focus on increasing testing. But testing was often not accompanied by wider approaches that address the social and cultural drivers of sexual health behaviour.

• There were promising signs that early diagnosis and initiation of treatment, and increased use of PrEP might be helping to reduce positive diagnoses in London.
Conclusion

• Closer partnerships are needed between specialised services and other health services, including GPs, and with social care services.

• NHS England should support the development and adoption of new models of HIV care (after a new Government is formed).

• Stronger national leadership is needed to take action to reduce stigma, both in general and in non-HIV-specialist health care, and to support and co-ordinate the roll-out of future models of HIV care and develop the HIV workforce.

• HIV services must be designed locally to reflect the diversity of needs.
What Can We Do?

• We are unique, amazing people but we terrible at self-promotion and shouting about what we do! We devalue, undersell and over simplify our work and it’s complexity (Alison Leary)
  • Realise that we have a wealth of knowledge and experience. Let others know
  • Network – don’t assume other nurses will do this
  • Talk – spread the word at work, to your team, CCG’s, patient forums
  • Publish – write about what we do and get it in print.

• Tell us! NHIVNA is your organisation and we work for you. We also report into:
  • Clinical Reference Group – want to know any issues that effects patient care.
  • FHIVA (Federation of HIV Associations) use the power of our colleagues.
HIV Service Specification

• The HIV CRG act as the advisory board to NHS England
• The HIV CRG service specification places advanced nursing practice as fundamental to deliver integrated care for specialised HIV services.
• It is due to be rewritten – get involved, the voices of nurses need to be heard.
• The role of nurses in the management of stable patient clinics, over 50 clinics, community and complex care management need to be highlighted.
• Evidence what you do as much as you can!
What Are You Talking About Shaun?

• Raise your voice whether you are POLITICAL or ‘political’
• Be an advocate for your patients – don’t let our services suffer
• Get involved if you feel something isn’t fair – don’t allow support services to go without a fight.
• Answer questionnaires, comment on draft guidelines, complain!
• We should be proud to be HIV nurses. We work smart, we add value and constantly go the extra mile.
Thank You!