

# HIV NURSING

CARING FOR PEOPLE AFFECTED BY HIV

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## **Aims and Scope**

*HIV Nursing* has been developed as a forum for those at the forefront of caring for people affected by HIV. The journal is supported by a highly respected Editorial Board drawn from a wide range of nursing specialties. This is further strengthened by an Advisory Panel who will be making regular contributions to the journal.

*HIV Nursing* is intended to provide a medium for communication on issues relating to HIV care, which will be run by the care professionals for those involved in the day-to-day matters affecting the lives of patients.

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# Adherence: still the Achilles' heel?

Juliet Bennett

Independent Nurse Advisor

Welcome to the autumn edition of *HIV Nursing*, in which we cover 'Health promotion and adherence' as well as including the Abstracts from this year's conference.

There are interesting insights in Cathy Ormiston's article exploring the use of nurse prescribing in the field of HIV. From her research, Cathy concludes that the benefits of nurse prescribing broadly outweigh the disadvantages. However, more robust research into this skill development is needed, with an emphasis on gathering patient views and experiences.

We are pleased to hear from Liverpool's HIV Community Nursing Team on their exercise to identify gaps in care and seek improvements, in the highly challenging arena of continued care for complex patients.

Also in this edition, Pauline Jelliman reports on her work with an educative and supportive women's health initiative in the north of England. 'Between the Sheets' has received impressive initial feedback and has huge potential for developments in the future. She urges nurses, especially those in specialist roles, to pursue issues which come directly from patients – being proactive in seeking out unmet needs and creative in exploring ways to meet them.

Finally, Rachel Bath's presentation, of work trialling opt-out HIV testing across different areas within a London NHS trust, was very well received in Birmingham and is written up here. Rachel highlights some essential components for such an initiative to succeed. Before implementing HIV testing in novel settings, the testing team needs a good understanding of how a department operates, and effective communication must be established between the visiting HIV team and permanent staff in the novel setting. In order for such initiatives to be sustainable, she writes, staff must be well supported and able to take ownership of testing within their local setting.

## Time to refocus?

Part of our role as promoters of health is to offer support around treatment adherence. This topic seems to have taken rather a back seat of late – perhaps eclipsed by ground-breaking advances such as treatment as prevention (TasP) and the fervent debate about biological cure. Clearly, however, adherence to treatment remains the cornerstone of success for all strategies involving use of HAART, whether to enhance the health and wellbeing of individuals living with HIV, or as a

method of preventing infection and/or reducing onward transmission. Perhaps we need to consider whether we have become a little complacent: is it time to refocus on adherence?

The proactive, and recently renamed, International Association of Providers of AIDS Care (IAPAC) last year published a new set of evidence-based guidelines [1]. There is a shared focus, on:

- **entry into/retention in care**
- **adherence to treatment**

These two areas of care are viewed as interrelated and integral to treatment success. Recommendations in several key areas include: strategies for facilitating retention in care; monitoring adherence to HAART; and interventions to bring about improvements. The guidelines also look in some depth at the specific needs of several marginalised groups, such as: pregnant women, people with mental health concerns, those who use drugs, and the homeless – making strong recommendations for future research in these areas.

IAPAC stresses that, although the advances in pharmacology have been remarkable in this area, many people remain unable to benefit fully from them – certainly, we all continue to see many patients who struggle to take their drugs consistently. The reasons for this vary, but in the developed world may include: late diagnosis, erratic clinic attendance, mental health problems and drug tolerance issues. The importance of 'all-round success' was neatly observed: '... ultimately, both individual and public health depend on helping patients to successfully negotiate all of the steps of this treatment cascade' [2].

Summarised below are several recommendations from this IAPAC document, along with BHIVA guidance also published in 2012 [3], which I see as key to our role as nurses. There is much other material of interest and value within both these guidelines. If you have not already done so, please do take a look at them in their entirety.

## Sticking at adherence

Monitoring adherence remains a key aspect of our role, even with today's simplified regimens and improved tolerability. Monitoring effectively should identify many of those at risk of virological failure due to reduced adherence, as well as assessing the effect of interventions and guiding service and resource allocation to support those who are vulnerable. Many studies use combined measures

(such as pill counts plus self-report) to improve sensitivity and specificity, because each method has strengths and limitations. Both BHIVA and IAPAC suggest patient self-report as a user-friendly and relatively accurate method – with BHIVA indicating a preference for a series of validated questions preceded by a permissive statement [4].

Also proposed by IAPAC is the use of pharmacy refill data where appropriate. However, biological sampling, microchip electronic dispensing devices and pill counts should not be used routinely. The latter is particularly labour intensive – and in my experience often felt by patients to be a ‘policing’ approach at odds with our attempts to work in partnership and build relationships on mutual trust and respect. BHIVA stresses that the beliefs of patients about their need for ART, and any specific concerns they may have about it, should be fully explored before initiating treatment. Whilst this is established doctrine to us as HIV nurses and we have various ways of incorporating it into our practice, there are perhaps certain areas of our profession where a more research-based exploration of these issues, constructed to be consistent and systematic, could be productive.

It is also essential that this adherence assessment does not descend into tokenism or be afforded only to perceived high-risk patients, tempting as this may be in hectic, time-limited clinics. Regardless of measurement method, we really should acknowledge that adherence is a factor that varies with time and must be repeatedly assessed. Can any one of us claim to do *all* of this, *all* of the time, with *all* of our patients ... in a proactive, systematic and evidence-based way?

## Building on improvements

As we all know, considerable progress has been made in improving tolerability and pill burden – known to be important determinants of treatment adherence for many people. Several recommendations are included in both sets of guidelines to this effect. In addition, a review of the evidence concluded that some commonly used self-management adherence tools (including pillboxes and medication planners or calendars), have been associated with improved adherence and viral load suppression in some studies [5]; whereas the IAPAC guidelines fall short of making such recommendations due to a lack of evidence. On the other hand, they do advocate the use of more interactive reminders. These may include texting dose prompts, clinic appointment reminders via mobile phones, follow-up phone calls and the use of reminder prompts. However, these should only be one element of a comprehensive approach which includes education and support on a one-to-one basis. Furthermore, although group work is not ruled out, current evidence is deemed insufficient to advocate one over the other.

IAPAC states that the evidence base suggests a benefit in providing some form of discussion-based support to individuals; but that such interventions should be carefully matched to clinic populations, needs and resources. Interestingly, and surprisingly perhaps, evidence for the use of peer support apparently remains inconclusive – because most studies to date have explored it alongside other interventions and not in isolation.

## Auditing non-attendance

In contrast to the exploration of these issues in the IAPAC document, the BHIVA guidance [3] makes no substantial comment on this issue. However, an audit was very recently run by BHIVA to look at the size of this problem in the UK [6].

Together with the HPA, they used surveillance data to identify:

- patients seen for HIV care in 2010 with no linked care report from any site in 2011, and no linked death report;
- new diagnoses in 2010 with no linked care report from any site in 2010 or 2011, and no linked death report;
- [in Scotland] patients identified by clinics as seen for care in 2010, and not known to have been seen there or elsewhere in 2011.

Figures 1 and Figure 2 show the data that emerged, prompting the worrying conclusion that a possible 20% of the UK tested population was not currently accessing care.

The authors recommend that HIV services should audit non-attendance at least annually and seek to re-engage patients where necessary. Similarly, the 2013 Standards [7], at Standard 2, state that ‘services must have mechanisms in place for those who miss appointments or transfer their care to another centre, to ensure people with HIV are retained in specialist care’.

## Taking the lead

The Abstracts are included within the editorial content, and we hope that members find it useful to have this permanent record of the wide range of activities that NHIVNA colleagues are involved in, and routinely contribute to our annual event. An impressive total of 43 Abstracts were accepted this year and all were of a high quality, with the current issue theme being well represented. Several presentations looked at rolling out HIV testing. The diversity of patient experience in this context – for example, of fathers, teenagers and women – and meeting the needs of these groups, were important areas of practice addressed by several authors and speakers.

Nurses are clearly thinking about the impact of many factors on regular clinic attendance, and making inroads towards addressing some of these.

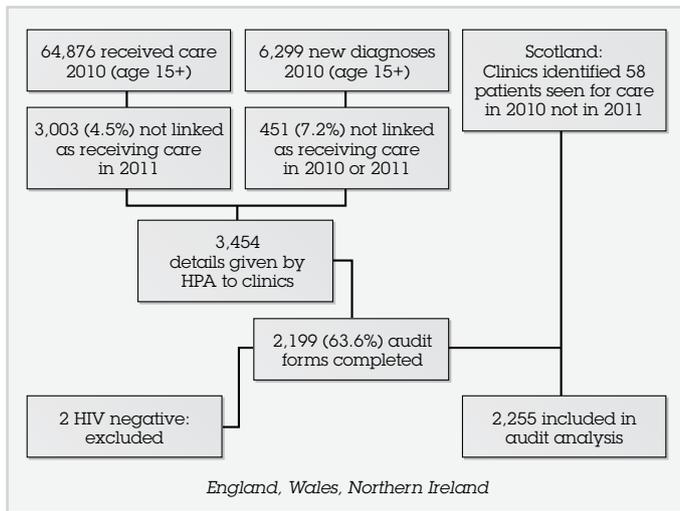


Figure 1: British HIV Association (BHIVA) audit outcomes [6], slide 4

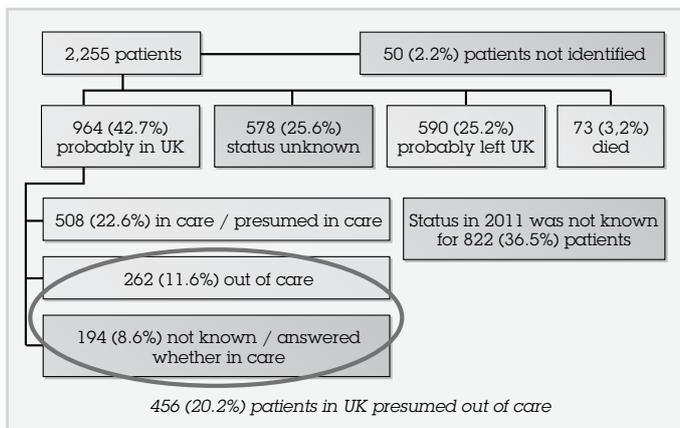


Figure 2: British HIV Association (BHIVA) audit outcomes [6], slide 7

One example was Poster abstract P8 which discussed the implications for those who disengage from treatment due to beliefs inconsistent with conventional medical knowledge. In addition, Poster abstract P27 explored the impact of faith-based healing and cure claims, which heighten risk of patients being lost to follow-up.

Other innovations presented, such as virtual clinics, integrated care pathways, improvements in communication, and normalising HIV testing, should also make a difference – but the clear need remains for all these initiatives to be properly evaluated. This presents an opportunity for all nurses to take the lead in developing local strategies to explore and address the issue of retention in care.

Please do share your ideas and practices with other NHVNA members via our website, on this important element of care provision.

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# HIV nurse prescribing: a review

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## Introduction and background

Advanced nursing practice is a term frequently used in the UK since the early '90s – however, its remit continues to be debated and explored [1]. Some definitions, particularly the older ones, do not include prescribing [2]; while the Royal College of Nursing raises the question of whether it is a level of nursing practice or a defined role [3]. It has also been argued that the autonomy necessary for the advanced practice nurse is epitomised by independent prescribing skills [4].

This current nurse prescriber role, following Department of Health (DH) amendments [5], could be viewed as one of the most controversial skills of the advanced nurse practitioner as it crosses over into the traditional medical role [6]. NHIVNA has supported HIV nurses in exploring the evolution of advanced practice, while also posing the question: is nurse prescribing simply a convenience for doctors as their own caseloads and work demands increase ... or does it improve the nursing care that we deliver? [7]. Additional skills should enhance care whilst maintaining the 'essence of nursing' [8] – an echo of the Francis Report, which identified a startling lack of basic nursing care [9].

Nurse prescribing has evolved alongside the development of advanced nursing practice [2] over the last three decades, initially covering any licensed medicine within the nurse's level of competence, in 2006 [10]; and subsequently being extended to unlicensed drugs, in November 2009 [11]. Roles once considered doctors' territory are now performed by advanced practice nurses – such as history-taking, leading clinics, physical assessment and prescribing [10]. Of these, only prescribing is required to be recorded as a separate qualification by the Nursing & Midwifery Council (NMC) [12]. The current NMC total for independent nurse prescribers is now nearly 27,000 – around 4.5% of all registered nurses [12], compared to 3.1% at the last tally in 2007 [13]. Unfortunately, the areas of healthcare these nurses work in are not logged, so it is difficult to assess how many HIV nurses are qualified prescribers.

Having completed the Independent Nurse Prescriber part of my Master's course, I remained ambivalent to the benefits of incorporating this skill into practice and was curious about how other HIV specialist nurses saw nurse prescribing. A brief scoping literature search identified only one relevant UK article, published in 2008, on how this prescribing role was evolving in HIV nursing

practice [13]. I chose this research topic for the dissertation which would be the final chapter of my Master's degree.

Following liaison with NHIVNA colleagues who produced this article, I built on their 2007 research to examine the views of HIV specialist nurses in 2012 on the impact of adding prescribing skills to their patient care role.

## Aim

The aim was to produce a reliable record of the experiences of HIV nurse prescribers in 2012, identifying any overlap and shared experience with other chronic illness nursing, and exploring how this informs the future of HIV nursing.

## Literature

An initial literature review found a significant amount of research and discussion papers around nurse prescribing. However, legislation that extended nurses' rights to prescribe meant that only post-2006 literature was considered applicable. Prescribing research by nurses working with chronic illnesses, such as diabetes, respiratory conditions and multiple sclerosis (MS), was felt to be comparable – specifically after BHIVA reclassified HIV as a chronic condition [14].

## Method

Review of all relevant literature identified four clear themes, which formed the basis of the questionnaire created for HIV nurse prescribers. These themes echoed those of the 2007 research mentioned above [13]:

- benefits of nurse prescribing;
- barriers to nurse prescribing;
- effects on multidisciplinary relationships;
- educational support.

An 18-item questionnaire was created in email-compatible format using Survey Monkey, and NHIVNA was asked to mail it to members. This approach was the best available to reach a representative sample of HIV nurse prescribers, given limited time and resources [15]. The 2007 research had identified 10 HIV nurses qualified to prescribe, which the writers felt was close to the then current UK total of qualified HIV nurses [13].

To encourage participation, most questions were closed and multiple-choice style. The four identified themes were examined, supplemented by factual questions about the prescribers and their practice.

The survey ran over a 6-week period in April and May 2012. Unfortunately, the response was low, with 15 replies – although subsequent discussion and audience participation, at NHIVNA's 2012 conference, indicated at least 30 HIV nurse prescribers among the membership; in addition to HIV nurse prescribers who are not NHIVNA members.

## Results

### 1. Respondents' background

Most respondents had qualified as prescribers in the last 2 to 4 years – that is, since the last research in 2007 (Figure 1).

Regarding practice level, 66.7% identified as Clinical Nurse Specialists and 13.3% as Advanced Nurse Practitioners, thus senior nurses on pay bands 7 and 8, as would be expected [3] and as found in surveys of other areas, such as primary care [16,17].

Most respondents wrote 11 or more prescriptions a week; 30.8% as lone prescribers and 46.2% having one or more prescribing nurse colleagues in their team. Caseloads exceeded 200 patients for 61.5% of respondents.

A study of independent prescribers carried out for the DH [18] found that 86% of qualified nurse prescribers were currently prescribing, and 71% of qualified pharmacists. It was concluded that nurse independent prescribing is currently a prominent feature in primary care and also common practice in secondary care settings.

### 2. Prescribing behaviour

Once background information was established, the questions moved to respondents' prescribing



Figure 1: Question 1 with results.

practice, looking at drugs most commonly prescribed, prescription frequency, and contexts – for example, dual infections or pregnancy.

As expected, antiretroviral medications figured most prominently, with topical agents, treatments for other GUM conditions and antiemetics/antidiarrheals also prescribed often (Figure 2). The HIV nurses prescribed a wide range of drugs which fell within their competencies, as supported by wider UK findings in 2010 [18].

Most respondents prescribed in pregnancy, dual infections and for those deemed complex by the team; all did repeat prescriptions; 53.8% initiated and changed antiretroviral regimens; and 53.8% prescribed PEP. These were interesting findings, because patients with dual diagnoses, pregnant or considered complex may be initially excluded from the nurses' patient group, particularly as HIV specialist nurses are increasingly running asymptomatic HIV patient clinics [19–21]. As this was only a limited survey, it is difficult to focus on the individual prescriber's situation – for example, had prescribing developed over time as the nurses' competency grew; and what factors were

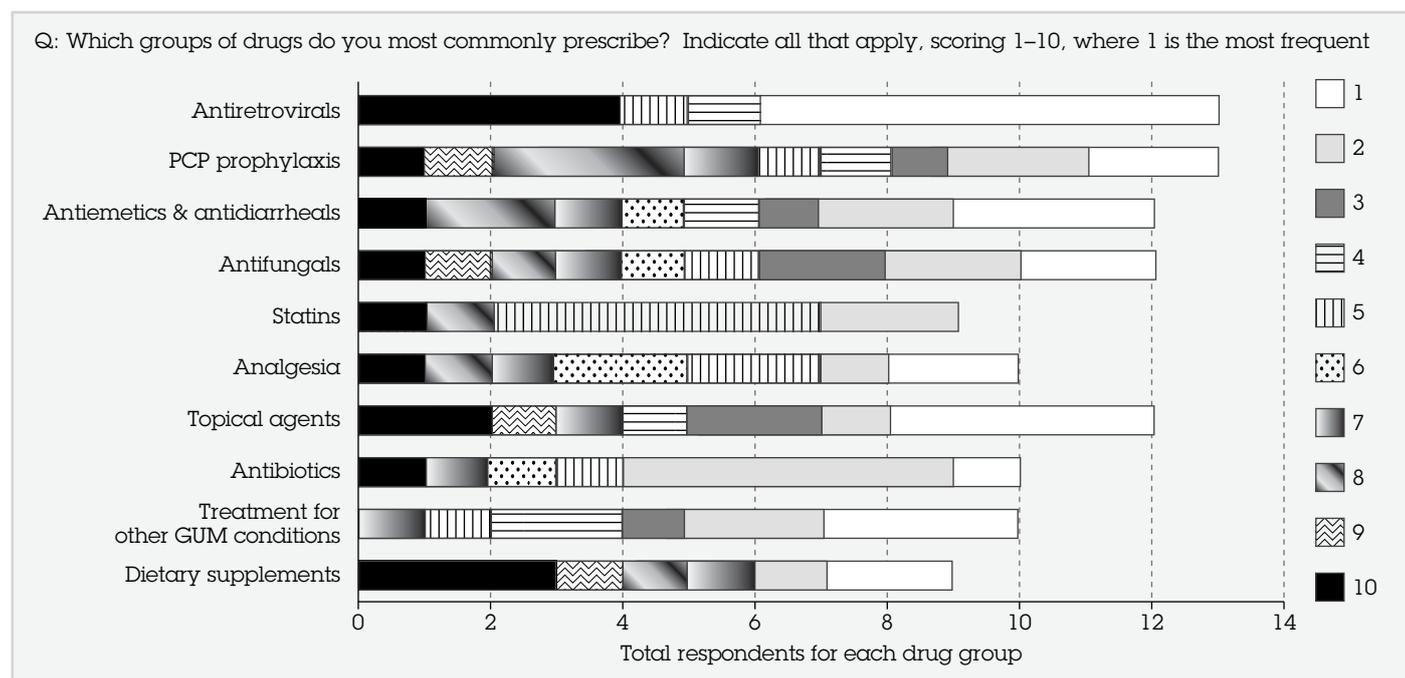


Figure 2: Question 7 with results.

influential in prescribing behaviour? A more in-depth study might explain areas where patterns were not clear – for example, some nurses excluded from prescribing in pregnancy did prescribe for complex patients.

### 3. Benefits and barriers

Seven potential benefits, and disadvantages, were drawn from the extensive literature review, and respondents were asked to rank their significance within the added function of prescribing.

All respondents perceived benefits to nurse prescribing, with easier patient access to medication as the most significant (Figure 3). Studies of patients with other chronic conditions have echoed this, noting their satisfaction and confidence in the nurse prescribers [13,22,23]. Patient satisfaction, listed second, can be one product of the long-term relationship between HIV nurses and their patients [13] – which is further enhanced as prognosis continues to improve [14].

Other significant benefits to the nurses' role of incorporating prescribing skills were recorded as:

- more role autonomy;
- improved time efficiency;
- holistic care;
- job satisfaction.

The same benefits identified by this relatively small study are cited repeatedly in other articles reviewing nurse prescribing [24,25] and are proposed as affirmation for the development of this role [13].

Disadvantages focused on increased pressure on nurses to diagnose, stressful medical responsibilities and patient demands (Figure 4). The medical

profession, particularly early on in the development of non-medical prescribing, were keen to point out that prescribing without training in diagnosis is unsafe, and that doctors spend 4 years of their training focusing on diagnosis [26]. In response, the NMC has repeatedly re-examined and re-evaluated the training and assessment for non-medical prescribers, as well as updating requirements [12].

Half the respondents said that introducing prescribing skills to their practice had increased prescribing disagreements with medical staff and negatively impacted on working relationships. Further detail would be of interest here: one 2007 study notably observed that, as nurses' confidence grew and their prescribing skills developed, they felt more able to participate and challenge prescribing decisions made by medical staff [27].

Most respondents related logistical problems when they first qualified as a prescriber. Specialist pharmacy support was recorded by 69.3%.

### 4. Supervision and education experience

Access to ongoing training to support their prescribing skills was reported by 76.9% of respondents (Figure 5). Due to the construction of this question, it was difficult to establish how many different types of support each respondent had and whether this profile is generally representative of HIV nurse prescribers. Early studies of nurse prescribing reported little clinical supervision and managerial support [28], so these results suggest that the situation has greatly improved.

Generally, respondents recorded ongoing support and positive multidisciplinary relationships. Over 60% received in-house and external training on prescribing. This is reassuring, given the employers'

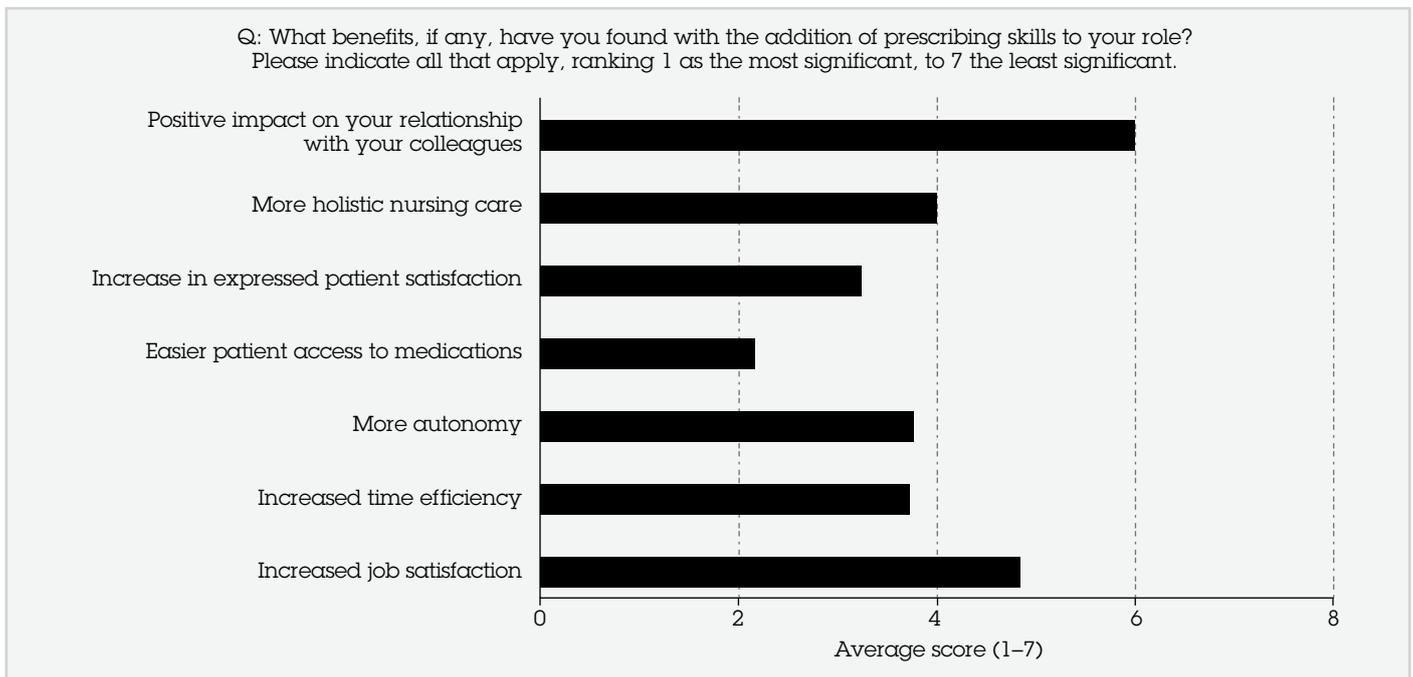


Figure 3: Perceived benefits with results

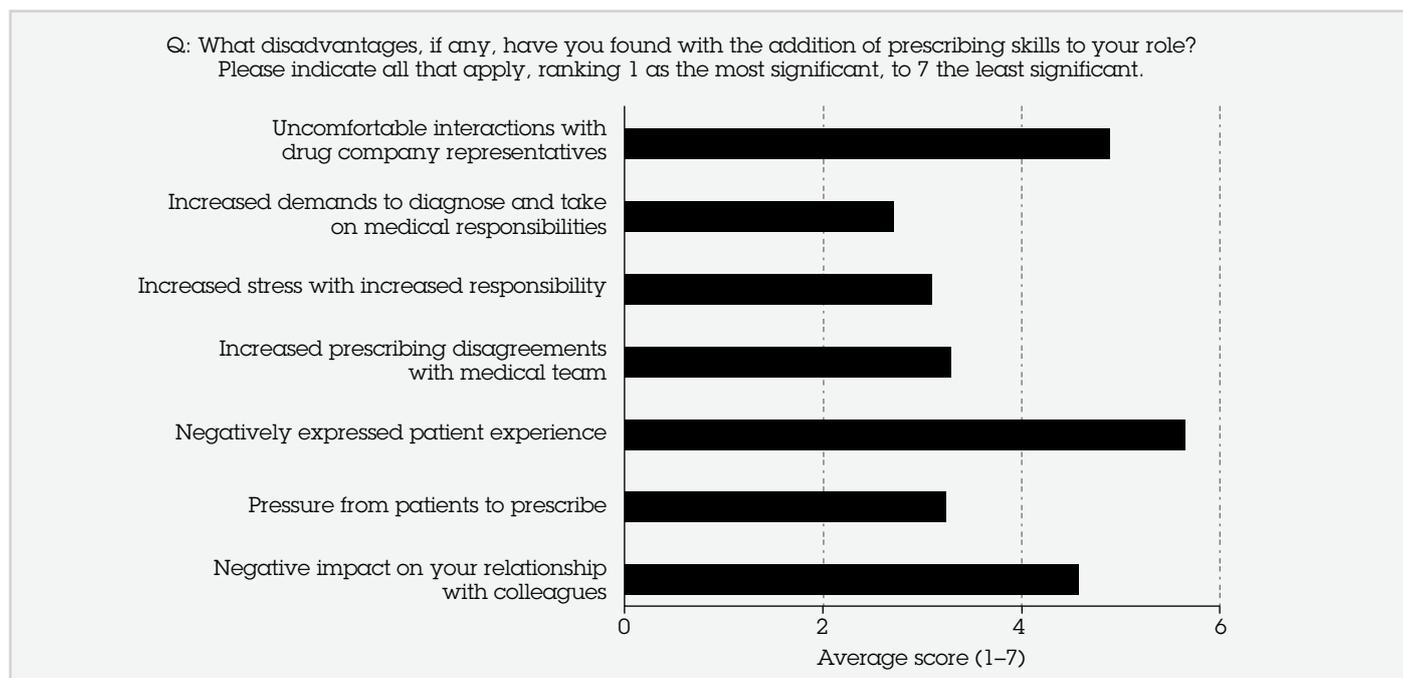


Figure 4: Perceived disadvantages with results

responsibility to support continuing professional development (CPD) in their staff [29].

### 5. Individual comments and overview

Further comments were invited at the end of the survey, and these fall into four categories:

- expansion of nurse-led clinics;
- medicalised role development;
- skill development;
- no development.

Most respondents felt that their use of prescribing skills had fed into the development of nurse-led stable patient clinics; however, others saw this process as purely management driven. Mixed

comments were received about this development in the nurses' role. Some felt it had grown out of demands by doctors who, when busy, would give nurses the easier or less desirable tasks, such as repeat prescribing ... leaving the question open regarding future developments in nurse prescribing. Would these be dictated by whatever doctors choose to throw at nurses next? Some respondents felt their prescribing skills were developing, whilst others felt they were static.

In summary the study found that HIV nurse prescribers were experienced nurses working in teams, prescribing regularly within their competency and developing their roles. These nurses are increasingly working with more complex

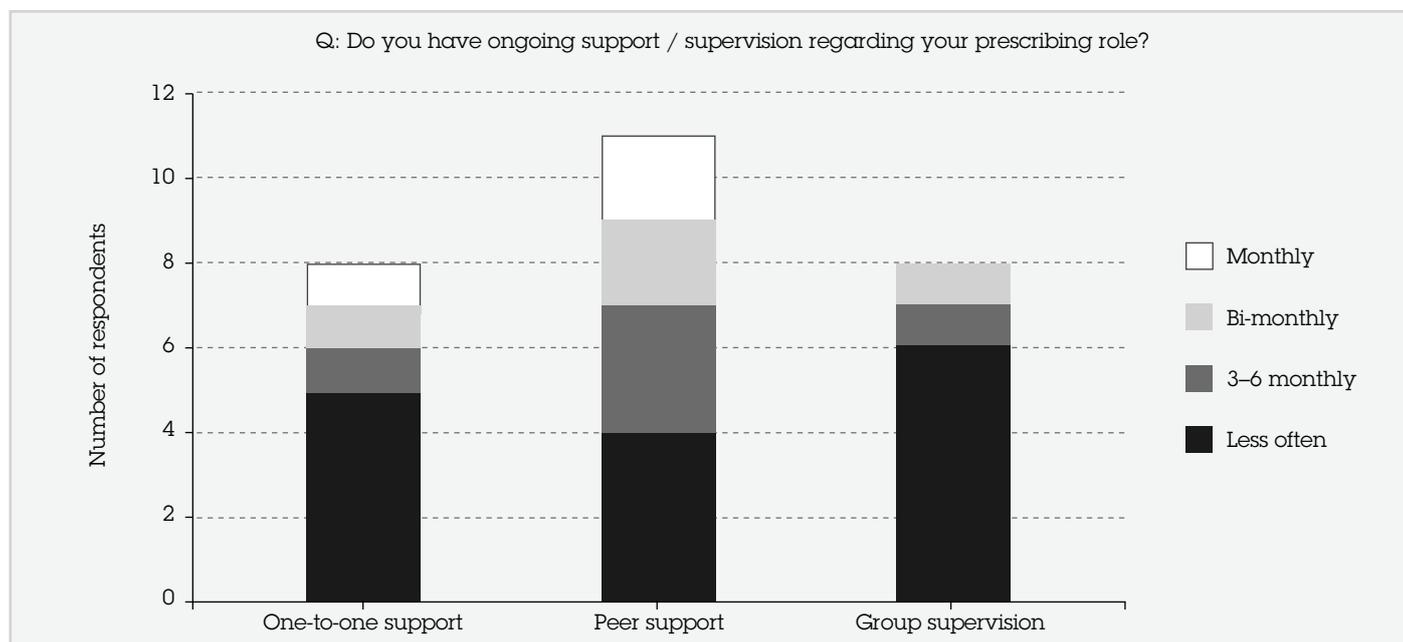


Figure 5: Ongoing support/supervision with results

patients and their prescribing needs – identifying ongoing benefits to patients, themselves and the wider teams. Disadvantages were less apparent – being mainly pressure to diagnose and work in an increasingly medical way. Progressive changes, in line with nationally examined developments, were found in CPD in the workplace, with variable supervision and support available to individuals.

## Conclusions and recommendations

Overall, the study found that the benefits of introducing nurse prescribing into HIV nursing outweigh the disadvantages – increasing time efficiency, patient satisfaction, freeing up doctors for complex cases and encouraging skill mix, supported by research from areas of chronic illness nursing.

Although the survey response was low, it did highlight a lack of clarity on the exact number of qualified HIV nurse prescribers and how to reach them. When compared with the only other published UK research into HIV nurse prescribing [13], numbers are increasing in line with nurses in all areas, particularly those working with chronic illness and in primary care. The gradual and sustained progress seen in nurse prescribing through the literature appears to be mirrored in HIV nursing [22].

It is clear that nurse prescribing is an advanced skill and can be advantageous to nurses developing their role. However, Department of Health guidance first stated in 2004 that management should work with individuals on skill and role development as a joint process [30]; and it has also been stressed that nurses should not feel like 'cheap labour' in comparison to doctors [16].

Certain aspects of this research are significant when producing recommendations for future work:

*Firstly*, this was a small-scale study with a low response rate. This study size indicates that generalising results to the wider population needs to be viewed with caution [31].

*Secondly*, although interviewer influence was minimised by the email format, to encourage participation in the absence of prompting, questions were kept to a minimum and most were closed [15]. These circumstances indicate a recommendation for more in-depth research – to establish HIV nurses' prescribing behaviour in greater detail and explore multidisciplinary relationships.

*Finally*, this survey focused on nurses' views. Gaining patient views on the impact of nurses prescribing in HIV care would greatly enhance the evidence for nurses utilising this skill. As caseloads continue to grow, regular review of patient views on our input is essential to shape future service development.

It is important to disseminate the research, informing HIV nurses of their progress and ensuring it is in step with other areas of nursing practice. As a small and intensive speciality, HIV can often be isolated from mainstream nursing, mirroring the experience of our patients. As this research has filled a small gap, so it has highlighted further areas to explore.

The role of the advanced practice nurse is an evolving one that seems to fit into the UK's ever-changing National Health Service (NHS) which faces repeated challenges from financial cutbacks and growing patient demands. HIV nursing similarly appears to be taking up this challenge, with its flexible nature [21] and its calls for more robust research into this skill development – focused on prescribing competencies and underpinned by patient views, whilst keeping in sight 'the essence of nursing' [8]. Nurse prescribing is now an established feature in contemporary healthcare, active in all areas of care including HIV. Its status is supported by the findings of this research and by a recently published Department of Health study with a wider scope [18], which evaluated nurse prescribing as a major success that is widely integrated into UK healthcare delivery.

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## HIV Nursing 2014

*Now is the time* to plan ahead and decide what you will contribute in 2014!

*Themes are already in place for next year's issues:*

### **14.1 Research/Advanced practice**

**Copy date: 3 March 2014**

### **14.2 Community update/Innovations**

**Copy date: 22 April 2014**

- Have you conducted research or instigated practice that has improved care for your patients?
- You may have recently completed a dissertation or degree and would like to present your findings.
- Or perhaps you would like to comment on a specific issue or review a book you have found valuable.

★ ★ ★ ★

We welcome all articles, letters, case reports and other contributions of interest to healthcare professionals working in the field of HIV – and would very much like to hear from NHIVNA members. The usual word count is around 2000 but shorter pieces are also acceptable, and non-themed contributions are welcomed.

★ ★ ★ ★

Guidance is available from Editorial Board members, who will be pleased to offer suggestions and answer any questions you may have. More information is available on the NHIVNA website.

If you are interested in having your work published, or would like to know more,  
*in the first instance please contact:*

**[naomi@mediscript.ltd.uk](mailto:naomi@mediscript.ltd.uk)**

Abstract O1

To test or not to test, that is the question

A Waters<sup>1</sup> and E Purcell<sup>2</sup>

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**Background:** Lack of knowledge of HIV may lead to stigmatising attitudes by health care workers. Stigma in health care settings can lead to a decrease in uptake of HIV testing. National guidelines state that it should be within the competency of a nurse to obtain consent and conduct an HIV test. HIV testing of NHS staff has not been widely studied however the fear of testing may be related to stigma.

**Methods:** A cross-sectional study of a sample of nurses (n=144) in a large multicultural London hospital in a HIV high prevalence area from all clinical departments using self-completed structured anonymous questionnaires. The aim of this study was to explore nurses' attitudes towards HIV testing of patients and self-testing which was part of a larger survey of knowledge and attitudes to HIV.

**Results:** The mean age of the sample of nurses was 43.3 years with a range of 22–67 years. Respondents were born in 24 different countries with the two largest groups being 44% (n=57) born in the UK and 27%, (n=34) in Africa.

Table 1

	n(%)			n=
	Yes	No	Don't Know	
Every patient should be offered HIV testing when they are admitted to hospital.	54(38)	61(43)	27(19)	142
Patients should be offered HIV testing if they are from a country with high risk of HIV.	96(67)	23(16)	24(17)	143
Patients should be offered HIV testing if they are homosexual.	73(51)	38(27)	31(22)	142
I would like to be able to self-test anonymously for HIV using HIV rapid test kits.	53(37)	56(39)	33(24)	142
Hospitals should supply HIV rapid test kits to allow staff to self-test for HIV.	67(47)	47(33)	28(20)	142

**Conclusion:** Nurses in this survey were more accepting of patients who were at higher risk of HIV to be tested rather than every patient. Implementing the recommendations for HIV testing emphasises the importance of decreasing stigma toward and improving knowledge of HIV testing. The goal of normalising HIV testing by offering an HIV test to everyone at admission however may be difficult due to financial restraints within Trusts.

Knowing one's HIV status is important for all including nurses. One third of the nurses agreed they would like to self-test anonymously. Further examination of this as a way to remove the stigma would be required to justify anonymous self-testing as a way to increase HIV testing amongst nurses.

Abstract O3

'Virtually' satisfied: we've developed a virtual clinic service, but is it safe and does it meet the needs of patients?

M Owen, S Harris, J Barnes, C Cheung, K Gandhi, R Cook and G Hickinbottom

Birmingham Heartlands Hospital, Birmingham, UK

**Background:** Clinical Nurse Specialists assessing newly-diagnosed patients in Nurse-Led Clinic were struggling to arrange appropriate doctor follow-up because of pressure on available appointments.

The multidisciplinary team agreed that stable patients were attending for a doctor review more frequently than necessary. Was there potential to reduce these visits whilst still providing safe monitoring and care? Clinical Nurse Specialists and Pharmacists felt they could develop/deliver a telephone consultation service to reduce clinic visits and free up doctor appointments.

Many people are now truly 'living' with HIV, perhaps raising children, studying, working or all three! Patients felt clinic visits were difficult to schedule into busy lives and costly in terms of time and travel.

**Methods:** An eligibility criterion was agreed to encourage appropriate referrals. The patient books an appointment slot on Tuesdays/Wednesdays and must be available when we call at that time. A patient information leaflet and clinic proforma were developed. The appointment includes a review of recent blood results, an assessment of well-being, adherence to medication, additional medication changes and if all is well, appropriate follow-up appointments are made, with a prescription arranged for collection.

A patient questionnaire was compiled to assess satisfaction.

HIV Consultants were asked to provide feedback, especially around patient safety.

Examples of results from 85 patient surveys returned:

- 92% of patients found virtual clinic more convenient than attending in person
- 99% found length of telephone appointment to be suitable
- 98% felt the appointment had met all of their needs
- 90% had remembered their appointment date and time
- 100% felt the staff member calling was organised and friendly/helpful
- 96% wish to continue having virtual clinic appointments

**Conclusion:** An increase in available doctor appointment slots enables newly-diagnosed patients to be seen promptly. Patients are extremely happy with the service, many wanting more virtual appointments. 5 HIV Consultants consider that the patients have received a high standard of care, with no evidence to suggest that patient safety has been compromised. Virtual Clinic will therefore continue to play a significant part in patient care.

Abstract O2

Missed opportunities

S Chidzomba and V Ennis

Birmingham Heartlands Hospital, Birmingham, UK

**Introduction:** Early diagnosis and testing for HIV is paramount in preventing opportunistic infections and complications of late diagnosis. The problem identified is missed opportunities for early HIV testing. The aim is to identify the missed opportunities through education and avoid onward transmission of HIV and minimise costs. The objective is to educate other health professionals the importance of testing and early diagnosis of HIV.

**Method:** A retrospective study of three patients diagnosed with advanced HIV was undertaken to identify any missed opportunities where an HIV test was clinically indicated in primary and secondary care. Past medical histories were analysed alongside the UK national clinical guidelines for HIV testing to identify opportunities where an HIV test would have been appropriate.

**Results:** The analysis revealed that over a period of time patients attending primary care with clinical indicator diseases should have prompted an offer of an HIV test. In one case the patient developed shingles twice and had weight loss over a two year period. Patients attending health care services such as primary, secondary and tertiary care should be offered a diagnostic test for HIV in accordance with current national guidelines. In addition to these patients who attended the walk in sexual health clinic with clinical indicator diseases for HIV infection are more likely to be offered an HIV test than those who attended the GP practice with similar symptoms. Late diagnosis is associated with increased HIV mortality, impaired response to HIV medication and increases costs to the health care service. The earlier HIV is detected, the more likely treatment will be successful.

**Recommendations:** The three cases exposed a wider issue of reluctance to test for HIV. This is in part due to lack of education regarding clinical indicator diseases. Education programmes at all levels of health care professionals should be established and continued efforts should be made to normalise and make HIV testing routine. This will also prompt health care professionals to offer an HIV test to all patients presenting with symptoms relating to the UK national guidelines HIV testing.

Abstract O4

Community HIV support: next steps?

A Bamford

Sussex Community NHS Trust, Brighton, UK

**Background:** The shift of HIV care from acute to chronic illness requires a new approach – a self-management model for people living with HIV in the community, in which patients assume an active and informed role in their healthcare.

Such a model was commissioned in September 2010. The Community HIV Specialist Service includes HIV nurse specialists, mental health nurses, and access to social care, psychology and health trainers. We also have a contract with a local voluntary organisation to provide inpatient beds.

**Method:** The service's key theme is self-management for clients. Management of a case would include full assessments; personalised care plans, and defined timescales for any interventions. There is a clear patient pathway through the service through a tiered approach, by which the community nurse specialist or community psychiatric nurse contacts the patient and completes an assessment. When the episodes of care are completed then the patient is discharged from the service. Access to inpatient beds is via eligibility criteria ensuring equity of use.

**Results:** It has taken time to embed the model into practice for both nurses and patients, and our service is now in the last year of its contract. Working with subcontractors has given increased choice and flexibility to patients, and regular contract meetings enable reviews and changes to be made. A service user group is now well established and provides patient feedback on developments and ideas. We've faced challenges, and we've discussed and shared our learning across the service. Working as part of a HIV network has encouraged us towards stronger partnership working. We also train GPs to raise awareness of the HIV community and to promote HIV testing in primary care.

**Discussion:** Our new model has meant a cultural change for both workers and patients, requiring support around supervision, clear objectives, and dealing with patient expectations.

With the current political and economic climate, and the new NHS commissioning regime, we all face uncertainty about the future of community HIV services. How we develop HIV care in the community should be based on understanding local need, demonstrating clear outcomes, and cost effective services – so let's get started!

Abstract O5

Development of an integrated care pathway (ICP) for HIV outpatient care in Scotland

L.Panton<sup>1</sup>, D Clutterbuck<sup>2</sup>, S Wielding<sup>2</sup>, K Bethell<sup>1</sup> and D Wilks<sup>1</sup>

<sup>1</sup>Regional Infectious Disease Unit, Edinburgh, UK and <sup>2</sup>Chalmers Centre, Edinburgh, UK

**Introduction:** Health Improvement Scotland Standards for HIV Prevention, Treatment and Care (2011) require the development of an ICP for HIV care. The objectives of this project were to:

- Develop and pilot an ICP for the first three months of care following an HIV diagnosis in two units (a genito-urinary medicine (GUM) clinic and an Infectious Diseases (ID) unit) providing very different models of care to a total of 1300 people
- Use the ICP to ensure consistency of care across the different care models.

**Method:** A multi-disciplinary team of 20 volunteers from both units including patient representation and a local ICP expert met from April 2010. Process mapping was conducted leading to a draft version being pre-piloted on 10 patients. After further extensive redrafting, an ICP document commenced a 1 year pilot in April 2012. Information is collected under five main headings -history, examination, investigations, screening and ongoing care. If care is not delivered as planned the reason (variance) is recorded. The Clinical Nurse Specialists introduce the ICP and co-ordinate the pathway of care depending on clinical need. ICP completion is reviewed at new patient meetings. Variance analysis highlights gaps in care provision.

**Results:** ICP was completed for a total of 55 of 63 newly diagnosed or transferring care patients. Of 24 essential components, a mean of 19.9 in GUM and 16.8 in ID were completed.

Completion of was high for sexual health in both units (53/55) and lowest for 'plan for out of hours care' (13/55). Variances were well recorded for consent to GP disclosure (not completed in 17, variance recorded in 12) but less well for cardiovascular risk assessment (not completed in 37, variance recorded in 15). Completion was not 100% even for components identified by the ICP group as essential (e.g. STI screening not completed in 15/55, variance only recorded in 9).

**Conclusion:** The introduction of a paper-based ICP has been challenging. To avoid duplication of work the ID team made some alterations to the document. There were no consistent differences in completion of different components between units. The aggregate results for the 24 essential components will be fed back to a joint meeting in July 2013 to identify areas for quality improvement, and agree 5 priority areas aiming for 100% variance recording. The next phase will be to roll out the ICP in electronic form.

Abstract O7

Operational barriers to the implementation of opt-out HIV testing in novel settings

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Barts Health, London, UK

**Background:** National guidelines recommend routine HIV testing in medical admission units (MAUs) where local HIV prevalence exceeds 2 per 1000. Although HIV testing has been rolled out in MAUs across the UK, HIV testing remains rare in intensive care (IC) settings where patients may present with HIV indicator conditions. MAU and IC are highly pressurised environments; patients have complex needs and require a range of medical interventions. The introduction of novel interventions such as HIV testing can therefore present challenges to staff.

**Methods:** Opt-out HIV testing was introduced in both MAU and IC in our hospital with a local HIV prevalence of 5.95 per 1000. We present testing rates in both settings, and explore differences in logistics in order to inform quality improvement in both programmes.

**Results:** Since opt-out HIV testing started 13 months ago, testing rate (n/N (%)) in MAU is 1509/17652(7.7%). In IC the rate is 457/927(49.2%) in 5 months. This difference is statistically significant (p<0.001).

Operational differences exist in the 2 settings which impacted on how opt-out testing was conducted in MAU and IC. (See table 2)

	MAU	IC
Average patients seen per month	1000	181
Nurse to Patient Ratio	1:8	1:1 OR 1:2
Admission bloods carried out?	No-often bled in A&E first	Yes-routine bloods taken from every patient
Blood tests taken by?	Doctors/phlebotomists	Named nurse
Mean length of patient stay in days	2	5
Need to obtain consent?	Yes patients are conscious	Many patients unconscious/lack capacity so done in "best interests"

**Conclusion:** Both MAU and IC have seen an increase in rates of HIV testing. Testing in IC has been a particular success with rates of 49%. In IC settings patient care is provided in a structured routine approach with a small staff to patient ratio. HIV tests can be added to blood tests that are routinely performed by nursing staff who have taken ownership of opt-out HIV testing in IC contributing to the high rates of testing. Challenges to testing have been identified within MAU. Most significantly, patients are referred from different locations, with acute symptoms requiring attention. So there is no routine approach to admission into which HIV testing can be incorporated. Difficulties arise when patients have previously been bled, or care is taken over by another speciality. Opt-out testing in IC and MAU has been a success, despite challenges in MAU. To improve the delivery of opt-out HIV testing within MAU, we must address operational challenges and learn from the many successes of IC.

Abstract O6

HIV Complex Case Audit

R.Downes

Liverpool Community Health NHS Trust, Liverpool, UK

**Background:** Complex cases command a huge investment both in terms of nursing time and resources. Often care outcomes can be disappointing, even following years of engagement. There is a service requirement for the team to access regular Clinical supervision, this is undertaken as a team and has proven to be invaluable in supporting the nursing team through some very difficult and often extremely challenging situations whilst managing complex cases.

A previous audit had highlighted that complex cases often have chaotic lifestyle usually involving substance misuse as a component; this is a continuing trend in some of the complex cases cared for by the HIV Nursing team.

**Aims/Objectives:** This audit was undertaken to identify possible gaps in care provision and seek out drivers for change. Highlighting areas of best practice by exploring both MDT involvement and improvement in CD4 counts and Viral load in response to intensive support were also areas for review.

**Method:** A sample of 14 patient records were audited against a proforma over a 3 month period. Completed forms were forwarded to trust research and audit team for analysis and reporting.

**Conclusions:** The results of this audit highlight that MDT working is crucial to care provision in complex case management. The quality of care is greatly enhanced by patients having access to a broad spectrum of AHP's who engage and communicate with each other and ensure the patient is the focal point for decision making. Time spent on none face to face activity or patient related activity with patients and stakeholders in care is equal to or often greater than face to face patient contact. It is important this "Behind the scenes" activity is recorded in any data collection used for any service commissioning purposes to portray a true reflection of service activity and patient demand. On-going engagement with complex cases over many years has had a major impact on patient mortality with 64% of cases audited achieving an undetectable viral load, effectively switching of HIV activity, promoting in most cases, immune reconstitution.

**Recommendations:** Late diagnosis continues to be a major problem for HIV services. This team is already proactive in community HIV testing; a way forward is to explore engagement strategies with local CCG's, GPs & practices. Outreach testing in non-clinical settings, engaging with local communities and key stakeholders is crucial to promote HIV testing, to align with NICE Guidelines & BHIVA.

Abstract O8

The experience of a recent diagnosis of HIV for men who have sex with men: an interpretative phenomenological analysis

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Despite HIV being present for over three decades, there is a dearth of qualitative evidence in relation to a recent diagnosis of HIV as experienced by men who have sex with men (MSM). Many studies have been undertaken using quantitative approaches and have relied on participants recalling their experiences of their diagnosis, with some studies undertaken as long as 23 years later. This study aims to explore the experience of MSM in the first three months of their diagnosis. It set out to elicit the feelings and emotions expressed by MSM who have been recently diagnosed with HIV; explain what an HIV diagnosis means to recently diagnosed MSM; and examine the experience of health and social care interventions during this time.

An interpretative phenomenological analysis (IPA) approach was utilised throughout this study. MSM who had received a diagnosis of HIV in the preceding three months were invited to participate. Charitable and voluntary organisations advertised the study through their Internet and social media pages. Nine men were recruited from across the United Kingdom. Semi-structured interviews lasting between one and two hours were undertaken and relied on the process of people making sense of their world and their experiences.

The men requested an HIV test for a variety of reasons including a period of continuous illness; belief about sexual risk behaviours and previous sexual partners; or as part regular testing practice. They reported effective and negative experiences of receiving their diagnoses from healthcare professionals and this impacted on where they chose to continue their care. Initial disclosure patterns were limited to a 'need to know' basis and many of the participants sought support from friends, partners and work colleagues during this time rather than family members. Some expressed a desire to move from where they were living to be able to identify themselves with others with HIV, but others were frustrated by the 'expertise' of individuals who had been diagnosed for some time. All reported that they understood HIV to be a long term condition though a couple of men were not sure if they believed this. For those commenced on antiretroviral therapies, there was a challenge in getting to grips with the new regimes and how this made them feel, and coping with the side effects of the medication. These findings may help health professionals to identify further strategies of support in the initial weeks following diagnosis.

## Abstract 09

### Evaluation of fitness for purpose in provision of an innovative culturally sensitive HIV counselling approach:- An Interpretive Phenomenological Analysis (IPA)

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**Background:** African women are most represented service-users of HIV services, as most are diagnosed following routine antenatal screening. Although majority of them suffer from the psychological impact of being infected and accepting the diagnosis but are reported to be reluctant to access existing psychotherapy/counselling services, very little is known about their reasons. One service-user feedback survey shed some initial light. Cultural background has an impact. Although there is a plethora of literature advocating on the importance of culturally sensitive counselling services provision, still scant work relates to HIV-counselling. An award winning innovative culturally-appropriate counselling was set up. Therefore it is of paramount importance to gain enhanced understanding of those who access service more for planning and provision of fit for purpose services.

The study intent was to:

- Have an in-depth understanding through exploration of the lived experiences of HIV sero-positive African childbearing migrant women living in London.
- Evaluate and compare the efficacy of existing and alternative culturally sensitive models of counselling provisions to inform policy and practice.

**Methods:** A purposive sampling of a total of the 15 women participated in in-depth qualitative semi-structured tape-recorded interviews. IPA is used as the research methodology appropriate for the study population, research question sample size. Thematic data analysis method was undertaken for the verbatim interview transcription.

**Results:** Participants explored their experiences and the existence of barriers to effective helping by comparing the models. What emerged were the tension, links and paradoxes of the African philosophical sense of interdependent self as expressed against the existential anxiety and implications of isolation/aloneness in the context of the impact of HIV diagnosis and inherent stigma. Emphasis was on the significant positive impact of provision of situation-specific counselling by a counsellor from a similar cultural background whilst they felt more understood compared to counselling westernised approach with therapist of a different cultural background. Long term as opposed to time-limited counselling was preferred. Importance on African heritage and identity was flagged out as a distinct important counselling aspect.

## Abstract 010

### Narratives of individuals and couples in relationships with one known HIV-positive partner (serodiscordant relationships)

K Rogers

Anglia Ruskin University, Cambridge and Chelmsford, UK

**Background:** Knowledge about how the Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) affect individuals and couples is changing. In order to understand the complexities of relationships where one person is known to be HIV positive, new theoretical constructions are needed. Within this qualitative study, Strauss and Corbin's (1990, 1998) grounded theory methodology was used to construct a substantive theory of serodiscordant relationships. Symbolic interactionism provided a theoretical framework to understand these relationships from the perspectives of 'actors' for whom serodiscordance has symbolic meaning. This proposed oral presentation explores the interpersonal and social experiences of both the HIV-positive and negative partners in serodiscordant relationships.

The research aims to understand the experiences of individuals and couples in HIV serodiscordant relationships.

**Methods:** Through direct involvement in data generation, transcribing, analysis and theory construction, the researcher repeatedly interacted with and immersed in the data. Ethical approval was granted by the South East London Research Ethics Committee (REC) 1. Participants were purposively recruited from three NHS Genitourinary Medicines (GUM) clinics in North East London. Theoretical sampling focused on seeking to clarify concepts that emerged from data. 32 narratives were generated from 24 individuals and couples in current serodiscordant relationships. A qualitative data analysis software 'Maxqda' facilitated data management and analysis.

**Results:**

- Themes from the study include
- Surviving serodiscordance
- Supporting serodiscordance
- Disclosing serodiscordance
- Maintaining/staying in relationship

**Conclusion:** Albeit in different guise, HIV-positive individuals and couples are confronted with psychosocial experiences and HIV is still a stigmatising disease with no cure. In order to understand and explain 'how individuals and couples experience HIV serodiscordance', it is essential to discover the meanings from those who interpret the relationships through symbolic interactions and interpretations.

*The research provides evidence that informs policy and develops interdisciplinary practice on HIV serodiscordant relationships.*

## Abstract 011

### What are you trying to say?: pilot study results

M Croston

North Manchester General Hospital, Manchester, England

**Background:** Communication impacts on psychological distress and morbidity, adherence to treatment, quality of life, and satisfaction with care, complaints, litigation, and finally stress levels in healthcare professionals. A significant consequence of poor communication is the impact that it has on psychological morbidity. Research suggested patients do not disclose many of their concerns and healthcare professionals do not pick up all the things that they have been told. Communication skills training are designed to give healthcare professionals the skills and confidence needed to elicit patients concerns.

**Methods:** The participants (n=20) were asked to subjectively rate self-efficacy for 16 skills/situations using a modified version of the self-efficacy questionnaire. Participant's attitudes and beliefs towards the likely consequences of their communication behavior were assessed using a modified version of the outcome expectancy questionnaires. Participants were also asked to provide feedback on the course content, supportive material, perceived transferability of skills into practice and asked if they would recommend the course to a colleague. Participants were invited to provide feedback to the researcher anytime after the day by sharing any thoughts that may have come to mind as a result of their own personal reflection.

**Results:** Participant's self-efficacy scores increased significantly post study day. Participants self efficacy rating support anecdotal reports that participants feel they know how to establish patients feelings, but do not know how to manage these once elicited. Outcome expectancy results showed consistent improvements, which mirrored what is observed within the wider literature. The most predictable changes occurred in relation to participant's beliefs that patients would raise important concerns without being asked. Post study day participants felt less likely to feel responsibly for solving all their patients concerns. Participant's scores positively increased around their attitudes in relation to their own skills when responding to difficult questions. Participants felt the skills that they had learnt would be easily transferable to their clinical practice.

**Discussion:** The use of cue based assessment and interviewing approach has been shown to improve patient's outcomes, increase patient's satisfaction and compliance with treatment, reduce consultation times and complaints.

## Abstract 012

### Masculinity, fatherhood and HIV: how has HIV impacted on experiences of fatherhood? A Foucauldian Discourse Analysis

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**Background:** This study uses Foucauldian discourse analysis to better understand the experience of fathers living with HIV. Fathers have been largely ignored by studies of the family and HIV. In comparison to mothers there is also a lack of fathers affected by HIV in health and support services. There exists a stereotype of the absent father, particularly in families affected by HIV. However, up to 50% of HIV positive heterosexual men in the UK show a desire for fatherhood and 1 in 7 fathers in the UK are the primary carers for their children. Research on child development has emphasised the importance of fathers.

**Methods:** Six in depth semi-structured qualitative interviews were conducted with fathers living with HIV and analysed using Foucauldian discourse analysis. The participants were service users with a third sector charity organisation. Interview agenda included questions about fatherhood, parenting, masculinity, stigma, communicating about HIV and experiences of health care and support.

**Results:** Discursive constructions of fatherhood and HIV may enable and constrain certain behaviours within the family. These discourses suggest links between masculinity and responsibility for HIV. HIV is discussed as a positive force in some fathers' lives, encouraging men to take up new subject positions, namely that of the responsible father, which would not have been possible without HIV. Mainstream discourses on HIV are taken up and reworked by fathers as a means of coping with the effects of illness. These constructions interact and collide with wider hegemonic masculine ideals of fatherhood. The impact of HIV on parenting, communicating about HIV, co-parent relationships and health care and support are also discussed.

**Conclusion:** These findings have important implications for working with fathers and families affected by HIV. They highlight the importance of working with fathers in gender specific or gender sensitive contexts. They also suggest opportunities for building positive identities and relationships and coping with the psychological challenges of HIV for fathers. Further research into fathers affected by HIV is called for.

**Abstract P1**

**Self-efficacy and communication skills**

M Croston

*North Manchester General Hospital, Manchester, England*

**Background:** Self-efficacy has previously been studied within the scholarly literature in relation to the communication between healthcare professionals and patients. Highlighting that nurses who were uncertain about their abilities to talk openly with patient patients were less likely to use behaviours that facilitate patient's disclosure of concerns. The literature suggests that self-efficacy contributes to the healthcare professionals communication patterns and should be considered in skills training programmes.

**Methods:** Using a Heideggerian phenomenological approach, 10 members of the North West HIV Alliance were asked to answer the following two questions: 'The conversations I find most difficult are', and 'I find these difficult because ...'.

The study aimed to establish what conversations nurses felt they had the most difficulties with in order to shape future research projects and form the content of an advance study day for HIV nurses.

The narrative accounts were analysed for common themes.

**Results:** Themes that emerged included initiating potentially embarrassing conversations or distressing conversation, challenging patients 'risky/non-compliant' behaviour, giving significant information, and addressing adherence issues with patients.

The reasons why these conversations were challenging for nurses also shared common themes, lack of confidence and self-belief, perceived role boundaries (is this my job) and fear of consequences (what happens if).

**Conclusion:** Despite the small scale nature of this study it gives insight into the day to day challenges nurses face when providing patient care and provides opportunities to develop strategies to assist these expressed concerns.

Although, the consensus is that communication skills training is an important aspect of care. The content and method of skills training is still subject to much debate.

**Abstract P2**

**A national evaluation of HIV nurses' knowledge, attitudes and practices towards 'treatment as prevention' (TasP)**

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<sup>1</sup>*Freelance Nurse Consultant, Nationwide, UK*, <sup>2</sup>*University of Nottingham, Nottingham, UK* and <sup>3</sup>*North Manchester General Hospital, Manchester, UK*

**Background:** There is now strong evidence indicating that a significant reduction in HIV transmission can be achieved when HAART is started early in the course of infection and an undetectable viral load is achieved and sustained in HIV positive individuals. The British HIV Association treatment guidelines (2012) now recommend that clinicians should discuss the evidence for the effectiveness of antiretroviral treatment as prevention (TasP) with all patients with HIV.

Nurses are involved in all aspects of service delivery for people living with HIV and it is essential that they have the knowledge, skills and confidence to address the potentially complex issues that TasP may raise for patients. In the UK, there is a lack of information about HIV nurses' views on TasP and on their related training and support needs. This is a gap that this project proposed to fill.

**Aims:** To evaluate self-perceived knowledge, attitudes, skills and practices of nurses working in the field of HIV in the UK in relation to TasP.

**Methods:** Ethical approval was obtained from the University of Nottingham, Faculty of Medicine and Health Sciences Ethics Committee.

A concurrent mixed methodology is being used, consisting of an on-line survey and semi structured interviews conducted by telephone. This paper will focus on the survey findings.

All NHVNA members (n=244) were sent an on-line questionnaire during April 2013. This consisted of approximately 20 questions to assess (1) knowledge, understanding, experience and confidence in discussing TasP in clinical settings, (2) the perceived impact of TasP on clinical practice, and, (3) further education and training needs.

Data analysis will take place in May 2013. Data will be analysed in SPSS using descriptive statistics and correlation tests to determine the extent to which factors such as geographical region, clinical setting or years of experience influence experiences and perceptions around TasP.

**Discussion:** The discussion will identify areas for further research and will make recommendations for service innovation and development of educational resources.

**Acknowledgements:** This study has been conducted by NHVNA with support from a grant from Gilead Sciences.

**Abstract P3**

**Determining effective practices of referring HIV positive teenagers to a third sector support service**

K Forbes and A Barnes

*Body & Soul, London, UK*

**Background:** There are an estimated 3,258 people aged 24 years and under living with HIV in the UK<sup>1</sup>. A third sector organisation based in London holds a weekly support service for 13-19 year olds living with and affected by HIV, with the aim to improve health, well-being and quality of life. It is vital that the service is easily accessible, approachable, useful and relevant to the group. Exploring service users' experience of referral provides valuable information on referral practice and allows referrers and the supporting organisation to ensure pathways meet service user needs and preferences.

**Methods:** Questionnaires were verbally conducted either in person or over the telephone during March 2013 with a convenience sample of 20 service users aged 13-19 who had registered with the organisation during 2011/12. The questionnaire was composed of 4 open and 9 closed questions.

**Results:** Of the 20 respondents, 9 were male and the mean age was 15.1 years. 15/20 were referred from a health professional at their HIV clinic. 1/20 contacted the organisation directly, for 16/20 their referrer called for them (3/20 couldn't remember). Of the 16 who did not call themselves, 10 said that they wouldn't have called if someone hadn't done it for them. 10/20 attended for the first time with someone else, of whom 4/10 said they wouldn't have come alone if that person couldn't accompany them. On the first service visit, 20/20 attended a workshop and 7/20 saw a counsellor. 16/20 came back the next week. When asked 'why do you access the service now?' half or more of the participants responded: 'to see my friends', 'to learn more about HIV', 'to be around other people who are affected by HIV' and 'to talk openly about how I feel about HIV'. 20/20 respondents thought other people their age who are affected by HIV would like to know about the organisation and 20/20 could verbalise how they would describe and recommend the organisation to a peer.

**Conclusion:** This study highlights the critical importance of referrals by healthcare professionals, and specifically the action by the healthcare professional of arranging for the young person to access support services for the first time, without which only a small percentage of those in need of support would access the service. Given that psychosocial support is highlighted in the CHIVA Standards of Care as a vital element of the package of care given to young people living with HIV, referral to support groups should be routine.

<sup>1</sup>HPA, 2012

**Abstract P4**

**Between the Sheets: A qualitative review of issues faced by women living with HIV in relation to sexual activity**

P Jelliman

*Liverpool Community Health NHS Trust, Liverpool, UK*

This is a patient engagement project influenced by Health and Social Care Act 2012 Greater Voice for Patients. Effective nurse / patient relationship enabled disclosures relating to issues faced by WLHIV & sex. The frustration conveyed was alarming and emotive. Common themes were, unmet need for women to explore and discuss sex, Confusion re undetectable viral load & infectivity, Disclosure, A loss of sensuality, perceptions of future celibacy, fear of rejection, violence or abuse within sexual relationships. Women who verbalised anxieties were encouraged to form a focus group to participate, contribute and facilitate the delivery of the Between the Sheets project.

**Objectives:**

- Provide a safe, inclusive female only event where WLHIV can explore issues relating to sex.
- Impart appropriate information via expert presentations /personal stories.
- Provide interactive workshops to address sensuality, empowerment and self esteem.
- Facilitate networking opportunities & peer support.
- Evaluate current experiences, & identify future support.

The project was awarded a Public Health Grant. A project group supplemented focus group, to support & ensure the event was delivered safely. Pre event Questionnaire examined issues such as stigma, disclosure, sex negotiation, confidence, support, safer sex, PEPSE, the effect of HIV on sexual relationships, link between violence abuse & HIV, Viral Load interpretation. This provided rich data demonstrating an unmet need. Excellent feedback was received from 67 attendees for presentations, workshops demonstrating appropriate content. Powerful, inspiring personal stories were presented by WLHIV. Evaluation identifies clear future support topics. 45% linked HIV and abuse. 23% disclosed Bi sexuality, posing inclusion issues. 50% identified as Black underrepresented on focus group 67% did not consider HIV a disability. Recently, the focus group have delivered a feedback event, attended by commissioning groups, doctors, patients and voluntary sector representatives. Evaluations were presented, and group work undertaken to identify progression. Future funding has been secured.

Fantastic event which should be repeated and expanded on. In a time of austerity, well done to funders and organisers for pulling off a powerful, innovative event the empowering impact of which has been felt by everybody I have spoken to today.

**Abstract P5**

**Well-aware**

N Mozagba and A Marie Tranter

Infectious Disease Outpatients Unit, Birmingham Heartlands Hospital, Birmingham, UK

**Background:** The BHIVA guidelines state that specific investigations and assessments need to be carried out to maintain the health of people living with HIV. A year after setting up the Annual health clinic, an audit was conducted against professional guidelines to determine the effectivity of the intervention. Alongside this a patient satisfaction survey ran to obtain a patient perspective in order to gather the whole picture.

**Method:** A questionnaire was handed out to patients who had attended AHC between June 2012 and April 2013. Patients were asked to complete questions about the clinic as a whole and specifics such as the time of the appointment and the information they received about the AHC prior to their attending appointment. Questions generally required a 'yes' or 'no' answer and at the end of the questionnaire patients were asked to leave written comments regarding suggestions for improving the AHC and any additional comments they wished to add.

**Findings:** Overall feedback has been favourable with most enjoying the experience of seeing different health professionals in a 'one-stop shop'. There are a few remarks about the length of time spent at the appointment which has improved over time with a more co-ordinate approach. Patients found the service to show a high level of professionalism, they are also happy with the annual health check: it helped them to find out how well they are doing, also to identify issues they may have and act upon with the assistance of the correct professional.

**Conclusion:** The AHC is the only opportunity for stable HIV patients to get the opportunity to be fully assessed at least once a year as advised by the BHIVA guidelines. The absenteeism was marginally improved with a reminder text sent a few days before the appointment. Some patients reported being unsure about the nature of the clinic as appointments were sometimes made over the phone, this was resolved by giving the patient an information leaflet on arrival and the nurse verbally explaining the clinic, and giving the patient the opportunity to ask questions. The demand for the clinic has increased over time, thus the clinic moved from fortnightly to weekly. Patients suggested to be asked if they want to attend with a partner. Some others suggested having the clinic run on different days. To satisfy the raised demand for the clinic, we are planning to add more slots, resolve some logistic problems to concentrate the service in one place.

**Abstract P6**

**Awareness of communication skills training within HIV nursing practice**

M Croston

North Manchester General Hospital, Manchester, England

**Background:** The Department of Health published a consultation for the NHS in (2009) 1. Which places emphasis on respect, dignity, and the need to value each person as an individual finding the time to listen and talk when it is needed and make the effort to understand.

British Psychological Standard (2011) 2 also aims to improve the psychological assessment and support to patients with HIV.

**Objective:** The aim of the survey was to gauge professional opinion regarding communication skills training. Also to ascertain what training respondents were aware of or had attended.

**Methods:** A survey was sent to NHVNA, North West alliance members and nurses at North Manchester General Hospital who worked with HIV-positive patients

**Results:** Out of the 49 surveys' completed 22.4% (n=11) were male 77.6% (n=33) female.

The majority of the respondents had been qualified for 20+ years 57.1% (n=28) providing care for HIV patients for a variety of different time frames, 0-5 years, 26.5% (n=13), 5-10 years 26.5% (n=13), 10-15 years 8.2% (n=4) 15-20 years 18.4% (n=9), 20+ years 20.4% (n=10). 53.2% (n=25) of respondents reported receiving formal training in communication skills .51.0% (n=25) had received formal training in counseling skills with 47.95 (n=23) attending Motivational-interviewing training. Training in communication models that address emotional concerns of patients (SAGE and THYME) was heard of by 39.6% (n=19) of respondents with only 4.25 (n=2) receiving training in the model. 87% (n=41) had not heard of cue-based communication as an approach to eliciting patients concerns.

**Discussion:** A significant number of nurses had received some form of communication skills training. With the majority of respondents expressing an interest in attending further communications skills training

1. Department of Health (2009) The NHS Consultation; Securing the NHS today for generations to come, Department of Health.
2. British Psychological Society (BPS), British HIV Association (BHIVA) and Medical Foundation for Aids and Sexual Health (Medfash) (2011) Standards for psychological support for adults living with HIV.

**Abstract P7**

**Pain Management Group**

R Downes

Liverpool Community Health NHS Trust, Liverpool, UK

This exciting and innovative peer support group evolved following a lengthy consultation held with a patient who had a very late HIV diagnosis and as a consequence is quite disabled by peripheral neuropathy. The patient was asked what else I could do to improve her quality of life; she replied, 'Enable me to meet others with the same problem'. A few embryonic ideas were emailed to and fro and the group was then formed with myself, a Community based Clinical Nurse Specialist in HIV, a Counsellor and a Therapist, both employed by local HIV voluntary support agency. This meets the recommendations of The Health and Social Care Act 2012, 'a greater voice for patients' and stresses the importance of the role of the specialist nurse in developing expert programmes of patient care and clinical outcomes.

The group meets monthly for a 2 hour session broken down into a clinical session and a therapy session. The first meeting was attended by 8 patients and was used to outline a mission statement, core values, aims and objectives along with identifying any professional input the group might like to invite as guest speakers. A program is outlined for 12 monthly meetings and clinical guest speakers include a pharmacist, physiotherapist, medicines management, chronic fatigue specialist and a pain specialist. Therapies include massage, art work, acupressure, reiki and meditation. There are also sessions exploring mindfulness, sleep and a session on pain and emotion in addition to what one might expect; the principles of pain management, assessment of pain and clinical investigation, anatomy and physiology of the pain process plus exercise and pain. A garden allotment has been secured for the group to access weekly. This provides benefits such as physical activity, peer support, comradery and increase in self-worth.

The group members are encouraged to keep a reflective diary. Results so far have been promising and the group are growing in confidence, ability and their understanding of pain as an individual experience, we plan to evaluate the project after 12 months to further develop the concept.

**Abstract P8**

**Effect of antiretroviral treatment non engagement due to beliefs inconsistent with conventional medical knowledge**

L Johnson, S Dartwaite and M Croston

North Manchester General Hospital, Manchester, England

Although the national press and advocacy groups are aware anecdotally about individuals who disengage from Anti-Retroviral Therapy (ART) because of a belief that is inconsistent with conventional medical knowledge (e.g. faith healing or alternative therapies) little is known about the impact this has on patient outcomes We retrospectively identified 9 patients accessing care through our clinics in the last 10 years who had disengaged from ART for reasons that were not reconcilable with conventional medical thinking and assessed their outcomes.

We excluded cases where the belief was felt to be secondary to a mental health diagnosis or the responsible clinical team felt the individual lacked capacity.

In this group there were 5 black African women, 1 black African man and 3 white men. Reasons for non-engagement were a religious belief in 5 patients, a belief in alternative therapies in 3 and a belief in a pharmaceutical industry conspiracy in 1. 2 patients had a history of mental health problems predating their HIV diagnosis and 2 patients were diagnosed with depression during follow up.

The median CD4 count at diagnosis was 220 (IQR 78 to 399) and the median best CD4 on treatment was 509 (IQR 207 to 737) with the median lowest CD4 count off treatment being 49.5 (IQR 28 to 78). All patients took ART with the median time from diagnosis to stopping or declining therapy was 21 months (IQR 18 to 64 months) although in 4 patients adherence was thought to be sporadic throughout their clinic history.

In addition to the significant fall in CD4 noted above, all patients experienced AIDS defining illnesses after stopping ART, however as of date of submission only 1 patient has died. Illnesses included 2 cases of HIV encephalopathy, a CMV retinitis, a cryptococcal meningitis and a cerebral toxoplasmosis. Significant resources were utilised attempting to re-engage these individuals in therapy including an adherence nurse, a specialist HIV psychologist, Psychiatrists and multiple multi-disciplinary meetings. Significant hospital bed days were also needed to address the complications of untreated HIV.

Patients whose belief systems conflict with conventional medical knowledge and who do not engage with ART are a group who suffer a significant range of HIV related morbidities that would not be expected given the cohorts CD4 zenith and also consume a significant amount of medical resources. Identifying successful evidence based strategies that address this would save resources and most importantly improve the well being of our patients.

**Abstract P9**

**The effectiveness of a single intervention short film on adolescent perception of people living with HIV- a pilot study**

A Barnes and K Forbes  
Body & Soul, London, UK

**Background:** Adolescent HIV knowledge is not protective against HIV related stigma; adolescents with high levels of HIV knowledge report stigmatising behaviours and attitudes towards people living with HIV. The purpose of this study is to show the effectiveness of a single-intervention short film (UNDEFEATED) on creating self-reported change in adolescent perception of people living with HIV and HIV-related stigma.

**Methods:** Approximately 150 young people participated in a Year 10 assembly that screened UNDEFEATED. After the film, young people answered a short questionnaire that combined closed and open-ended questions. Survey administrators collaborated with the Year 10 Head to ensure the survey and surveying methods were in-line with institutional procedures. Students were advised that this questionnaire would help determine the utility of UNDEFEATED in a classroom setting, and that there would be no negative repercussions from providing feedback.

**Results:** 153 students completed feedback surveys. On the closed-ended questions, 65% felt that they learned more about stigma and discrimination from watching the film. 67% agreed that the film made them think differently about people living with HIV. Open-ended questions reinforced the aforementioned data. Open answers to the question, 'How do you think this film impacts on the way you feel about people living with HIV?' yielded desirable feedback in 142 out of the 153 respondents. Qualitative feedback included, 'It made me realise that just because the person has HIV you should never hate them or treat them horribly', 'It made me understand that they suffer much more prejudice than I thought', 'It makes me think that they're not treated equally and it's not fair', and 'I don't find them disgusting anymore'.

**Conclusion and Recommendations:** This pilot showed positive evidence from both open and closed questions that this intervention was effective in adolescent participants in achieving short-term self-reported improvements in perception of people living with HIV. Given the intervention's short length and ease of administration, this data is encouraging. To better demonstrate intervention effectiveness, it will be tested amongst a larger, more diverse sample. Additionally, more rigorous evaluation including pre and post testing and measurement of long-term change could help justify use of the intervention in classroom settings.

**Abstract P11**

**The experience of men who have sex with men in responding to and coping with HIV in the first year following diagnosis: a systematic review of qualitative evidence**

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The University of Nottingham, Nottingham, UK

At the end of 2011 there were an estimated 96,000 people living with HIV in the United Kingdom, with men who have sex with men (MSM) making up 47 per 1000. New diagnoses of HIV among MSM have been increasing since 2007 and in 2011 47% of these were late diagnoses. This is despite a slow and significant decline in late diagnoses among MSM over the last decade. The illness trajectory for many HIV positive people has changed since the advent of widespread antiretroviral therapies in 1995. A diagnosis of HIV has many effects on the emotional and behavioural health of MSM. There is a body of evidence that has offered reflections on the HIV diagnosis experience for MSM. Whilst this evidence is useful in providing some understanding of the response and coping strategies employed by MSM following diagnosis, the main criticism is that the studies tend to be retrospective with participants being diagnosed for between 1 and 23 years. This can be problematic as some diagnoses were received prior to antiretroviral therapies being used more widespread. Therefore it was necessary to explore what is known of the experience of MSM in the first year following diagnosis.

A systematic review of qualitative evidence was undertaken utilising a three-step search strategy of common literature databases for published and unpublished evidence. Using PICO, evidence was included that focused on MSM and their experience of responding to and coping with HIV in the first year following diagnosis. Studies were excluded if they were published prior to the widespread use of antiretroviral therapies in 1995. Papers were retrieved and assessed by two reviewers using a standardised critical appraisal checklist from the Joanna Briggs Institute Qualitative Assessment and Review Instrument. 966 papers were identified initially but only 4 were included in the review following assessment of methodological quality.

Synthesis of findings from the included papers generated the identification of three categories which addressed a mix of emotions as an immediate response; thoughts on a disrupted life; and a re-imagined future. Meta-aggregation of these categories led to the production of a comprehensive statement that a diagnosis of HIV in MSM can be experienced along a continuum from disability to relief and leads to disruption in sense of self and re-imagining of future life, which is influenced by personal experiences of the infection, information gathering and health professionals' responses.

**Abstract P10**

**A service improvement based needs assessment to identify the fears of young people of different age groups living with and affected by HIV**

K Forbes and A Barnes  
Body & Soul, London, UK

**Background:** By identifying specific fears of young people living with and affected by HIV (YPHIV), we better understand how to support this group of vulnerable individuals. Through comparing the fears of progressing age groups, we can prioritise the interventions and support provided at each stage using a lifecourse approach. This service improvement based needs assessment will influence programming and help tailor interventions to address HIV-related fears according to age.

**Methods:** On three occasions over 27 months (November 2010–February 2013) service users of a third sector support service for YPHIV aged 10–12, 13–19 and 20–29 attended workshops on Fears and HIV. In each workshop participants wrote down and anonymously submitted their fears. These fears were then categorised and an expert facilitated an immediate group discussion.

**Results:** The fears mentioned in each discussion were categorised according to themes as below. Each individual fear raised was recorded, even if it had been already mentioned by another member of the group.

Age Group	Number of participants	Total number of fears collected (average number per participant)	Medication (% of total)	Stigma & Disclosure (% of total)	Death (% of total)	The future and transmission (% of total)
10-12	8	8 (1)	0	1 (12.5)	2 (25%)	5 (62.5%)
13-19	53	101 (1.9)	12 (11.9%)	28 (27.7%)	25 (24.8%)	36 (35.6%)
20-29	15	47 (3.1)	6 (13%)	18 (38%)	7 (15%)	16 (34%)

Additional fears disclosed include:

- medication security by both the older age groups
- development of another chronic illness
- drug resistance

**Conclusion:** This small needs assessment revealed commonly experienced fears, across the ages (death, purposeful and accidental disclosure, adhering to medication) which clearly need addressing regularly, but also some less common yet valid and reasonable fears which will also influence future planning. The small sample size is a limitation when it comes to comparison, but from this initial assessment it appears that fears around medication, stigma and disclosure increase as YPHIV grow older, but fears around death decrease. Fears around the future and passing on of the virus were present across the ages.

**Abstract P12**

**Opt-out HIV testing within intensive care in a large urban hospital: an innovative testing initiative**

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<sup>1</sup>Barts Health, London, UK and <sup>2</sup>St George's University of London, London, UK

**Background:** UK guidelines recommend increasing opt-out HIV testing in a range of medical settings in areas of high prevalence. Routine testing in acute medical settings is commonly practiced, however it remains rare within intensive care (IC) with evidence of missed opportunities for HIV diagnosis in IC patients. In this setting the consequences of a missed HIV diagnosis may be particularly critical as it may prevent appropriate immediate life-saving treatment.

**Methods:** We have started an opt-out HIV testing initiative within IC, in a hospital with an existing opt-out testing scheme in the acute medical admissions unit and a high local HIV prevalence of 5.95 per 1000. All patients admitted to IC or the high-dependency unit (HDU) non-electively are informed that they will be tested for HIV unless they opt-out. Those lacking capacity to consent are tested in their best interests based on high local prevalence. Our HIV-testing team, comprising an HIV consultant, registrar and nurse facilitator worked with IC staff to develop guidelines. The testing team also provided training, support and patient information material to IC staff to facilitate implementation of the intervention. We provide preliminary data from the first 3 months of the project.

**Results:** Of the 461 patients admitted to IC/HDU in October-December 2012, 59.7% (n=275) were tested for HIV. In the 3 months prior to opt-out testing the rate was (28/432; 6.9%; p3) and was instrumental in guiding investigation and treatment. He was successfully discharged from hospital having commenced treatment for HIV and B-cell lymphoma. One further patient had an equivocal HIV test result, but was negative on repeat testing.

**Conclusions:** We believe this service development to be the first of its kind in the UK to deliver routine opt-out HIV testing within an IC setting. It is a sustainable model with HIV staff providing training and support to IC staff, who deliver the testing. This strategy has resulted in a significant increase in HIV testing rates within an IC unit serving a high-prevalence local population, and will guide life-saving management in patients who test positive.

## Abstract P13

**Breaking bad news in HIV – lessons to be learnt from other disease areas? 'Teaching a new dog old tricks?'**M Roche*Brighton & Sussex University Hospitals NHS Trust, Brighton, UK*

**Background:** Much of the literature/research regarding breaking bad news relates to delivering poor prognosis to palliative patients. However, clinicians often use guidelines set out for palliative patients when delivering bad news to patients who are not necessarily palliative, as the term 'breaking bad news' is often used for that moment when clinicians give a patient 'negative information' about a diagnosis, treatment options or prognosis. The aim of the study is to systematically review existing research on delivering bad news looking at the impact of this both from the patients and healthcare professionals' perspective, and review how this is reflected in existing HIV guidelines and competency frameworks.

**Method:** A systematic review of the literature using variations on the term 'breaking bad news' was completed in both Pubmed, Cinahl and Ovid. Only those articles which were original research, written in English and completed since 2005 were included in the review. The data from each of the articles reviewed was then analysed using a narrative synthesis approach, which allows for themes which are then sub-analysed into codes. These themes and codes are then to be further analysed using the same narrative synthesis approach to see to what extent they are reflected in guidelines and competency frameworks for delivering bad news to HIV patients. This part of the review is yet to be completed.

**Results:** The main themes which have emerged from the systematic review include, cultural and environmental issues, information withholding, communication issues (verbal versus non-verbal), treatment options, skill sets of healthcare professionals and, assessment and understanding of patient needs. The extent to which these are currently encompassed in guidelines and competency frameworks is being undertaken at the moment and the results will be available in advance of the NHIVNA conference.

**Conclusions:** As stated above the overall extent to which the themes from the research are reflected in current guidelines and competency frameworks is currently underway. However, the lack of research in this area specifically relating to HIV would indicate that the only lessons to be learnt are from other disease areas.

## Abstract P14

**The development of a competency based HIV testing guideline for TB nurses**P Jelliman*Liverpool Community Health NHS Trust, Liverpool, UK*

Currently the community TB team refer all HIV tests into the community HIV team. This is not best practice as it does not align with employing NHS Trust strategic objectives, national guidelines (BHIVA testing guidelines, & NICE guidelines, both HIV & TB, & global (WHO CDCs, and UNAIDS). This guidance was therefore a driver for change in practice. Referrals increase the workload of the HIV team in respect of patient activity, paperwork & referral management. According to guidelines, there is a concept from local to global initiatives to normalise, and promote HIV testing, with an aim of early diagnosis. Patients with TB should be tested for HIV. TB team also administer BCG vaccine to eligible neonates, & there is a requirement to establish HIV status of the mother. Referral on hinders the patient journey into timely, appropriate, specialist care if they have HIV, and delays BCG vaccine for the baby. The tests therefore should be undertaken by the TB team at the point of contact.

**Aim:** To develop a competency based clinical guideline to enable TB nurses to undertake HIV tests in a safe, timely manner.

**Method:** Develop the guideline & competencies, review documentation, & submit for approval by NHS Trust clinical policy group.

Undertake a SWOT analysis to scope the need & impact of the project.

Develop a GANNT chart to manage the change in practice and provide a timeplan for implementation.

Action learning sets were developed to provide a 2 way communication opportunity between the teams, motivate & support TB nurses, & provide education relating to HIV.

Apply a theoretical change model to ensure an effective project plan.

Provide ongoing support to TB team especially if they have a positive test result.

**Conclusion:** Guideline is approved & available on staff intranet. By TB nurses undertaking HIV tests, they are increasing their knowledge, skills & expertise, promoting increased efficiency & enhancing the patient journey. This change in practice has released capacity within HIV team to enable them to support a caseload of complex patients, and provide support & education to GP practices & other community nurses in relation to HIV testing. This addresses the requirement to increase & normalise HIV testing. There is scope for any community nurse to refer to the guideline when a testing opportunities present. This change is sustainable as it has no cost implications, & staff have reassurance of ongoing support.

## Abstract P15

**The complexity of disclosure: positive mother to negative children**R Burridge, L Ohen, S Hunte and C Agei*GSTT Community Health Services, London, England*

As a community specialist team we have found we are working with increasingly complex families. The importance of a positive parent sharing her/his diagnosis with their children has been well documented and of course with this comes the necessity to make sure those children have at sometime been tested themselves.

This case study discusses many of the problems raised when it is too late for the positive parent to take the lead to tell her children as she no longer has the mental capacity to do so, due to HIV related dementia.

The importance of long term case management where the client and children have a trusted health professional who works with them both at home and in clinics becomes very relevant when there are many professionals involved from community and hospital.

This case study involved coordinated multi professional work.

The family to be discussed include a mother who has had a positive diagnosis for over 10 years but has not engaged with treatment on a regular basis. She has three children aged 17, 15 and 12. The mother has always been clear that she does not want her children to know her diagnosis and informed professionals that the children had all been tested negative when younger.

Sadly, over the next few months, she continued to decline in health and is deemed to no longer have mental capacity. It is then recognised that the children have actually never been tested and remain unaware of their mother's diagnosis.

This case study looks at how we dealt as a multi professional team with these complex issues involving case conferences to discuss 'best practice' for the mother and the children. The study looks at how we told the children their mother's diagnosis, leading to the three children being able to be tested for HIV themselves.

The study discusses the outcomes for both the mother and the children and the lessons learnt by the professionals involved.

## Abstract P16

**'Are we there yet?': Raising the profile of HIV for non-HIV healthcare workers**T Buckingham, R Burholt, T Keith, E Nixon, A Parkhouse, N Perry, H Renton, J Roberts and M Roche*Brighton and Sussex University Hospitals Trust, Brighton, UK*

**Background:** The profile of HIV continues to evolve and the needs of people living with HIV remain complex and many need to access other services outside of the HIV setting. In addition, there sometimes appears to be anxiety amongst non-HIV specialist healthcare workers looking after people with HIV.

The aim of this project was to measure the knowledge and attitudes of nursing staff in caring for people with HIV, to inform education strategies and to raise the profile of HIV care across the Trust.

**Method:** A steering group was established to explore promotional opportunities within the Trust.

Ten basic HIV questions were developed and using Survey Monkey were distributed over a three month period via the Trust info-net supported by the chief nurse.

A specific World AIDS Day [WAD] 2012 event was planned to disseminate the results and to promote HIV awareness amongst health care professionals.

**Results:** There were 348 respondents of which 5% looked after patients on a regular basis. 63% reported having some knowledge of HIV and 90% were aware that antiretrovirals need to be given at the same time every day. However, 30% of respondents thought personal protective equipment was required for looking after people with HIV. 40% felt there should be an alert on patient notes. In addition 67% replied that HIV testing should only be carried out by a specialist.

Following the WAD event the project team were invited to run two workshops at a local conference for healthcare assistants and to present at an additional conference for nurses and midwives. There have been further requests for HIV awareness training and some work is currently being undertaken to increase HIV training in the undergraduate nursing curriculum.

**Conclusion:** While it is reassuring that nursing staff perceive they have some knowledge around HIV and treatment, this project indicates that ongoing education and training is required in non-HIV settings even in high prevalence areas. This also demonstrates that raising the awareness of HIV through Trust communication networks can promote further training opportunities. This is particularly significant as people with HIV increasingly come in to contact with other healthcare workers outside of the HIV setting.

## Abstract P17

**The experiences of HIV nurses conducting research in a HIV nurses network**M Jones<sup>1</sup>, J Bennett<sup>2</sup>, R James<sup>3</sup>, J Roberts<sup>3</sup>, N Petty<sup>4</sup>, N Perry<sup>3</sup><sup>1</sup>East Sussex Healthcare NHS Trust, Eastbourne, UK, <sup>2</sup>Freelance Nurse Consultant, London, UK, <sup>3</sup>Brighton and Sussex University Hospitals NHS Trust, Brighton, UK, <sup>4</sup>Clinical Research Centre for Health Professions, Eastbourne, UK  
On behalf of the Sussex and Surrey HIV Nurses Network (SSHNN)**Background:** The Sussex and Surrey HIV Nurses Network meets four times a year providing an educational programme including clinical updates, conference feedback and research processes. NHIVNA has championed nursing research and the concept of HIV nurses networks; the NHIVNA Conference Best Poster Award 2012 recognised research carried out by nurses across the HIV network.**Aims:** Part A: The aim of this project was to evaluate the views of nurses who attend the network meetings and to assess their involvement in the research project

Part B: To further explore the nurses views on participation in the research project.

**Methods:** A: An online survey sent to all members of the group with an invitation to participate in a focus group.

B: A focus group conducted after the results of the survey have been reviewed

**Results:** A: 39 nurses were sent an email invitation to participate; 23 (59%) nurses completed the online questionnaire, 70% of whom had attended at least half the previous year's meetings. 10 had attended sessions about the research process, all of whom found them helpful. 17/19 were aware of the research project and of these 7 played an active role in at least one aspect; 14 would have liked to play a more active role but were prevented from doing so by a variety of reasons including: insufficient time, skills and experience.

B: 5 had attended the focus group training; 3 of these had facilitated a focus group as had one other. The training was helpful to 2 but not the third and one suggested that holding the training just before facilitating a group would have helped.

Other findings included: not all nurses' participation is supported by their employers and logistics for attending after work meetings affects some; Several nurses made positive comments about participating in the network research project and 13/15 would be interested in future network research. There was also positive feedback about network meetings. 15/19 were on NHS pay bands 6 or 7. Median years as a HIV nurse was 10 (range

**Conclusion:** Conducting nursing research through a HIV nurses network is possible and can be fulfilling to nurses who participate.

## Abstract P19

**Does the dual testing strategy under-diagnose latent TB infection in HIV-infected individuals?: A 1 year experience in a TB high incidence Area in the UK**M Curtiss<sup>1</sup>, T Wambaa<sup>1</sup>, S Dawson<sup>1</sup>, E Pease<sup>1</sup>, J Ashby<sup>1</sup>, S Menzies<sup>2</sup> and A Ainley<sup>2</sup><sup>1</sup>BHFT, Berkshire, UK, <sup>2</sup>HWPB Foundation Trust, Berkshire, UK**Background:** HIV patients with latent TB infection (LTBI) have an 8% annual risk of developing active TB compared with a 5-10% lifetime risk in HIV-negative individuals. NICE recommends screening HIV patients for LTBI and giving chemoprophylaxis if positive. We introduced a screening service in July 2011 and report our first year's experience.**Methods:** From July 2011, newly diagnosed and established HIV-positive patients identified at our HIV clinic were screened for LTBI as per NICE guidance (CG117, 2011); patients with CD4 counts >200 cells/mm<sup>3</sup> (Group 1) had an Interferon Gamma Release Assay (IGRA) (T-SPOT®.TB); those with a CD4 count ≤200 cells/mm<sup>3</sup> (Group 2) had an IGRA followed by a Mantoux test (TST) if this was negative. If any test was positive, a Chest Clinic referral was made to exclude active TB and provide chemoprophylaxis.**Results:** Forty four patients that attended the clinic at times suitable for sample transportation were screened.

Within Group 1 (n=33), the IGRA was positive in 3 patients (9%), negative in 26 (79%) and non-diagnostic in 4 (12%). Of the 3 positive patients, 1 had previously completed chemoprophylaxis for active TB and the other two were both commenced on chemoprophylaxis. In the non-diagnostic group, 1 had a subsequently positive QuantiFERON® IGRA test (QFT) and treatment for LTBI. 1 had a negative QFT and TST and no treatment was commenced. Two patients were lost to follow-up.

Within Group 2 (n=11), no cases of LTBI were detected. The IGRA was negative in 10 patients (91%) and non-diagnostic in 1 (9%). Subsequent TST screening has been negative in all 6 patients that have attended to date. The patient with the non-diagnostic test deferred follow-up.

**Conclusions:** Screening for LTBI using the NICE guidelines is successful in the less-immunocompromised HIV population, but may under-diagnose LTBI when the CD4 count is ≤200 cells/mm<sup>3</sup>. Specimen transport issues and poor attendance has been a real limitation and has prevented all eligible subjects being appropriately screened.

## Abstract P18

**The role of the community HIV CNS in complex case-management of HIV positive individuals**

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Case-management is a concept that is widely used among several care providers in the UK and worldwide. It is however, a concept that is ill-defined and poorly understood.

Looking at literature and practice, it appears that the interpretation of what case-management means depends on the service/setting and the person providing the case-management.

This paper aims to clarify the term 'case-management' as it is used in literature and by the Community HIV CNS team.

Within our area there is a high HIV prevalence ranging from 13.9 per 1000 population to 7.5 per 1000. The London average is 5.4 per 1000 in comparison to the UK average of 1.9 per 1000.

The three boroughs we cover also have a high rate of late HIV diagnoses (late presenters) and have marked deprivation and social inequalities. We have large ethnic minority communities whose residents are mainly Sub-Saharan African descendants. Health Protection Agency data of our area in 2010 also identifies significant rates of new HIV diagnoses amongst MSM (men who have sex with men).

Our caseloads consist of clients with very complex needs. These clients represent approximately 5-10% of the total HIV cohort in this area.

This paper will explain the case-management criteria used by the HIV CNS Team and spell out why we use this approach for our client group. The paper will also explore the desired outcomes of case-management. We intend to describe and define what it entails to case manage and give an example of the case-management pathway used. We will also look at the limitations and difficulties we face as community CNS case managers.

## Abstract P20

**PEPSE as prevention: an oxymoron?**

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**Background:** There is an overall reduction in HIV infection rates amongst heterosexual men and women, while infection rates among men who have sex with men (MSM) continues to rise. There is, therefore, an observed discrepancy between the role and purpose of PEPSE as a risk reduction strategy *vis-à-vis* the evidence of a persistent increase in the HIV incidence rate worldwide, particularly among MSM.**Aims:** To identify the role of PEPSE as prevention strategy and its influence on sexual behaviour in MSM.**Method:** A literature review was undertaken using different electronic databases, to look at the impact of PEPSE on sexual choices in MSM, both in the pre- and post-ART eras. A total of 54 papers were examined. The review was undertaken through a variety of online databases, including CINAHL, Cochrane, British Nursing Index (BNI), PubMed, Athens, Google. Only peer-reviewed journals were included in the search. Search words included, 'HIV post-exposure prophylaxis'; 'sexual behaviour'; 'risk taking'; 'men who have sex with men.'**Results:** The search revealed a vast body of literature on the observed changes in risk taking behaviour in MSM since the introduction of PEPSE, with many researchers arguing that PEPSE does influence sexual behaviour in MSM, by engendering over-reliance on medications and by reducing interest in safer sex practices; and others affirming it does not. There was considerable paucity of qualitative research. Of the 54 paper examined, 13 were qualitative research, based on phenomenological or ethnographical approach to explore sexual behaviour in MSM. Quantitative research on this subject usually combines mathematical modeling and surveys to quantify behaviour.**Conclusion:** Whilst there is circumstantial evidence to support the case that the availability of PEPSE has signalled a paradigm shift in the choice of sexual behaviour in MSM This literature review has also highlighted the importance of adopting comprehensive strategies to reduce onward transmission of HIV, of which PEPSE remains one. Frontline practitioners should be aware of the potential pitfalls of over-reliance on medication, and should reflect on how research based evidence is generated, how it is implemented, and to what extent it informs clinical practice.

**Abstract P21**

**Applicability of stable patient HIV service provision for young adults**

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**Background:** The 2011 BHIVA Guidelines on routine investigation and monitoring of adult HIV-1-infected individuals propose that stable patients (VL <50 c/ml, CD4 count >350 cells/μl) adherent to antiretroviral therapy (ART), may only require 6-monthly outpatient follow-up. This audit assesses whether this service model is applicable to young adults attending a designated young persons' service.

**Method:** Single centre retrospective case note audit of all young adults attending a young person's HIV clinic for >1 year with an undetectable viral load (VL <50 c/ml) for >6 months and CD4 count >350 cells/μl. Reasons for attending clinic between October 2011–October 2012 and the resulting services provided were recorded.

**Results:** Of a cohort of 91 young people; 38 (42%) met stable patient criteria; median age 21 years (range 17–28), 21 (55%) female, 78% black African origin and 36 (95%) acquired HIV perinatally. The median outpatient attendances in the 1 year was 4 (IQR 3–5). 31 (82%) patients had a new medical diagnosis requiring treatment or referral; infective(10), cardiology(4) dermatology(5) orthopaedic(2) gynaecology (3) renal(2) ophthalmology(1) endocrine(1) hepatology(2) nonsclerotic portal hypertension(1). 4 (10%) patients required inpatient care during the year. 29/35 (83%) individuals known to be sexually active had at least one sexual health screen. 15/18 (83%) sexually active females had a cervical smear and 11 (61%) were provided with a long-acting contraceptive. 2/38 patients required partner post exposure prophylaxis and 8/38 had documented partner disclosure issues. 71% of patients received hepatitis B vaccination. Drug/alcohol misuse requiring intervention was documented in 6 (16%) patients. 13% of patients' social, financial or housing issues were addressed at the clinic. A psychological issue requiring ongoing intervention was documented for 13 (34%). 92% of patients saw more than 1 member of the multidisciplinary team within the audit period.

**Conclusion:** This audit highlights the varied and complex needs of this young adult population. Despite patients being stable on ART and at least 1 year post transition from paediatric to adult services, patients required high levels of multidisciplinary support to maximize physical, sexual and psychological health. Surprisingly, 10% of designated 'stable patients' required admission; the definition of stable patient may differ for those who have lived with HIV from birth for more than 2 decades.

**Abstract P22**

**Are Health and Wellbeing Boards in higher HIV-prevalence areas prioritising HIV prevention?**

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**Background:** The Health Protection Agency (HPA) identified 35 Local Authorities (LAs) with diagnosed HIV prevalence >2 per 1000 population aged 15–59 and with >50 individuals diagnosed late between 2008 and 2011. The HPA identified men who have sex with men (MSM) as the priority for prevention in 10 LAs; African communities the priority in 10 other LAs; and both the priority in 15 LAs. From April 2013, LAs are responsible for public health. In preparation, each LA has to identify clear public health priorities in a Health and Wellbeing Strategy (HWBS). The authors sought to establish whether HIV prevention is being prioritised in these higher prevalence areas.

**Methods:** Each LA's Joint Strategic Needs Assessment (JSNA) and HWBS were searched for the words HIV, sexual health, gay men (or MSM or LGBT) and African and the content assessed. The HWBSs indicate when HIV is a priority so subjective assessment was not necessary.

**Results:** 68% of JSNAs in higher HIV prevalence LAs included data on HIV and communities most at risk, 32% did not. More than half of LAs in higher HIV prevalence areas did not prioritise HIV. Only 20% of LAs prioritised HIV in both their JSNA and HWBS. 24 of 35 (68%) JSNAs included content about HIV, sexual health, gay men and African communities. Two JSNAs did not include any of the words searched for, including Manchester. 9 JSNAs did not include content on all the topics. Of those 9, 2 are LAs where both African people and MSM are priorities for HIV prevention; Birmingham included nothing about HIV and Brent no information about MSM. 5 of the 9 are LAs where MSM are considered in need of HIV prevention; 4 made no mention of MSM and 4 no mention of African people, including 3 which mentioned neither. No mention of MSM was made in 2 JSNAs for LAs where African communities are the priority.

7 of 35 HWBSs had not yet completed a HWBS. Of the remaining 28, 11 (39%) had prioritised HIV in their HWBS, 6 (21%) had not prioritised HIV but had addressed improving sexual health in general. 11 (39%) had no HIV priority: of these, Brighton and Hove, Camden, Hackney and Manchester have diagnosed HIV prevalence >5 per 1000.

**Conclusion:** HWBSs don't always reflect the data and recommendations in an LA's JSNA. Some LAs had understood the issue, e.g. setting targets to reduce late diagnosis in their HWBS. BHIVA and community organisations should contact HWB members in higher prevalence areas to present the case for HIV to be included as a priority in their HWBS.

**Abstract P23**

**Are generic antiretroviral drugs truly cost saving?**

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**Background:** In 2010/2011, HIV Commissioners in our region withdrew payment for the fixed drug combination Combivir, forcing a switch to individual components. This was deemed clinically acceptable and annual savings of £44k were expected. Preliminary work on drug costs alone estimated a much smaller saving.

**Aims:** We estimated the true costs of switching Combivir to its component drugs and patient outcomes with the new regime.

**Methods:** 65 patients used Combivir during the study period, 22 were excluded (temporary patients, lost to follow up, PMTCT only), leaving 43 patients. We used case notes to document each clinic visit or phone call in the 12 m pre- and 12 m post-switch, including clinician seen, pathology tests, and ARVs prescribed. We compared costs in these time periods using local pathology and drug costs. We also recorded viral load (VL) at 1 year post switch, and any patient-reported problem during the switch period.

**Results:** The difference in cost between pre- and post- switch is not significant. Post-switch care is more expensive by £40 per patient annually (95% CI £672 to £753) giving a total increase in costs post-switch in our 43 patients of £1742/yr.

Patients had more clinician contact post-switch (mean = 7.2 visits) compared to pre-switch (mean = 4.9 visits), leading to £60 additional cost per patient post-switch (95% CI £29–£92). Mean drug costs per patient were slightly less post-switch (£7,093 vs £7,140) and pathology test costs per patient were slightly more post-switch (£140 vs £113); neither were statistically significant. Five patients (12%) reported problems with the switch; 1 felt unable to take the new tablets and switched back days later, wasting 3 months of drugs. One patient developed a rash and 3 contacted the clinic due to confusion about the doses or timings. One patient had a detectable VL (411 copies/uL) at 1 year post switch. He had a history of adherence issues and a VL of 71 copies/uL pre-switch.

**Discussion:** As further generic antiretroviral drugs become available, pressure may be placed on clinicians to switch from fixed dose combinations to components if the direct drug cost is less. Our work shows that the additional clinical costs involved in this may outweigh or negate the simple cost savings of the drugs. Additionally, a switch may cause confusion or new side effects for some patients, risking loss of adherence. Hence caution needs to be exercised when considering the utility of generic antiretroviral drugs on cost grounds alone.

**Abstract P24**

**The importance attributed to religious belief plays an important role in the attitude of UK nurses towards people with HIV**

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**Background:** The aim was to survey registered nurses for their level of knowledge of HIV, their self-reported attitudes towards HIV infected patients and determine associated factors. Lack of knowledge of HIV may lead to stigmatising attitudes by health care workers. Studies show stigma in health care settings lead to a decrease in uptake of HIV testing. National guidelines state that a nurse should have the competence to obtain consent and conduct an HIV test. There is little literature on the knowledge and attitude levels of registered nurses in the UK.

**Methods:** A cross-sectional study of a sample of nurses (n=144) in a large hospital from all clinical departments using self-completed structured anonymous questionnaires. Descriptive analysis using frequencies was used to examine demographic variables, knowledge and attitude scores and to describe the sample participants. Spearman's rho non-parametric test was used for all correlations as not all of the data was normally distributed. Non-parametric tests, Kruskal-Wallis and Mann-Whitney U, were used to look for associations between continuous dependent variables and the dichotomous background variables.

**Results:** Mean age was 43.3 years. 24 countries of birth were reported. The overall mean knowledge score was 19/25,77%(Median 80 IQR 68–84). The mean attitude score was 4.06 (SD 0.45, Minimum 2.64, maximum 5), the median was 4.08 (IQR 3.76–4.40), the higher the score the more positive the attitude with undecided (3) the neutral point. Nurses who felt religion was 'very important' to them had statistically significant worse attitude scores (Mdn 3.88) compared to other groups 'important' (Mdn 4.40, p<0.001), 'not so important' (Mdn 4.30, p<0.001), 'not at all important' (Mdn 4.36, p<0.001). A strong religious belief was associated with lower knowledge scores.

**Conclusion:** The importance attribute to religious belief appears to influence attitudes toward HIV-infected people. Although overall knowledge was good and attitudes were positive those who self-identified that religion was very important to them had lower knowledge attitude scores. On-going dialogue with religious communities is essential. In addition innovative ways need to be developed to get training to those who need it, for example short in-services on the wards, train the trainer and e-learning programs.

## Abstract P25

**Anal cancer screening in the United Kingdom: a national survey of perceptions and practices among sexual health clinics**J Vera<sup>1</sup>, K Demarcke<sup>1</sup>, L Greene<sup>1</sup> and M Nathan<sup>2</sup><sup>1</sup>Imperial College London NHS Healthcare, St Mary's Hospital, London, UK and <sup>2</sup>Homerton University Hospital, London, UK

**Background:** The incidence of human papilloma virus (HPV) associated squamous cell anal carcinoma is increasing among HIV-infected individuals. In this population screening for anal intraepithelial neoplasia (AIN) could potentially prevent excess morbidity and mortality from anal cancer. The aim of this study was to assess the awareness and practices regarding anal cancer screening in a sample of Sexual Health Clinics in the United Kingdom.

**Methods:** Between August and December 2012, we conducted a national survey of anal cancer screening. The web-based survey was sent to the Lead Consultants of 116 sexual health clinics from England, Wales, Scotland and Northern Ireland. Survey data was collected and analysed using a web-based data collection service (Survey Monkey™).

**Results:** We obtained responses from 73 (62%) sexual health clinics, of which the majority 69 (95%) also provide care for HIV-infected individuals. From these clinics 52(72%) have a HIV cohort of more than 100 patients (range = 50 to >1000), with a proportion of men that have sex with men (MSM) of 46% (range = 10% to 82%). Regarding knowledge of anal cancer risk factors and screening approaches, 67(96%) are aware of the increased risk of HPV-associated anal cancer in HIV-infected individuals and 65(93%) have an understanding of screening methods for prevention of anal cancer such as digital rectal examination, anal cytology and high resolution anoscopy (HRA). Only 4 (5%) clinics currently have an anal cancer screening service, consisting of screening predominantly HIV-infected MSM and those with history of multicentric HPV-genital disease using anal cytology and/or HRA for the identification of AIN. 15(21%) of clinics responding are planning to set up a screening service in the future, while other clinics are waiting for national guidelines. Interestingly, 21 (30%) of respondents do not consider screening for anal cancer to be effective in the prevention of HPV-associated anal cancer among high-risk groups.

**Conclusion:** Awareness of risk factors and screening methods for HPV-associated anal cancer among a sample of Sexual Health Clinics in the United Kingdom is high. Despite the increasing risk of HPV-associated anal cancer in high-risk groups such as those with HIV infection, only a minority of Sexual Health Clinics are offering anal cancer screening at present, although more clinics are planning to do so in the future.

## Abstract P26

**As HIV moves towards a chronic disease, how involved are patients in their own care?**N Perry<sup>1</sup>, J Bennett<sup>2</sup>, M Jones<sup>3</sup>, R Janes<sup>1</sup> and J Roberts<sup>1</sup><sup>1</sup>Brighton and Sussex University Hospitals NHS Trust, Brighton, UK, <sup>2</sup>Freelance Nurse Consultant, London, UK and <sup>3</sup>East Sussex Healthcare NHS Trust, Eastbourne, UK

**Background:** Service provision within the NHS has changed, with limited resources and a governmental drive to encourage people to take responsibility for their health. The Standards of Care for People Living with HIV state that HIV+ individuals should be enabled to maximise selfmanagement and should have opportunities to be actively involved in decisions about their health care (BHIVA, 2012). This study explored the lived experience of people with HIV accessing healthcare services and to what extent health needs are being met.

**Method:** Ethics approval was granted for this qualitative study. Participants aged 18 or over, diagnosed for more than 1 year were invited to participate. Recruitment was via posters in both clinical and community settings. Written information was provided prior to participant's consent being obtained. Focus groups were recorded, transcribed and analysed using thematic analysis.

**Results:** Five focus groups were conducted with a total of 16 participants, 9 female; 7 male. Length of diagnosis ranged from 18 months to 25 years. The emergent themes were: Managing own health: this is hard to achieve in reality and participants still wanted to rely on healthcare professionals. Stigma: is a significant issue within the general community and when accessing other healthcare services. Experience of using services: participants stressed the importance of continuity of care, building a relationship with their HIV doctor and barriers to accessing GP services. Changing/future service provision: attempts to 'normalise' HIV were felt to be unrealistic. The need to access different specialties led to concerns linked with stigma and being seen by non HIV specialists. Empowerment: a sense that those diagnosed longest felt more empowered and had a sense of knowledge and control over their condition. Coping with daily life: Chronic fatigue and uncertainty about living with a long term condition was a common concern.

**Conclusion:** Despite professionals viewing HIV as a manageable condition the majority of participants expressed concerns about changes in service provision and the impact on doctor-patient relationships. Participants diagnosed the longest felt more involved in decisions and were more likely to express their opinions. Those diagnosed for less time were more likely to accept the changes. Stigma in the workplace and across other healthcare settings was expressed by all as a concern.

## Abstract P27

**The impact of faith-based 'healing' and 'cure' claims on Africans living with HIV in the UK**

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**Background:** Faith plays a vital role for many African people and communities - the 2001 UK census shows that approximately 69% of Africans living in the UK identify as Christian, and 20% as Muslim. In terms of health, faith and prayer can be a source of strength and support for people living with HIV, however there can be negative consequences of the interaction between faith and HIV. There are increasing reports of claims by faith leaders of faith 'healing' and 'cures' where people living with HIV are influenced to stop taking their treatment and rely instead on prayer. Over the past 18 months we have carried out a programme of research to investigate the impact of these claims.

**Methods:** The research was conducted in three stages:

- 1) An online-based survey of community-based and other service provider organisations working with Africans living with HIV.
- 2) An expert seminar, which brought together a multi-sector group of individuals with representatives from statutory, voluntary, academic and clinical sectors.
- 3) Qualitative interviews conducted with members of the African community, including people living with HIV who had been affected by 'healing' claims.

**Results:** The survey recruited 14 organisations, including 8 community organisations, and asked them to respond to a series of questions about faith healing with reference to the service users of their organisations. Of the respondents, 7 were aware of cases of people being told they had been 'healed' and being told or pressured to stop taking medication by faith leaders. Most respondents were aware of more than one case of faith 'healing' claims and pressure to stop taking medication with one knowing of at least 5 cases. At least 15 separate cases were identified in the survey. In some of the reported cases treatment was restarted, but in others the health and mental health of clients declined, in some cases leading to death. The seminar uncovered similar findings, indicating the issue is widespread and being responded to at local levels but with a lack of overall response. The qualitative interviews are ongoing.

**Conclusion:** The findings from all three phases of the research indicate that cases of faith 'healing' claims are widespread across the UK, and becoming more common. The nature and impact of these claims varies, but in all cases pose a risk to the health and wellbeing of individuals affected. There is a lack of joined-up approaches or consensus in responding to the issue, which needs to be addressed.

## Abstract P28

**HIV and psychological support: a psychological needs assessment of adults living with HIV**A Ray<sup>1</sup>, C Anderton<sup>1</sup>, SY Teo<sup>2</sup>, A Evans<sup>2</sup> and G Latchford<sup>3</sup><sup>1</sup>School of Medicine, University of Leeds, Leeds, UK, <sup>2</sup>Centre for Sexual Health, Leeds Teaching Hospitals Trust, Leeds, UK and <sup>3</sup>Leeds Institute for Health Sciences, University of Leeds, Leeds, UK

**Background:** The link between HIV and poor mental health is well established, with significant individual and public health implications. Recent publication of Standards of Care for People Living with HIV in 2013 has drawn attention to the unmet need for psychological support among the HIV-positive population in the UK and advocated for change. Providing services requires support from commissioning bodies however, and context-specific evidence of need. We aimed to gain an understanding of the psychological needs of adults attending a HIV clinic, to explore current support, and to establish the need for further services.

**Methods:** We designed a screening tool to establish baseline psychological need. This included the Hospital Anxiety and Depression Scale (HADS), the Distress Thermometer (DT), and questions regarding current support and future need. This was distributed to adults attending a regional HIV centre based in genitourinary medicine.

**Results:** 80 completed questionnaires were received (53% male, 47% female, mean age 39 years). HADS scores revealed 40% of respondents had clinical anxiety (12.7% severe) and 31% had clinical depression (17.7% moderatesevere). The DT identified 28.8% as having poorly controlled distress with 62.5% of these directly attributing their distress to HIV. Only 9 participants (11%) reported receiving any type of formal psychosocial support at the time of assessment, 5 from their GP and 4 from a psychiatrist or psychologist. Those who requested mental health support all had clinical levels of anxiety or depression. No participants scoring in the normal range requested support.

**Conclusion:** There is a high level of unmet mental health need in this population. A point prevalence of anxiety and depression of 40% and 31% respectively in this population is far greater than in Britain as a whole (10%). Respondents had poorly controlled distress which they often attributed to HIV. Those in the clinical ranges for anxiety and depression were appropriately indicating a need for psychological support. Appropriate psychological services specifically addressing the distressing impact of HIV, including stepped care for the range of severity should be made available to this population, as suggested by the 2013 Standards of Care and 2011 Standards for Psychological Support. Our evidence suggests that services would be used efficiently by those with a real mental health need, and resources not wasted by those without need.

**Abstract P29**

**Ensuring implementation of BHIVA guidelines and pathways in HIV case management: an integrated care solution**

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**Background:** Integrated care pathways (ICPs) are structured multidisciplinary care plans which detail essential steps in the care of patients. The development of ICP methodology has been supported by the NHS since the late 1990s and processes such as the ICP Assessment Tool (ICPAT) have made the implementation of robust ICPs possible. Systematic review of the implementation of ICPs has shown that ICPs can effectively support proactive care management, adherence to guidelines, improve physicians' agreement with treatment options and support decisionmaking. A multidisciplinary team applied this process to health care of people with HIV across the UK to adopt a defined standard of case management based on BHIVA guidance, which provides robust definition for both standards of care and model care pathways for service delivery which has not been undertaken previously.

**Methods:** Using a proprietary process of facilitation and iterative development, this multidisciplinary working group of HIV specialists comprising representation from around the UK has developed an ICP for non co-morbid outpatient HIV care in accordance with ICPAT standards and current best-practice thinking.

**Results:** The ICP forms comprise a streamlined and easy to implement solution for structuring each consultation along the patient pathway. The forms ensure that the full HARS dataset is collected for each patient as they progress along the pathway. The HIV ICP comprises:

- A process map defining the consultation flow along the patient journey
- A set of forms for use at each consultation, ensuring that appropriate assessments and interventions are performed according to BHIVA guidance
- A comprehensive support booklet, containing the full evidence base for HIV management with instruction for managing implementation of the ICP This ICP is available in Word format so that it may be easily modified and implemented by HIV teams across the UK.

**Conclusion:** Adoption of the ICP by HIV teams across the UK may facilitate implementation of BHIVA guidelines, collation of the HARS dataset and equity of service provision. In addition, the ICP forms are designed to encourage primary care teams to support parts of the patient journey where specialist resource is not required. This group proposes that the HIV ICP offers a useful solution to structuring HIV case management within the challenging economic constraint faced by the NHS.

**Abstract P31**

**Calabash at George House Trust: innovating to support HIV-positive African men in the North West**

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**Background:** In September 2011, George House Trust (GHT) received a two year grant from the Henry Smith Charitable Trust to provide a highly innovative service focussed on HIV positive African men/fathers. The Calabash project is an extension of previous work by GHT to support families, which had revealed specific issues for African men: a group that is often stereotyped and marginalised.

**Methods:** Calabash uses a combination of group work and one to one sessions to support HIV positive African men on a range of issues such as: HIV diagnosis; immigration; poverty and destitution; disclosure; employment advice; adherence to medication and so on. The project is led by an African man, supported by a group of HIV positive male African volunteers.

**Results:** To date, Calabash has supported 55 HIV positive African men. The service has: held over 150 one-to-one sessions; hosted 10 workshops sessions, attended by between 8 and 17 men, and held a reflective residential weekend, attended by 8 men. The main issues affecting men who attend the service are: understanding HIV and health management; stigma and discrimination; immigration issues; family issues; relationships problems and long distance families; poverty and destitution; difficulties in integration, and employment. Many of the men have multiple partners and the project encourages them to be open about this in order to best manage these lifestyle choices. A key finding has been that group sessions on employment and setting up in business have been the best attended and this has been influential in how the project has developed whilst it retains its original focus on health and parenting. Sessions on domestic violence are also planned.

**Conclusions:** Calabash has been successful in engaging hard to reach and marginalised HIV positive African men. It is a ground breaking and highly innovative project. It accepts their lifestyle choices and encourages them to be open about them in order to improve health outcomes. Key to its success has been its willingness to adapt and innovate to reach those whose experience of stigma makes them unwilling to approach HIV services.

**Abstract P30**

**Description of new referral data gathered by phone from a third sector support service for adults living with and affected by HIV, 2012**

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**Background:** People living with HIV may have multiple factors impacting their wellbeing. This needs assessment for service improvement summarises the baseline information gathered during the telephone referral process of 254 adults (age 20+) to a third-sector organisation during 2012.

**Methods:** When a new referral contacts the organisation basic demographic information and the individual's urgent needs are recorded: age, gender, whether or not the individual has a child/children; and whether the individual was presenting with any of the following immediate needs: problems with physical health, any mental health problems, need for psychosocial support, need for practical support (e.g. legal help, help regarding immigration status, but excluding support around hardship grants, benefits or housing/ homelessness), support in applying for a hardship grant, help in understanding/applying for benefits and problems regarding housing or homelessness.

**Results:** Of 254 adults who were referred by telephone, basic information was taken from 252. Information on immediate needs was taken from 186 individuals. 23% presented with problems with physical health, 12% with mental health issues and 45% were in need of psychosocial support. 29% needed practical support, 17% needed help with applying for a hardship grant, 11% needed assistance with benefits and 21% had an immediate housing situation. 50% of females and 42% of males presented with 2 or more immediate needs. 54% of females and 40% of males had children. 58% of the females and 37% of males with children presented with multiple immediate needs.

**Conclusion:** A significant proportion (73%) of individuals approaching the organisation vocalised an urgent need for help during the initial telephone referral. Females are more likely to present with an urgent need and multiple urgent needs compared to males. Women with children are more likely to present with multiple immediate needs compared to women without children. This data provides a singular snapshot of the need profile presented upon telephone referral. It is likely that these results are underreporting the true situation. In order to have a clearer picture of the complex needs of this population, further research is advised.

**Abstract P32**

**Failure to achieve an adequate CD4 count response despite regular engagement in HIV care and consistent viral suppression**

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**Background:** To investigate the proportion of people who start ART with CD4 <100 cells/mm<sup>3</sup>, are subsequently regularly monitored with consistent viral load (VL) suppression (≤50 copies/mL), yet fail to achieve an adequate CD4 count response (>200 cells/mm<sup>3</sup>) in the first five years on ART.

**Methods:** Eligible participants started ART after 1st January 2000, with at least one year of follow-up on ART. Participants were further required to have achieved VL suppression by nine months after starting ART and to have maintained this for up to five years of follow-up. Participants were required to be regularly engaged with care (≤6 months between each consecutive VL assessment). Linear regression was used to estimate a CD4 count trajectory for each participant who did not achieve a CD4 count >200 cells/mm<sup>3</sup>, to predict the timing of reaching this value.

**Results:** From a total of 1,212 starting ART with pre-ART CD4 <100, only 168 (14%) participants met the stringent criteria and were included in analyses. Median (IQR) follow-up was 2.9 (1.7-4.7) years, participants were 26% men-who-have-sex-with-men, 18% black heterosexual men, 29% black heterosexual women, 2% injecting-drug-user, 24% other + unknown, median age 39 years at start of ART. Of these, 45 (27%) did not achieve a CD4 count >200 cells/mm<sup>3</sup>. The median follow-up on ART for those who did and did not achieve an adequate CD4 count was 3.4 and 2.0 years, respectively. Among those who did achieve CD4 > 200, median time to this was 1.4 years. Morbidity/mortality rates for those who did and did not achieve an adequate CD4 count were 2.7/100 person-years (95% CI 1.3, 4.8) and 9.2/100 person-years (4.4, 16.9), respectively. Using the individual estimates of CD4 count trajectories, we predicted that the median (IQR) time to an adequate CD4 count response in people who did not achieve a CD4 count >200 cells/mm<sup>3</sup> over observed follow-up would be 2.4 (1.4-4.5) years. When including those projected to reach 200 by 5 years, the predicted proportion of people who do not achieve a CD4 count >200 after 5 years of ART is 12/168 (7.1%).

**Conclusions:** In a strictly defined group of people with regular monitoring and consistent VL suppression, we predict that only a small minority do not achieve an adequate CD4 count response after five years of ART. Inadequate CD4 response is associated with greater clinical consequences. Care should be taken over interpretation as the participants in the analyses were a select subgroup of people with HIV.

**Abstract P33**

**Skin cancer in aging HIV-positive patients**

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**Background:** Cutaneous cancers are the most common malignancies; Multiple studies have shown an increased risk of skin cancer for immunosuppressed transplant recipients. National Institute for Health and Clinical Excellence (NICE) guidelines recommend these patients receive regular skin checks for timely detection and management of cutaneous malignancies. Human immunodeficiency virus (HIV) patients are also at increased risk of cancers, such as Kaposi sarcoma and lymphoma; however, since the advent of highly active anti-retroviral therapy (HAART) the incidence of these acquired immunodeficiency syndrome (AIDS) defining malignancies has declined. Unfortunately, the incidence of non-AIDS defining cutaneous malignancies continues to increase with the increasing life expectancy of HIV patients and presently accounts for most cancers in this group. Currently, there is limited data about the rate of skin cancer among older and long-term HIV patients. We report the proportion of attendees to an 'Over-50 clinic' with previously undiagnosed skin cancer to inform the debate as to whether routine skin screening is necessary in this group.

**Methods:** We undertook a prospective observational service evaluation to establish the prevalence of skin cancer in HIV patients over the age of 50 years. Patients attending the 'Over-50 clinic' were invited for a skin examination. A full medical history was taken from each patient before proceeding to a full skin check including the oral mucosa and perianal area. Management recommendations for detected skin cancers were provided accordingly.

**Results:** Forty patients were invited and accepted screening over a 3-month period. 32 participants were white, men who have sex with men with an average age of 59 years [50–78]. The mean duration of HIV diagnosis was 15 years [0–29] and mean duration of HAART was 12 years [0–25]. Two-thirds of participants were well controlled with normal CD4 counts and undetectable viral loads. Over 58% of the study participants had a history of previous or current cancerous or precancerous lesions of the skin. Ten (25%) had a previously undetected skin cancer identified during the study, mostly basal cell carcinomas.

**Conclusion:** We have identified a high rate of previously undetected skin cancer amongst HIV patients older than 50 years. Routine skin examination will allow older HIV patients to benefit from early detection of skin cancer, decrease morbidity and perhaps mortality in this high risk group of patients.

**Abstract P34**

**HIV testing in clinical indicator diseases in outpatient settings: offer and uptake rates and impact of educational and active interventions**

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**Background:** Approximately 50% of patients with late HIV diagnosis have accessed healthcare in the prior 2–3 years. HIV associated clinical indicator diseases (CID) seen in outpatient clinics (OPD) are proposed as an opportunity for earlier diagnosis in multiple testing guidelines. Expanded testing pilots show that whilst testing is acceptable to patients, offer rate by clinicians is low. Strategies to increase offer rate are needed. This study assessed the impact of a targeted OPD educational programme with and without additional individual case note prompts for patients with a CID as a strategy to increase HIV testing.

**Methods:** A 2 stage prospective study over a 12 week period during 2012 in Dermatology (D), Gastroenterology (G) and Haematology (H) OPD at 2 University hospitals. Clinicians received an education programme about significance of late HIV diagnosis, highlighting CID relevant to their field (as per national testing guidelines). For D OPD, stage 1 (6 weeks) consisted of preidentification of CID and insertion of a prompt to offer HIV testing. Stage 2 (6 weeks) relied on clinician identification of a CID only (no prompt). For G and H OPD, stages were reversed. The option of testing using serum or oral sampling was given. Test offer and uptake rate was compared with/without prompts and across age, gender and ethnic groups.

**Results:** 4191 patients were eligible. 608 (14.5%) were identified with a CID (D 8.9%, G 18.3%, H 22.7%) of whom 25 (4.1%) were known to be HIV positive, and 115 did not attend. 468 evaluable subjects were male (251, 54%), of white UK ethnicity (302, 65%) and with median age 51 years. Overall test offer rate was 82/468 (17.5%) and was significantly higher during the prompt stage (74/216, 34%) vs education alone (8/252, 3.1%);  $p < 0.001$  for total population and for each of D, G and H. There was no difference in offer rate by age, gender or ethnic group. Uptake was 61/80 (76.3%) and similar across OPD, demographic group, and prompt usage. Of those testing, 28/61 (46%) used oral sampling. No new cases of HIV infection were identified.

**Conclusion:** Test offer rates by OPD clinicians is low despite the high rate of HIV infection in OPD attendees with CID, national recommendation for testing in this setting and targeted educational intervention. Novel strategies to prevent missed diagnosis are urgently needed. Individual case note prompts significantly increase test offer rates, and this effect is lost if the strategy is withdrawn.

**Abstract P35**

**Opt-out HIV testing in the accident and emergency department 'majors' is effective and acceptable to patients and health care workers**

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**Background:** HIV positive patients continue to be diagnosed with late stage disease. Many have previously sought healthcare outside of traditional HIV testing settings and opportunities to diagnose HIV infection earlier may have been missed. Strategies to reduce the rate of undiagnosed and late diagnosis of HIV are recommended especially for areas where the local prevalence of diagnosed HIV is greater than 2 in 1000. In our area the estimated rate is 4.7 per 1000. Experience in Antenatal, TB and Genito-Urinary Medicine (GUM) Services demonstrates that Opt-Out testing is most effective. We introduced Opt Out HIV testing in the Accident and Emergency (A&E) Department 'Majors' section of a District General Hospital serving an ethnically diverse population.

**Methods:** The HIV Testing in A&E working group initiated a teaching and advertising programme among health care workers (HCW). At inception, all patients in A&E were informed by poster, information sheet and verbally that an HIV test was routine for any person having blood taken unless specifically declined. Blood test orders are placed electronically. GUM Services provided oversight and results management.

**Results:** After 26 weeks of the programme 52% of eligible patients (3250) had an HIV test. Only 10% of patients actively declined a test. In 38% of instances, HCWs either did not offer or did not request an HIV test. 58% of attendees were of Non White Ethnicities. HIV testing rates were similar across ethnicities and by gender and age (range 15–103 yrs). Black Africans were most likely to have had a test (60% uptake rate overall), Black Caribbeans were least likely to decline a test if offered (8% decline rate). 9 new HIV positive patients were identified. 2.8/1000 compared to an estimated expected rate range of 1–2.3/1000. A further 9 patients tested HIV positive but transpired to have been previously diagnosed elsewhere. 4 of these 9 had left active care and have since been re-engaged in care and treatment. In total, 5.5/1000 tested HIV positive compared to an expected 4.7/1000 for our population, notwithstanding the partial testing rates observed. Testing rates have risen as the programme has become established and staffs have identified scenarios where test offer and performance was being omitted.

**Conclusion:** Opt Out HIV testing in the Accident and Emergency Department 'Majors' section is feasible and an effective strategy for HIV diagnosis. It is acceptable to patients and Health Care Workers.

**Abstract P36**

**Project 'Test the Hospital'**

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**Background:** In areas where HIV prevalence exceeds 2 per 1000, BHIVA guidelines recommend opt-out testing for all general medical admissions in order to prevent late diagnosis and allow for optimal management. In response, opt-out testing is being introduced in Medical Admissions Units (MAU) and Emergency Departments (ED). Opt-out testing also occurs nationally in Antenatal Clinics (ANC) and Tuberculosis clinics (TB). These programmes are often initiated and managed vertically. Joining up the different initiatives within the hospital as part of a 'test the hospital' strategy may be helpful to improve coherence and implementation. In our inner London teaching hospital we combine Opt-out testing initiation with programme monitoring, to ensure efficient testing within relevant area.

**Methods:** Staggered introduction of routine opt-out testing has occurred in nine clinical areas within our hospital, which has a local HIV prevalence of 5.9/1000. We present the results of a series of snapshot audits on HIV testing from seven areas namely: MAU, ITU/HDU, Lymphoma, TB, Viral Hepatitis, Elderly Care Psychiatry (ECP) and ANC. Within MAU and ITU/HDU staff have been educated to incorporate opt-out testing as part of admission. Staff in ECP have been supported to test those with a clinical indicator of dementia. Here we report preliminary data from the first 3–12 months.

**Results:** Rates pre and post-intervention:

	HIV Tests Pre Intervention	HIV Tests post intervention	Positive results post intervention
MAU	50/4009 (1%) 6/12	848/6279 (12%) 8/12	10
ITU/HDU	28/432 (6.1%) 3/12	275/461 (59.7%) 3/12	1
ECP	0/15 (0%) 1/12	39/48 (82.9%) 3/12	0

**Abstract P37**

**National HIV Testing Week: An intervention for raising awareness and encouraging HIV testing**

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**Background:** Late diagnosed HIV is a significant problem across the UK, with approximately 1 in 4 of all people with HIV currently untested. HIV testing remains stigmatised and underutilised. As part of HIV Prevention England (HPE), Terrence Higgins Trust coordinated the first National HIV Testing Week (NHTW) to encourage awareness, provision and uptake of HIV testing among gay men and African people.

**Method:** NHTW was delivered through partnership working with HPE local delivery partners, clinics and other services who were encouraged to participate. A wide range of events including increased testing hours and venues were supported. A 'flash logo' for the week was made available for use by all on existing materials and posters distributed to HIV clinics. Additional clinic hours were promoted on an online clinic finder and in local media, and an online risk assessment tool promoted which directed users to the clinic finder if the result indicated testing. A full risk assessment report was offered via email to users who provided their email address. Regional testing opportunities and awareness raising events were advertised through a dedicated NHTW Facebook page and a Twitter hashtag. Press releases about the week were sent to appropriate media.

**Results:** NHTW delivered over 800 additional hours of HIV tests across the country. An average of 575 people per day used the online clinic finder with a peak of 2,766 on the first day of NHTW. A total of 118 news items were placed in digital, print and broadcast media, with an audience reach of nearly 10 million. The NHTW Facebook page attracted 2,582 Likes and reached 151,590 at its peak. More than 55 organisations working in HIV and sexual health provided support, HIV testing and related events. BHIVA supported NHTW extensively. NHS Medical Director Sir Bruce Keogh included NHTW and the importance of reducing late diagnosis of HIV in a circular for doctors in England. The Health Protection Agency will analyse testing numbers and diagnoses to evaluate further impact. In feedback, the most common concern was a desire for more time to plan for 2013.

**Conclusion:** NHTW was a highly acceptable and popular intervention which energised testing initiatives and awareness across England and the target groups. It achieved good coverage across social and traditional media and amongst key health influencers. Dependent on final evaluation, it is likely to be repeated in 2013 with better notice.

**Abstract P38**

**HIV and risk behaviours among people who inject drugs in the UK: 30 years on**

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**Background:** People who inject drugs (PWID) are known to be at high-risk of HIV. We report on the epidemiology of HIV among PWID in the UK over the past 30 years.

**Methods:** Data on PWID (aged ≥15) diagnosed with HIV in the UK to the end of 2011 were analysed to examine demographics, late diagnosis (CD4 count <350 cells/mm<sup>3</sup> within 3 months of diagnosis) and mortality. Quality of HIV care of PWID in 2011 was assessed, alongside HIV prevalence and risk behaviours of PWID participating in the 2011 Unlinked Anonymous (UA) Survey.

**Results:** Over the past three decades, 5600 PWID were diagnosed with HIV; new diagnoses peaked at 417 in 1986, decreasing to 132 in 2011. The male to female ratio has remained relatively consistent at 2:1, while median age at diagnosis has increased gradually from 29 in 1984 to 36 in 2011. The majority of diagnoses have been among white PWID born in the UK and Europe. Late diagnosis has remained high: 52% in 2011; 39% of PWID were also diagnosed with AIDS. The 2011 mortality rate of PWID diagnosed with HIV was 26 per 1000, 5 times higher than that of the total diagnosed HIV population (aged 15–59; England and Wales). Of the 132 PWID newly diagnosed in 2011, 86% were linked to care within a month of diagnosis and 88% were retained in care 1 year after diagnosis. Among 1610 PWID seen for care in 2010, 94% were retained in care in 2011, 87% were receiving antiretroviral therapy (ART) as per BHIVA guidelines, and 86% had a viral load <50 copies/ml after a year of receiving ART. After a year in care, 69% had a CD4 count ≥350.

The UA Survey shows the variation in HIV prevalence among PWID over time (0.61–1.8%), with prevalence 1.0% in 2011. In 2011, 77% of survey participants reported ever being tested for HIV, 71% ever imprisoned, 77% ever homeless and only 19% reported consistent condom use with multiple partners. In the last month, 37% had shared injecting equipment, 32% injected crack, and 35% injected into their groin.

**Conclusion:** The HIV epidemic among PWID in the UK has remained relatively contained compared to other European countries, most likely due to prompt implementation of an effective national harm reduction programme. However, reported risk behaviours among PWID indicate the potential for HIV prevalence to increase if high quality services for PWID and HIV testing uptake are not maintained. Though quality of HIV care among PWID is excellent, this population appears to have poorer outcomes than other people living with HIV.

**Abstract P39**

**Patient and physician preferences regarding medications for HIV treatment**

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**Background:** The range of antiretroviral drugs available has increased considerably over the past 10 years. NICE guidelines (2009) state the importance of understanding patient preferences regarding treatment to optimize adherence. The present study was designed to elicit patient and physician preferences for HIV treatment options using stated preference survey.

**Methods:** Two stated preference surveys were developed from published literature and from interviews with patients (n = 5) and physicians (n = 2). Eight key attributes were identified: *Treatment benefit, Risk of rash, Risk of kidney stones, Risk of jaundice, Risk of diarrhoea, Risk of psychological effect, Risk of heart attack, and Long term safety profile*. Two hundred HIV patients and 125 NHS based physicians completed on-line surveys and data were analysed using the conditional logit model whereby the odds ratios (ORs) indicated the likelihood of choosing a treatment. Utility values were calculated using a mapping function of the EQ-5D-5L.

**Results:** Patients placed most importance on treatment effectiveness (OR=1.030 95% CI = 1.023–1.037) and long term safety profile (OR = 1.061 95% CI = 1.042–1.080). The avoidance of all side effects was valued, particularly risk of psychological consequences (OR = 0.978 95% CI = 0.974–0.982) and heart attack (OR = 0.977 95% CI = 0.973–0.980). Patients valued the avoidance of diarrhoea (OR = 0.991 95% CI = 0.985–0.996) to the same extent as the avoidance of jaundice (OR = 0.990 95% CI = 0.982–0.997). Physician results were similar, although they were more influenced by treatment effectiveness than patients (OR = 1.110 95% CI = 1.093–1.126) and risk of serious side effects (OR = 0.971–0.988, p>0.05). Like patients, they preferred treatments which had a long established safety profile (OR = 1.061 95% CI = 1.040–1.082). Patients with detectable viral load had lower utility values (mean = 0.483) than patients with non-detectable viral load (mean = 0.641) (p<0.01).

**Conclusions:** Treatment effectiveness and long-term safety profile were the most important drivers of treatment choice for both patients and physicians. Patients valued the avoidance of certain side-effects including rash, diarrhoea and jaundice which were of equal importance. Physicians placed more value on treatment effectiveness but placed no value on avoiding some side effects (e.g. diarrhoea, rash). Considering the perspective of patients when making treatment decisions may result in improved adherence and better treatment outcomes in HIV.

**Abstract P40**

**Real-life clinical experience with Eviplera™**

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**Background:** Rilpivirine/tenofovir/emtricitabine (Eviplera™) is a once daily single tablet regimen (STR) option and is licensed for naïve patients. Emerging data supports its use in Protease Inhibitors (PI) and efavirenz switch where it is an attractive option because of the STR formulation. This is a descriptive analysis of Eviplera™ use in a large cohort.

**Methods:** Pharmacy and laboratory databases were interrogated and clinical records reviewed; trial patients were excluded.

**Results:** 79 patients in total received Eviplera™ with 25.5 patient-years (PYs) of experience; median age 44 years (IQR 37, 50), male 75%. 16% were naïve to ART. For those who were Antiretroviral Therapy (ART) experienced switching occurred for regimen simplification in 39%, CNS side effects of Efavirenz in 29%, and gastrointestinal toxicity with existing ART in 12%; 20% had other reasons for switching including lipid elevation and abnormal Liver Function Tests (LFTs). 52% were switched from PI-based regimens and 41% from Non- Nucleoside Reverse Transcriptase Inhibitors (NNRTI)-based regimens. Of the 37 patients who were switched whilst undetectable and had follow up viral load, 97% remained undetectable over a median follow-up of 4 months; the 1 patient who became detectable had a viral load of 59. Of the 17 patients who were not undetectable at switch (median viral load of 292 copies/ml (range 44, 70321 copies/ml), all remained undetectable at the end of follow up (median 4 months). 68 patients had baseline and follow up renal monitoring data. All had baseline estimated Glomerular Filtration Rate eGFR of >60 ml/min. 2 patients had a reduction in eGFR to below 60 ml/min (From 60 to 56 ml/min at 3 months and from 69 to 58 ml/min at 4 months). 63% had an increase in serum creatinine-median 7 µmol/L (range 1, 22 µmol/L) after median 3 months follow-up.

**Conclusions:** Although cohort analyses have inherent limitations, our patient series supports that Eviplera is an effective regimen for patients wishing to switch therapy. The small increase in serum creatinine reinforces the importance of regular renal monitoring.

**Abstract P41**

**Five years of experience with raltegravir in a large HIV centre**

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**Background:** Raltegravir (RAL), the first integrase inhibitor, was licensed by the European Medicines Agency in December 2007 as a component of antiretroviral therapy (ART). Real-life antiretroviral experience is informative and complements trial data, so we evaluated our RAL use in naïve and experienced patients, including those with hepatitis and mycobacterial coinfection, and off-licence use.

**Methods:** Pharmacy and HIV database records were used to identify all adults who had taken at least one RAL dose outside of clinical trials. Demographic, clinical and laboratory data were collected from patient records using a standardised form.

**Results:** Data from 215 individuals provided 502 patient-years (PYs) of RAL use. Median duration of use was 2.6 years (interquartile range [IQR] 0.8, 3.5). 166/215 (77%) were male; median age 43 (IQR 37, 49); 155 (72%) Caucasian and 54 (25%) African/Caribbean. 189 (88%) were ART-experienced with median baseline CD4 count 324 cells/mm<sup>3</sup> and 26 naïve with median baseline CD4 54 cells/mm<sup>3</sup>. Of those not on ART immediately prior to RAL initiation (*n* = 52), median viral load (VL) was 66650 copies/mL. Doses other than 400 mg bd were used in 26: 16 (7%) individuals on 800 mg bd (15 of whom were on rifamycins) and 10 (5%) on 800 mg od. On 800 mg od; 5 had reported very poor adherence whilst the other 5 remained virologically suppressed after median 2.4 years. RAL was used in hepatitis B and C co-infection in 35 individuals (92 PYs), none of whom stopped RAL for hepatotoxicity. 22 individuals had mycobacterial co-infection; one of whom stopped RAL for potential toxicity (peripheral neuropathy). RAL was started during an inpatient stay in 40/215 (19%), of whom 18 were naïve. Overall, 18 individuals stopped RAL due to ART-related side effects, 13 of whom (6% of total) were judged probably related to RAL. Six females started RAL in pregnancy, 5/6 as treatment intensification (at median 32 weeks gestation) and one switch from protease inhibitors for tolerability reasons (at 35 weeks). All had VL <40 at delivery and HIV-negative infants with no complications. 10/215 (5%) stopped RAL due to virological failure, of whom 2/4 with successful sequencing showed RAL resistance (one Y143R; one Q148R).

**Conclusions:** RAL appears safe in clinical practice, with no evidence of excess toxicity above that indicated by clinical trials. It has been used safely and effectively in pregnancy and with co-infections. Once daily dosing seems effective where adherence is good.

**Abstract P42**

**The emergence of new viral strains following treatment failure in an HIV-positive cohort infected with acute HCV**

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**Background:** In hepatitis C virus (HCV)-infected patients, the virus circulates as a mixture of closely related but distinct genomes called quasispecies. The hypervariable region-1 (HVR-1) is the most heterogeneous region of the HCV genome and is an excellent target for sequence analysis to distinguish between different variants. We studied the dynamics of quasispecies in preand post-treatment samples taken from patients who failed standard of care therapy in a rare HIV/acute HCV cohort of 160 patients.

**Methods:** A group of 16 patients failed to respond to treatment. A 220 bp region of the E2 envelope gene including (HVR-1) was amplified using nested RT-PCR using a combination of genotype-specific primers. PCR products were sequenced by direct sequencing (DS), clonal analysis (CA) and next generation sequencing using a pyrosequencing approach (NGS). Phylogenetic trees were constructed using the maximum likelihood (ML) method.

**Results:** Using DS, in the 16 patients that failed treatment (6 relapsers, 6 null responders and 4 partial responders), 60% of patients had evidence of a 'new variant' post-treatment. However, CA and NGS results revealed that 66% of such 'new variants' were present in pre-treatment samples, representing new dominance of a pre-existing minority strain that was not detected by DS. Only 3 patients had completely new strains, which were presumed to represent reinfection. NGS was superior to CA in detecting the dominance of pre-existing minority strains in 25% of patients. Both techniques detected multiple strains in 50% of patients that were missed by routine diagnostic methods (DS).

**Conclusion:** In HCV treatment failure, the emergence of new viral strains may most commonly be attributed to new dominance of pre-existing minority variants rather than re-infection. NGS could become an important screening tool at baseline for decision making when treating HCV-infected patients to identify mixed infection, particularly in the context of treatment decisions involving genotype-specific direct-acting antiviral agents.

**Abstract P43**

**Reviewing BHIVA guidelines on screening for latent TB infection in HIV-positive patients in a high TB and HIV prevalence area in the UK**

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**Background:** HIV-positive individuals with latent TB infection (LTBI) are more likely to develop rapidly progressive active TB with reactivation rates of ~10% per annum or ~50% cumulative lifetime risk. BHIVA recommends the use of interferon release gamma assay (IGRA) for screening LTBI according to: TB risk in the country of origin ARV duration and CD4 count. The aims of this project were i) to audit new BHIVA LTBI screening guidelines in a busy clinic; ii) to investigate retention in HIV care prior to a TB diagnosis.

**Method:** We performed a review of patients using paper and electronic records. i) All new HIV diagnoses attending during 10/2011–10/2012 were reviewed according to BHIVA guidance. ii) All TB diagnoses in the same period were reviewed for prior HIV care.

**Results:** 63 new diagnoses of which 38 (60%) were females; 60% Black Africans, 17% Black British/Caribbean/Black other, 8% Indian subcontinent, 6% East European, 3% South Americans and 3% UK Caucasians.

Risk category	Applicable for screening	No. screened	Positive T spot	Negative T spot	Active TB
High *	34/38	16/34	5/16	9/16	4/38
Medium**	15/23	9/15	3/9	6/9	1/23
Low	1/2	0	0	0	0

Reviewing our entire patient cohort during the study period eight patients had active TB; 5/8 (62%) patients were diagnosed with active TB and HIV simultaneously; 3/8 (38%) patients were lost to follow up and presented with advanced HIV disease and active TB (all extra-pulmonary TB).

**Conclusion:** BHIVA's stratified approach to screening for LTBI means targeting high-risk groups to avoid unnecessary tests and cost. Testing can be improved in our clinic. We found it is essential to ensure adequate infrastructure is in place to best perform the tests. In addition to screening, to prevent TB in our clinic, consideration for retention in care services are important.

# HIV complex case audit 2012/13

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## Background

Complex cases command a huge investment, of both nursing time and NHS resources. Care outcomes are often disappointing, even following years of engagement, and at our regular clinical supervision sessions the HIV Community team have often highlighted the challenges they face in supporting complex cases. The service requirement upon us to access regular clinical supervision, as a team, has provided much-needed support through some extremely challenging situations whilst managing these patients.

Three BHIVA guidelines are used as model-of-care frameworks for our team in managing complex cases:

- Treatment guidelines 2012 [1];
- Opportunistic infections guidelines [2];
- Investigation and monitoring guidelines [3].

A previous audit undertaken by the HIV Community team highlighted that complex patients often have chaotic lifestyles, with substance misuse a common component – and the cases cared for by our team are no exception.

## Objectives

This audit was undertaken to identify possible gaps in care provision and seek out drivers for change. Highlighting areas of best practice was also in the audit remit – through exploration of MDT involvement and of improvement in CD4 counts and viral load, in response to intensive support.

## Methodology

This local audit reviewed the HIV Community team's complex case load of 14 patients, all of whom were eligible. Care records and referral backgrounds were reviewed for clinical information and medical histories. This information then

formed the basis of the audit proforma, which comprised 34 questions in various formats. Data were collected in January 2013, within the HIV Community team premises; and forwarded to the Clinical Audit Department for scanning, verification and analysis, with results collated at March 2013.

## Key findings

### Personal and domestic

- Males outnumbered females\* (64%) (Table 1)
- High proportion identified as White British (72%) (Table 2)
- Half occupy social housing (51%) (Table 3)

### Care and clinical

- Many diagnosed late – CD4<100 (Table 4) (86%)
- Many have history of treatment failure or switches (86%) (Table 5)
- Many have history of life-threatening or AIDS-defining illnesses (93%) (Table 6)
- Many have home-based contact (93%) (Table 7a)

\*NB: the audited sample derives from an urban catchment unusual for its 60/40 (approx) split in MSM/heterosexual transmission rates – see Conclusion. Please note that percentages are provided as a quick overview and are not absolute amounts.

**Table 1: Age and gender**

Age	20–29 yrs	30–39 yrs	40–49 yrs	50–59 yrs	Total
Male	0	1 (12%)	4 (44%)	4 (44%)	9 (64%)
Female	2 (40%)	1 (20%)	1 (20%)	1 (20%)	5 (36%)
Totals	2 (14%)	2 (14%)	5 (6%)	5 (6%)	14

**Table 2: Sexuality, transmission, ethnicity**

Sexuality	Transmission via	Ethnicity
Heterosexual 7 (50%)	Unprotected sex 6 (43%)	Black/Black British 1 (7%)
MSM 7 (50%)	Anal 5 (36%)	Dual Heritage 1 (7%)
Lesbian 0	Vaginal 0	Asian 1 (7%)
Transgender 0	Oral 1 (7%)	White British 10 (72%)
	IVDU 1 (7%)	NR 1 (7%)
	Other 1 (7%)	
Totals 14	14	14

NR, no response

- Many have a physical disability (79%) (Table 7b)

#### Other services

- Some access formalised psychological care (36%) (Table 7a)
- This group uses a broad spectrum of health-related services (Table 7b)
- All have social worker and/or voluntary sector input (100%) (Table 7b)

## Lessons learned

### 1. MDT working

**Finding:** The results highlight that MDT working is crucial to care provision in complex case management (Tables 6, 7a, 7b), and these patients need support from a broad spectrum of advanced health practitioners to avoid decline in physical or mental health.

**Recommendation:** To provide optimum patient care, agreed strategies must be in place for these services to engage and communicate as effectively as possible, ensuring always that the patient is the focal point for decision-making.

### 2. Modes of contact

**Finding:** The data show that time spent on patient contact other than face to face (eg telephone dialogue), or patient-related activity with both patients and care stakeholders, often equals or exceeds time spent on face-to-face patient contact (Table 7a).

**Recommendation:** Behind-the-scenes work must be constantly and accurately recorded in patient notes so that any data collection informing service commissioning will provide a true reflection of service activity and patient demand.

### 3. Staying power

**Finding:** Perseverance by the team with complex cases over many years has had a major impact on patient mortality, with 65% of cases audited now

**Table 3: Home setting**

Lives alone		With partner		With children		Carer responsibility	
Yes	9 (64%)	Yes	4 (29%)	Yes	3 (21%)	Yes	3 (21%)
No	5 (36%)	No	10 (71%)	No	10 (72%)	No	9 (69%)
				NR	1 (7%)	NR	2 (14%)
<b>Totals</b>	<b>14</b>		<b>14</b>		<b>14</b>		<b>14</b>
Owner/occupier 3 (21%), Private tenant 3 (21%), Social housing 7 (51%), Supported housing 1 (7%).							
NR, no response							

achieving an undetectable viral load – effectively switching off HIV activity and in most cases promoting immune reconstitution (Table 5).

**Recommendation:** It is important to make the case for ongoing engagement in the long term and promote it as a viable strategy that yields results. This area of patient need should be given a high profile when communicating with clinical commissioning groups (CCGs).

### 4. Early testing

**Finding:** Late diagnosis of HIV continues to be a major problem for HIV services despite years of campaigning for normalised HIV testing and earlier diagnosis [4] (Table 4). The vast majority of late diagnosis/complex cases are diagnosed in secondary care settings (Table 4).

**Recommendation:** The key to alleviating late diagnosis, and the problems that issue from it, is for the team's existing high profile in community HIV testing to be raised still further. They should seek to change thinking among CCGs and primary care through engagement and dialogue with local bodies – to normalise and promote testing in primary care by all means possible. They should constantly explore new ways to encourage primary care colleagues to be proactive and vigilant, so that the recommendations of recent NICE guidance can be realised [5,6].

## Conclusion

To tackle the above, an action plan template was devised – with start/finish dates, and results to be

**Table 4: Circumstances at diagnosis**

Date of test	Testing care service		CD4		Viral load	
1991–1995	2 (14%)	Primary 1 (7%)	0–50	8 (57%)	0–49,999	3 (21%)
1996–2000	3 (21%)	Secondary 11 (79%)	51–100	4 (29%)	50,000–99,999	1 (7%)
2001–2005	1 (7%)	NR 2 (14%)	100–200	0	100,000–199,999	3 (21%)
2006–2010	7 (51%)		>200	2 (14%)	>200,000	2 (14%)
2011 to date	1 (7%)				Not recorded	5 (37%)
<b>Totals</b>	<b>14</b>	<b>14</b>		<b>14</b>		<b>14</b>

NR, no response

**Table 5: Current clinical status**

Managed by		On HIV treatment		Switch/failure history		CD4 count		Viral load	
LCSH*	4 (29%)	Yes	12 (86%)	Yes	12 (86%)	100–199	4 (29%)	70	1 (7%)
ID team**	7 (50%)	No	1 (7%)	No	2 (14%)	200–299	3 (21%)	79	1 (7%)
HIV Community team (remotely)	2 (14%)	NR	1 (7%)			300–399	1 (7%)	40,000	2 (14%)
NR	1 (7%)					400–499	1 (7%)	Undetectable	9 (65%)
						≥500	4 (29%)		
						Declined investigations	1 (7%)	Declined investigations	1 (7%)
<b>Totals</b>	<b>14</b>		<b>14</b>		<b>14</b>		<b>14</b>		<b>14</b>

NR, no response

\*Liverpool Centre for Sexual Health; \*\*Infectious Diseases team

**Table 6: Post-diagnosis history**

Referred to HIV Team		Switch/failure history		Admitted with HIV-related condition(s)? Which?	
1991–1995	1 (7%)	Yes	12 (86%)	Yes: MAI, Cryptococcal meningitis	1 (7%)
1996–2000	2 (14%)	No	2 (14%)	Yes: CMV retinitis, Erythema nodosum	1 (7%)
2001–2005	2 (14%)			Yes: HIV encephalopathy, epilepsy, PCP, anaemia	1 (7%)
2006–2010	7 (50%)			Yes: MAI, PCP, cerebral toxoplasmosis, cryptococcal disease	1 (7%)
2011 to date	2 (14%)			Yes: MAI, peripheral neuropathy	1 (7%)
				Yes: TB, oesophageal candidiasis, perianal HSV	1 (7%)
				Yes: Lymphadenopathy	1 (7%)
				Yes: PML, degenerative spinal cord compression	1 (7%)
				Yes: Kaposi's sarcoma	1 (7%)
				Yes: Oesophageal candidiasis, lymphadenopathy	1 (7%)
				Yes: PML	1 (7%)
				Yes: HIV encephalopathy	1 (7%)
				Yes: PML, PCP	1 (7%)
				NR	1 (7%)
<b>Totals</b>	<b>14</b>		<b>14</b>		<b>14</b>

NR, no response

**Table 7a: Ongoing care profile**

Psychological care*		Face-to-face meetings		Face-to-face last 6/12		Total contact last 6/12**	
Yes	5 (36%)	Weekly	10 (71%)	>10 meetings	2 (14%)	0–49	4 (29%)
No	9 (64%)	Fortnightly	1 (7%)	>20 meetings	5 (36%)	50–99	9 (64%)
		Monthly	0	>30 meetings	7 (50%)	>100	1 (7%)
		Less often	1 (7%)	>40 meetings	0		
		Patient-led	2 (14%)	>50 meetings	0		
<b>Totals</b>	<b>14</b>		<b>14</b>		<b>14</b>		<b>14</b>

\*Clinical psychologist 2 (40%), Counsellor 3 (60%), Psychiatrist 3 (60%), Formal mental health diagnosis 4 (80%); Total 5. NB: multiple answers selected.

\*\*Hartington Road Clinic: Yes 4 (28%), No 9 (65%), NR 1 (7%); Home: Yes 13 (93%), No 1 (7%).

Sahir House: Yes 3 (21%), No 9 (65%), NR 2 (14%); Phone call to patient: Yes 12 (86%), No 2 (14%).

Case discussion with other healthcare professional or voluntary sector: Yes 14 (100%).

NR, no response

Table 7b: Ongoing care profile (continued)

Core Care Plans in place*		Care package in place (social care)		Physical disability		Housebound		Wheelchair user		Housing adaptations reqd		Shared care with other services	
Yes	13 (93%)	Yes	5 (36%)	Yes	11 (79%)	Yes	2 (14%)	Yes	2 (14%)	Yes	5 (36%)	Yes**	12 (86%)
No	1 (7%)	No	9 (64%)	No	3 (21%)	No	12 (86%)	No	12 (86%)	No	9 (64%)	No	2 (14%)
Totals 14		14		14		14		14		14		14	

\* Number of Core Care Plans in place: one 1 (7%), two 7 (50%), three 6 (43%).

\*\* Shared care with: social worker 12 (100%), voluntary sector 8 (67%), district nursing 1 (8%), SALT 3 (25%), Dietetics 2 (17%), Physiotherapy 3 (25%), OT and other services 5 (42%); Total 12. NB: multiple answers selected.

NR, no response

reviewed and signed off by the HIV Community team at regular meetings. Across the service the team resolved to adopt the, 'make every contact count' approach, to promote HIV testing when and wherever possible.

Healthcare settings vary widely across different parts of the UK but many of the issues highlighted here will apply to other HIV patient cohorts, where local teams are well placed to initiate dialogue and set targets that will work and have relevance within their own areas. An example is that local (Liverpool) HIV statistics differ from other urban areas, with an approximate 60/40 split in MSM/heterosexual transmission rates – and the team has responded with an initiative to explore and focus on the needs of heterosexual women living with HIV.

One of the original aims of the audit was to highlight gaps in the HIV Community team service provision. Whilst no gaps were highlighted in the post-diagnosis support service offered, the issue of late diagnosis remains a major problem for HIV services across the board. The audit found that the vast majority of complex cases were diagnosed in secondary care, with opportunities having been missed for earlier diagnosis and the associated reduction in morbidity. In response to this, a late diagnosis group has been formed, involving the regional network and comprising HIV commissioners, HIV consultants and specialist nurses. In addition, the team has taken part in a training session for local GPs to promote HIV testing in primary care.

The HIV Community team felt that their commitment to ongoing patient engagement was substantiated by the audit, which also highlighted an example of best practice: achieving and maintaining an undetectable viral load has for some of the patients audited has been an excellent

outcome in itself for those individuals. However, this is often accompanied by a poor response in terms of CD4 counts, a recognised consequence of late diagnosis. Our team also recognises that expected care outcomes for some complex patients can lead to disappointment. Expected outcomes are agreed by working collaboratively with the patient, other healthcare workers, allied professionals and the voluntary sector – with every effort being made to ensure the process is as consultative and inclusive as possible. However, the reality may be that in some cases we are simply aiming too high.

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# Between the Sheets:

## support for HIV-positive women in relation to their sexual activity, framed around their engagement and expressed needs

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### Introduction

The Between the Sheets (BTS) project was conceived and developed by myself and three women living with HIV (WLHIV), the focus group. This was supported by a project team from Liverpool Community Health NHS Trust (LCH), and the voluntary agency Sahir House, Merseyside's support agency for those infected with or affected by HIV or AIDS. The HIV/AIDS community nursing team has been operational since 1993, providing specialist nursing care, support and advice to patients, professionals and carers across Liverpool communities. This affords the privileged position of supporting patients in their own homes. As community nurses nationally will agree, patients are often more relaxed and willing to talk with greater openness in their own environment. This nurse/patient relationship is described as 'the prime therapeutic tool' [1] and was the catalyst for change, for the BTS project to evolve. From personal and intimate conversations with WLHIV, relating to HIV and sexual activity, commonalities emerged.

### Issues

- A perception of an unmet need for women, to explore and discuss their sexual activity, in relation to an HIV diagnosis;
- Many women highlighting that they felt confused as to the relevance of an undetectable viral load in relation to infectivity;
- Difficulties in disclosing their HIV status to new partners: the 'tell and kiss, or kiss and tell' scenario;
- A loss of sensuality, and perceptions of future celibacy;
- Fear of rejection, violence or abuse within sexual relationships.

The frustration conveyed by the women was both alarming and emotive. Despite safer sex messages from various sources, my aim was to explore what actually goes on 'between the sheets'. Just how difficult is it for WLHIV to negotiate the kind of sex they want? How and when does disclosure take place? How often is abuse or violence within a sexual relationship a cause or result of HIV?

Following consideration of how my specialist nurse role could be used to support WLHIV with these

intimate and sensitive issues, BTS was set up to ensure that their needs were appropriately and effectively addressed.



### Patient involvement

One of the themes identified in the Health and Social Care Act 2012 [2] is a drive for local and national initiatives for patient involvement across the NHS. It states:

'If ... putting the patient first is to be made a reality, the system that emerges must be grounded in systematic patient involvement to the extent that shared decision making is the norm.' [3]

In the section, 'Greater voice for patients' [4], the Act also states, 'It is important to provide a strong forum where the views and experiences of patients, carers and the public can influence the commissioning process and improve the quality of health and social care services. All sources of user feedback enable providers to assess the quality of their services.'

The above statements were central in the formation of our focus group.

### Aims

- Increase understanding of the impact HIV has on the sexual activity of WLHIV;
- Use evaluation data to effectively plan future events.

### Objectives

- Provide a safe, inclusive forum where WLHIV can explore issues relating to their sexual activity;
- Impart health messages and factual information via expert presentations/personal stories;
- Provide interactive workshops to address sensuality, empowerment and self-esteem;
- Facilitate networking opportunities to provide peer support;
- Evaluate experiences of women currently, and establish support provision for the future.

### Strategy for change

The potential for engagement in this highly sensitive area had never been explored among this patient group. A number of local initiatives were undertaken, within the strategy for change, the

main focus being on stakeholder engagement. As a result, the women were able to verbalise anxieties via the focus group. This stakeholder engagement gauged the appetite of patients to: become involved, consider participation, contribute to, and facilitate delivery of the event.

## Methodology

1. A qualitative focus group was formed consisting of an HIV specialist community nurse and WLHIV.
2. A public health grant awarded by the local primary care trust was secured by the commissioning organisation of LCH, through development of a bid.
3. Various venues were considered as part of the stakeholder engagement, and consensus gained on a well established female-only organisation that supports and educates women.
4. Within the organisation, I initiated and led a project group hosted within LCH, consisting of internal stakeholders whose skills covered: communications, equality and diversity, information governance, audit, analysis and admin – with support from senior management.
5. Priority consideration was given to confidentiality and sensitivity during promotion. Event details were imparted personally to WLHIV, electronically and by post to HIV clinics and the voluntary sector.
6. Pre- and post-event anonymous questionnaires were devised. Pre-event captured baseline information on experiences of WLHIV in relation to sexual activity. Post-event provided evaluation, asking women to identify future support.
7. Regular meetings were held with focus and project groups.
8. Volunteer support was identified and ongoing collaboration put in place.

The workshop evaluations provided excellent feedback from attendees and facilitators, delivering messages of empowerment and self-esteem. Figure 1 shows how the women were able to seek out and express a sense of self-worth.



## Pre-event questionnaire

This consisted of 14 questions covering areas such as stigma, disclosure, sex negotiation, confidence within sexual relationships, where to access support, issues around condoms, PEPSE, the effect of HIV on sexual relationships, incidence of violence and abuse where HIV is a cause or consequence, and the influence of viral load on sexual activity. The result was wide-ranging and rich data. Selected examples of the questions and responses are below:

*Are you comfortable about disclosure of your HIV status to sexual partners?*

The response was 'no' from 48% of the women, indicating the enormity of the issue of disclosure. A further question revealed 65% stating their need for support around disclosure:

'I have never had support around this and I have been diagnosed 17 years. I have had to fumble my own way through the pitfalls of disclosure and the consequences – which have sometimes been violent, either verbal or physical.'

'Disclosure is never clear cut, depends on the circumstances. Sometimes people have known my status before we get together sexually, sometimes in the course of courtship, usually before intercourse. Now my viral load is undetectable, I may not disclose if it is just casual sex.'

*What are your thoughts and feelings as a woman if you need help/support/advice regarding your sexual activity?*



Figure 1: 'I am valuable': artwork created at one of the event workshops

Responses were mainly negative:

'I feel lost – who could understand what I need to consider? Embarrassed to talk even to female professionals.'

'I don't deserve a sex life. I used to love sex.'

'Very, very, very isolating. Gay men get loads of support and seem more open about sex. Where can I go to talk about HIV and sex as a woman? Nowhere.'

'I have never met a woman who has HIV, I would like to ask how they coped telling their partner.'

'I have never had any support around my sexual activity. I have never been empowered through education to be able to negotiate the sex I want or safe sex.'

'I feel isolated as a woman with HIV. There is nowhere to talk openly. My own culture prevents me talking about sex, let alone HIV as well.'

'Stigma still exists for women with HIV.'

*Have you ever experienced violence or abuse by either a partner or someone else because of your HIV status in a sexual relationship?*

Nearly half, 45%, of respondents said yes to this question. Responses included:

'The father of my kids [is] constantly throwing it in my face, and violence.'

'...emotional violence when you are just left for another woman ...'

'Mentally – they freaked out, thinking you could catch this from kissing. This abused my mental state of health.'

'I never experienced physical abuse, but after disclosing to someone they started to talk down to me and treated me like I was contagious.'

'Mental abuse ... emotional abuse ... financial abuse ...'

'Well, I suppose you live with the guilt of being HIV and transmitting to another person.'

'I have been spat at, battered and raped because of my HIV status. I have been verbally abused and sexually denied or manipulated by sex either being granted or denied.'

'Intimidating behaviour, bullying, financial abuse, blackmail, threat of criminalisation.'

'Verbal abuse like "dirty slag", and "whore". I don't deserve that.'

'Name-calling, threats of disclosure to others that don't need to know.'

'In marriage or long-term relationships sex is sometimes forced, or expected and undertaken as a given (or a right).'

For such a high proportion of these WLHIV to disclose HIV as a cause or consequence for violence or abuse was an alarming response, echoing a recent feasibility study [6]. Despite global interest in this subject, little UK-based evidence is available to support this association, and the area is strikingly under-researched.

*How has your sexual activity/relationships changed since your HIV diagnosis?*

All responses except one illustrated a negative impact:

'It makes it all complicated.'

'At first, thought I could never have sex again.'

'It has become difficult to have a normal relationship.'

'Just don't bother having sex, I'm just terrified.'

'My relationships have been more short term and often based on poor choice, having what was on offer rather than what I truly deserve.'

## The event

### Numbers

- A total of 67 women attended. There are 203 WLHIV in Liverpool and 323 in Merseyside [5].
- 85% were aged between 25 and 59.
- The ratio of WLHIV compared to men is almost equal in Liverpool [5], yet evaluation indicates women feel unsupported around sexual activity.

### Content

- Presentations delivered by healthcare professionals all received excellent feedback and demonstrated appropriate content:
  - i. 'Contraception and HIV: considerations and options'
  - ii 'Unprotected sex in the ART era – protection, pleasure and procreation'
  - iii 'Criminalisation and prosecution'

### Individuals

Four powerful, personal stories were presented by WLHIV, disclosing both positive and negative experiences, and how living with HIV impacted on their sex lives. The evaluations were astounding, demonstrating a positive, inspiring impact. Two focus group members had never spoken about their HIV in public. This gave them a huge sense of pride and ownership of the project.

### Empowerment

In addition to the presentations, a number of workshops were facilitated by qualified, well respected therapists:

- i. 'Speak up: how to confidently communicate your sexual needs'
- ii 'Your personal pleasure map'
- iii 'Big love creative boudoir' (Figure 1)

'Always scared about sex since my diagnosis. Always scared that I will be left behind.'

'I can never have sex without thinking about HIV. It's always there at the forefront of my mind.'

'Just go through the motions now. Don't really enjoy it.'

*Are you aware of where to access help in the event of a condom breaking or not using one at all (PEPSE, morning-after pill, STI screen)?*

The response by 48% of women was that they did not know where to access help in this context – clearly indicating the need for education and support to ensure timely intervention.

*If you have a partner, do you feel your current relationship has been adversely affected by your HIV status?*

All responses showed negative effects on relationships:

'Have struggled with it when having sexual contact.'

'Hard to talk about...'

'We argue and he makes me feel small.'

'Living in denial has taken its toll on present relationship but it's taken time for me and my partner to accept.'

'We talk about HIV all the time, not our relationship. It shouldn't all be about HIV. What about just living my life? I can't live normally.'

'Yes, it changes things about sex for ever.'

'Wouldn't have a long-term partner now. Too complicated and they can use the fact you have HIV against you.'

'Took ages for him to accept me for me and not HIV.'



## Post-event evaluation

Feedback regarding venue, catering and organisation was positive without exception, and participants valued a safe, female-only space.

Asked which topics they needed support with in the future, the women identified these main themes:

- confidence in disclosure: how and when;
- support for women to explore their sexual activity and be empowered in their sex lives;
- pregnancy;
- practical information about HIV and sex 'in real life';
- negotiating safer sex;
- couples issues;
- how to deal with the stigma and discrimination;
- using a female condom/dental dam;

- peer support;
- 'funky, nice, safe things' to do with one's partner;
- more around: violence towards women; African women's issues, its effect on their ideas of sexuality; what sexuality means for a woman;
- 'more input like this event', held regularly.

Suggestions as to how this support should be provided included:

- referral to counselling/sex coach;
- 'buddying' with positive women;
- involvement with other peer-led safe activities and groups;
- other women-only events;
- more creative workshops/events held in neutral settings;
- repeating the same format in future events;
- growing the event and its outcomes further – perhaps starting a blog;
- developing a regular women's group that explores sex issues.

General feedback included:

'Fantastic event which should be repeated and expanded on. In a time of austerity, well done to funders and organisers for pulling off a powerful, innovative event – the empowering impact of which has been felt by everybody I have spoken to today. Thank you.'

'I loved this and it helped me so, so much.'

'Today I spoke to a significant number of women who had never either met another positive woman or felt able to talk about their HIV. It reminded me how important peer support/networking is, in a safe place. Excellent that it is women only.'

'A beautifully put-together event, bringing together and empowering women to feel comfortable together, and explore ideas of their sexuality.'

## Sexuality

Sexuality was not disclosed by 69%, possibly indicating discomfort in disclosing heterosexuality. Bisexuality was disclosed by 23%. Although this was a relatively small sample, these clients are very marginalised, and change by services is needed to ensure inclusion.

## Ethnicity

Exactly half the attendees (50%) identified as black, yet none wished to speak in front of other people. However, post-event data demonstrated a need and desire for women from black and ethnic minority groups to 'have a voice' and be represented. This was addressed at the feedback event, where an African lady eloquently shared her experiences of sex and HIV. Her culture dictated that, when her husband

died of AIDS, she became the property of her brother-in-law, from whom she subsequently experienced abuse as a consequence of her HIV. She said that, after seeing how safe the initial event was, she felt more confident to speak publicly.

### Disability

Asked if they perceived themselves as having a disability, 67% did not, 15% did, and 18% did not respond. The Disability Discrimination Act 2005 states that a person with HIV is 'deemed' to be a disabled person, for the purposes of the legislation [7]. Anyone with cancer, MS or HIV is now protected against unfair treatment – in the workplace, education, housing, or in accessing services – from the point of diagnosis. These changes have been made in recognition of the stigma often associated with a diagnosis of these conditions.

### Outcomes to June 2013

- GBV and HIV now on domestic violence and safeguarding agenda for LCH;
- Unmet need demonstrated via evaluation;
- Funding secured for next event;
- National Patient Safety Awards finalist;
- *Nursing Times* publication [8];
- *Baseline* publication [9];
- NHIVNA conference Poster Presentation delivered;
- Inclusion of project artwork secured as part of HIV Heritage Project (Liverpool Museum).

### Next steps

- Grow focus group to incorporate a wider membership of WLHIV;
- Expand project group to include a wider membership of professionals;
- Develop support and promotion through 'friends of BTS';
- Explore website potential;
- Run event twice a year;
- Achieve investment or resource reallocation to benefit *all* WLHIV, in relation to sexual activity – and promote inclusion;
- Consider inclusion footprint for future events;
- Explore research potential;
- Explore HIV testing initiatives to encourage greater uptake by women – along the same lines as NICE guidance on MSM and black African communities in England [10,11]. In North West England, women have the lowest uptake of testing [5].

other stakeholders. Evaluation data were presented, and discussions held, on how WLHIV want to progress with the project considering the above points. One WLHIV reported that the event had a profound positive effect on her, resulting in handling a potentially difficult situation differently. She presented her story at the feedback event.

I would urge nurses, especially those in specialist roles, to pursue those issues that come directly from patients. Although it may not always be possible to offer events like this one, all nurses should be able to exercise influence and bring about changes which will enhance the health and wellbeing of the patients they support.

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### Conclusion

The feedback event was very encouraging, with good attendance by WLHIV, potential funders, professionals working in HIV and

# An opt-out testing study: The Royal London Hospital

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## Background

In 2008 BHIVA's testing guidelines advocated routine opt-out HIV testing for all patients registering with a general practice; and for all admissions to acute medical units, where the prevalence of diagnosed HIV infection exceeds 2 per 1000 [1].

During 2009 to 2010 the Department of Health (DH) and Health Protection Agency (HPA) funded the HIV Testing in Non-traditional Settings (HINTS) study [2]. The aim was to look at the feasibility and acceptability to staff and patients of routinely offering HIV tests in four contexts: acute admissions, emergency, general practice and clinic [3]. This review involved opt-out testing in eight non-traditional settings across the UK, and the key finding across all study sites was that routinely offering tests to patients is operationally feasible and acceptable to patients and staff [2].

However, apart from these pilot studies, expansion of opt-out HIV testing to non-traditional UK settings is not well documented, and the need for increased testing remains significant.

Currently there are 96,000 people living with HIV in the UK, 24% of whom are unaware of their status according to HPA estimates. Late diagnosis remains a problem, with 50% of 2011 new diagnoses recorded at <200 CD4; while heterosexual diagnoses are also increasing year on year [4]. There has never been a more important time to increase HIV testing in non-traditional settings, in order to curb onward transmission by reducing late diagnosis.

## 'Test the Hospital' project

The Royal London Hospital serves a population where the local prevalence of HIV is 5.95 per 1000 – neighbouring boroughs of Hackney and Newham having a prevalence of 7.6 and 6.2 per 1000, respectively [4]. Routine HIV testing in the acute admissions unit is therefore recommended.

However, being part of the UK's largest healthcare provider, and having such high prevalence of HIV, suggested that a more innovative approach was needed to expansion of testing throughout our hospital. To answer this need, we instigated 'Test the Hospital'.

## Key roles

Setting aside issues of laboratory workload, the HPA has pinpointed three key areas of focus for the expansion of HIV testing into non-traditional settings. These are:

- training and education
- HIV care pathway
- evaluation [5]

To implement the above, a registered nurse experienced in HIV medicine and testing was appointed to facilitate the initiation of opt-out HIV testing within non-traditional settings, with support from HIV registrars and consultants.

The role of this HIV testing facilitator was to provide training and support to clinical staff through continuous monitoring, evaluation and introduction of new ideas, thus embedding opt-out testing into their daily routine. Rather than carrying out any tests, s/he would work at sustaining the process within the clinic setting.

## Choice of test method

*Point-of-care testing* has proved effective in clinical practice. These tests are easy to use and non-invasive, with the rapid result eliminating the later recall of patients, and the associated anxiety [5,6]. However, they also require specially trained staff, regular quality-control checks and, for some brands, specific storage [6]. An instantaneous result is advantageous in a sexual health clinic, where staff are trained to give positive diagnoses in a confidential setting and are allocated time to counsel the patient. This test also works well in outreach programmes and in rural areas, where serology turnaround takes longer.

*Serology testing* offers benefits that theoretically make it a more compelling choice for a leading London teaching hospital. The lab can provide an HIV antibody result in 6 hours, staff are already trained to take blood, and almost all patients attending A&E or Acute admissions have blood tests done. However, a daily turnover of 50 patients makes this unworkable in practice. Acute admissions are already stretched for time, with typical comments including, 'I don't even know what the patient looks like, I just order bloods and prescribe medication based on the presentation'. Therefore, expecting staff in this

setting to give a new HIV diagnosis would seem unrealistic, and unfair to the patient – possibly even deterring them from accessing services in the future.

*Project choice:* In the HINTS study, salivary point-of-care tests were used in A&E, and HIV serology tests in the Acute admissions unit. Each location tested around 60% of eligible patients, suggesting that uptake was not influenced by patient preference for one method over the other [3].

All our opt-out testing initiatives have therefore used HIV serology tests, which we consider a more sustainable method: staff can take ownership of testing initiatives within their area or department, and new employees do not need additional training.

## Pre-project training

Standard operating procedures and guidelines were drawn up in collaboration between the HIV team and staff from each clinical setting.

Training was provided by the HIV testing facilitator, as follows:

- basic HIV education (or education regarding indicator conditions, depending on existing knowledge);
- background to opt-out testing initiative;
- consent;
- implementation;
- follow-up of results.

Staff were given the opportunity to discuss concerns or anxieties, with the predominant themes relating to anxiety about offering a test, and possible patient response.

Another critical consideration for the testing facilitator was familiarity with day-to-day work in these different clinical settings, gained by spending time working alongside them. An understanding of routine pressures and targets was necessary to establish where on staff's priorities HIV testing would fit in.

## Implementation

### 1. Acute admissions

Opt-out HIV testing was implemented in the Acute admissions unit in February 2012, with all patients over the age of 16 being offered an HIV test.

### 2. Intensive therapy

In October 2012 our Intensive therapy unit (ITU) became the first in the country to implement opt-out HIV testing. Evidence suggests frequent missed opportunities of HIV diagnosis in intensive therapy units, and some experts believe that ITU admission should automatically be seen as an indicator for HIV [7]. Therefore, all non-elective ITU admissions are offered a test, with testing also undertaken in the 'best interests' of any patients unable to consent.

### 3. Emergency department

From March 2013 to July 2013 a pilot study was carried out, looking at feasibility and acceptability of opt-out HIV testing in our hospital's Emergency department. All patients over the age of 16 already having bloods taken were offered an HIV test.

### 4. Other locations

'Test the Hospital' opt-out HIV testing also takes place within Elderly care/psychiatry and the Fast response team, who see patients with suspected deep-vein thromboses.

### 5. Monitoring role

In addition, we provide a monitoring function to the areas where HIV testing is carried out as a national standard, namely antenatal clinics and in the treatment of tuberculosis, lymphoma and hepatitis, to ensure target testing rates are being met and that any new diagnoses are referred appropriately into HIV services. By running joint clinics with these specialities, we are able to provide co-infected patients with the best possible care.

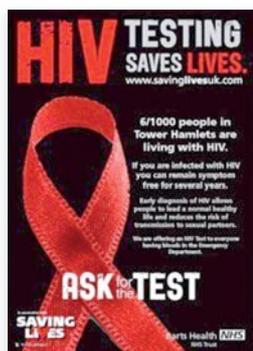
Rachel won **NHIVNA Best Oral Award** at this year's conference for her presentation on this project, entitled, 'Operational barriers to the implementation of opt-out HIV testing in novel settings'. See: [www.nhivna.org/AnnualConference2013ScholarAwards.aspx](http://www.nhivna.org/AnnualConference2013ScholarAwards.aspx)

**Table 1: HIV testing rates (n) per patient turnover (N) before and after intervention with opt-out testing**

Description	Pre intervention n/N (%)	Post intervention n/N (%)	New positive tests since intervention
Acute admissions (AA)	50/4009 (1) 6 months	1727/18602 (9.2) 15 months	10
Intensive therapy unit (ITU)	28/432 (6) 3 months	596/1107 (58.8) 7 months	3
Emergency department (ED)	147/ (0.02) 2 months	1638/5671 (29) 2 months	7
Elderly care/psychiatry (ECP)	0/15 (0) 1 month	91/172 (53) 6 months	0

## 6. Publicity

Support received from the charity 'Testing saves lives' played an important role in publicising the service on offer and in encouraging patient uptake. Posters were displayed in all hospital areas where tests were being carried out, while media coverage helped explain and promote the ongoing testing process in the Emergency department [8].



## Results

Table 1 shows testing rates [number of tests (n) per patient turnover (N)], before and after implementation of opt-out testing in all settings. The difference between these testing rates is statistically significant ( $P < 0.001$ ).

Post intervention, the testing rate for Acute admissions was 1727/18602 (9.2%) in 15 months. In ITU the rate was 596/1107 (53.8%) in 5 months. The rate in the Emergency department was 1638/5671 (29%) in the first 2 months of the pilot. In Elderly care/psychiatry, the testing rate was 91/171. At the time of writing, no data were available for the Fast response team, as opt-out testing had only started in the previous month.

Twenty new HIV diagnoses have been made through our opt-out testing initiatives, all of which are now being followed up by HIV services. Of these, 13 have been late diagnoses with CD4 counts  $< 250$ . Two had been recently infected with HIV and presented with symptoms of seroconversion. A further seven patients who were lost to follow-up have now been re-engaged in care.

## Discussion

Implementation of opt-out HIV testing in non-traditional settings at The Royal London Hospital has been a success, with testing rates in each area showing a significant increase.

Rates vary within the different settings, with ITU and ECP managing to consistently test over 40% of patients and ED showing a rate of 29% – whereas AA only achieved 9.2%.

Over the last year the testing team has worked closely with Acute admissions to establish why testing rates remain low within this setting. It has become apparent that operational barriers specific to this department have impacted on the way opt-out testing is conducted. Most significant is that patients are referred from different locations, with varying acute symptoms that need urgent attention. There is thus no routine admission process into which HIV testing can be incorporated. Difficulties arise when patients have previously had blood tests, or if

their care is subsequently taken over by another speciality before further bloods are taken.

Testing in ITU has been particularly successful due to the tightly structured care routine and low staff-patient ratio. The set-up allows nursing staff to have solid ownership of the programme; furthermore, HIV tests are easily included in routinely performed bloods. Similar factors have contributed to the success of opt-out testing within the ED.

## Conclusion

Expansion of HIV testing to non-traditional settings in areas of high prevalence is essential to reduce late diagnoses, associated with a tenfold risk of dying within 1 year.

Before implementing HIV testing in novel settings, a good understanding of how a department operates is essential, as is good communication between the testing team and the novel setting team.

For such HIV initiatives to translate into long-term practice, reliance on the HIV team should be avoided: instead, staff need effective support to take ownership of testing within their local setting.

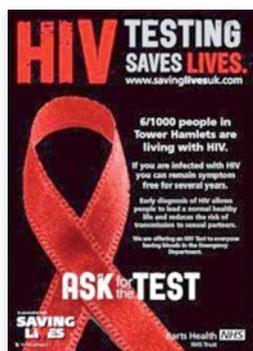
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