Proving the worth of HIV nurses

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Abstract
Rarely have nurses had to justify and quantify their role. However, since the recession in 2008 and far-reaching cuts across health care, nursing roles have been put under scrutiny. Nurses now have to work to outcomes and targets for the first time, and the value of the nurse, their role and worth to health care is being questioned. Once seen as a safe role within care many nurses now feel pressurised to justify and expand their role to add value. But what does this mean? How can nurses prove their worth and add value, and what tools are available to facilitate this change?

Keywords: added value, worth, validation, HIV nurses

A. Revalidation

This article has been prepared with continuing professional development (CPD) in mind and can be used to support your revalidation. It is estimated that 2.5 hours of CPD activity will be required for completion of the reading, 'time out' activities, the quiz and for writing a brief reflective account in relation to your learning and its applicability to your practice. There is a self-assessment quiz at the end of this article for you to assess what you have learnt.

B. Aims and intended learning outcomes

After reading this article, undertaking the activities and completing the self-assessment quiz you should be able to:

- describe your role as a nurse and your place within health care and the multidisciplinary team (MDT);
- demonstrate how you can show your worth within health care;
- discuss the specific aspects of your work where you feel you add value; and
- evaluate your role and discuss the added value it brings to health care.

C. Introduction

Nursing has many varied definitions:

> *'Nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. Nursing includes the promotion of health, prevention of illness, and the care of ill, disabled and dying people. Advocacy, promotion of a safe environment, research, participation in shaping health policy and in patient and health systems management, and education are also key nursing roles.'* [1]

adding:

> *'The unique function of nurses in caring for individuals, sick or well, is to assess their responses to their health status and to assist them in the performance of those activities contributing to health or recovery or to dignified death that they would perform unaided if they had the necessary strength, will, or knowledge and to do this in such a way as to help them gain full of partial independence as rapidly as possible.'* [1]

The World Health Organization states:

> *'nursing encompasses autonomous and collaborative care of individuals of all ages, families, groups and communities, sick or well and in all settings. It includes the promotion of health, the prevention of illness, and the care of ill, disabled and dying people'* [2]

whereas:

> *'21st Century nursing is the glue that holds a patient's health care journey together. Across the entire patient experience, and wherever there is someone in need of care, nurses work tirelessly to identify and protect the needs of the individual. Beyond the time-honoured reputation for compassion and dedication lies a highly specialised profession, which is constantly evolving to address the needs of society. From ensuring the most accurate diagnoses, to the ongoing education of the public about critical health issues; nurses are indispensable in safeguarding public health.'* [3]

All of these definitions encapsulate so much of what nurses do today, however, in climates of tightening budgets, shrinking resources and evidence-based practice, nurses are being asked to prove that what they do has merit and asked to prove what value they bring to their role, moreover what added value they bring. The Nursing and Midwifery Council (NMC) state that nurses make up the largest proportion of the workforce across health with a total of 706,252 (nurses, midwives and nurse associates) in England [4], and globally within the field of HIV, nurses make up the largest workforce.

For decades nursing has been an assumed profession, assumptions that the work they do is needed, has worth and value with the proof being a healthier population, a reduction in hospital admissions, deaths and an increase in population age. Nurses are seen as heroes, hardworking angels, and rarely have they had to justify their roles. This is changing, especially for those clinical specialist roles that may be seen as a 'luxury'. Foster stated that when frontline nursing is stretched, most often during the winter, the Clinical Nurse Specialist (CNS) group are called upon to undertake frontline shifts, often because they are unable to tangibly prove their worth to senior managers [5]. Therefore, there is a belief that they have capacity. This group has been vulnerable for a number of years and subject to cost-cutting measures, blaming the lack of role clarity

on multiple roles, bands and titles for staff employed as CNSs with many delivering significantly extended and advanced practice, which was not captured well via clinical coding. Foster ends her article by stating, *'organisations must implement robust governance structures to record competency, enable clarity of roles, and ensure the delivery of safe, quality care.'* Multiple roles and titles have also been discussed by Leary *et al.* who stated that these multiple titles and unclear roles are *'confusing to the public, employers and those commissioning services'*, demonstrating previous assumptions that advanced practice labels are only associated with career progression and are unsound and should be addressed by the regulator [6].

Minimal staffing levels for patient care has ensured that ward and clinic-based nurses have a defined role as part of a team to supply consistent, safe care whereas clinical nurse specialists, nurse practitioners are seen as other [6–8]. Read demonstrated the value of the CNS, using a number of case studies, and that work carried out by the CNS might otherwise be completed by a more expensive resource [9], as did an economic assessment carried out by Watson in 2015 [10].

Time out activity 1

Briefly describe your role as a nurse, this should take up no more than 10 minutes.

Now think about how have you described what you do as a nurse?

What words have you used to explain what you do?

Would you describe your role differently to you manager?

Are there other words you could use to describe what you do?

Within HIV care, nurses have seen their role change over the last 30 years (see Figure 1). Initially as providers of acute, terminal care in the 1980s and early 1990s, managing the care of predominantly younger gay men dying of AIDS, until highly active antiretroviral therapy (HAART) came in during the mid 1990s and nurses developed the role of adherence and symptom control specialists, to today where the nurse's role is that of case managing and supporting long-term healthcare, self-management and promotion of health.

The HIV nurse's role should not be underestimated. HIV nurses take a variety of roles: they are working and leading HIV clinics, specialist hospital wards, providing case management in the community and offering support in care homes. Nurses work in education, sit on local and national trust boards, develop policy and work in the HIV voluntary sector. Nurses are involved in every stage of HIV diagnosis and treatment from initial testing to specialist case management (see Figure 2).

D. What is value?

How would you describe and quantify value? In terms of money, is value the cheapest or is value better quality 'buy cheap, buy twice'? Is value about the experience, is time valuable? When you think of value what do you believe? Imagine buying a cake, do you get a cheaper cake that tastes good or do you buy the more expensive cake that tastes great? Sometimes this will depend on your own finances, sometimes it will be the situation, are you buying the cake because you want it for yourself or is this a special occasion for someone you love? Do you make a cake which, financially, may be cheaper but will take up your 'valuable' time? Would the person value the homemade

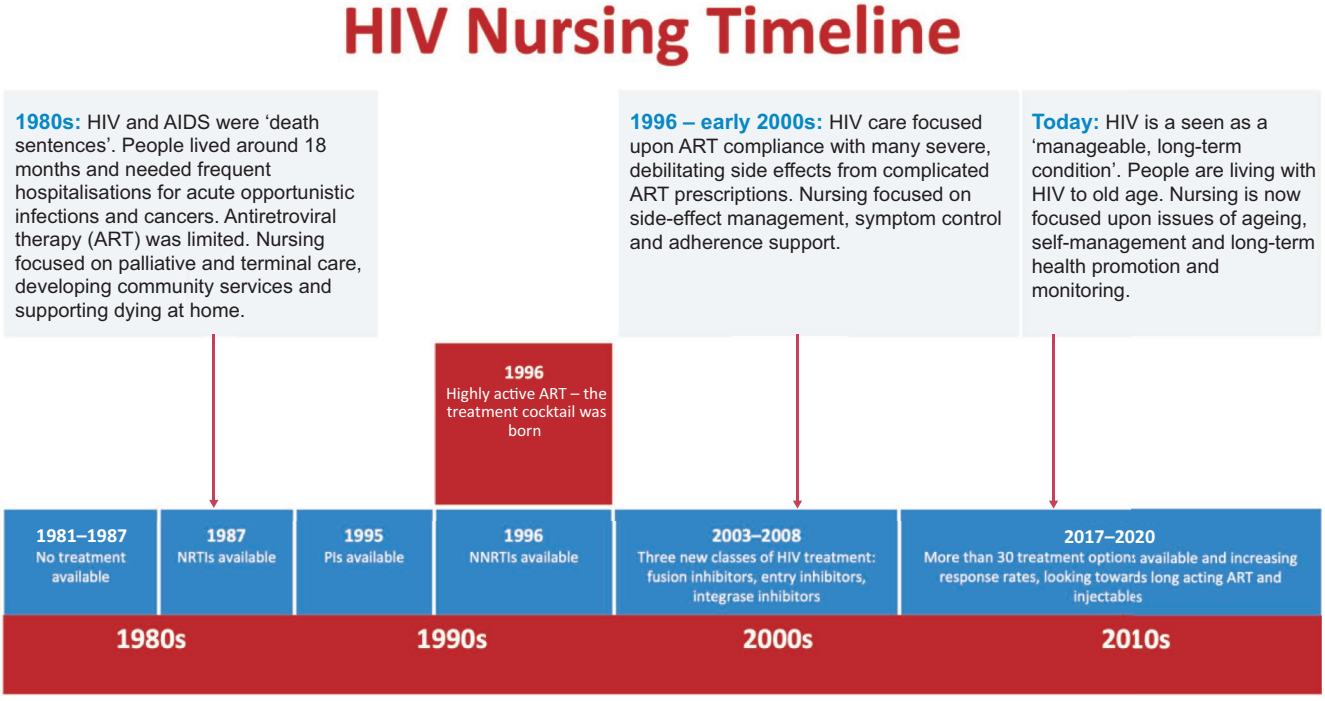

Figure 1: HIV nursing timeline. ART: antiretroviral therapy; NRTI: nucleoside reverse transcriptase inhibitor; NNRTI: non-nucleoside reverse transcriptase inhibitor; PI: protease inhibitor.

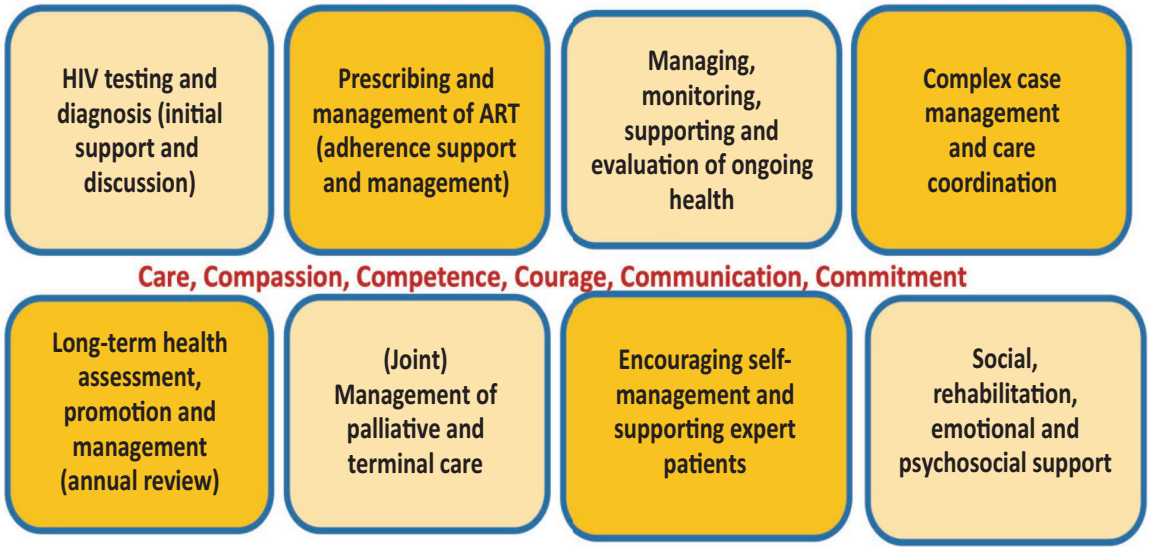

Figure 2: HIV nursing roles. ART: antiretroviral therapy.

cake more or a shop-bought one? In health care we can *'achieve the best outcomes, do it with minimal cost and do not sacrifice quality'* [11]. Porter said:

> *'Value should always be defined around the customer, and in a well-functioning health care system, the creation of value for patients should determine the rewards for all other actors in the system. Since value depends on results, not inputs, value in health care is measured by the outcomes achieved, not the volume of services delivered, and shifting focus from volume to value is a central challenge.'* [12]

Value-based care can also be defined in terms of the *'health outcomes achieved per pound spent'*, and health services can create added value by focusing on how the service is organised, performed and paid for in relation to the outcomes achieved in terms of patients' health and experiences of health services [13]. Nurses contribute to creating value in health care as:

- a key structural component in the provision of healthcare services (skills, knowledge); and
- leaders and innovators in improving processes and the organisational environment in which healthcare services are delivered (such as specialised nurse-led services that prevent onward cost, for example infection control). The value of nursing in health care is a function of both cost and quality [14].

E. Leading Change Adding Value

Recognising the nursing's potential to manage challenges in health care and shape its future, NHS England published a national framework for all nursing, midwifery and care staff in England. *Leading Change, Adding Value: a frame-work for nursing, midwifery and care staff* focuses on improving care by demonstrating the nurse's impact and reducing unwarranted variation in care [15]. It builds upon the six aspects of 'Compassion in Practice': compassion, care, commitment, courage, competence and communication, and is directly aligned with the NHS's *Five Year Forward View* in seeking to develop new ways of working that are person-focused and provide seamless care across the boundary that has traditionally separated health and social care [16]. The National Framework aims to target three crucial gaps identified in the *Five Year Forward View*. These are:

- **Health and wellbeing:** without a greater focus on prevention, health inequalities will widen and our capacity to pay for new treatments will be compromised by the need to spend billions of pounds on avoidable illness.
- **Care and quality:** health needs will go unmet unless we reshape care, harness technology and address variations in quality and safety.
- **Funding and efficiency:** without efficiencies, a shortage of resources will hinder care services and progress.

Leading Change Adding Value gives 10 aspirational commitments shown in Box 1.

Time out activity 2

Look at your current job description, does this accurately describe what you do?

Are there areas of you role that are missing, are there described roles that you don't do?

In line with the '*Leading Change Adding Value*' commitments how many of these are you doing now, and if so is this reflected in your job description?

F. Proving your worth

This next section is adapted from an article written by Alison Leary in 2011 [17]. Rarely has the role of the nurse been fully explored. There is an implicit understanding of what nurses do, needing very little, if no, evaluation and reassessment of their role. However, due to the recent and possibly current recession there have been huge financial cuts, service reorganisation and changes in 'safe' staffing levels. All nurses need to demonstrate their worth and value in the workplace. Traditionally this may have been carried out by 'time

Box 1. Aspirational commitments from NHS England's *Leading Change Adding Value* [15]

1. Promote a culture where improving the population's health is a core component of practice, such as sign posting or referring to supportive services, providing annual reviews or responding to your local HIV population's need, such as setting up HIV testing services in churches, sex venues or LGBTQ+ bars and clubs.
2. Increase the visibility of nursing and midwifery leadership and input to prevention. This can be achieved by championing and extending prevention and health promotion responsibilities or collectively supporting a 'social movement for health', including social media, national campaigns and local action, such as supporting the work of organisations like the British HIV Associations (BHIVA) '*Standards of Care*'; the National HIV Nurses Association's (NHIVNA) support of issues around pre-exposure prophylaxis (PrEP), U=U (undetectable=untransmissible); or taking on board the annual health review and developing annual reviews in your clinic.
3. Work with individuals, families and communities to equip them to make informed choices and manage their own health. This can be achieved by making every contact count, making the most of the time we have with patients, such as discussing long-term health promotion, or offering other nurse-led services (e-clinics, apps etc.)
4. Focus on individual-centred care, putting people, their families and carers at the centre of developing and delivering all aspects of their care; providing equal importance on meeting the physical and mental health needs. From the beginning of HIV care, nurses have worked holistically, realising that HIV effects and affects every part of someone's life, not only physical health but their work, home, relationships, etc.
5. Work in partnership with individuals, families, carers and loved ones, something that HIV nurses have encapsulated since the 1980s, looking at supporting not only the person living with HIV but their family or significant others. This also involves working effectively with the voluntary sector, thereby looking outside health and social care provision.
6. Actively respond to what matters most to staff and colleagues. This can include arranging study sessions, mentoring or supporting staff, discussing case studies, evaluating conferences and study sessions, and developing future training based on these evaluations.
7. Lead and drive research for evidence in care. This can be achieved by writing up an audit for a conference or writing an article or case study for a journal, such as *HIV Nursing* or *Nursing Times* etc. A good example of this would be NHIVNA's *Research and Development Strategy for HIV Nurses* [26].
8. Provide the right education, training and development such as developing research [26] and educational strategies to develop the HIV workforce.
9. Have the right staff in the right place at the right time. Evidenced in NHIVNA's advanced nurse document and ensuring that we recognise and challenge staffing levels or conduct audits to demonstrate the benefits of additional staff.
10. Champion the use of technology and informatics to improve practice, address unwarranted variations and enhance outcomes, such as developing electronic clinics, skype clinics or innovative ways of working in the community.

and motion' studies where the nurse would account for what they do and when, looking at downtimes and describing their tasks, and where they fit in the MDT. In her article 'Proving Your Worth', Leary suggests that nurses think about and demonstrate their value before their manager moves them elsewhere, stating clearly that the nurse shouldn't assume that their managers understand the full extent of what they do? Leary's work is very much based on the role of the CNS but in the current climate this could and should apply to all nurses. Historically the CNS role has been deemed the most 'at risk', seen as a luxury with anecdotal praise for what the role achieves but no understanding of the nurse's worth and value within health care. CNSs have also done very little until recent times to show this worth [7,10,18]. With sweeping financial and resource cuts and the introduction of the NMC's demands around revalidation, all nurses should now have the ability to assess, evaluate and prove what they do on a day-to-day basis, however difficult they may find it. This may involve demonstrating not only how the nurse keeps up to date in their practice but how they spend their time at work? Can they describe the complexity of their work and quantify their contribution to safety, quality and efficiency? Nurses often fail to think about the impact their role has, and this may only be brought up in revalidation, appraisals or performance reviews when the nurse is forced to think about, discuss and demonstrate their impact on the patient and service they are working for. Leary sets out ways that nurses can enhance their profession and prove the worth of their work. Leary sets out the following, which has been adapted to reflect the work of HIV nurses:

Be an HIV specialist and add value as a generalist

Since the early 1980s HIV care has been a highly specialist service with HIV clinics providing a sheltered, non-judgmental, stigma-free, confidential, one-stop shop. However, over the past 15 years or so HIV services have changed. Increasing numbers of people living with HIV taking more sophisticated antiretroviral therapy (ART) has meant the need for less ongoing monitoring and a tightening of resources, hence reduced clinic visits. There has been a push to move some services to the community, such as HIV testing. People living with HIV are encouraged to have a GP who is aware of their diagnosis. Specialist HIV pharmacies are now only dispensing ART, with all other generic medications sourced by general pharmacies or home delivery. An ageing, physically and socially complex HIV population means that those living with HIV need to access other specialties such as cardiology, oncology, renal and endocrine services, which can lead to issues of discrimination, stigma and lack of confidentiality. With some people living with HIV failing to engage with other services or needing additional support and advice, HIV services, and those working there, are having to manage issues other than HIV and become more generalist in their outlook. When thinking about planning and conducting annual health reviews, how much of this is specialist HIV care (very little) versus how much of this is general health care and health promotion? However, the HIV nurse rarely, if ever,

overlooks issues of health unrelated to HIV with an implicit understanding that they are working holistically with an individual living with HIV. For example, rarely is the management of medication compliance done in 'HIV' isolation, the HIV nurse will support someone taking their generic medications alongside HIV, recognising and reporting expiry dates, low stock and drug–drug interactions [19]. The same can then be said about mental health and/or drug and alcohol services which tend to work in silos with little cross sharing of information, in some cases passing the patient from one specific service to another with no resolution, ending with the HIV nurse case managing the patient with the other services referred in and out as needed. This has been reflected in the recent National AIDS Trust (NAT) document, *Providing coordinated care for people living with HIV* [10,18,20].

Leary asks specialist nurses to consider if their work is truly specialist. Asking them to think about whether they are doing the work of someone else or acting as an administrator? In HIV care this is often the case, with strict boundaries around social care, mental health and district nursing, HIV nurses often pick up tasks that others services should (but can't or won't) do [7,18]. This may include completion of benefit forms, signposting or referral to voluntary services, making calls to GPs, hospitals and support groups. Issues that should be taken up by other services are not. Is it that the HIV nurse can ultimately see that by not making a call, filling in a form or informally supporting someone with extra visits or phone calls, the health of their patient may suffer?

Leary asks that nurses think about the uniqueness of their work and whether they are using in-depth technical knowledge to help manage a caseload towards better outcomes. Within HIV care, nurses often pick up drug interactions, or through vigilance, learn something that they need to act upon, something that someone less skilled wouldn't necessarily pick up. This may be via a phone or face-to-face conversation or noticing something about the patient's appearance or demeanour. For community nurses that could be noticing issues at home such as hoarding, chaotic environments, patient temperature, cleanliness or infestation. A simple question like 'Can you show me where you keep your ART?' can reveal more areas of concern.

The language we use

Leary advises nurses to describe their role in the use of 'appropriate but not simplistic' language. For example, 'I manage and support the continuing care of people living with HIV' is better than 'I care for people with HIV' or 'I care for people living with HIV by assessing, monitoring and responding to their ongoing general and HIV health needs' is better than 'I support the needs of people living with HIV'. Think about how you describe your role and what you do, and don't downplay what you do, 'I made a few phone calls' does not fully explain the communication that is needed, for example, in referring someone for peer support, in the 20-minute conversation with a patient who feels isolated, in managing someone with a personality disorder who may have left 20 messages overnight and needs reassurance, or for referring a patient to a GP or community service that may prevent an unplanned hospital admission. Although this may take time to document or discuss, a brief explanation of the range of issues you have managed over a shift is preferable to reducing this to 'I made a few calls'.

The role of nurses is difficult to evaluate

Leary states that the CNS role is often invisible because much of it contributes to patient management through increasingly complex care pathways, adding that the (specialist) nurse acts as a 'fail safe' in preventing injury, detecting symptoms and often dealing with issues before they become complaints [21]. However, there is a perception that the contribution made by some nurse roles is intangible and difficult to describe. Some services have broad outcomes with 'avoidance of hospitalisation' being the main one which is a fairly intangible outcome to measure. This may certainly be the case within HIV care where hospitalisation may be caused by a myriad of issues associated with HIV, but not under the remit and responsibility of the specialist nurse, for example acute or long-standing mental health issues, drug or alcohol-related admissions. Some outcomes are easier to measure, such as managing the treatment adherence of a patient who is detectable and proving that the nurse's input has ensured undetectability, or that the nurse's management of a patient has shown a reduction in GP visits or ambulance calls [10]. The role can be also be justified with quantitative data backed up with descriptions of the nurse's role and examples of work scenarios such as case studies. As Leary states, *'Gather your facts and prepare your case.'*

Rescue work and vigilance

Leary also says that the nurse's contribution to patient safety is immense and involves rescue work (first described by Silber *et al.* in 1992 [22]), which includes the early detection of impending deterioration and taking pre-emptive action to prevent adverse events/hospitalisation. Within HIV care this can involve in-depth physical, psychological and socioeconomic assessments, carrying out an annual health reviews or discussing health promotion, such as smoking cessation, increasing exercise, change of diet, or reducing drug or alcohol intake. For nurses who prescribe, this could also involve physical examinations and detection of illnesses or infections, recognising drug errors or interactions, addressing insomnia or anxiety caused by illness or ART.

Leary also includes vigilance in the nurses contribution involving active patient monitoring and is a cornerstone of patient safety. Preventing unscheduled admission is integral to the work of many specialist nurses. For example, do you intervene if a patient needs symptom control and refer them to the GP, community services or appropriate acute service well before the patient is forced to attend the emergency department? How can you demonstrate this? Vigilance, detective work,

nosiness, gut feeling, it's all the same and involves pre-emptive measures that will enable the person living with HIV to live a healthy, active life. Vigilance can be recognising that someone looks different (unshaven, no make-up, looks unkempt), is quieter or more talkative than normal. It can involve scanning someone's room and noticing a pile of bills that haven't been opened, a cold room, unclean smells, evidence of increasing drug or alcohol use, the person is untidy, they have cancelled appointments or uncharacteristically failed to attend clinic when they have run out of ART.

Time out activity 3

Your manager/commissioner states that your role is no longer required, how would you convince them otherwise?

What would be the consequences to your colleagues, your patients and HIV clinic if your role was taken away?

Think about the wording you use and Leary's advice to convince your manager to keep you [17].

G. What can you do?

1. **Use language appropriately**. You case-manage, advise, monitor, assess and evaluate. We also care and support but nurses need to lose words that downplay what they do!
2. **Collect quality data about what you do**. Think about the small stuff. Patient conversations that reveal something not noted before MDT discussions may throw up new issues that the nurse can manage. Service audits are useful tools to show what nurses do, for example something simple like noting every call made or patient conversation. In the community, for example 'calling a GP to discuss a patient' does not fully show the 14 calls or emails the nurse made trying to get through to the GP.
3. **Get involved**. Is there nurse involvement in all areas of HIV care? Where is the nurse's voice? Don't assume there always is and assume someone else will do this. Even in perceived small surveys and studies, it is important to add a nurse voice, more so if this is part of service development, such as NHS England's *HIV Service Specification* [23] or BHIVA's *Standards of Care for people living with HIV* [24]. Adding a nursing comment or suggestions to online surveys shows presence and commitment to driving HIV care forward. Once a document is out it's a futile exercise complaining about the lack of a nurse voice.
4. **Discuss and write about what you do**. Don't assume that the people you work with know what you do. You can change this with small strategies such as having 10 minutes at a meeting to talk about your role in HIV care, or present a case study, particularly those cases for which there may not seem to be a solvable action but one in which HIV nurses led the way (or started the conversation). Present information from conference attendance or talk at conferences about HIV service innovation, case studies or audits.
5. **Don't be shy**. How many times have you heard 'It's not just me, it's the whole team' at conference, if you're *the* nurse in the research or MDT then it's you. Thank your colleagues, but don't downplay your nursing role when in reality the nurse developed, led and wrote up the research or audit.
6. **Innovate.** Discuss and develop nurse-led services. Are there are opportunities, not only around stable patient clinics and annual review, but for nurses to lead on management of complex care and the care coordination of HIV, as highlighted by NAT [20]? Nurses clearly have a role in the coordination of care, should take a lead as the named nurse coordinator and not sit behind their HIV consultant colleagues.
7. **Provide and present evidence** (publish, case studies, conferences). Discussing a complex case study at a conference is a good start as it's something you'd know well and your role in the case is well defined. Go to any international AIDS conference and nurses rarely appear on panels, as keynote speakers or as authors of posters. This suggestion may also involve requesting funding to go to conferences and developing a strategy to feedback to colleagues. In reality nurses downplay their role in management of care and this needs to be addressed. A nurse colleague from the Association of Nurses in AIDS Care (ANAC) suggests to all members to ask questions at conferences and to state that they are nurses when asking, to make the audience aware of nurse colleagues and to challenge panels where there is no nurse presence (even more shocking when the panel discussion maybe a discourse around issues such as nurse-led projects, future of HIV services and any area where nurses have input).
8. **Developing a future HIV workforce**. Advanced nurse practitioners with formal training in physical assessment and non-medical prescribing should be the norm [25]. Do HIV nurses need to enhance their role to drive nursing forward [26]? Yes, they do, but HIV services also need knowledgeable, experienced, skilled nurses of all grades and disciplines to shape and develop a future service [27,28]. Developing the next generation of HIV nurses, future training, and opportunities for student and newly-qualified nurses needs HIV nurse enthusiasm and input.

Time out activity 4

Think about the future of HIV services, how do you feel they will change and what would you do now to secure the HIV nurse role in the next 10–20 years?

H. Conclusion

Modern nursing has been around for centuries and has changed its scope as nurses continues to develop their roles. Within HIV care the nurse's role has changed rapidly over the past 30 years showing their flexibility and resilience. Proving the worth and value of the nurse and describing their role can be difficult at first,

as downplaying the nursing role perhaps comes easier than upselling what they do, it can also take time and energy. But this is also a task that can be completed as a group (in a clinic, on a ward) or by developing and writing a case study with a colleague. HIV nurses have the skills, knowledge and talent but need to unlock their vast potential, something HIV nurses need to think and act upon now … before somebody else does.

I. Acknowledgement

Funding

This article has been supported by an educational grant MAC AIDS. The company has had no editorial input to the article.

Conflicts of interest

Shaun Watson is current Chair of NHIVNA and has undertaken non-promotional and advisory work with several pharmaceutical companies (Gilead, ViiV and MSD).

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