

# 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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# Current issues in HIV community care: a time of change and challenge

Shaun Watson

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Welcome to the 2014 Community issue of *HIV Nursing* journal. As a Clinical Nurse Specialist I always try to champion community care and issues, and in the present changing and unsettling times it has, yet again, become the hot topic. The joy of editing this journal is that I can basically make it what I want, and for this issue I thought about my caseload and the problems I am experiencing: accessing general practice; recreational drug use; adherence and the thorny issue of 'dosette box' management; outreach testing; and the increasing difficulties patients are having with changes to the welfare benefit system and how we support those undergoing what can be stressful reviews or assessments.

Pauline Jelliman looks at a problem that community nurses have battled with for decades: the management, monitoring and refilling of 'dosette boxes', and her article *To dosette or not to dosette: that is the question* highlights the issues many of us have with patients who are vulnerable, isolated or cognitively unable to adhere to and manage their medications, especially when we have the added complexities of multiple diagnoses and polypharmacy. Pauline's team also undertook an audit looking at outreach HIV testing, and their article *HIV outreach testing activity audit 2013/14* addresses something that many nurses are involved with, or soon will be, as we look at more creative ways to capture the 25% of people who aren't aware of their HIV status. Capturing unknown and late diagnosis is always an issue and encouraging GPs to think about HIV is a constant struggle. For those living with HIV accessing your GP has been discussed, studied and debated throughout the history of HIV. With an ageing HIV population who should provide care and what should that care look like? Whose responsibility is it? Should HIV be moved to generic care or remain a speciality? What about the thorny issues of confidentiality, communications, drug interactions and misdiagnosis? The list of questions and concerns are endless. Angelina Namiba's article *HIV and the GP: a patient's perspective* gives a personal perspective as well as discussing Positively UK's study talking to those living with HIV about their experiences and thoughts on GP care. There is still a lot of work to be done by both the HIV speciality and primary care services and I'm sure this debate will run for a few more years.

Recreational drug use and its effects upon the individual have been well documented; however, over the past few years we have witnessed an increasing number of issues encroaching upon our work – whether it's an individual taking more risks with their sexual health or the effect of drug use on their adherence. Discussing drug use can be difficult and framing questions in the correct manner may mean the difference between an open, honest consultation and alienating a patient so they stop engaging in services. For me I feel it's an issue of 'Whose problem is this, ours or theirs?' How do we manage our thoughts and feelings around a perceived problem for which there may be no easy answer or remedy? David Stuart's article *Sexualised drug use by MSM (ChemSex): a toolkit for GUM/HIV staff* is insightful and the toolkit he has developed will enable open, two-way communication.

To end this issue we look at the welfare benefits system which has always been difficult to negotiate. Nurses are frequently asked, or need to ask, complex questions around a patient's personal finance or their ability to apply for benefits. There are considerations around poverty and its effect upon an individual's health. Matt Wills' article *For whose benefit? HIV and the new welfare benefits: a professional view* looks at the recent, complex changes to the system and highlights two cases that show the difficulties faced by those who may rely upon welfare. This is followed by *A guide to writing letters to support a benefit claim*. This was highlighted as an issue at a recent NHVNA study day with many participants feeling that they needed some guidance on what to say in letters and how best to support patients who may be anxious about a benefit cut, dealing with poverty or the pressure to take on work when they may have been out of the job market for years, sometimes decades. We are very proud to have worked with National AIDS Trust for these guidelines.

I hope you enjoy this issue and find some of the articles and resources thought-provoking and useful to your work.

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# To dosette or not to dosette: that is the question

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**H**IV specialist nurses still encounter patients who struggle with the required level of adherence to anti-retroviral therapy (ART), to enable attainment and maintenance of an undetectable HIV viral load. There are many interventions available for nurses to utilise in order to support patients in commencing and maintaining ART. There should be an ultimate aim of patients reaching self-management (BHIVA Care Standard 9). One intervention, which may appear basic in essence, but in fact is essential for some patients, is the initiation and maintenance of a compliance aid. By the nature of the intervention, HIV specialist community nurses are best placed to initiate and manage it in a domiciliary setting.

Therefore, the aims of this article are:

- To clarify the professional guidance for HIV community nurses undertaking the practice of secondary dispensing published by the Nursing and Midwifery Council (NMC) (2010), Standards for Medicines Management [1]. To inform HIV community nurses of the systems they need to have in place to ensure good clinical governance, patient safety, and that they are working within their scope of practice.
- To inform members of the multidisciplinary team (MDT) that the initiation and management of a compliance aid by HIV community nurses is an intervention which requires a robust assessment, appropriate documentation, knowledge of relevant guidelines, MDT discussion, and is a crucial element of a comprehensive adherence support package provided by specialist HIV community nurses.

Tacchi and Scott (2005) [2] describe the influencing and contributing factors to inadequate adherence as being:

- Cognitive (poor memory)
- Physical (difficulties in managing packaging)
- Polypharmacy
- Burden of side effects
- Beliefs and attitudes of the patient in relation to their health
- Perception of their illness
- The behaviour of family and friends

Although the work of Tacchi and Scott [2] relates to psychiatry, the issues which affect adherence are



appropriate to HIV care. Specifically, the importance of adequate adherence is addressed by British HIV Association (BHIVA) Standards of Care [3], which state:

*People living with HIV should have access to adherence support, which should be provided by staff with appropriate skills, when starting or switching ARVs and at any time when viral failure or suspected low adherence occurs.*

According to the Nursing and Midwifery Council (NMC) (2007) [1], Standard 9 says:

*Registrants may in exceptional circumstances label from stock and supply a clinically appropriate medicine to a patient, against a written prescription (not Patient Group Direction [PGD]), for self-administration or administration by another professional, and to advise on its safe and effective use.*

Secondary dispensing involves the transfer of medicines from the manufacturer's original packaging into a compliance aid. This process uses medicines that have already been dispensed by a pharmacist and re-packages them for an individual patient. Monitored dosage systems (MDS) or blister packs are compliance aids which are dispensed, labelled and sealed by a pharmacist.

Following a literature search, there are few papers relating to nurses undertaking secondary dispensing. Davies and Taylor (2009) [4] state:

*Secondary dispensing is not a formally agreed or defined process, and the legal basis for such practise is unclear, therefore undertaking such an activity potentially puts the individual practitioner at professional risk.*

Nurses should be aware of the associated risks, and the practice should only be undertaken if it is not possible to have the compliance aid filled by a pharmacist, which is the ideal situation. The NMC states:

*The patient has a right to expect that the same standard of skill and care will be applied by you in dispensing into a compliance aid as would be applied if the patient were receiving the medication from a pharmacist. This includes the same standard of labelling and record keeping.*

Davies and Taylor (2009) [4] concur with the NMC, by recommending all dispensing should be undertaken by a pharmacy service in a flexible, timely manner; however, when this is not possible, local protocols should be developed such as nurse secondary dispensing.

It is imperative that registered nurses are aware of, and adhere to, NMC (2010) Medicine Management Standards [5] in relation to compliance aids, and are accountable for their use. Section 2 of the Standards in relation to dispensing, states:

*If under exceptional circumstances you, as a registrant, are engaged in dispensing, this represents an extension to your professional practice. There is no legal barrier to this practice. However, this must be in the course of the business of a hospital, and in accordance with a registered prescriber's written instructions.*

Commonly, anti-retroviral (ARV) medication is dispensed from the pharmacy in the acute setting, which is not usually commissioned to fill compliance aids. This is mainly due to it being a labour-intensive process which carries substantial costs. There may be different arrangements in your area. This, however, is just one element of a comprehensive adherence package, which can be provided by HIV community nurses. This provision is dependent on the existence of appropriate frameworks. Visiting patients at home provides a unique insight into potential barriers which may impact on the patient's ability to adhere to ART. This essential information is best shared with the hospital HIV team, and GP if appropriate, to influence ART management and enhance patient care. The NMC (2010) [5] advise that prior to nurses adopting this practice, other solutions should be considered, such as reminder charts, psychological support, large print labels or non-childproof tops. Additionally, if nurses opt to repackage dispensed medicinal products into compliance aids, they should be aware that this carries a risk of error, and patient safety is paramount. The NMC (2010) [5] also recommend that nurses confirm the appropriateness of re-packaging dispensed medicinal products with the dispensing pharmacist. Regarding storage, NMC Medicines Management Standard 6 [5] advises that all medicines should be stored in accordance with the patient information leaflet, and in accordance with any instruction on the label.

There are both limitations and benefits to nurses undertaking secondary dispensing. The limitations include the following:

- In addition to specialist ARVs, there may be GP-prescribed medicines. HIV community nurses may therefore become involved in overseeing unfamiliar medication. Consideration as to how the patient will cope with such medicines should be made, and discussed with the GP and community pharmacy.
- Some drugs may not be suitable for compliance aids. Nurses should be aware that drug properties may change when repackaged and therefore may not be covered by the manufacturer's product licence. Some drugs may be affected by moisture, heat or light. It is worth noting that containers including drying agents usually indicate relative instability of the drug when exposed to moisture. Smith and Church (2006) [6] raise doubts as to the stability of medicines that have been transferred to compliance aids, and question deterioration in quality and efficacy reduction. They comment on the lack of available evidence relating to drug stability, when products are removed from original packaging and dispensed into a compliance aid. Therefore, manufacturers generally do not recommend this practice; however, they should be able to provide advice. Compliance aids should be stored at ambient temperature, in a dry environment and away from direct sunlight. Drugs which require refrigeration, are effervescent, dispersible, or light sensitive, should be excluded [6]. The following should also be excluded:
  - PRN medication
  - Non-tablet/capsule formulations, i.e., suppositories, liquids, powders.
  - Drugs which may cause skin reactions/hypersensitivity reactions on prolonged contact, e.g., chlorpromazine
  - Drugs with cytotoxic potential
- The effectiveness of compliance aids is not evidence-based.
- There may be an issue of unclear accountability if the device is filled by a member of a community nursing team but actually administered by someone else.
- The compliance aid may be difficult to operate for patients who have peripheral neuropathy, for example.
- Incorrect operation may be a problem, for example using it the wrong way round, resulting in night medication being taken in the morning. The patient may be selective in the pills they take, for example they may choose to omit Septrin but actually omit an ARV.
- There is no proof that the patient has actually taken the medication; they may have disposed of it, rendering the practice reliant on self-reporting. This also applies to patients who do not use a compliance aid, and would eventually be reflected in a detectable viral load.
- Secondary dispensing may encourage dependency; therefore the importance of reassessment and promotion of self-care is paramount.
- Careless storage may present potential access to medication to vulnerable adults or children who live with the patient.

- Initiating and managing a compliance aid may be time-consuming for community nurses.
- If the patient is socially isolated, there may be no representative available to collect medication. This may have particular relevance in the event of a current regimen requiring a change. The collection and delivery of medication could lead to an increased workload for dispensing nurses. The NMC support transportation (Standard 7) [5], stating:

*Registrants may transport medication to patients including controlled drugs, where patients, their carers or representatives are unable to collect them, provided the registrant is conveying the medication to a patient for whom the medicinal product has been prescribed, (for example, from a pharmacy to the patient's home).*

- Initiation of a compliance aid has no value for patients who have no intention of taking their medication.
- It may be difficult to distinguish between those medicines which require special directions, for example dietary requirements, which may be essential for the medicines to be effective or to avoid side effects.

Despite limitations and potential margins for error, and if undertaken with caution and following professional guidelines, the practice can prove beneficial.

Secondary dispensing into a compliance aid provides:

- An opportunity to identify and challenge missed doses during monitoring via home visits.
- An opportunity to supervise, support and teach patients and /or significant others to safely and effectively adhere to their prescribed regimen.
- Identification of trends determined by alcohol or recreational drug issues which influence adherence at certain times.
- Insight into other barriers to adherence which can then be addressed.
- An opportunity to check medication stock and ensure that older stock is being used first.
- An extra safety mechanism to identify occasional prescribing errors or dose changes, which can then be corrected. This is beneficial for patients who may have limited understanding of their medication.
- A safety mechanism in the event of pharmacies dispensing medication from a different manufacturer, resulting in an unfamiliar pill colour or shape. This may not always be conveyed to the patient despite pharmacy checks.
- An opportunity to ensure adequate stocks of ARVs are maintained, which otherwise may result in unintentional non-adherence.

- Appropriate management of urgent medication changes in situations when there is no access to the dispensing pharmacy, when drugs need to be added or removed, or dose changes are required. This contributes to reducing medication wastage, and confusion for the patient resulting from the change.
- Monitoring of side effects and tolerability, via home visits, which then informs the MDT of potential or actual problems in a more effective and timely manner. This may remove the need for additional clinic or ward attendance.
- A crucial opportunity for meaningful engagement and relationship-building between patient, significant others and community nurse, by initiating and managing a compliance aid for a short term.

## Communication

For secondary dispensing to be undertaken by community nurses, effective communication is vital. MDT communication was recommended by the Care Quality Commission (formally Healthcare Commission) (2007) [7] as one of 10 focus areas for a vision for medicines management. They state:

*MDT working should be the norm. Doctors, nurses and allied health community teams collaborate and work with those using their services to deliver safe, effective individual medicine-related care.*

Following MDT discussions, a detailed account of the ARV regimen should be provided on discharge from hospital or from the clinic. Accompanying this, should be a letter detailing the prescriber's knowledge of the secondary dispensing arrangement, and agreement for the practice taking place for that particular patient. This could be included in a routine discharge or clinic letter.

## Assessment and documentation

These elements are imperative when managing a compliance aid.

The NMC (2010) [5] state:

*Registrants must assess the patient's suitability and understanding of how to use an appropriate compliance aid safely.*

They recommend careful attention to assessment, and reassessment for continued appropriateness of the device, and utilisation of a locally recognised assessment tool, such as the one shown in Figure 1.

The assessment should be reflected and documented in the patient record, evidencing 'exceptional circumstances', following exploration of other options with a pharmacist and the MDT. Whether or not the benefits of a nurse undertaking secondary dispensing outweigh the risks should be

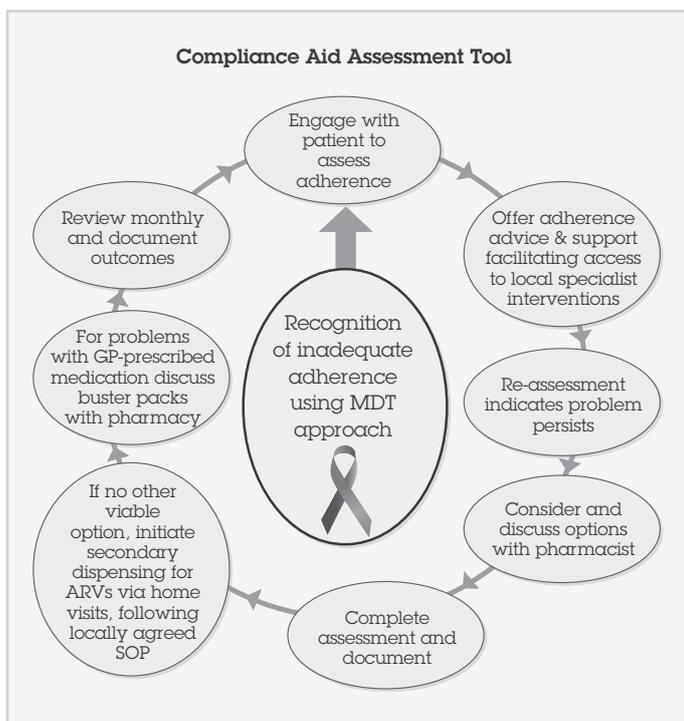


Figure 1: Locally recognised assessment tool.

considered and documented. All patients will need to be regularly assessed for continued appropriateness of the aid.

The assessment, reassessment and outcome of the intervention should be evidenced in the patient record, which should also reflect professional guidance, NMC (2010) [5]. The compliance aid must be fully and clearly labelled. This should include:

- The patient's name and date of birth
- The name and strength of the drug
- The means of clearly identifying each drug, e.g., colour, shape
- The dose and the number of pills to be given at each time

Additional documentation to be kept in the patient's home with the device should include:

- A signature sheet, clearly showing the date, name, signature and job title of the dispensing nurse. This needs to be updated each time a compliance aid is filled.
- Drug information leaflets and original packaging containing the current prescription. The NMC (2010) Medicines Management Standard 6 [5] advises all medicines should be stored in accordance with the patient information leaflet, and in accordance with any instruction on the label.
- A contact sheet containing details for the dispensing pharmacy, HIV consultant, hospital specialist nurse, community specialist nurse and GP.

## Choice of device

This is an important consideration, and should be relevant to the patient's needs. Compliance aids are referred to as a dosette boxes, monitored dosing system/blister packs, and pill dispensers. There are many products available on the market, which can be bought by patients for personal use from discount shops and chemists, provided by pharmaceutical representatives or provided by a pharmacist. Some even have the days of the week and times available in braille. Others may have integrated child locks and alarms. The device should be easy to clean. Smith and Church (2006) [6] discuss the risk of physical, chemical and microbiological cross-contamination, as dosette boxes are not disposable whereas blister packs are. If a nurse is dispensing into a device, then it is imperative that a card insert or label is available containing correct patient and medication details. This should be checked against the prescription at each visit. The devices used by our team are approved and ordered by a pharmacist (see Figure 2).

## Standard operating procedure

The NMC recommend that nurses' employers need to be made aware of secondary dispensing, and the activity should be covered by a standard operating procedure (SOP) [5]. The latter should be developed collaboratively with local medicines management teams, dispensing pharmacies and prescribers. An SOP will ensure standardisation, support and clarity for nurses relating to NMC guidelines. It should encompass the following:

- Correct labelling of compliance aids
- Checks for expiry dates
- Checks for name, strength, dose and directions of drugs against original packaging
- Checks that correct drug and dose are dispensed into device
- Communication with patient or significant other relating to additional instructions
- Infection control considerations such as hand washing, ensuring the device is clean and dry, and minimal handling of medication

The SOP should include an appendix which lists the registered nurses authorised to carry out secondary dispensing. They should be, for example, a



Figure 2: Dosette boxes used by our team.

registered nurse, within the HIV team, who has:

- Received the appropriate training and is competent
- Has the approval of their line manager, who will sign authorisation to secondary dispense HIV medication into an approved compliance aid

## Training

Additional training in medicines management should be included in each staff member's professional development plan, and nurses should be able to evidence medicines management mandatory training. Their competencies should be signed off by the line manager, and should reflect knowledge of the legal aspects and responsibilities of secondary dispensing undertaken by nurses.

## Errors

If a dispensing error or near miss is made, the incident should be reported as per local procedure. Nurses should refer to local medicines and management of incidents policies used by their employing NHS trust.

## Audit

Secondary dispensing by nurses should be regularly audited within the team incorporating aspects such as:

- Documentation in the patient's home
- Documentation in the patient's case notes
- Medication errors
- Adherence outcomes

## Case study

Jack is a 32-year-old male diagnosed late with progressive multifocal leukoencephalopathy (PML). This rendered him immobile, incontinent, and with swallowing and speech difficulties. He had a PEG feeding tube *in situ*. He was discharged home after 6 months in hospital under the care of Ruby, his mother, who was incredibly anxious about care responsibilities, in particular, medication. A social care package was in place which provided carer support four times a day. Home visits from occupational therapy (OT), district nurses (DNs), GP, physiotherapy, speech and language therapy (SALT), PEG nurse, and community equipment team were all in place. Jack's medication had previously been given via his PEG tube, which Ruby had learned how to manage in hospital. However, his swallowing was reassessed by the SALT team and deemed safe. He started eating solids and drinking thickened fluids. His ARVs were prescribed in tablet form instead of liquids, and he was to commence taking them orally. Ruby's anxiety was heightened and she discussed her concerns about giving him the wrong medication. There was no other health care professional, apart

from the HIV community nurses, who had in-depth knowledge of ARVs and who could provide the necessary adherence support. Ruby was stressed and often tearful, especially when she was faced with a large supply of medication.

Following discussion with the dispensing pharmacy and MDT, a compliance aid was agreed and sourced. The HIV specialist nurses initiated and managed secondary dispensing for 1 month, enabling Ruby to observe and begin to familiarise herself with the regimen. GP-prescribed medication was dispensed into an MDS by community pharmacy, and delivered to the house every 3 weeks. During the second month, Ruby dispensed ARVs with supervision by the HIV nurses. She gained confidence after 3 months, and is now competent in managing the compliance aid. She understands all aspects of the prescribed drugs, timings and dietary requirements. Over time DNs, OT, SALT, and PEG nurses have discharged Jack and he no longer has a care package. HIV community nurses continue to visit weekly, to support the family in relation to HIV diagnosis, which is only being addressed now as the routine has settled at home. In collaboration with the hospital HIV team, community nurses obtain his 3-monthly monitoring bloods, relay and interpret results with Jack and Ruby to ensure understanding. Jack requires an ambulance to take him to clinic. They live in a tiny terraced house in the inner city, where the presence of an ambulance attracts unwanted attention. None of the neighbours are aware of Jack's HIV diagnosis. Jack therefore only attends clinic every 6 months, and as Ruby has limited availability due to her carer's role and no transport to collect medication, the HIV community nurses assist by checking stocks, requesting and collecting ARV prescriptions when necessary. Jack now has an undetectable HIV viral load and a climbing CD4 cell count.

In this case, adherence issues were identified early, discussed with the MDT, and via ongoing agreed home visits the correct intervention was initiated, aligning with NMC guidelines [5]. Had the HIV community nurses not initiated and managed the compliance aid in Jack and Ruby's case, in a timely way, such an astounding outcome may not have been achieved. The benefits of undertaking secondary dispensing clearly outweighed the risks, and the family are now independent in terms of successfully managing ART.

## Conclusion

In summary, secondary dispensing undertaken by HIV specialist community nurses can clearly enhance overall care in relation to optimum adherence to ART. It should not be routine, and should only be practised in exceptional circumstances. However, any patient can purchase a compliance aid for personal use. The MDT may

not even be aware of this, how it is used, stored, cleaned or indeed how many weeks of medication is dispensed at any one time. But for nurses, the practice should be undertaken with caution, and embed all the elements discussed throughout this article.

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# HIV outreach testing activity audit 2013/14

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## Background

Public Health England (PHE) 2013 reported that approximately 98 400 people were living with HIV in the UK in 2012, and that an estimated 21 900 were unaware of their HIV status [1]. Late diagnosis of HIV is associated with increased morbidity and mortality. Diagnosing people early also reduces transmission of HIV to other people (BHIVA Standards of Care, 2013 [2]). The reason for undertaking this audit was to demonstrate that the HIV community nursing service in Liverpool is able to engage with high-risk client groups, and to offer testing and health promotion advice in line with national guidelines. According to the Centre for Public health at Liverpool John Moores University [3] the dominant mode of HIV exposure is between men who have sex with men (MSM), which makes up 51% of new cases in the North West of England, and 33% of cases were from Black and minority ethnic groups. The proportion of people diagnosed late has declined over the past decade from 58% in 2003 to 47% in 2012 [1]. However, national experts recommend an acceleration in HIV testing, which is supported by a wealth of evidence such as the Halve It campaign [4], the Terrence Higgins Trust *It Starts with Me* campaign [5], the BHIVA Care Standards [2] and the BHIVA testing guidelines [6].

The following guidelines influence the practice of the HIV community team and are used as a model of care:

- PH34: Increasing the uptake of HIV testing among men who have sex with men: National Institute for Health and Care Excellence (NICE) guidance, March 2011 [7]
- PH33: Increasing the uptake of HIV testing among black Africans in England: National Institute for Health and Care Excellence (NICE) guidance, March 2011 [8]
- UK National Guidelines for HIV Testing: British HIV Association (BHIVA), British Association of Sexual Health and HIV, British Infection Society, 2008 [6]

## Aims and objectives

The Audit was undertaken to ensure that testing activity within the HIV community service was aligned with 2011 NICE guidelines (PH33 and PH34, [7,8]) and BHIVA/BASHH/BIS testing guidelines (2008) [6], and to highlight any issues from which we could learn in order to ensure the best practice.

## Methodology

Forty patient records were audited by the HIV community nursing service. The outreach settings where HIV tests were carried out included: Asylum Link, which helps and supports asylum seekers in Liverpool; Armistead, which offers support, information and sexual health promotion to lesbian,

gay, bisexual and transgender (LGBT) community and sex workers; Sahir House, which is the support, information and training centre offering a wide range of services to individuals and families living with or affected by HIV in Merseyside; and the community clinic which is the HIV community nursing service base. The team also undertakes domiciliary testing in exceptional circumstances.

Data collection occurred throughout August 2013 using an audit pro forma which comprised 19 questions in various formats. Data were collected by the HIV community nursing team and were submitted to the clinical audit department to be scanned, verified and analysed.

## Conclusion

A majority of the patients tested were men (88%), 48% of whom identified themselves as MSM. This was because the highest uptake was via Armistead. Here, staff were mobilised to work within the gay quarter and actively encourage men to access the outreach testing sessions, thus underpinning the effectiveness of outreach work and collaborative working. It also demonstrates that the testing carried out by the HIV community service in Liverpool aligns with the Trust's strategic objective of integration, and complies with National Guidelines [6–8]. This emphasises the need to take into account potential barriers to HIV testing, such as stigma or lack of access to services, and for testing to be delivered in a non-judgmental, innovative way [7].



Thirty percent of the sample group identified as Black African and 13% of the sample group identified as Asian. Again, this highlights that the community HIV service in Liverpool is reaching and testing the higher risk groups. Twenty-three percent of patients required a consultation in a language other than English. These consultations were

offered via the use of Language Line, a telephone interpretation service, and an information leaflet developed by the service to be used in outreach testing programmes. The leaflets are a tool to impart basic information about HIV transmission and are available in 13 languages. Information is also presented in cartoon format to ensure inclusion for those with poor literacy skills. This demonstrates the fact that the HIV community service embeds equality and respect for diverse cultures as a crucial aspect of their role. NICE guidance (2011) [8] recommends that the test needs to be suited to a person's age, culture and gender. The community nurses therefore align with NICE guidance (2011) [8], BHIVA Standards of Care, 2013 [2] and BHIVA/BASHH/BIS testing guidelines (2008) [6], which provide the evidence base underpinning this initiative.

Of those tested, 88% were male, meaning that only 12% of the patients included in this audit were female. This statistic highlights that women are a client group who are harder to reach and to offer HIV testing, and indicates the need for innovative ways of working which enable women to access HIV testing. In 2012, 67% of men and 33% of women living with HIV were receiving HIV specialist care in the UK [1]. In 2012, a higher number of heterosexual women (1530) compared to men (1050) were newly diagnosed with HIV. These findings underpin the importance of increasing the uptake of testing amongst women.

Eighteen percent of patients tested for HIV were over 60 years old, with a majority (78%) being between 20 and 49 years of age. This demonstrates that age should not influence whether or not we test, but rather there is a need to be open and accessible to all.

All patients were registered with a Liverpool GP, indicating that they had never been offered a test in primary care or were reluctant to ask. This highlights an issue: that GPs are not routinely offering HIV tests. This could be due to a lack of confidence; however, it highlights the need for educating GPs and other health care professionals

### Key findings

- Males outnumbered females (88%).
- Almost half the male patients were MSM (48%).
- 30% of the sample identified as Black African and 13% of the sample identified as Asian.
- 18% of patients were over 60 years of age.
- All of the patients tested were registered with a Liverpool GP (100%).
- The majority of patients self-referred for a test (78%).
- Half the sample refused to consent for their personal details to be entered onto the electronic clinical system (50%).
- 90% of patients were given HIV prevention advice at the point of contact.
- A small minority of patients requested a test due to a history of intravenous drug use (IVDU) (3%).
- Half the patients were signposted to other services and also required further sexual health screening (50%).
- Almost one-quarter of patients required a consultation in a language other than English (23%).

## Recommendations

- To establish new and innovative ways of engaging with women in order to enable access to HIV testing within Liverpool community settings. To utilise the English classes at Asylum Link to raise HIV awareness generally. To raise awareness within churches and faith groups where Black/ethnic minority groups attend. Also to target GP surgeries in higher prevalence areas and promote normalisation of testing within these venues, especially to women, who were underrepresented in the audit.
- To increase education amongst GPs and other health care professionals, relating to HIV testing, with the aim of reducing late diagnosis. To normalise and increase the uptake of testing in a variety of settings aligning with NICE and BHIVA/BASHH/BIS testing guidelines [6–8].
- Stigma remains an issue as indicated by the reluctance of patients to consent to personal details being entered on the clinical system used by the team. The continuing need to educate communities and health professionals to challenge stigma remains.
- Continue to offer testing in the same or similar venues, Armistead, Sahir House, Asylum Link and domiciliary.
- Continue to disseminate the importance of HIV testing as a prevention strategy.
- Continue to explore diverse initiatives to address language barriers, such as developing the use of electronic devices to impart appropriate information.
- Educate other health care professionals that age should not be an exclusion factor when offering an HIV test. Consideration of age is required due to an ageing HIV population.

to routinely offer and normalise HIV tests. NICE guidance [7] emphasizes the need for GPs in primary care to be initiating testing. The guidance also indicates that many health professionals lack confidence in using their existing skills in relation to HIV.

Half of the sample group (50%) refused to consent to their personal details being entered onto an electronic clinical system used by the team, despite being given assurances that it was a secure and confidential system. This may indicate that fear around disclosure and stigma still exists.

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# HIV and the GP: a patient's perspective

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## Background

People living with HIV and taking antiretrovirals (ARVs) are now living longer [1-3], ageing with HIV and inevitably developing associated health conditions. Many of these conditions, including COPD and diabetes, are much better managed by general practitioners [4]. Over the past few years, there has been a move to manage long-term conditions, including HIV, within the community [5,6]. There is therefore an increased need for people living with HIV to access their local GP services. However, a significant number have traditionally only accessed health care through their HIV acute centres.

In this article, I will discuss my experience of accessing GPs (from the HIV patient's community perspective) gained through qualitative research that Positively UK carried out in 2010 [7]. The research looked at both the good and the not-so-good patients' experiences of accessing GPs. The resulting report, *Primary Care Access: How General Practice Can Better Respond to the Needs of Patients Living with HIV*, recommended different models of care that could be adopted to better meet the needs of patients and GPs.

## Personal perspective

I was diagnosed with HIV nearly two decades ago. Interestingly it was my GP who suggested that I go for an HIV test, after I had had hepatitis B. Having moved house, I disclosed to the new GP and the next GP I registered with when I moved house again. It never once occurred to me to not tell my GPs about my HIV status. Perhaps it was because it was my GP who asked me to test. It was also especially important for my GP to know my status when I had my baby as I had to access them for baby monitoring, vaccinations etc.

Initially I accessed almost all of my care at the HIV clinic. I live in Hackney and received my HIV care at the Imperial NHS Healthcare Trust in Paddington. Although it was quite a trek, I was, for many years, quite happy to make the journey, preferring to go all the way and sit in the walk-in clinic for hours rather than go to my GP, even for minor ailments. The reality is, I had never really explored what the GP could offer me and had not had that much encouragement to do so. I was also very happy with the full health care I received at my HIV clinic and saw no reason to change.

Over the past couple of years, I have started accessing my GP more. This is mainly because of

communication from the clinic regarding the move to managing long-term conditions within the community. The clinic made it clear that they would only see me for HIV-related issues and that I would need to go to my GP for any other ailments.

Once I started accessing my GP, I realised that it made so much sense. For instance, in terms of accessibility my GP is only two roads away from my house; they have evening opening times; you can walk in most days of the week if you have no appointment – as long as you are prepared to queue up by 8:30 am. The GPs at the practice are very knowledgeable and none of the GPs or the practice nurse have even raised an eyebrow when I have told them my HIV status!

I guess the only downside is that I have to have repeat prescriptions for my high blood pressure tablets and a previous recurring toe nail problem; it's quite expensive. Generally though, I have never had cause to complain about any of the GPs to whom I have disclosed over the years. But that's my perspective, and I am aware that many of my peers in the HIV community do not share the same view.

## The Primary Care Access project (PCA)

The PCA project was commissioned by the then NHS Kensington and Chelsea and NHS Westminster Primary Care Trusts. We were tasked with developing a model of care that would enable people living with HIV to better access their GPs. People living with HIV were involved at all stages of the project, which was led by a steering group of health care professionals and commissioners.

## Method

Initially we carried out a literature search and review. We then conducted a pre-survey questionnaire with 200 patients to find out their attitudes to accessing primary care services. Following this we conducted the main survey over 5 months, through structured one-to-one interviews and focus group consultations, with three target groups of people. The target groups comprised in total: 82 patients living with HIV; three GPs; two practice managers and six HIV clinicians. It was very difficult to find GPs to interview and take part in the focus group discussions. This was despite having written to, emailed and telephoned a significant number of GPs in the sample area.

## Patient questions

We asked patients a series of questions to explore their health care needs; experiences of accessing primary and acute care; and both good experiences as well as barriers they had encountered. We then asked them how these barriers could be addressed, presenting different care models and asking them to indicate which they preferred.

## GP and practice manager questions

We asked GPs and practice managers to describe the level of service currently provided to patients living with HIV; what concerns, if any, they had around providing care for patients; and how these could be addressed. We also asked them to identify any support needs and to indicate what models of care they preferred.

## HIV clinician questions

We asked HIV clinicians to describe their current model of care; what their roles and responsibilities are towards patients; any concerns they had around the current set-up; their experiences of working with GPs; and what elements of care should be provided by GPs. We also presented models of care and sought their preferences.

### Models of care presented

- **Current model:** This model of care of patients has developed historically over nearly 30 years, with people accessing acute clinics of their choice for HIV management. This is in contrast to GP services which can only be accessed in the community.
- **The Brighton model:** Brighton and Hove PCT introduced a Local Enhanced Service (LES) in 2008 for the provision of primary care for patients living with HIV. GPs can voluntarily enter into the LES and are reimbursed for activities undertaken under the terms of this contract. This includes compulsory attendance at HIV awareness training, registering a minimum number of patients living with HIV and monitoring a prescribed list of health concerns (e.g., cardiovascular disease).
- **The Manchester model:** In 2008 Manchester PCT, in a move to support the update of GP services for patients living with HIV, introduced compulsory training for GPs and incorporated this into existing contracts. Guidelines for the management of patients were also produced which encompassed disclosure and confidentiality. This was complemented by a mentor programme to support access to GPs for patients living with HIV.

## Good practice

Patients did not only focus on the challenges of accessing GPs. A significant number reported being happy with the service they received from their GPs:

### Concerns raised

The main concerns raised by patients covered the following areas:

- **Clinical competence:** Some patients were worried that their GP may not be able to treat complications associated with their HIV. For instance, dealing with issues around drug interactions: 'I just don't trust them to really understand some of the issues around HIV care, the interaction of different drugs. Because I have co-infection with hep C, I think it's quite a complex thing to monitor and manage and I just don't think they would have the expertise.'
- **Confidentiality and trust:** Some patients were not sure that their information would be kept confidential.
- **Discriminatory practice:** Although this was not widespread, some patients reported experiencing discriminatory attitudes from their GPs: 'Like when I told him when I was first diagnosed. I got a completely ridiculous comment like – what's someone like you doing getting something like that? I was so shocked I just said well what do you think? I am a human being. I have sex like everybody else!'
- **Communication:** Communication, or rather lack of communication, between HIV clinicians and GP was seen as an issue even where patients had disclosed and given permission for their HIV clinicians to contact/update their GPs as and when necessary.
- **Accessibility and choice:** Some patients reported GP practices refusing to register them. However, as the majority had not asked for a reason why, it was not clear whether the rejection was due to their HIV status or other reasons such as the practice not taking on new patients. Another issue related to this was the fact that many patients reported seeing a different GP each time they went to the surgery. This they found to be a challenge, especially having to repeat their story over and over to the different GPs.
- **Quality of care:** This was mainly around what the patients termed the 'ping-pong' effect. Even where patients had disclosed to their GPs, many reported repeatedly being sent back and forth between their HIV clinicians and GPs. Each clinician decided the issue in question was the responsibility of the other to treat.

'I've disclosed to my GP, and I have never once had any cause for concern.'

Similarly, HIV clinicians also reported good relationships with some of the GPs they worked with:

'When they are good, they are really good. Like GP X. He's doing HIV testing in his practice. He's great, he's really switched on.' or 'I actively encourage people to have their GPs involved because I figure GPs are the people reading stuff that I might not have read about. There are a lot of chronic things; we are dealing with an aging population now. GPs are best placed to deal with these things.'

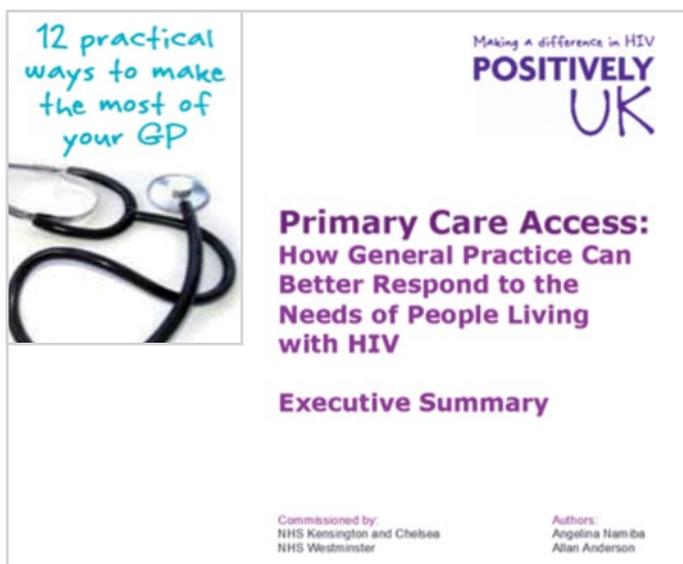


Figure 1: Positively UK's resources on making the most of your GP.

## Recommendations

At the end of the study, participants came up with a number of recommendations they felt would enable patients to better access their GP services. These included:

- 'Transition' GPs in HIV clinics: GPs who would work in HIV clinics for a limited period to support the transition of patients in primary health care services.
- An increased role for the Clinical Nurse Specialist (CNS) and Nurse Practitioner (NP): The CNS already works with patients in the community. As such it was felt that they are best placed to aid the transition process and continue their role.
- Having a pool of 'super GPs' where patients would be referred: Both patients and clinicians alike acknowledged that there are already a significant number of GPs who do a fantastic job around working with patients living with HIV. Therefore, develop a model of care with a pool of super GPs trained to care for patients living with HIV.
- Training and support for patients to access primary care with confidence: This training would be delivered by voluntary sector agencies who have experience in working with patients around enabling them to access, engage with and stay in care.
- Training to cover areas around: improving access to your GP – how to register; reasons to have a GP; what to ask; complaints procedures; and what can a GP do for me?
- Improving the ability to disclose to GPs, how and when: What information do I need to include and why? Increase the ability to have control of your health care – self management; good doctor-patient relationship; asking questions; and which ones?
- Getting involved in the GP consortia in your local area.
- Training for GPs: Training around increasing the capacity for HIV testing, understanding of HIV treatment, social and psychological aspects of living with HIV.

From a patients' perspective, what emerged from the study was a clear need for reassurance for patients. Patients were more than happy to access the GP services if they could have reassurance in the following areas:

- Competence: That their GPs are confident and competent around managing patients living with HIV; that they are able to recognise what illness/medical complaint is HIV related; and that they are confident in dealing with drug-drug interactions. And especially where patients have multiple/other conditions.
- Confidentiality: That their information would only be shared on a 'need-to-know basis'. And that they could be reassured about who has access to what information and why.
- Care without discrimination: That their care will not be affected simply because of their HIV status. And that they would be treated just like other patients in the surgery. That they wouldn't be discriminated against because of their HIV status.
- Communication: That this would be effective, especially where disclosure has taken place. Knowing that information will be shared between the health care professionals.
- Confidence: That health care providers are confident about who is responsible for what aspects of their care. And indeed who has ultimate responsibility for their care.

Finally, all hoped and wanted reassurance that recommendations from the study would be meaningfully considered, and that the most robust models will be implemented in order to ensure equality of care for patients with HIV wherever they live.

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## Sexualised drug use by MSM (ChemSex): a toolkit for GUM/HIV staff

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Tina', 'Meph' and 'G', street names for the three round-peg recreational drugs that don't fit too neatly into the square holes provided by the substance misuse or GUM/HIV sectors (Table 1). The sexualised use of these three drugs (crystal methamphetamine, mephedrone and GHB/GBL) by men who have sex with men (MSM) has become the new public health concern in London, New York, Los Angeles, San Francisco, Sydney, Melbourne, Berlin and Cape Town, with reports of these ChemSex behaviours being linked to rising HIV and hepatitis C infections [1].

ChemSex involves the use of any combination of these three very potent drugs to facilitate and enhance sex, and is associated with multiple partners, condom-less sex, harder sex practices and fetishes, the eroticisation of injecting practices and the abandonment of boundaries/self-care brought on by the powerful disinhibition that these drugs induce. In addition to the obvious sexual health consequences, users commonly report compulsive use/addiction, 'benders' that last 2 to 4 days, psychosis, chronic depression, the inability to have sober sex, the estrangement of family/support networks, disinterest in non-sexual social activities and other mental health/wellbeing issues [2]. Furthermore, GHB/GBL has been associated with several fatalities caused by acute toxicity, and the withdrawals associated with physical dependence can be complicated to manage, and potentially fatal [3].

Whether these trends ought to be addressed within GUM/HIV, or the (perhaps) more obvious choice of the substance misuse sector, has been a debate waged over the last 2 years amongst the relevant stakeholders. Challenges to the substance misuse sector have been the novel pharmaceutical and behavioural characteristics associated with ChemSex trends; the sector is arguably entrenched in its historical expertise of heroin/crack-cocaine/alcohol use, by (predominantly) heterosexual, street homeless drug users. The

sometimes challenging and unfamiliar practices of hardcore gay sex by a very different population, driven by unfamiliar motivations (such as internalised homophobia, shame around sex, HIV stigma, the proliferation of sex Apps on Smartphones - e.g. Grindr - and the culture of gay saunas) presents a difficult shift of pace for traditional drug services.

In contrast, GUM/HIV services are not only very well attended by MSM, but staff in these clinics are well versed in the variety of sex practices of diverse populations. The challenges lie in the poor familiarity with substance misuse interventions, acute dangers associated with certain substances/addictions, relapse prevention techniques and harm reduction knowledge. Further challenges exist in the monitoring/recording of this form of drug use on existing databases designed exclusively for sexual health.

The debate, over which sector ought to be providing the support and interventions, was ultimately resolved by the MSM drug users themselves - choosing to seek support and disclose ChemSex behaviour to GUM/HIV clinicians, and demonstrating a vast reluctance to attend statutory drug services.

In response to this, and despite there being no precedent or tariff for a full-time drugs worker in GUM/HIV, the Chelsea and Westminster NHS Foundation Trust chose to flout usual practice, and create a full-time substance use practitioner post in January 2014, at its 56 Dean Street clinic in London's Soho, which had been at the forefront of these ChemSex presentations. Within the first month of this post, and following some in-house training for clinicians, 110 patients had disclosed and requested support around ChemSex behaviours, with only two of these having ever previously accessed support from a statutory drug service. Thirty-one of these men had sought PEP (post-exposure prophylaxis) following a ChemSex episode, with 18 of them

**Table 1: Popular ChemSex drugs: summary**

Known as / abbreviation	Full name	Administration
Crystal meth, meth, tina	Crystal methamphetamine	Smoked or injected
GBL, G	Gamma-butyrolactone	Ingested orally
GHB, G	Gamma-hydroxybutyrate	Ingested orally
Meph, drone, meow meow, MCAT	Mephedrone	Snorted or injected

having been enrolled on multiple PEP courses (one reported as many as 14 courses, most uncompleted due to chaotic drug use). The same data show multiple re-infection of hepatitis C (including among non-injecting HIV-negative drug users), ignorance around injecting practices and sharing of injecting equipment, poor adherence to ART (antiretroviral therapy) and rare if any memory of sober sex. There was also a high level of ambivalence and/or reluctance to make changes around drug use, demonstrating the need for tailored, skilled interventions in this setting.

## The toolkit

Addressing ChemSex trends within GUM/HIV services does not require clinicians to be expert substance use interventionists; and despite the mandate to address these behaviours and harms in GUM/HIV, we clinicians need not feel overwhelmed by our own ignorance of certain sex practices or substances used.

The most common fear expressed by nurses regarding ChemSex presentations was that *should*

## Case report

BH is a 26-year-old gay male who is HIV negative and who presented to his GUM clinic seeking PEP following a ChemSex party that lasted 2 days, and during which he had condom-less receptive anal intercourse with four men of unknown HIV/HCV status. He usually uses condoms 'when he can', and was no stranger to GBL, mephedrone and crystal meth use, though was injected with crystal meth for the first time by a partner at the party and described a feeling of invulnerability and a powerful desire to indulge erotic risky sexual fantasies, such as he had seen in pornography.

*(BH had disclosed his drug use to another GUM clinic 2 years previously when presenting with symptoms [discharge], but had walked out angrily when a nurse suggested a referral to a drug-support service for his 'addiction' problems; BH claims his drug use is recreational and non-problematic.)*

PEP was prescribed for the patient; it was his second course of PEP in a year, though drug use had not been identified at the first PEP presentation (he had only been asked about injecting drug use at the first presentation, to which he honestly replied 'No'). Prompted by some ChemSex toolkit questions made available during training, the clinician asked some non-invasive questions designed to encourage self-reflection from the patient. Further questions ruled out the risk of any acute use-related dangers BH might be exposed to, such as dependent use/withdrawal or drug-induced psychosis. The issue of sexual consent while under the influence of drugs was also raised, as BH had been so highly

intoxicated from a large dose of GBL that he could not recollect certain periods from the extended sexual episode.

Again, the patient communicated his enjoyment of drug use, claiming that sex without drugs was 'boring', was 'over too quickly', and that he never felt horny without drugs. He also claimed that ChemSex was 'normal' in London, and that the clinician shouldn't 'freak out' about it. Declining the offer to chat with the drugs advisor in clinic, BH did take home some harm-reduction information and targeted documents [4] written for ChemSex play.

Upon his first PEP follow-up appointment, BH requested to speak with the in-house drugs advisor for some safer injecting information; this had been prompted by his desire to negotiate hepatitis C risks he had read about in the literature that he had taken home with him. During this 30-minute consultation issues were raised such as his desire (and fear) of relationships, an exploration of the pros and cons of sober sex, peer pressure/anxiety he felt while using Smartphone sex Apps and his reluctance/fear to discuss HIV with unfamiliar sex partners. Upon further reflection, BH identified that when sober and in bed with a partner he felt unattractive and unsexy, and had persistent unwelcome thoughts about HIV transmission. Though reluctant to commit to any changes around his drug use, he agreed to attend further appointments with the drugs advisor for more exploration of the issues; and a month later, reported feeling emboldened to seek a more fulfilling sex and romantic life.

**Questions to ask in clinic**

(Clinicians can use the colloquial terms if they are comfortable; it diminishes the patient's perception that you might be judgemental, and encourages honest disclosure.)

- Do you use party drugs for sex?
- (and if so ...) tina, mephedrone or GBL?
- Are you taking G every day? (and if so for 7 days or more ... it can be dangerous to stop without medical advice)
- How long do you stay awake for?
- Have you had any bad experiences? (e.g., paranoia or passed out from G overdose)
- Do you sometimes regret the choices you make when high?
- Were there any highly intoxicated moments when you might have engaged in some sex that you can't remember / might not have consented to?
- (If HIV positive) Do you sometimes forget to take your meds when high?
- When did you last have sober sex?
- What is your non-sexual / non-clubbing social life like?
- Are you slamming (injecting)? Do you know where to access clean needles?
- Are you aware of hep C risks from shared needles, lube, toys, fisting, douching tools, toothbrushes, razors?
- Do you know about the right doses and time intervals when using GBL? (You do not need to know this yourself; refer patient to online resources [5])
- Do you want to talk to someone about playing more safely with drugs?

they ask the right question, they may receive an answer that demonstrates their ignorance; and so they refrained from asking the question in the first place.

There is no harm in not knowing the answer to everything. Once our patients know that we are not judgmental, and that we care for their wellbeing, they are usually very happy to talk us through the things we are less experienced with.

Clinician: *'Forgive me; I'm not too familiar with some of these drugs, or ChemSex, but I'm not judgmental at all, just eager to provide the best care that I can. Can you tell me more about it? And I'll find the right person or service for you to speak with if you'd like any support.'*

## Acute concerns

Aside from the sexual and BBV transmission risks which GUM/HIV clinicians are familiar with, there are a few urgent medical concerns that ought to be ruled out, for all ChemSex presentations.

- If patients are using GHB/GBL, check if they are using every day (for 7 consecutive days or more); in this case, they should be advised *not* to stop

**Patients presenting with (mild) drug-induced psychosis**

- Typical presentation:

I was at this sex party, and everyone was acting really weird; they were whispering about me, they locked the doors and they mixed the drugs with other strange stuff.

I don't know why, but they had some weird agenda. I think they were secretly filming me during sex to upload later online. When I left I could hear them following me and I kept seeing the same car outside my house. I couldn't use my phone or laptop, because I'm sure the webcam was bugged somehow. There were people listening at my door and watching through the windows.

The trauma of this memory can sustain these perceptions of belief for many days, even after the person has stopped using drugs and got some sleep.

- Suggested response to patient:

That sounds really frightening and I'm sorry that happened to you. You have the choice to call the police, or go to A&E if you feel unsafe or unable to go home.

We do hear stories like this sometimes. There is a common symptom called 'drug-induced psychosis', where our mind can play tricks on us while we're exhausted from lack of sleep and drugs. I'm not saying this didn't happen to you, and it does indeed sound very frightening. You are safe here; just keep your mind open to the possibility of those common symptoms, and that you might be safer than you feel.

A short, light, smiley conversation in clinic can often change the person's mindset. A risk assessment, as to how safe the patient feels, and whether they are a risk to themselves or others, ought to follow. Refer to A&E if in doubt.

using without medical advice from an addiction service. If they have no more supply of GBL, they ought to go immediately to A&E where they would be treated with benzodiazepines to keep them safe. Call ahead to ensure the A&E duty staff are aware of the GBL withdrawal dangers, which include confusion and delirium, and can be fatal.

- If patients present with what appears to be drug-induced psychosis (commonly caused by methamphetamine/mephedrone use/lack of sleep), they can sometimes be reassured that they are safe. Some drug services might prescribe 5 mg diazepam twice daily for 2 days. Assess whether or not the patient is a risk to themselves or to others, and refer to A&E if you feel it appropriate.

## The golden rule

Remember that patients presenting to HIV/GUM services may not be seeking any support around their drug use, and interventions should not be imposed upon them. A drug user is the best person to define if they have a problem, not us; our judgment may discourage them from accessing our

services again. Refrain from using terms like 'addict', 'addiction', 'drug abuse' and 'drug misuse' (drug use is preferable). It may be challenging for us as health workers to see self-harmful behaviour, but the golden rule of substance use work is to keep the client engaged; the right time will come for a drug user to ask for help, and if he remembers a caring, informed and non-judgmental consultation with your clinic, he will be highly likely to seek support from you when that time comes.

## Referral pathways/online resources

*GBL dependent use (physical addiction, usually several doses daily for 2 or more weeks)*

These patients ought to be advised to continue taking the drug as they require it and referred to their local drug service for an assessment. Not all national drug services are informed about GBL dependence, and some are not funded or equipped to provide a GBL detox; and so it is wise to provide a letter or document [6] for the patient to take with them, or to have a consultant contact the drug service on the patient's behalf. A GBL detox service based in London, but accessible to people nationally, is the Club Drug Clinic [7] (Central North West London NHS Foundation Trust).

If the patient has no more supply of GBL, and is unable to get more, acute withdrawal symptoms could set in within the hour; these patients ought to visit A&E as quickly as possible, preferably with a letter [6] or some communication from a consultant.

*Clean needles are available from:*

- Most local drug services
- Some pharmacies that participate in needle exchange schemes
- Some A&E departments
- A few GUM/HIV clinics
- Online distributors (for a price)

Safer injecting information is available through most drug services, and online [8] (though it is best to search for a site linked to a specialist service).

## ChemSex support

Very few drug services nationally have been trained in providing ChemSex support for MSM. That is not to say those untrained are incapable; many will be able to adapt their interventions for this patient group. A video of a ChemSex intervention (role play) using motivational interviewing techniques, and made for training purposes, can be found online [9].

The services specialising in ChemSex support that can be accessed by MSM nationally (though the services are based in London), are 56 Dean Street GUM/HIV [10] (Chelsea and Westminster Hospital mNHS Foundation Trust) and Antidote [11] (a drug

and alcohol service for the lesbian, gay, bisexual and transgender communities, part of the London Friend Wellbeing charity). The Code Clinic [12] (also at 56 Dean Street) is a walk-in ChemSex clinic on Tuesday evenings managed in partnership by 56 Dean Street and Antidote, London Friend.

Harm-reduction information for these drugs/behaviours can also be found online [13].

## Conclusion

Arguably the greatest accomplishment in public health and HIV has been the easy accessibility of GUM services for MSM; of all the social and most-at-risk groups, MSM have excellent experiences and relationships with sexual health services, and it has curbed the transmission of HIV and other STIs remarkably over the last 20 years. This is likely to be the greatest asset we have in addressing this phenomenon/syndemic of HIV/HCV/STI/mental health/sexualised drug use by MSM. Despite the challenges, complexities and harms of ChemSex, we can have faith in our ability to support our patients with these issues: simply by providing a safe place to disclose these novel behaviours, by providing a sympathetic ear and a few simple, targeted questions that may be the first step toward support and recovery, for a group that urgently need our care, and who represent an urgent public health concern.

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5. See: <http://code-clinic.webs.com/ghbgbl.htm>
6. See: [www.code-clinic.co.uk/Emergency%20Services%20letter%20generic.pdf](http://www.code-clinic.co.uk/Emergency%20Services%20letter%20generic.pdf)
7. See: <http://clubdrugclinic.cnwl.nhs.uk>
8. See: [www.code-clinic.co.uk/saferinjecting.htm](http://www.code-clinic.co.uk/saferinjecting.htm)
9. See: [www.davidstuart.org/chemsex-intervention](http://www.davidstuart.org/chemsex-intervention)
10. See: [www.chelwest.nhs.uk/services/hiv-sexual-health/clinics/56-dean-street/56-dean-street](http://www.chelwest.nhs.uk/services/hiv-sexual-health/clinics/56-dean-street/56-dean-street)
11. See: <http://londonfriend.org.uk/get-support/drugsand-alcohol/>
12. See: [www.code-clinic.co.uk](http://www.code-clinic.co.uk)
13. See: [www.code-clinic.co.uk/druginfo.htm](http://www.code-clinic.co.uk/druginfo.htm)

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# For whose benefit? HIV and the new welfare benefits: a professional view

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In the early days of HIV, physical, emotional and financial services were in abundance. The reality was that people living with HIV had a reduced lifespan so services rallied round with specialised housing, high-level benefits and services readily available and easy to access, usually enabled by a team of highly skilled nurses, doctors and social workers. Today most people living with HIV are leading longer, healthier lives, however, and some are experiencing housing and employment difficulties and financial pressures, with many of the specialised services long since closed down or moved into generic services. Over the last few years Government legislation and welfare benefit reform have resulted in an increase of people presenting in financial need nationally, which has been reflected in people accessing HIV clinics. In 2010 the National AIDS Trust (NAT) identified that people living with HIV (PLWHIV) were more likely to experience financial hardship compared to the general population [1] with as many as one-in-six PLWHIV having suffered severe poverty in the past 3 years, and around one in three claiming some sort of benefit [3]. Whether PLWHIV are being reassessed, or losing some of their benefits, or making a claim under the new benefit system, it can be an extremely stressful time with little or no support if they are not sure where to look for it. In 2008 poverty was highlighted as an issue [2]. The study, by Ibrahim *et al.*, found that PLWHIV in London ... faced social and economic hardship, particularly Black African and other ethnic minority groups. A national hardship fund for people with HIV, run by the Terrence Higgins Trust (THT), registered a 63% increase in 2013 for those needing emergency help because their benefits had been stopped [3]. This news has not come as a surprise to many people working within HIV as we regularly see people struggling to live in poor/inappropriate housing on limited financial resources.

Since 2010 I have been employed as the HIV Social Care Coordinator providing support to complement the medical team at the Jonathan Mann Clinic, Homerton Hospital, London. We work closely with third-sector providers, as well as statutory agencies, in an attempt to provide a holistic package of support for people who access the clinic for their HIV care. From a few studies, and anecdotally, we know that people with complex social care needs are less likely to be effectively managing their healthcare needs, including adherence to prescribed antiretrovirals

(ARVs) [4,5]. In the clinic we have frequent discussions with people about the importance of adherence, and their response is that they are struggling or unable to access food and appropriate housing. For people with immigration issues this is not uncommon, and has been a challenge for some time. But when considering Maslow's Hierarchy of Needs (Figure 1), we are predominantly working with the most basic of needs such as food and shelter, which should be a given in an economically developed country. However, we are seeing an increasing number of people who are struggling financially, who have the right to access welfare benefits, and yet present in clinic with adherence issues relating to financial difficulties. These are people who have had their payments stopped or suspended for various reasons, and as a result have no access to money. These can be people on Job Seeker's Allowance (JSA) who have been sanctioned because they have not been 'actively seeking work', or people on Employment and Support Allowance (ESA) who have failed their ATOS 'medical' (ATOS Healthcare were the organisation who carried out medical assessments on behalf of the Department for Work and Pensions), and are deemed able to work, despite a clinician having provided them with a sick note. This can result in some of the most vulnerable people in society being left destitute, without help.

Having worked in the social care system since leaving school I'm the first to admit that things need to change. There are a minority who do commit fraud, but it's wrong that the reforms are affecting those who actually need the help, but aren't able to effectively advocate for themselves. They end up falling through the system until, in the case of our cohort, someone asks the rights questions in a routine appointment and identifies that there is a problem. I always encourage people to appeal these decisions as some do seem particularly harsh, and in most cases when accessing specialist advice, these appeals are successful. This highlights the importance of having access to good quality welfare benefits advice in the first place, which is something that isn't always that easy to secure for people themselves. Various services have experienced financial cuts over the past few years just at a time when there is an increase in people who need advice, support and advocacy to maintain their basic needs.

Within the field of welfare benefits we are now seeing many changes during this government's

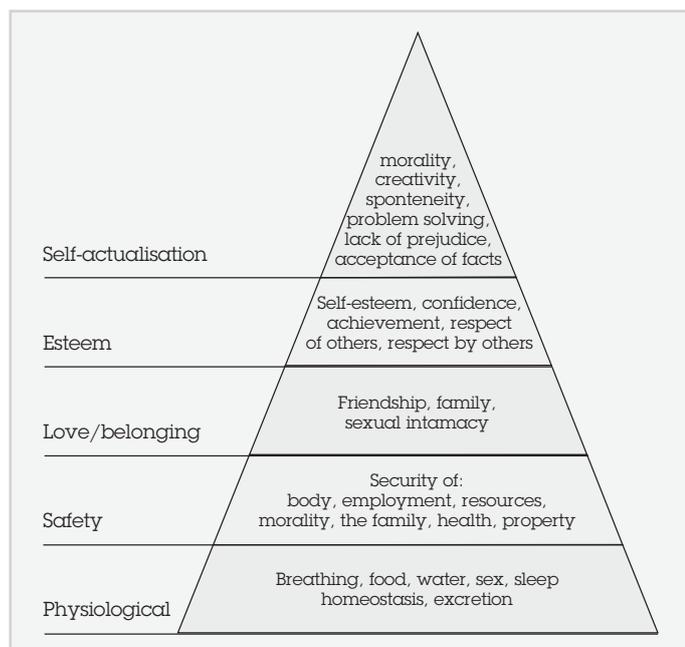


Figure 1: Maslow's Hierarchy of Needs.

term of office which are going to have a direct effect on people with whom we work. The under-occupancy rule or 'bedroom tax' (where council and housing association tenants will have their housing benefit entitlement reduced if the council decides their home is too big for their needs), and changing DLA (Disability Living Allowance) over to PIP (Personal Independence Payment), although only affecting new claimants at the moment, has caused people real anxiety and has seen an increase in requests for advice from our team. The impending threat of Universal Credit, being introduced across the country at various times, is also a huge worry for people who hear part-stories, media backlash and then read of delays in implementation with a lack of clarity as to when and how things will change.

To emphasise the reality of what is happening now I will present two case studies:

#### Case study 1: Mohammed

Mohammed is a 41-year-old Ethiopian who was given leave to remain in the UK in 2011. He has type 2 diabetes with associated diabetic retinopathy. At the point of his HIV diagnosis he had TB co-infection with a CD4 count of 155 cells/ $\mu$ L and viral load of 16,500 copies/mL. He has restricted mobility and ongoing visual impairments which affect his everyday life. He was initially placed on Employment and Support Allowance (ESA) pending assessment in 2011. As he has issues with his postal deliveries he has refused postal contact from the clinic. He presented in crisis in 2012 stating that his ESA payments had been suspended and he didn't know why. I contacted ESA on his behalf and his payments had stopped because he had not completed an ESA50 'Capability to Work' form. Mohammed had presented in clinic in severe

distress, believing that it was a conspiracy against him because he was not born in the UK. He stated that he had not received the form and was going to take the Government to court as he now had no money for food. We asked for a review of his situation and appealed the decision against him. I referred him to Positive East, a local HIV support and advocacy charity, who had a dedicated worker to support people through the appeals process. We also completed a referral to The Food Chain, who offered to deliver groceries on a weekly basis for a set period of time. He had previously been awarded Disability Living Allowance (DLA) as a result of his multiple health needs. He had anxiety about not being able to pay his housing service charge as he had heard stories where people had been taken to court for falling into arrears, so we rang the housing provider to explain the situation and ask for leniency in his case. Within the discussion he had stated that he couldn't take his medication as he had no food to be able to take his medication with. We secured him a small grant for food vouchers which he used to buy food to last him a few days until the grocery deliveries arrived from The Food Chain. His consultant and I wrote letters in support of his case and the implications of his complex needs on his ability to look for and maintain work. He agreed to keep taking his medication and continued to attend appointments to check on his progress.

Eventually his case was presented at a tribunal and Mohammed was awarded ESA Support Group, for those with significant support needs. The advice worker who supported him in the tribunal contacted me to let me know the good news, but stated that Mohammed broke down in tears as the Judge delivered his verdict. At his next appointment we discussed this and he explained that he had been so stressed and anxious that he felt that he had been living in a shadow for the past few months while he was waiting for a decision. He related it to the 8 years he had spent waiting for a decision from the Home Office, being in limbo, not being able to plan for the future. We discussed support available, but he refused a referral to our in-house psychologist and he assured me that things now were looking much better for him. However, Mohammed has since had his ESA payments suspended on two occasions, which have subsequently been overturned. On both occasions it related to him not attending an ATOS medical. I believe that he has not received the request to attend. He is a very organised man, who will present in clinic asking for support with letters he receives if he is not sure what he is expected to do. Unfortunately, as I write this I have received a call from Mohammed who has told me that his ESA has been stopped again, due to not attending an ATOS medical. Luckily, this time he actually thought it was funny, almost an expectation of the system in which he has to navigate. I have spoken to the DWP

on his behalf and we have started the appeal process again. I have also spoken to a very helpful advisor who, having seen the reams of case notes, devised an alternative strategy to try and stop this happening again. All of Mohammed's post from DWP will now be sent to his local Job Centre, which he has agreed to attend to check for post on a fortnightly basis. This should resolve further issues and reduce the instances of financial crisis for Mohammed.

### *Case study 2: Juliette*

Juliette was initially referred to me for support in 2012, as she was having problems with her Job Seeker's Allowance. Her advisor at the Job Centre had, at that time, stated that she wasn't looking hard enough for work, despite her engaging in voluntary work to improve her CV. Due to her having her medical appointment at Homerton, she missed her signing-on date, and reluctantly disclosed her HIV diagnosis to her advisor. She states that she instantly felt judged and found the experience particularly difficult. Her advisor told her that she should in fact be applying for Employment and Support Allowance (ESA) and to consider applying for Disability Living Allowance at the same time. This resulted in her discussing it with her consultant, who instantly referred her to me for advice and support.

In our initial meeting she was clearly angry, distressed and confused as to why she should be applying for ESA when she had just been advised that her CD4 count was 850 cells/ $\mu$ L and her viral load was undetectable (<40 copies/mL). After completing an assessment with her I agreed that I believed that she would struggle to meet the criteria for ESA and, as she didn't have any mobility problems or identified care needs, she would struggle to meet the criteria for DLA. Juliette was worried as she had been informed that her JSA payments had been sanctioned for a month as she had not been actively seeking work. This left her with only Child Tax Credits and Child Benefit for the rest of the month to survive on for herself and her two children. Having previously been diagnosed with depression and given anti-depressants, Juliette was worried that the stress of the situation could result in a deterioration of her emotional wellbeing; however, she was reluctant to consider resuming any medication for this. She did agree to a referral to our in-house psychologist. To alleviate her financial concerns a referral was made to The Food Chain, who agreed to provide grocery deliveries to the family for 6 weeks, pending reassessment. I also arranged an appointment with Positive East to offer advice and support regarding her situation. However, the following day, having spoken to Positive East, it was agreed that there were no merits in making an application for ESA and DLA, as Juliette had agreed, and we attempted to appeal her JSA sanction. In the interim Juliette also

applied for hardship support from the Job Centre, which was approved.

Juliette contacted me 2 weeks later to say that her JSA had been reinstated and she was clearly relieved. She had liaised with her housing provider to inform them that there may be a break in payments as she was anxious about the threat of eviction from her home, especially for her children, the eldest of whom was sitting her GCSEs. She also informed me that she wanted to change her advisor at the Job Centre as she was frustrated about how the situation had come about and didn't feel she had been treated appropriately. I wrote a letter in support of this in an attempt to advocate for Juliette in resolving any difficulties that may remain.

As time went on, I bumped into Juliette in clinic when she attended for her routine appointments. She stated that things were OK, she was engaging with her new advisor and she attended the appointments as she was required to. She had discussed the possibility of learning new skills to improve her chance of securing employment and so had enrolled on a computer access course offered to her. Things seemed good and Juliette reported that she was happy and content. As always, the offer for her to access for further support was given, in case further issues arose.

Three months ago, Juliette presented in clinic requesting an appointment. When I saw her she was tearful and distressed, stating that her JSA had been sanctioned once again. She had been due to attend an appointment with her advisor the previous day, but had received a call from the school to say her daughter had collapsed, so rushed straight to the school, therefore missing the appointment. She had presented the following day to explain her situation and was told to go and complete a form and bring it back, but there was a sanction in place. We completed a request for consideration, provided a supporting letter and also requested hardship payments. Juliette was clearly frustrated and felt that she was being victimised by the system. In our discussion she actually stated that she didn't want to appeal, as there was little point. She believed that they (the DWP) had made their decision and that she was being made to suffer. In the appointment Juliette explained that her engagement with our in-house psychologist had been sporadic and that she wanted to try and re-engage. Follow-up appointments were made with our in-house psychologist and me. Reluctantly, she agreed to appeal the decision and this was done during the appointment.

At her next appointment Juliette appeared frustrated and in low mood. When I asked how things had been going she shrugged and said that nothing had changed. On probing further, Juliette reported that she had been so frustrated with the situation with her JSA that she had stopped taking her Aripiprazole for the past week. She had rearranged

her psychology appointment as she felt she didn't want to talk at that time; she didn't believe it would have helped. A lengthy discussion took place between Juliette and myself about the welfare benefits system and the processes and timescales involved. We discussed the medication situation with our lead HIV nurse who spoke to Juliette about her adherence and the importance of working with us if she had been feeling she wanted to stop, and she was given the option to restart her medication, which she did with telephone support during the first month. Bloods were taken on the same day and a follow-up appointment was made for the following month. We also advised Juliette that if she wanted to she could meet with the HIV specialist pharmacist, who could also offer support with future adherence issues. Juliette attended her follow-up appointment and stated her situation had improved; that she had had her JSA reinstated and had engaged with her advisor. From a medication point of view, she reported excellent adherence and had started accessing our in-house psychologist for long-term support.

## Conclusion

Unfortunately, Mohammed and Juliette's cases are not unusual. I'm lucky that I work in a proactive team of professionals from the clinic and some inspirational external service providers who enable us to offer support to those in need. The frustration felt by many when things go wrong for people is a daily occurrence. I'm conscious that I also work in a system that has significant restrictions placed upon it, ever more so by changes in legislation impacting on our patients. The complexities of the welfare benefit system are well documented and lamented across the sector, and the ongoing changes have created much debate from all sectors of society. I see people on a daily basis who are struggling to cope financially, but also struggling to navigate through the complexities of a very convoluted system. This has prompted the team at the Homerton to secure funding to provide additional support for people in these areas, with direct support from organisations such as Positively UK. We now have three additional members of our team, employed and trained by Positively UK, to work directly with people to help them through the system, people who have themselves experienced the systems and support available. These 'peer navigators' are working with us throughout the week and are adding a further dimension to the multi-disciplinary team, and although it's early days we can see people increasing their engagement with services. People who are unable to advocate effectively for themselves are usually the ones who struggle the most and end up in severe financial need. Without the specialised

support services available, and effective joined-up working, this situation will only get worse and I believe we will see more people presenting in crisis. From this perspective, we need to be working proactively to ensure the vital specialised services and advice organisations are maintained, in order to be able to keep fighting for the rights of those who are unable to fight for themselves.

This article has highlighted the complexities of welfare benefits for patients, but healthcare professionals can also struggle with the complex benefit system and its many changes. It's hard enough keeping up to date with changes to ARVs and the evolving landscape of HIV funding, and it may be all too easy to think 'this isn't healthcare so someone else can sort it out', but we are now, more than ever, needed to add our expertise to someone's benefit claim, usually through writing letters of support.

In an addition to this article Shaun Watson (HIV Clinical Nurse Specialist), Sarah Radcliffe (NAT) and I have devised 'A guide to writing letters to support a benefit claim' to offer some guidance on what to write (or not to write) in a supporting letter. This article appears in this issue immediately below this article.

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## Further reading

THE Hardship Fund can be found at:  
[www.tht.org.uk](http://www.tht.org.uk)

The Food Chain website is: [www.foodchain.org.uk](http://www.foodchain.org.uk)

Benefits information may be found at:  
[www.gov.uk/browse/benefits](http://www.gov.uk/browse/benefits)

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# A guide to writing letters to support a benefit claim

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There are ongoing changes happening to the UK welfare benefits system and many of our patients will be affected. There are two main benefits that many of our patients access:

## *Employment and Support Allowance (ESA) is replacing Incapacity Benefit*

The ESA capability assessment looks at a person's ability to work including areas such as concentration, manual dexterity, mobility and their ability to perform actions relating to work. There are two strands to this benefit so patients will either be placed in the 'work-related activity' group (expected to soon move into work) or the 'support' group (unable to work at present). Many of our more complex patients will be in the support group.

## *Disability Living Allowance (DLA), gradually being replaced with Personal Independence Payments (PIP)*

These assessments look at a person's ability to perform the tasks of daily living such as bathing, feeding, dressing, mobilising and accessing their community. People who are in work can also apply for this benefit.

It is helpful to keep in mind that both assessments are of 'functionality' – that is to say, the Department for Work and Pensions (DWP) does not take any interest in someone's primary diagnosis, only how it may affect their ability to perform day-to-day activities.

The criteria for the new benefits, ESA and PIP, are much stricter and it is now increasingly difficult for people to access benefits unless they have significant health needs.

Everyone who has been getting Incapacity Benefit will eventually be re-assessed for ESA in order to keep getting support. Within the ESA assessment, called the Work Capability Assessment (WCA), people are expected to complete a questionnaire (ESA50) within a strict timeframe to continue to receive payments. Any delays in supplying the DWP or ATOS (the company who medically assess claims) with information can result in suspensions of payment.

DLA is being phased out from 2013 and is being replaced by PIP. New claimants are now applying for PIP, which has much stricter criteria to meet for

people to be eligible for support. People who are currently in receipt of DLA will be reassessed and this process is due to start in 2014 in some parts of the country, in cases where someone has a fixed-term DLA award that is coming to an end. From 2015, the remaining DLA claimants will start being re-assessed for PIP. The first step in making a PIP claim is to complete a new form when contacted.

Part of the assessment/re-assessment process is to provide robust evidence of ongoing health issues that prevent the applicant from seeking or continuing work. Patients need to provide as much evidence as possible to support their claim/application and will need to request supporting letters from everyone involved their current care.

### Some points to consider

- *Be specific*  
The most helpful evidence directly addresses the assessment criteria, which for both ESA and PIP look at claimants' ability to perform daily activities (please see the appendices for the relevant functional criteria).
- *'If they want information they can write to me'*  
A supporting letter in the first instance may be enough. If the application is refused because robust evidence was not provided and the case therefore goes to appeal, there is the likelihood that benefits will be suspended until the appeal is resolved, thus leaving the patient open to stress and poverty for weeks/months.
- *It's not all about HIV*  
For those who have multiple health issues, supporting letters should be sought from all involved in their ongoing care, for example oncology, rheumatology, endocrinology, cardiology etc. Think about who provides psychosocial/emotional support, such as mental health services, drug and alcohol agencies, social services, volunteer agencies etc. Are these agencies providing letters to support this application?
- Some GPs will charge for letters so patients should only be advised to access GP letters if they have significant interaction with them.

### What should be included in the letter?

- How long the patient has lived with HIV, the most recent CD4 cell count, viral load and antiretroviral medication (if taken). Keep in mind that decision-makers are not medical experts so it is helpful to explain what these clinical indicators mean (e.g., what a very low CD4 cell count means in terms of immune function and any risk to the patient of being required to seek work).
- Relevant ongoing issues (such as co-infection, side effects etc).
- Past issues should only be discussed if they are relevant to health now. 'When he was diagnosed he had PCP and oral candida which required hospitalisation' may have no bearing on the patient years later; however, a cancer, tuberculosis or hepatitis diagnosis may have some bearing on their physical/mental health.
- Abbreviations need to be fully explained and expanded if necessary (CD4, VL, PML, HCV etc).
- Limit the use of statements such as 'In my professional opinion this patient cannot work.' These kind of statements need to be backed up with facts. 'In my professional opinion he is unable work due to HIV-related lipodystrophy, which has stripped the fat from his buttocks and lower limbs making it very uncomfortable and painful for him to sit for more than 15 minutes at a time' is a more acceptable sentence.
- Stick to what you know. A patient may mention an issue that they would like to be included in the letter but which has never been mentioned/documentated before (such as that they are medicating with herbal or over-the-counter medications – e.g., for insomnia, constipation, diarrhoea). This could be covered in the letter with a phrase such as 'During our conversation he stated that ... he had tinnitus/lower back pain/haemorrhoids' etc.
- Be honest about the patient's abilities and general health. Patients may ask you to slightly exaggerate/embellish the truth, but you need to be professionally accountable and your patient should have a realistic expectation about their capabilities. Some patients will need to move to Job Seeker's Allowance (JSA) whilst others main remain in the 'Support' or Work-Related Activity Group (WRAG) arm of Employment Support Allowance.
- If the supporting letters don't mention it, don't do it. Unfortunately some patients have been known to suddenly stop medications (especially antiretrovirals) for no apparent reason, or they have overmedicated or undermedicated, faked injury or used mobility aids. If there is no mention of these symptoms, issues or aids in the letter the assessing agency may seek another opinion and thus delay/suspend payments.

### Bad (1) and good (2) examples of a supporting letter

(1): *To whom it may concern,*

Re: John Brown (13/12/1975)

Flat 1a, Kings Street, LONDON WC2 3NP

*I am writing to let you know that I believe that Mr John Brown should not be working or made to look for work. He has not worked for a significant period of time and would find it very difficult to secure employment at this stage. He is prescribed antiretroviral medication which can have side effects which can restrict people's ability to work. I think it is unreasonable to expect him to be looking for work at this time, especially in this economic climate.*

*Yours sincerely*

*Keith Smith,*

*Clinical Nurse Specialist*

(2): *To whom it may concern,*

Re: John Brown (13/12/1975)

Flat 1a, Kings Street, LONDON WC2 3NP

*I am writing this letter to support Mr John Brown's ESA assessment. I have supported John as his Clinical Nurse Specialist for the past 3 years. His current health issues are as follows:*

- *HIV – John was diagnosed with HIV 13 years ago. He is under the care of Dr Green at Queen Mary's Sexual health & HIV Centre. His initial CD4 cell (immunity) count was very low at 23, which indicated a severely depleted immune function. His most recent CD4 cell count is 455 and his viral load is undetectable (12/10/2013). He is taking antiretroviral medication.*
- *Peripheral neuropathy – John has severe pain in his lower limbs. He is seeing Dr King's pain specialist team (who I understand will provide a separate letter). This pain affects his ability to walk or stand for extended periods. He walks with a stick and is taking several analgesics for pain control.*
- *Depression – John is supported by the community mental health team (they have been asked to provide a letter of support). He has a past history of depression and is taking antidepressants.*

*Due to John's chronic pain and depression I feel that he is unable to seek work. I am aware that he seeks support from the local HIV agency where he takes part in the group work and has massage therapy for pain control.*

*If you need any further information please contact me.*

*Yours sincerely*

*Keith Smith,*

*(Clinical Nurse Specialist)*

## What else can be offered?

Patients can be referred to agencies that will support them with getting back to work, for example The Shaw Trust ([www.shaw-trust.org.uk](http://www.shaw-trust.org.uk)), Positive East ([www.positiveeast.org.uk](http://www.positiveeast.org.uk)), Positively UK ([www.positivelyuk.org](http://www.positivelyuk.org)), Terrence Higgins Trust ([www.tht.org](http://www.tht.org)) or other local HIV/employment agencies. This list is not exhaustive and each area should have a local HIV organisation/Citizens Advice Bureau that can offer advice and information about available schemes.

*These guidelines were devised and edited by:*

- (a) Shaun Watson:  
(Clinical Nurse Specialist for HIV)
- (b) Matt Wills:  
(HIV Social Care Coordinator, Homerton Hospital)
- (c) Sarah Radcliffe:  
(Policy & Campaigns Manager, National AIDS Trust).

### *Appendix 1: Functions considered by the Work Capability Assessment (WCA) for ESA:*

1. Mobilising unaided by another person with or without a walking stick, manual wheelchair or other aid if such aid is normally, or could reasonably be, worn or used
2. Standing and sitting
3. Reaching
4. Picking up and moving or transferring by the use of the upper body and arms
5. Manual dexterity
6. Making self understood through speaking, writing, typing, or other means which are normally or could reasonably be used, unaided by another person
7. Understanding communication by (i) verbal means (such as hearing or lip reading) alone, (ii) non-verbal means (such as reading 16-point print or Braille) alone, or (iii) a combination of (i) and (ii) using any aid that is normally or could reasonably be used, unaided by another person
8. Navigation and maintaining safety, using a guide dog or other aid if either or both are normally, or could reasonably be used
9. Absence or loss of control whilst conscious leading to extensive evacuation of the bowel and/or bladder, other than enuresis (bed-wetting) despite the wearing or use of any aids or adaptations which are normally, or could reasonably be, worn or used
10. Consciousness during waking moments

*A more detailed list is found here:*

[www.disabilityrightsuk.org/employment-and-support-allowance-overview#appendix1](http://www.disabilityrightsuk.org/employment-and-support-allowance-overview#appendix1)

### *Appendix 2: Functions considered by the PIP assessment*

*Daily living activities:*

1. Preparing food
2. Taking nutrition
3. Managing therapy or monitoring a health condition
4. Washing and bathing
5. Managing toilet needs or incontinence
6. Dressing and undressing
7. Communicating verbally
8. Reading and understanding signs, symbols and words
9. Engaging with other people face to face
10. Making budgeting decisions

*Mobility activities:*

1. Planning and following journeys
2. Moving around

*More details can be found here:*

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/259831/pip-toolkit-factsheet-assessment-criteria.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/259831/pip-toolkit-factsheet-assessment-criteria.pdf)

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# ABSTRACTS

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From  
**NHIVNA Annual Conference**  
held in  
Cardiff  
26–27 June 2014

## Abstract O1

**Integrating the planning of HIV nursing services within NHS and HIV service indicators**

E Nixon and T Buckingham

Brighton and Sussex University Hospitals, UK

**Background:** The provision of HIV outpatient services are currently directed by a national HIV Service Specification that incorporates specialist and generic health policy objectives. At present the contribution of HIV nurses is being explored at a national level. The aim of this project was to plan and develop local HIV nursing services and map these within national HIV service requirements and outcome indicators.

**Method:** In a series of designated team meetings in autumn 2013, the HIV outpatient nursing and healthcare assistant team identified service development areas based on the needs of the local HIV cohort and drawing on the HIV Service Specification and BHIVA Standards. A two-year service development plan was agreed and formulated within the NHS Outcomes Framework.

**Results:** The key development areas are presented under the 5 NHS domains:

1. *Preventing people from dying prematurely*
  - Review of HIV Annual Health Check and risk assessment tools
  - Use of validated tools to assess alcohol and drug use
  - Incorporate health promotion interventions into annual health check
2. *Enhancing quality of life for people with long-term conditions*
  - Facilitating peer support and expert patient programmes
  - Utilise nurse triage to increase access to GPs (CQUIN)
  - Embed psychological/mental health assessments in routine practice
3. *Helping people to recover from episodes of ill health*
  - Build on links with inpatient ward and post discharge clinic
  - Review nursing service for HIV outliers
  - Review Daycare services and identify training needs / space
4. *Ensuring people have a positive experience of care*
  - Ongoing education /skills training/competency assessments
  - Increase nurse-led clinics for stable patients
  - Patient satisfaction surveys for all aspects of service
5. *Treating and caring for people in a safe environment*
  - Pathways for managing chaotic patients
  - Named nurse allocation
  - Lost to follow-up policy, pathways and clinics

**Conclusion:** This project has demonstrated how the planning of local HIV nursing services can be integrated into national outcome frameworks and may be a useful tool in illustrating the role of HIV nurses in meeting NHS and HIV specialist policy goals.

## Abstract O3

**The challenge of scaling up testing for HIV: a qualitative meta-synthesis of nurses' and midwives' views and experiences of the provision and management of routine 'provider-initiated HIV testing and counselling' (PITC)**C Evans<sup>1</sup>, S Nalubega<sup>1</sup>, J McLuskey<sup>1</sup>, N Darlington<sup>1</sup> and M Croston<sup>2</sup><sup>1</sup>University of Nottingham, UK and <sup>2</sup>North Manchester Hospital, UK

**Background:** 'Provider Initiated HIV Testing and Counselling' (PITC) is a key strategy in the global HIV prevention effort. In areas where PITC is recommended, all patients who come into contact with specific (non HIV-related) health services should be routinely offered an HIV test. PITC has met with variable success, and, in some healthcare settings (particularly in the UK), testing guidelines are not being adequately followed. In order to scale up PITC, it is essential to understand better the factors that facilitate or hinder policy implementation. Nurses and Midwives are two of the main professional groups involved in carrying out PITC, however little is known of their experiences in implementing this policy.

**Aim:** This qualitative systematic review sought to synthesise existing research (from any country and any healthcare setting) in order to understand Nurses' and Midwives' views and experiences of the provision and management of PITC.

**Methods:** A 3 step comprehensive search strategy was utilised to search 9 databases, grey literature and dissertations. The review followed a pragmatic meta-aggregative approach developed by the Joanna Briggs Institute (the 'JBI' - a global evidence based healthcare network), and it utilised the JBI Qualitative Assessment and Review Instrument (QARI).

**Results:** 15 papers relating to 12 research studies met the inclusion criteria (6 from high income and 6 from low income countries). The papers covered a diverse range of healthcare settings including A&E, antenatal, TB clinics, STI clinics, inpatient, outpatient and primary care.

The review identified 212 findings which were aggregated into 12 categories based on similarity of meaning. The categories were then further analysed to produce 5 inter-related synthesised findings, summarised below: -

- Acceptability
- Resources
- Organisational support
- Contradictions of PITC
- Emotional and moral burden

PITC is supported when it is understood as enhancing patient care and where it aligns with perceived professional roles. Where this is not the case (e.g. in A&E settings), staff can be resistant. PITC can be experienced as anxiety provoking and stressful, especially when giving results, when trying to apply a patient centred philosophy of care to a routinised process, and when encountering morally/ethically complex situations. A key finding is that PITC implementation is often hindered by significant challenges in fitting it into existing work patterns and workloads, with limited resources.

**Conclusions:** Successful implementation of PITC requires adequate resources and sustained organisational support, training and clinical supervision. In addition, more attention is required to address operational challenges.

## Abstract O2

**Qualitative exploration of Adult Nurses' perceptions of caring for a patient with an infectious disease, with a primary focus on HIV**

S Kavallares and J McLuskey

University of Nottingham, UK

**Background:** Studies have shown that stigma and discrimination amongst people living with HIV is still prevalent in healthcare. This study will therefore explore nurses' perceptions of caring for a patient with an infectious disease in a non-specialist setting, with a primary focus on HIV. This will evaluate if anxieties and discrimination is still prevalent in healthcare and if so, the reasons behind them as they can have detrimental effects to patient care. There is a growing HIV-population in the UK, with almost a quarter of people unaware of their status. HIV-associated stigma and discrimination increases the risk of depression and low self-esteem, which can become a major barrier to people accessing services for prevention, care and treatment. This has serious implications to health and wellbeing of those involved which is the foundation of nursing care.

**Methodology:** This study was conducted for an Undergraduate Nursing Master's Degree. The research was facilitated through a qualitative approach via in-depth semi-structured interviews with 12 registered adult nurses in two large teaching hospitals. All interviews were audio-taped, transcribed and analysed using thematic analysis. Three themes were produced: knowledge and education; feelings and anxiety; and stigma and preconceptions.

**Results and Conclusions:** The main findings revealed poor knowledge levels amongst the nurses, and all nurses were interested in an education programme if it were to be implemented in the future. This poor knowledge led to feelings of anxiety around certain aspects of care for patients' with HIV, such as handling blood and fluid products. Although all nurses believed they did not discriminate, this poor knowledge and anxiety lead to behaviours that could potentially be misinterpreted as discrimination. Although this was a small study, a lot was learnt about the nurse's perceptions, and the results have significant implications to future practise. The main reason for nurses not participating in prior education was the dislike of the new eLearning system and time constraints, which suggests that it may be beneficial to review existing available programmes.

## Abstract O4

**The importance of the relationship with healthcare teams in the first year of diagnosis for men who have sex with men – an interpretative phenomenological analysis**

J McLuskey, C Evans and P Callaghan

The University of Nottingham, UK

**Background:** Qualitative studies exploring the experiences of men who have sex with men (MSM) in their first year following an HIV diagnosis are few. Previous studies have been undertaken in retrospect or using quantitative methodologies and may have been subject to recall bias. This study aimed to explore the experience of MSM in the first year following 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.

**Methods:** An interpretative phenomenological analysis (IPA) approach was utilised for the study. MSM were invited to participate in the research during their first year of diagnosis. Nine men were recruited from across the United Kingdom through advertisements on social media pages of Charitable or Voluntary Organisations. Semi-structured interviews, lasting between one and two hours, were undertaken within the first three months following diagnosis and again at twelve months. These relied on the process of people making sense of their world and their experiences.

**Results:** Men's experiences over the first year were shaped by a number of factors. Men reported that the way in which the diagnosis was delivered impacted on their subsequent involvement with health services. For some this resulted in finding new services to provide care and for others it reinforced their positive regard for their healthcare team. Some men expressed a need to lead their decision making, whilst others wanted to be directed. The healthcare team were seen as important in enabling participants to develop strategies for managing their status so that they felt in control of the infection and not the other way around. Finally, the men reported that healthcare teams enabled them to consider their future in terms of being hopeful and effective managers of their infection rather than feeling that they need to abide by a label of being HIV positive.

**Conclusion:** The relationship with the healthcare team is an important factor in how men engage with health services in their first year of diagnosis. This is influenced by the actions of the healthcare team in the early weeks of diagnosis and the locus of control exhibited by the men themselves.

## Abstract O5

**Putting patients at the heart of the research process; The Lay Expert Advisory Panel (LEAP)**

C Hughes<sup>1</sup>, A Bain<sup>1</sup>, M Harrison<sup>1</sup>, G Bell<sup>1</sup>, H Donson<sup>1</sup>, J Boote<sup>2</sup> and C Bowman<sup>1</sup>  
<sup>1</sup>Sheffield Teaching Hospitals NHS Foundation Trust, UK and <sup>2</sup>Sheffield Health and Related Research, UK

**Aim:** To design, develop and sustain a patient and public involvement panel for HIV research.

**Background:** To increase the impact and quality of any research, it is becoming important to demonstrate active and significant patient and public involvement (PPI). With this in mind a Lay Expert Advisory Panel (LEAP) for HIV research was launched in March 2012. The aim of LEAP is to put the patient's perspective at the heart of the research process.

**Method:** A steering group was established to provide advice and guidance on the development of promotional materials which were sent to care providers and voluntary agencies to advertise the panel. Two launch events were held to discuss the aims and objectives of LEAP followed by informal networking and open discussion. The volunteers were given a written overview of what the membership might entail. Alongside the launch events, recruitment was also by face to face discussions with patients during clinic appointments. Interested volunteers were invited back for an informal interview. Members meet monthly to review research proposals, contributing to the development of methodology and materials. Training has been provided as required.

**Results:** Since its inception fifteen members have attended at least one meeting, with a core group of six enthusiastic and motivated members who attend regularly. LEAP is an established part of our research process which has made significant contributions to eight local or national studies, including: a study of adherence support requirements; racial differences in bone health; assessment tools for cognitive impairment; next-generation self-help resources; and an examination of the role of the advanced nurse practitioner in HIV services. LEAP has also provided a focus group discussion for a Public Health England study – Positive Voices.

LEAP members have presented their work at local and regional research forums highlighting their contribution to local research. This model has been cited as an example of good practice in regional PPI guidelines and has served as a template for other health conditions.

**Conclusion:** LEAP enables service users to contribute their perspectives to the way clinical research is commissioned, developed, managed and supported. They ensure the HIV research that is undertaken is relevant in reaching the goals of improving patient care, experiences and health outcomes.

## Abstract O6

**Telling their story: experiences of young women with perinatally acquired HIV regarding access to sexual and reproductive health services in Malawi**

G Mwalabu<sup>1</sup>, C Evans<sup>1</sup> and S Redsell<sup>2</sup>

<sup>1</sup>The University of Nottingham, UK, <sup>2</sup>Anglia Ruskin University, Cambridge, UK

**Background:** Globally, the number of adolescents living with perinatally acquired HIV continues to rise including in Malawi. To date, this group has received relatively less attention in the field of HIV care; however advances in treatment mean that perinatally infected adolescents are increasingly surviving into adulthood. There is a growing need for the development of appropriate care and support services for this group; however their sexual and reproductive health (SRH) needs remain poorly addressed.

**Research objectives:** This study aimed to explore perinatally infected young women's experiences of growing up with HIV in order to understand their SRH outcomes within their wider social, cultural and structural context.

**Methods:** A qualitative case study design was adopted whereby each 'case' comprised a female adolescent (15-19 years), a nominated caregiver and a service provider. Data was collected for 14 cases through in-depth interviews. The interviews with adolescents were based on an innovative visual method known as 'my story book' to encourage open discussion on sensitive topics. The study was approved by the University of Nottingham Research Ethics Committee.

**Results:** The study found that emotional, material and social support were essential in helping young women to build a sense of identity, but women's access to such resources were highly variable. Young women's strategies to seek love, acceptance or material advancement often led them to take sexual risks and left them with little control over their reproductive health. The study found that both service providers and care givers often 'turned a blind eye' to young women's sexual activities, leading to poor SRH outcomes. Lack of open discussion on SRH issues was related to cultural and religious norms and challenges in developing integrated models of service provision. Collectively, this created significant barriers for young women in accessing information, advice and contraception.

**Conclusion:** Addressing the complex needs of the young women poses a key challenge for Malawi's HIV services. One way forward is to explore ways in which services could develop integrated models of care, offering a 'one-stop shop' to this vulnerable group. Such a service should focus on providing continuity of care, practical support, expanded contraceptive services and support for young women who have become pregnant or have children. Staff training is essential to improve communication skills and to create a non-judgmental ethos of care.

## Abstract O7

**The PARTNER study: low risk of HIV transmission in sero-different partnerships in the context of ART but further follow-up required for MSM**

J Sewell and A Rodger

University College London, UK

**Background:** It is important to be able to quantify the risk of HIV transmission to better understand the potential benefits of ART in Treatment as Prevention. Current data is limited and largely focuses on vaginal sex.

**Methods:** The PARTNER study is an international, observational study focusing on the risk of sexual HIV transmission when an HIV positive person is on treatment. The study prospectively follows serodifferent couples (heterosexual (HT) and MSM) who had condomless penetrative anal or vaginal sex in the month prior to study entry, and where the HIV+ve partner is on ART. 6 monthly sexual behaviour questionnaires are completed by each partner and the negative partner tests for HIV. Only follow-up time that reported continued condomless sex; not using PEP or PrEP; and latest VL <200 c/mL, were included in this planned, interim, transmission rate analysis. For new diagnoses, samples were anonymised and phylogenetic analysis completed.

**Results:** By 1st November 2013, 1110 couples were enrolled. Of 1151 couple-years of follow-up, 894 were eligible (586 in HT and 308 in MSM). Follow-up results included almost 44,500 reports of condomless sex, 21,000 from anal sex. Couples had condomless sex a median of 45 times/year. At baseline, median duration on ART was 4.9 years and couples reported having condomless sex for a median 2 years. Condomless sex with a different partner outside the partnership during follow-up was reported by 27% of HIV negative MSM and 2% HT partners. Analysis of the eligible couple years showed that so far no phylogenetically linked transmissions have occurred within a couple in which the positive person was on ART, giving an overall transmission rate of zero. However, over a 10-year period, the upper 95% confidence limit for the overall transmission rate of a couple having condomless sex with undetectable viral load is 3.9%, and for anal sex is 9.2%.

**Conclusion:** The overall risk of HIV transmission (in the context of previous sex without transmission) through condomless anal or vaginal sex from HIV positive people on ART with plasma VL <200 copies/mL is extremely low. However, since the number of couples reporting anal sex was relatively low, the potential maximum risk estimate is higher. Additional follow-up in MSM is essential to provide more precise estimates for transmission risk and to inform potential scale up of ART for prevention. PARTNER study phase II (2014–2017) aims to recruit and follow-up a further 450 MSM couples.

## Abstract O8

**The views and experiences of HIV research participants in sub-Saharan Africa: a qualitative systematic review**

S Nalubega and C Evans

University of Nottingham, UK

**Background:** HIV clinical trials are increasingly being conducted in sub-Saharan Africa. There is a tension between the pressure to increase levels of research participation whilst at the same time ensuring informed consent and the protection of participants' rights. This review aimed to identify key issues that may affect HIV research, from the perspective of research participants, in order to scale up high quality ethical HIV research practice.

**Methods:** A systematic review of qualitative studies was conducted using a pragmatic aggregative methodology approach, developed by the Joanna Briggs Institute (JBI). The review included studies whose participants were current or former adult HIV research participants from sub-Saharan African countries. Nine databases were searched in June 2013, followed by hand searching of reference lists. Studies published between 1995 to present were considered. Eleven qualitative studies were included in the review. Methodological quality was assessed using the JBI's Qualitative Assessment and Review Instrument (QARI).

**Results:** The 11 studies reported findings from 461 participants. Findings from each study were extracted and clustered into 8 categories based on similarities in meaning. These were further synthesized into 4 directive findings, which were:

- (i) Benefits: Individuals are motivated to participate in HIV research due to a range of perceived individual benefits (e.g. free/adequate medical care), and also for altruistic reasons.
- (ii) Fears: Participation in HIV research can be associated with considerable fear and uncertainty, mainly due to HIV stigma and worries about potential harm from research interventions.
- (iii) Lack of clarity: Misconceptions about research and mixed/poor understandings of the research process and some key concepts are still common among HIV research participants.
- (iv) Social constructs: Participation in HIV research is strongly influenced by social relationships (e.g. support or disapproval of family or friends), social-economic and domestic factors (such as time or finances), and the nature of interactions with research staff.

**Conclusions:** The results show a willingness to participate in HIV research. Continued efforts are required to engage with communities to support research participation and to develop innovative ways to ensure and maintain informed consent. The majority of studies focused on experiences around research enrolment and retention. Research on participants' experiences of research (trial) closure is lacking, indicating an area where future investigation is required.

Abstract 09

**Homeless Hostel Outreach Clinic**

R Hawley

56 Dean Street, Soho, London, UK

**Introduction:** The aim of the clinic was to deliver specialist care to homeless clients that are known to be infected with or are high risk of HIV and viral Hepatitis. Historically these are very hard to reach patients who have multiple risk factors and high rates of non-attendance at traditional outpatient clinic models. Not having a fixed abode can lead to barriers to engagement with hospital based care. We aimed to design a holistic non-judgemental service that is easy for them to access  
**Methods:** An outreach service to a local homeless hostel was introduced in April 2013. The clinic is Doctor and nurse delivered.

We offer multiple services including HIV and Hepatitis C point of care tests (POCT), sexual health screens, vaccinations, cervical cytology, and contraception advice. We provide risk reduction advice for alcohol and drug use. And offer referrals to psychology. We also manage HIV and Hepatitis B and C positive clients and deliver antiviral treatment and monitoring on an ongoing basis

**Results:** In the first year of the service 53 new patients were seen many of whom returned for follow up. 77% of the attendances were male patients. 4 individuals are known HIV positive and 2 are undetectable on antiretroviral therapy. Of the 40 HIV POCT that we done there were no new positives.

28% of the patients were known to be Hepatitis C (HCV) positive. None of them were currently engaged in care. 28 HCV POCT were done. 8 of these were positive. All of these patients returned to the clinic for follow up care. One individual was commenced on HCV treatment.

A total of 9 clients declined HCV POCT but 6 did consent to serology which was negative.

One individual with chronic Hepatitis B (HBV) and HIV co infection has engaged in care. 8 clients started HBV vaccinations. 24 clients had already been vaccinated. 11 patients declined to start the vaccination course.

**Discussions:** The results show that the outreach clinic has been a success. We have identified that 43% of our client group are Hepatitis C positive and without this clinic may not be engaging with any health care.

At this hostel outreach clinic, working alongside a homeless specialist nurse, multiple patient needs are addressed in one clinic.

Abstract 011

**Too shy shy? Use of a patient-completed annual review questionnaire to obtain a recreational drug-taking history in an HIV outpatient clinic**

A Johnson and B Patterson

Chelsea and Westminster NHS Foundation Trust Hospital, London, UK

**Background:** The use of recreational drugs is higher in the HIV-infected population, particularly in HIV-infected men who have sex with men (MSM). Over the past 10 years, the scene has changed to incorporate "club drugs", illicit substances consumed in social situations to increase social disinhibition and heighten sensual and sexual experiences. Nurse-led annual screening was introduced in our clinic in 2012. This involves the patient completing a questionnaire on an electronic tablet and then being seen by one of the nursing team to follow up on issues raised within the questionnaire.

The questionnaire included a question about whether the patient uses recreational drugs and if so, which ones. Awkwardness and embarrassment of patient and clinician can be major barriers to effective communication when discussing recreational drug use and obtaining an adequate drug-taking history in a consultation.

**Methods:** All patients seen for annual review between July 2012 and December 2013 were included. Patients who answered Yes to the question regarding recreational drug use within the past 1 year were included and their electronic records from the previous year searched for a documented drug taking history and action taken.

**Results:** 158 patients were seen for annual review. 43 (27%) had used recreational drugs within the past year. All were men; 40/43 (93%) were MSM, 2/43 (5%) were heterosexual and 1/43 (2%) was bisexual. Median age was 42. All had been seen in the clinic at least once in the previous year.

Drugs used	N (%)	Used in addition to other recreational drugs (%)
Cannabis	22/43 (51%)	13/43 (30%)
Cocaine	18/43 (42%)	11/43 (26%)
Crystal meth	7/43 (16%)	7/43 (16%) all in addition to at least 2 other drugs
Gamma-butyrolactone (GBL)	8/43 (19%)	8/43 (19%) all in addition to at least 2 other drugs
Mephedrone	8/43 (19%)	5/43 (12%)
Ketamine	7/43 (16%)	7/43 (16%)

6/43 (14%) had a documented drug-taking history in their electronic medical notes within the previous year. 1/43 (2%) who revealed he used cocaine and ketamine for several years had no history of drug use documented in his notes. 6/43 (14%) were referred to a specialist club drug clinic following their annual review and 3/43 (7%) were referred to psychological medicine.

**Conclusion:** Recreational drug use is common in HIV-infected MSMs and requires an appropriately documented history to facilitate onward referral, support and risk reduction advice as necessary. The use of a patient-completed annual review questionnaire is beneficial to patients and clinicians to ensure this data is adequately captured, prompting further discussion and appropriate action.

Abstract 010

**Saving 1000s Lives – Identifying depression in adults living with HIV to improve patient outcomes**

S Warren, S Attridge and R Lendon

Cardiff & The Vale University Health Board, UK

**Background:** The link between HIV and Mental Health is well documented together with the psychological needs of HIV patients. The NHS Wales Saving 1000 Lives Campaign was set up to improve healthcare provision across Wales. One aspect of the campaign is to identify depression in patients attending hospital settings. To assist in this we piloted a standardised questionnaire for HIV patients. These results will also contribute to a larger review investigating links between depression and chronic diseases.

**Method:** The Saving 1000 Lives "How are you feeling?" questionnaire was given to all patients attending two HIV clinics from May-July 2013. Two screening questions assessed eligibility for 1) Chronic condition and 2) Depression. Participants then completed a Patient Health Questionnaire (PHQ-9), Hospital Anxiety and Depression Scale (HADS) and Distress Thermometer. Clinicians then interpreted the score to assess for either onward referral to psychiatric or counselling services.

**Results:** 158 patients completed the screening questions; 94 passed the screening questions and were eligible for the audit, the mode age category was 40-49 years old. Of the eligible 94 patients, 47% of patients (44) had a PHQ-9 score of greater than 10 (moderate to severe depression). 56% (49) patients scored 16 or more as assessed by the HADS screening tool signifying severe depression. Of those with severe depression 53% (26) patients were homosexual, 31% (15) were heterosexual and 14% (7) were bisexual. 13% patients scored 8-10 on the distress thermometer, signalling high levels of distress. This questionnaire identified 38 new cases of depression. 58% of patients felt the questionnaire was either quite helpful or extremely helpful.

Demographic	N	%
Male	82	87%
Female	12	13%
Heterosexual	29	31%
Homosexual	55	59%
Bisexual	9	10%

**Conclusion:** This audit shows that more than one third of all our HIV patients have severe anxiety or depression; which may only be apparent using a specific screening tool. Of those identified through screening, more than half have severe anxiety/depression. These patients may require more intense MDT input to ensure continuity of care and HIV viral suppression. The results also highlight the need for appropriate psychiatric services to be available to HIV patients. The use of the 1000's lives questionnaire was well accepted by patients. All new patients are now screened for depression to provide baseline scores for future comparison.

Abstract 012

**Breaking bad news: the HIV experience**

M Croston<sup>1</sup> and M Roche<sup>2</sup>

<sup>1</sup>North Manchester General Hospital, UK and <sup>2</sup>Brighton and Sussex University Hospitals NHS Trust, UK

The term "breaking bad news" is mostly associated with the moment when negative medical information has been shared with a patient or relative. However it can also be seen as a process of interactions that take place before, during and after bad news has been broken. Little research has been conducted within HIV care to explore the process of breaking bad news (BBN) within this disease area.

An online survey was sent to NHIVNA, BHIVA and BASHH members. Ethical approval was not required. Participants were asked to answer 15 questions designed to explore their knowledge, skills and perceptions in relation to breaking bad news.

1. to evaluate self perceived knowledge, perceptions and skills of healthcare professionals (HCP) who work in the field of HIV in relation to BBN
2. to inform the development of educational material and resources to support HCP.

Response rate n=178, Doctors n=103, Nurses n=58, Sexual health advisors n=8, other n=9. The majority of the respondents had over 10 years experience.

The following were considered important when delivering bad news:

1. Having time to spend with a patient (99.44% n=177);
  2. Using simple language (92.13% n=164);
  3. The environment where BBN is delivered (87.08% n=155);
  4. Having a clear plan of action (84.27% n=150);
  5. Avoiding medical terminology (76.40% n=136).
- 97.19% (n=173) of respondents felt listening to their patients concerns helped the patient cope. Being empathetic was also viewed as being essential 91.57% (n=163).

Despite participants receiving training in relation to BBN (62.15% n=110). 79.07% could not name the training model used. 66.72% (n=115) were not aware of any specific training in relation to BBN and where participants did identify training it appeared to be for medics and held within palliative care settings.

The real surprise in the data came in the any other comments section, which indicated the general feeling of respondents in relation to this topic. These comments were analysed and grouped into themes: HCP's Personal characteristic – giving hope, Impact of bad news – on going support, Being patient centred – Empathetic professional, Role modelling – experiences of BBN.

The qualitative statements have highlighted there are certain elements within HIV care that make this area of care unique, this is not reflected in the current body of evidence. Further research is suggested to explore this, as is the development of study days and e learning resources which explores BBN in HIV care.

## Abstract P1

**An examination of HIV services delivery in England and the contribution of nurses in advanced practice roles**H Piercy<sup>1</sup>, S Naylor<sup>2</sup>, G Bell<sup>2</sup>, C Hughes<sup>2</sup> and C Bowman<sup>2</sup><sup>1</sup>Sheffield Hallam University, UK and <sup>2</sup>Sheffield Teaching Hospitals NHS Foundation Trust, UK

**Aim:** This project aims to undertake a detailed examination of HIV services across the country to understand how advanced nursing practice currently contributes to HIV care and the potential for maximising their contribution. Ethical approval has been granted by Sheffield Hallam University.

**Background:** The health outcomes of those living with HIV in the UK have improved dramatically in recent years, largely due to major advances in anti-retroviral therapy. HIV is now considered a complex chronic medical condition and care is directed towards managing treatment and associated co-morbidities.

The HIV specialist nurse role has developed substantially the past three decades. However there is substantial variability across the country in terms of the nature and the extent of the advanced nursing role. A recent review of the literature indicated that there is limited understanding of the effectiveness of the role and the extent to which it contributes to care outcomes.

Changes to the funding of HIV care which took effect in 2013 will serve as a powerful catalyst to widespread implementation of changes in the organisation and delivery of care. Within this context there is significant interest and widespread support for developing and expanding the contribution that specialist nurses can offer to HIV care.

**Method:** This mixed method study will comprise three stages:

1. A stakeholder analysis exercise to capture national and local level insights into strategic and operational aspects of provision from a variety of perspectives.
2. A mapping exercise of HIV service provision across the country to detail variability and understand the contribution of the role.
3. Mixed method case studies undertaken in a sample of HIV services to build detailed insights into the contribution of nurses working in advanced practice.

**Findings:** Key issues identified by stakeholders in stage 1 will be presented, these will include insight into current provision across the country and the major challenges facing service delivery. Potential opportunities for maximising the advanced nursing contribution will be outlined, and appropriate evaluation measures considered.

## Abstract P3

**Review of post exposure prophylaxis services within an accident and emergency department**

J Harrison and H Reynolds

Royal Liverpool and Broadgreen University Hospitals NHS Trust, UK

**Background:** Within the UK, men who have sex with men (MSM) remain the highest group infected with HIV with new diagnoses on the increase. A vital element in promoting sexual health among this group is generating awareness of post exposure prophylaxis following sexual exposure (PEPSE). National and regional guidelines offer recommendations on the potential use of PEPSE in places of first contact and the importance of patient follow up in a specialist HIV centre. It is crucial that places other than specialist HIV centres implement these guidelines safely and effectively.

**Methods:** This project was undertaken to identify patients attending the Accident and Emergency (A+E) department for PEPSE out of hours over a 7 month period. The project assessed adherence to guidelines and the number of patients followed up in the Genitourinary Medicine department (GUM). Other areas for review included; awareness of PEPSE guidelines, current referral paperwork and patient information leaflets (PIL) which are used for those assessed for PEPSE upon arrival to the department. Meetings were held with key stakeholders involved in PEPSE in order to identify the current situation. Information was gathered on the number of referral forms completed, number of patients who attended GUM for follow up and patients who did not attend for follow up. The current paperwork was reviewed and areas for improvement were identified.

**Results:** The results of this project highlighted a significant need to improve the PEPSE service offered to patients in A+E. In a 7 month period 32% of patients did not attend follow up in GUM potentially increasing the risk of onward transmission. This review has proposed essential changes to improve the patient experience and safety, which included new PILs, an electronic referrals process, and making local guidelines widely available through a smartphone app.

**Conclusion:** Increasing awareness and ease of access of PEPSE guidelines assists medical staff in assessing and treating patients safely. The follow up of patients in a specialist HIV centre has been given greater emphasis with a GUM clinic pathway now being used for PEPSE patients. Assessing patient risk identifies the need for continuation or withdrawal of PEPSE treatment. Patients attending GUM for follow up also provides an opportunity for specialist staff to promote safer sex within high risk groups.

## Abstract P2

**Post exposure prophylaxis for HIV following sexual exposure (PEPSE) access audit**

S Warren, S Attridge and N Lomax

Cardiff &amp; The Vale University Health Board, UK

**Background:** The provision of PEPSE is now a frequent reason for attendance at GUM/HIV clinics. Many patients initially present to A&E for the commencement of PEPSE and face a number of barriers to obtaining PEPSE such as waiting times and having a sexual history taken. An audit to assess the patient experience of accessing PEPSE was conducted.

**Method:** All patients already taking PEPSE or requesting PEPSE between the 7th May 2013 and 16th December 2013 were invited to complete a questionnaire to evaluate their experience. An anonymous questionnaire was offered to patients at the end of their clinic appointment.

**Results:** There was a 100% acceptance rate for the questionnaire. 28 patients completed the questionnaire, 25 (89%) were able to access PEPSE at first attempt, 16 from our GUM clinic, 9 from A&E, 2 from SARC and 1 from another GUM clinic. 11 accessed PEPSE as they were advised to by a health professional, 3 were advised by a sexual partner, 7 based on advice from the internet and 7 based on word of mouth advice or had previously accessed PEPSE. 7 patients accessed PEPSE in the morning, 13 patients in the afternoon and 8 accessed PEPSE in the evening/night. The time delay in receiving PEPSE ranged from 10 minutes to 4 hours in GUM, (average wait 1 hour 50 minutes) 30 minutes to 5 hours in A+E (average wait 3.5 hours) and 6 hours in SARC (average 6 hours). 27/28 patients were given information on side effects, 2 patients were not informed about the full 28 day course by A+E. All patients who accessed PEPSE from GUM reported staff were caring and supportive.

**Conclusion:** Patients who initially accessed PEPSE from A&E experienced more of a delay than those attending GUM. PEPSE provision training for Emergency Nurse Practitioners who are permanent staff in A&E would assist in reducing the delay in A&E. All patients stated they would recommend PEPSE to a friend, suggesting that PEPSE was fairly well tolerated in this cohort. There is still a need to increase general awareness of availability of PEPSE to help reduce potential HIV transmission. This audit highlighted that most patients were able to access PEPSE without significant delays and emphasised the important role that A&E plays in PEPSE provision out of hours.

## Abstract P4

**Has the nature of HIV out-of-hours calls changed over time?**

M Roche, S Griffin, R Murdock, T Buckingham and E Nixon

Brighton &amp; Sussex University Hospitals NHS Trust, UK

**Background:** The HIV Service Specification & BHIVA Standard 3 outline the need for 24 hour out of hours advice for people living with HIV. In our local network, this service is provided by the nursing staff from the HIV inpatient unit utilising locally agreed guidelines

The aim of this paper was to audit out of hours activity against the guidelines and compare this with data from 2008.

**Methods:** 48 Out of hours calls were audited from January 2013 to January 2014 and these entered and analysed using excel. This was then compared with audit data from 43 out of hours calls made in 2007.

**Results:** The demographics of patients ringing for out of hours advice were very similar with 82% male and 18% female in 2008; 88% male and 12% female in 2014. The nature of the calls however has varied. In 2008 26% (n=11) were related to ARV's whereas this had risen to 40% (n=20) in 2014. In 2008 7% (n=3) of calls related to other drugs, this was 19% (n=8) in 2014. In 2008 none of the calls in the 'Other Drugs' category related to recreational drugs, in 2014 this was 50% (n=4). There was a slight increase in the number of calls that were symptom related; 26% in 2008 versus 31% in 2014. There was however a significant reduction in calls related to PEP; 33% (n=14) in 2008 versus 10% (n=5) in 2014.

In 2008 35% (n=15) of calls were referred to a physician; in 2014 this had increased slightly to 39% (n=19). In 2008 65% of calls (n=28) was purely nurse led and this had reduced to 50% (n=24) in 2014. In the remainder of cases 11% (n=5) referral or non referral to physician was not documented.

**Conclusion:** There was a significant difference in the number of calls over the audit periods that may indicate either a change in need or a lack of awareness about the out of hours service and further understanding is required on this. The changes in PEP enquiries and calls about recreational drug use indicate the need to regularly monitor the nature of calls and to provide education programmes for nurses that reflect local needs.

## Abstract P5

**Online support scores highly for patient satisfaction and demonstrates improvements in HIV knowledge and engagement with healthcare**

G Brough, D Branch and S Papaniri  
Terrence Higgins Trust, London, UK

**Background:** With over 8,000 registrations during the 3 years since its launch, the UK-wide interactive myHIV online service has become the largest network of PLHIV in the UK. Its innovative use of free interactive tools and online support via paid staff, volunteers and peers has made it a destination for information and support for newly and long-term diagnosed alike.

**Methods:** Snap-shot surveys are emailed to all members who have registered within quarterly periods over the course of the project. Initial data from the first two quarters (April – September 2013) was analysed for satisfaction levels and areas of improvement reported.

**Results:** 2,500 emails sent yielded 250 responses (10% response rate). Outcome percentages are reported only from those where an improvement could be made in each area. The highest ranking areas for improvements experienced were 'Improved knowledge of HIV' (77%), 'Improved knowledge of CD4/VL' (69.5%), 'Improved lifestyle' (69%), but there were also significant improvements in confidence around 'asking questions at Clinic' (63.5%) and 'discussing HIV status with others' (41.4%).

Although they were fewer in numbers, there were also members who reported having started to attend clinic appointments, registering with a GP or informing their GP of their HIV status, where they had not been previously doing so.

Members were asked if they used the site tools (36.7% did) and what was most useful to them personally. The top responses were information pages, CD4/VL tracking graph, appointment reminders, medication reminders and online discussion boards.

Overall satisfaction rating for the site was 90%, with 57.5% having used the site in the last 3 months. The online discussion boards also scored highly, with satisfaction at 82.5%, and 49% using the message boards in the last 3 months.

**Conclusion:** Accessing online community support via computer and/or smartphone can complement clinical support and significantly enhance patients' engagement with their own health and the services they receive. Despite initial pre-launch anxieties around the acceptability of storing personal health information about HIV online, patients are comfortable storing personal data and HIV-related health information online in an environment they perceive to be secure. This should be considered when planning future services, including patient-held records and information.

## Abstract P7

**HIV information booklet inspired by a work placement in Hyderabad, India**

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<sup>1</sup>Royal Liverpool and Broadgreen University Hospitals NHS Trust, UK, <sup>2</sup>Sahir House, Liverpool, UK and <sup>3</sup>Liverpool Community Health NHS Trust, UK

We began our project following acquiring the 'Nurses League Journal Travel Award' in 2011. We travelled to India in 2012 to work with a charity called LEpra. LEpra is an organisation who provides comprehensive medical and holistic services for those living with HIV. In Hyderabad, the charity runs various community clinics and outreach projects.

One experience, which stood out for us, was an outreach to the female sex workers. We travelled with staff to visit women who were based near an army barracks. They worked in the woods, hidden away. The women were vulnerable, fearful and scared for their own safety. The staff had built a good rapport with the women, supporting their emotional, sexual and psychological health needs. They informed and directed the women to appropriate services.

LEpra's services had information, posters and leaflets available to patients which were creative, understandable and used pictures to convey the message.

Upon our return, we were inspired to create an information booklet for newly diagnosed HIV positive patients accessing our service, a tool to signpost patients to services in the hospital and across the city. The aim was through collaboration with services available, a comprehensive, creative and accessible booklet could be produced to cater for the needs, questions and queries of a newly diagnosed HIV positive patient.

As part of our role as HIV Specialist Nurses we commissioned a steering group comprised of patients, nurses, doctors, and members of the voluntary and charitable sector. The group worked together to design the booklet, and then individuals were assigned sections to write.

A finalised version of the booklet has been completed and information includes: hospital clinics, ward admissions, research, hospital support, community support, community services, woman's health, men's health, lesbian, gay, bisexual and transgender, family health, and frequently asked questions.

The booklet has been assessed and approved by the Hospital Governance team and by a lay patient group.

Feedback from a sample group of HIV positive patients showed that: 92% thought there was a need for the booklet, 100% thought there was the right amount of information and 100% thought the booklet was clear and understandable.

We are confident that we have met the aim of our project to provide an informative, easily understandable and comprehensive booklet to be used by our newly diagnosed HIV positive patients.

## Abstract P6

**Standards of HIV care in an Inner-London outpatient clinic: time from diagnosis to first clinic appointment**

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**Background:** The current BHIVA standard is for patients to be seen by a HIV doctor within two weeks of a positive HIV test. Despite adequate capacity for new patients this target can be challenging to achieve. Local policy aims to identify patients quickly who have a CD4 <200. New "reactive" HIV results are flagged the same day.

**Aims:**

1. Measure the time from diagnosis to accessing HIV services
2. Identify patients with CD4 <200 (who need PCP prophylaxis) and determine how quickly this group is seen

**Methods:** A retrospective analysis of newly diagnosed people living with HIV and accessing HIV care services during 2013 at a large London teaching hospital. The site of referral was identified. Testing and attendance data was extracted from hospital systems (PIMS and EPR) and exported into Microsoft excel and analysed using STATA 13.

**Results:**

- A total of 66,980 HIV tests were conducted in 2013 in the area of study, with a prevalence of HIV positivity of 1.4% (984/66,980).
- 318/984 (32.3%) patients elected to have care locally.
- The median time from HIV diagnosis to the first HIV nurse's appointment was 12 days (IQR= 0-26), with a median of 16.5 (IQR=1-97) in women and 11 (IQR=0-22) in men.
- The median time from HIV diagnosis to the first HIV consultant appointment was 19 days (IQR=11-33), with a median of 18 (IQR= 9.5-33.5) in women and 19 days (IQR=11-33) in men
- The median time from HIV diagnosis to the first HIV consultant appointment was noted to be higher in the community-diagnosed cohort with 16 diagnosis 32.5 days (IQR=28-39.5) compared to 144 diagnosis in the GUM clinics 22 days (IQR=13-37).
- The median time between diagnosis and first HIV doctor appointment was 14 days for the 57 patients with a CD4<200 and 20 median to the first nurse appointment for the 52 patient with a CD4<200.
- 99% of people newly diagnosed with HIV had a CD4 count recorded in their clinical record at their first HIV consultant appointment.

**Conclusion:** There is a median time of 13 days (IQR=9-18) from the laboratory HIV positivity test to see a nurse specialist, 19 days (IQR=11-33) for the HIV doctor appointment, with women being seen 5.5 days later than men ( $p=0.583$ ). Patients with a CD4<200 are successfully seen more quickly. Community-based diagnosis forms the largest challenge to achieve the two-week standard, currently falling short by 17.5 days.

## Abstract P8

**HIV testing in primary care practice: the barriers of HIV testing**

S Mutambara

Sussex Community NHS, Crawley, West Sussex

**Background:** British HIV Association (BHIVA) 2008 guidelines recommend early HIV (Human immune deficiency virus) testing and the expansion of HIV testing outside the antenatal and sexual health clinic settings. In locations with HIV prevalence greater than two per thousand among 15–59 year olds, a routine offer of HIV test is recommended for all adults registering in General practice and all general medical hospital admissions.

This study aimed:

- To identify knowledge and availability of the BHIVA guidelines in GP surgeries and influence on HIV testing
- To identify barriers of HIV testing in the GP surgeries
- To assess awareness and knowledge of clinical indicator diseases

**Methodology:** Data was gathered through a Survey monkey questionnaire which was mailed out on 09/09/2013–09/10/2013.

**Results:** Thirty six (36) questionnaires were emailed to the population GPs and twenty three (23) (63.8%) GPs responded. Seventeen (73.91%) of these were not aware of the UK national HIV testing guidelines. Fifty per cent (50%) were not aware of the disease clinical indicators in which HIV test should be offered. Fifty six (56.52%) were able to list more than 3 clinical indicators. Within a year 72.75% of the GPs had offered between 1–5 HIV tests. Despite 81.82% expressing confidence in offering an HIV test the low numbers tested within a year does not appear to reflect this confidence. The barriers of HIV testing were

Consent process	52.94%
Insufficient time	41.18%
Lack of confidence	29.41%
Fear of offering the test	23.53%
Lack of knowledge	17.65%

**Conclusion:** The results of this survey provide evidence that the majority of GPs (73.91%) are not aware of the BHIVA guidelines for HIV testing. This could be why (50%) of the GPs are not aware of clinical indicators in the guidelines. While 82.81% are confident in offering HIV test the testing rate remains relatively low.

## Abstract P9

## Four-week window?

S Attridge

Cardiff &amp; The Vale University Health Board, UK

**Background:** The introduction of point of care tests (POCT) has increased access to HIV testing and is now seen as a routine aspect of clinical care. However, as with any clinical test the result should only be interpreted within clinical circumstances.

**Methods:** A 29 year old MSM attended for sexual health screening one week after unprotected insertive anal intercourse. He reported over 20 sexual partners with minimal condom use in the last 3 months. He complained of dysuria and a rash across his torso and back for the several days. Upon examination there was a petechial rash, no lymphadenopathy, genitalia was normal and a urethral smear was dry. Due to the presenting rash and risk for syphilis he was treated for syphilis. A routine MSM screen was requested - Chlamydia, Gonorrhoea, Syphilis, HIV, Hepatitis B&C.

**Results:** The initial HIV test was weakly positive on the VIDAS & ARCHITECT, (1.5 & 3 respectively). The point of care test was equivocal. The patient was then recalled for confirmatory bloods seven days later. The confirmatory HIV test was LiaTeck positive only on pg41, both the VIDAS and ARCHITECT were positive, 4 and 9 respectively, the POCT was weakly positive. His HIV viral load at this point was 842,181 ui and a CD4 count of 380 (42%). The HIV test was repeated again to observe for a change in values one month after potential exposure, the VIDAS and ARCHITECT remained weakly positive (2 & 4 respectively). The point of care had now reverted from a weak positive to negative (4 weeks after exposure). Six weeks after exposure his HIV viral load had decreased to 1,862 ui and his CD4 count was now 760 (46%).

**Conclusion:** Current BASHH guidelines state patients should not be made to wait 3 months for a HIV test, instead 4th generation HIV laboratory tests can be very reassuring and are highly likely to exclude HIV infection. Clinicians should be advising patients to seek venous blood sampling if their risk is within the 3 month window period. False negative POCTs could provide misplaced confidence in an individual's HIV serostatus – when they maybe most infectious.

## Abstract P11

## Clinical mentoring enables primary healthcare nurses to deliver South Africa's Nurse Initiated and Managed Antiretroviral Therapy (NIMART) programme

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**Background:** In order to deliver antiretroviral therapy (ART) to all those requiring it in South Africa, the Nurse Initiated and Managed ART (NIMART) programme was introduced in public primary healthcare facilities. Professional nurses were trained for this through classroom teaching and work-based mentoring.

A mentoring process leading to NIMART graduation and the award of a Certificate of Clinical Competency was set out by the Department of Health (DoH). The process includes demonstrating 54 clinical competencies and completing a clinical logbook recording the correct management of 80 patients.

In the districts of Tshwane, Nkangala, Capricorn and Vhembe, clinical mentoring is provided by the Foundation for Professional Development (FPD).

**Objectives:**

- To evaluate the effectiveness of the clinical mentoring process as described by the Department of Health.
- To identify the strengths and shortcomings of the mentoring process and to make recommendations for improvement.

**Methods:** A clinical nurse specialist from the UK conducted semi-structured interviews and focus groups at participants' places of work. The participants were professional nurses, facility managers, members of FPD mentoring teams and senior personnel in the DoH and FPD.

**Results:** 92 professional nurses were interviewed; the median time post-NIMART course was 25 months. 13% had completed the NIMART process, 8% receiving the Certificate of Clinical Competency; the median time to completion was 14 months. Reasons given for non-completion included infrastructural problems, high workload, lack of managerial support, insufficient paediatric cases, not wanting to lose mentoring support, etc.

**Table 1 The effectiveness of clinical mentoring as assessed by NIMART-trained nurses**

% nurses	Variable
94%	Mentoring improved nurses' confidence about managing HIV in PHC
94%	Mentoring made nurses feel more positive about managing HIV in PHC
91%	Nurses' relationships with mentors are effective or very effective
87%	Mentoring met more than half nurses' expectations
78%	The frequency of mentoring visits was 'about right'

Clinical indicators demonstrate health improvement since the introduction of NIMART.

**Conclusion:** Clinical mentoring has led to significant professional development, enabling professional nurses to successfully implement NIMART in South African primary healthcare facilities (Table 1).

Although the majority have not reached NIMART graduation, clinical mentoring has enabled nurses to successfully implement the NIMART programme in primary healthcare.

In the absence of any other measure of clinical competency, NIMART nurses should be encouraged to complete the process set out by DoH.

## Abstract P10

## New HIV diagnosis and disclosure evaluation

S Attridge and N Lomax

Cardiff &amp; The Vale University Health Board, UK

**Background:** An increase in HIV testing has necessitated an evaluation of the new HIV diagnosis pathway. A self administered questionnaire was devised to ascertain patients' use of community support groups, availability of appointments, disclosure to employers and willingness to discuss disclosure with staff.

**Methods:** A convenient sample of patients attending an outpatient based HIV clinic was legible for recruitment. Participants needed to be diagnosed HIV positive within the last 5 years. Data collection was between September and December 2013. Completed questionnaires n=37.

**Results:** The total number of patients diagnosed in the investigating clinic was 25 (68%). The location of those diagnosed elsewhere was not requested, however 5 patients were diagnosed by their GP, 2 at THT and 5 at unknown locations. The details of community support groups were given to 76% of patients. Only 8% of patients contacted THT within 2 weeks of diagnosis, no other support group was used. An appointment to see an HIV specialist within 2 weeks of diagnosis, was received by 76% of patients. Of those not receiving an appointment within 2 weeks, 3 were from the investigating site, 1 was from a GP and 3 were initially diagnosed elsewhere. Nearly 70% of patients discussed their new HIV diagnosis with friends within 2 weeks of diagnosis. However, only 40% of patients have disclosed their HIV status to their employer. Just over half of the patients felt comfortable discussing their diagnosis with anyone, 35% of patients felt they could ask any clinician for advice on disclosing their diagnosis; whilst the same percentage felt they would ask certain clinicians for advice on disclosure. 20% of patient had a negative view of asking staff for advice on disclosure.

**Conclusion:** This was a small study not designed to provide statistically significant results. These results can question the use of community support groups for the newly diagnosed in the investigating locality. The results suggest greater standardisation of information and appointments given to the newly diagnosed. Generally the clinic was viewed positively when providing support for discussing the HIV diagnosis to friends, sexual partners and employers, however further investigation and staff training needs to occur to examine the negative views of asking clinicians for advice on disclosure.

## Abstract P12

## What adherence support do patients require from an HIV service?

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**Background:** High levels of adherence to anti-retroviral therapies (ART) are necessary for the long term health of those with HIV and the prevention of onward transmission of infection. Lifelong adherence poses substantial challenges to many individuals for a multitude of reasons: effective support from HIV services is therefore essential. Understanding what constitutes effective support is important for service development. The aim of our study is to understand what aspects of care are important to patients in supporting their adherence to ART.

**Method:** This qualitative study involved two care centres – a sexual health clinic and an Infectious Diseases unit – in a provincial city. Semi structured interviews were conducted with a purposive sample of 23 HIV positive patients and analysed using a modified framework analysis approach.

**Results:** Four themes were identified that captured the important elements of adherence support: 1) being prepared for ART, 2) being supported to take the treatment, 3) providing a responsive service and 4) supporting engagement with the service. The relationships within which care was delivered and the impact that it had on the experience of care was an important cross cutting thread that ran through the themes. For example, collaborative decision making was an important element of being prepared for ART.

**Conclusion:** This study identified essential components of adherence support and provided insights into their importance from the perspective of the patient. Changes in commissioning will necessitate changes in the way services are delivered. These findings can be used to inform service developments to ensure optimal adherence support.

## Abstract P13

**Managing HIV patients lost to follow-up in the community (HIV CNS team)**

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 GSTT Community Trust, London, UK

**Background:** BHIVA guidelines recommend that all HIV patients who are ARV naïve and stable on treatment are monitored at least 6 monthly. Patients who are lost to follow up (PLFU) can have worse care outcomes and potentially increase onward transmission of HIV.

There are no agreed national guidelines to re-engage with patients who have been identified as lost to follow up. According to HPU 2011 data, around 5% of HIV patients are lost to follow up annually in the UK. There are limited studies to the reasons why patients stop engaging with their HIV care.

The definition of PLFU often differs between UK HIV clinics.

In our pilot, we have defined PLFU as non-engagement with the HIV clinic for more than 8 months after the last appointment, where patient is not known to be deceased and not having transferred to another clinic.

The HIV clinics often manage PLFU by phone calls and letters encouraging patients to re-engage with their care. As a HIV community specialist nursing team working in three busy city boroughs, it was felt that we had an opportunity to visit PLFU at home therefore adding another method to re-engage them with HIV care. As community nurses visiting patients in their homes, we have a unique position to assess and investigate the reasons why people stop engaging with their HIV care.

**Method:** A Pathway was developed with a HIV clinic and community HIV CNS's to manage PLFU. The HIV clinic would initially follow their protocol for PLFU. If the patient would continue to fail to re-engage with the clinic, they would be referred to the community HIV CNS team.

**Results:** The reasons for PLFU are complex and varied. They include difficulties coming to terms with HIV diagnosis, not seeing HIV/health as a priority, mistrusting health care professionals, health reasons preventing access to care (e.g memory problems), social and family difficulties taking precedence over health as well as immigration issues such as dispersal, mental health problems, drug & alcohol misuse and faith beliefs that do not support medical intervention.

**Conclusion:** Community HIV nurse specialists are in a unique position to enhance the pathways to re-engage patients. By developing robust pathways and working closely with the HIV Clinics there is an opportunity to improve outcomes for those patients who have complex reasons for not engaging with their HIV care.

## Abstract P14

**Mapping unknown territory: The narratives of couples in HIV serodiscordant relationships (SdRs) and the implications for policy and long-term supportive therapeutic practice**

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**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 poster presents summary of research on how HIV serodiscordant couples reconstruct relationships.

The research aims to understand how HIV serodiscordant couples reconstruct 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. 34 narratives were generated from 24 individuals and couples in current serodiscordant relationships. A qualitative data analysis software 'Maxqda' facilitated data management and analysis.

**Findings:**

Core category:

Reconstructing selves

Main categories:

- Surviving serodiscordance
- Supporting serodiscordance
- Disclosing serodiscordance
- Maintaining/staying in relationship

**Conclusion:** Albeit in different guise, HIV serodiscordant 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 P15

**Impact of integrated health and social care provision within a busy multicultural inner city HIV clinic**

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Homerton University Hospital NHS Foundation Trust, London, UK

People living with HIV have complex medical, social, psychological needs which are tightly interlinked and have both direct and indirect health consequences. Welfare reform has had a significant impact on our cohort's ability to manage their social care needs with a detrimental effect on mental and physical health as a result. Challenging non-medical issues are frequently brought into the clinical environment by patients who have low awareness of the services available and who struggle to negotiate the complexities of accessing appropriate sources of support. In February 2010 a dedicated HIV Social Care Coordinator was employed to provide integrated HIV social care from within an inner London HIV clinic, in an area of severe deprivation. This represents a service review after 4 years of service delivery. Aims: (1) To identify the impact having a dedicated Social Care Service (SCS) in the HIV clinic has had on service delivery and clinical care over the past 4 years. (2) To evaluate the Service Users' ability to manage their health and social care needs before and after interventions from the service.

**Methods:** Two anonymous questionnaires were developed, one for health/social care providers (1) and the other for users of the service (2). Both were adapted from a previous survey completed in 2011. Questionnaire (1) was completed by email and paper copy sent to clinic staff and external referral agencies that have had contact with SCS. Questionnaire(2) was offered to all previous and current service users who attended the clinic over a one month period.

**Results:** Questionnaire(1) had a response rate of 80% (24/30). 100% (24/24) of respondents reported support offered by the SCS had had a positive impact on patient care. Of the external providers, 100% (7/7) stated high levels of satisfaction with the appropriateness of referrals and improved communication. Questionnaire(2) had a response rate of 92% (55/60). The key issues for referral included Benefits 60% (33/55), Housing 60% (33/55) and Financial Hardship 55% (30/55). There was a marked improvement in self-identified concern regarding management of social care needs, after intervention.

**Conclusion:** Patients, nursing, medical and external service providers continue to express a high level of satisfaction with the improvement of people's social care needs as a result of this integrated service. This frees up clinical time to address clinical issues, despite ever increasing social care needs amongst our cohort.

## Abstract P16

**'Ask Me about HIV' – what are the anxieties and experiences of UK PLHIV in relation to disclosing their status?**

G Brough, S Papanini and W Harris

Terrence Higgins Trust, London, UK

**Background:** Surveys of the general public show declining HIV awareness and knowledge and ongoing stigmatising beliefs. To mark World AIDS Day 2013 and raise HIV awareness, we conducted a snapshot survey to collect users' views and experiences of attitudes towards HIV, along with their anxieties and experiences around HIV disclosure.

**Methods:** The online survey included multiple-choice and open text questions. The survey was circulated to and via members of our myHIV online forums and final survey data was collected from forum users, users of other HIV organisations and from social media.

**Results:** 531 people living with HIV completed the survey over 3 weeks. More than nine out of ten (93%) thought the public's understanding of the condition needs improving – with more than six out of ten (63%) describing it as 'poor' or 'very poor'. 88% of participants reported encountering one or more HIV myths during the last five years, giving a picture of the top myths that persist around the virus, such as: 'HIV and AIDS are the same thing' (63%); 'an HIV diagnosis is a death sentence' (52%); 'someone with HIV can't/shouldn't have a relationship with someone who doesn't have HIV' (47%); 'HIV is only an issue for gay men' (45%); 'there is a cure or vaccine for HIV' (37%). 83% of people with HIV could think of a time when they wanted to disclose their HIV status but didn't feel able to, due to anxieties relating to negative reactions (85%), confidentiality (79%) and ignorance (75%). The vast majority (80%) of those who answered the open questions reported negative responses to disclosure including rejection, insults, suggestions of imminent death and remarks about their appearance. The open questions also highlighted issues that people living with HIV felt should be further challenged in public debates, along with suggestions for improving public attitudes to HIV.

**Conclusions:** Although the survey was a rapid exercise to support media and campaigning work for World AIDS Day, it highlighted persistent myths about HIV and a variety of uninformed responses that people experienced when disclosing their status. Robust research is needed to assess the extent and nature of HIV-related stigma in contemporary Britain, as the findings show an extensive array of misconceptions and negative attitudes in the fourth decade of the epidemic.

## Abstract P17

**Increased hepatitis C rate reveals high recreational drug use within HIV-positive MSM in Northern Ireland**

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**Background:** Increasing recreational drug use (RDU) is fast becoming a problem in Northern Ireland. Drugs are easy to access and allow men to have marathon sex sessions with multiple partners. In the last 7 months in Belfast there have been 5 cases of acute hepatitis C virus (HCV) diagnosed, all were men who have sex with men (MSM), 4 were also HIV positive, the youngest was 48 years old.

2 reported self administration of intravenous drugs (IVDU) one of a legal high, the other reported injecting Ecstasy at time of sexual intercourse. 2 reported rectal administration with a needleless syringe, they were told it contained a legal high, both reported rectal bleeding and irritation, this occurred at a sex party organised via social media for BBCchem+ men. 1 denies any drug use.

**Method:** We collected data on recent / current RDU and sexual behaviour within HIV positive MSM. We identified 31 men who had been diagnosed with a sexually transmitted disease in the last year and targeted them. 29/31 responded to our questionnaire which was completed by telephone or face to face in the clinic.

**Results:** Mean age was 43 years old. 82.1% admitted to RDU, 69.5% used drugs while having sex, 56.5% reported RDU in the past year.

39.1% reported having more than one partner in the last 3 months, 38.8% reported unprotected active anal intercourse (UPAI), 44.4% passive UPAI, 13.7 also reported using sex toys for UPAI.

DRUG	% used	DRUG	% used
Legal highs	21.4	Viagra	25
Mephedrone	3.5	Other erectile dysfunction drugs	14.2
Ecstasy	21.4	Heroin	0
Cocaine	10.7	Acid or LSD	7.1
Ketamine	0	Crack	0
GBH	0	Poppers	71.4
Crystal meth	7.1	Steroids	0
Speed	17.8	Cannabis	39.2

31.2% reported RDU via their mouth (swallow / below tongue / gums), 68.7% via their nose, 31.2% inhaled (smoked) and 6.2% injected.

50% reported RDU with a regular partner in a private setting, 56.2% with a casual partner in a private setting. 6.2% reported use in private group sex. 25% of respondents met their partners via social media, 12.5% in a sauna, 18.7% in a local bar and 6.2% on cruising ground.

**Conclusion:** RDU is becoming a problem within Northern Ireland and with it an increase in risky sexual behaviour especially among the older men. As shown, it has contributed to a rise in HIV/HCV co-infection which is very worrying. Staff must be aware of commonly used RDUs, screen and educate patients on the potential hazards involved with using RDUs with sex.

## Abstract P19

**Sexually transmitted infection (STI) screening in an inner London HIV outpatient unit: positivity, partner notification (PN), and public health**

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**Background:** HIV positive individuals with acute STIs are more likely to transmit HIV during sex. Within the UK in 2012, 20% of new HIV diagnoses had concurrent acute STIs. Asymptomatic sexual health screening (SHS) should form part of the routine HIV care. PN of STIs may help reduce numbers of those with undiagnosed HIV.

**Aims:**

1. Determine characteristics and prevalence of positive STI in asymptomatic.
2. Evaluate HIV transmission risk based on the level of HIV viraemia.
3. Examine the time to treatment and partner notification (PN) for STIs diagnosed.

**Method:** Retrospective audit of asymptomatic STI screens done in the HIV outpatient clinic in the first quarter of 2013. Comparison made with asymptomatic screens done in local GUM clinic. Data was sought from clinic database.

**Results:** 352 STI screens were performed. There were 58 (16.5%) positive infections in 53 HIV infected patients. Local GUM clinic data from asymptomatic screening shows an infection rate of 6% by comparison ( $P < 0.001$ ). Of positive STIs in the HIV clinic:

- 87.9% (51) were diagnosed in men having sex with men (MSM)
- 55.2% (37) were rectal
- 48.3% (28) were chlamydia, 39.7% (23) were gonorrhoea and 12.1% (7) were syphilis.
- PN was initiated in 78% (45), and completed in 64% (37)
- 56.9% (33) of patients with STIs had a detectable HIV viraemia
- STIs diagnosed on separate occasions indicated 65.5% (38) with a VL of  $< 1,000$  and non-detectable, 8.6% (5) VL  $< 10,000$ , 10.3% (6) VL  $< 100,000$  and 15.5% (9) VL  $> 100,000$
- STIs took an average of 8 (7–10) days to diagnoses and 16 (9–19) days to treat.

**Conclusion:** Rates of STIs among HIV positive asymptomatic screens are significantly higher than rates seen in local GUM clinics over the same time period. Most infections occurred in MSM, in the rectum, and in those with detectable viraemia. Although HIV positive MSM may be sero-sorting, we must consider the risk of onward HIV transmission. PN is often incomplete, a missed opportunity for STI treatment and crucially a chance to reduce the pool of undiagnosed HIV infections. Resources must be allocated to improve PN in those group, and consideration given to early HAART in those with STIs who are at risk of transmitting HIV to their partners.

## Abstract P18

**High prevalence of sexually transmitted infections amongst patients newly diagnosed with HIV: a public health concern**

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**Background:** An HIV positive individual diagnosed with an acute sexually transmitted infection (STI) is more likely to transmit HIV during sexual intercourse. At our unit newly diagnosed patients with HIV without symptoms of an STI should be offered a sexual health screen (SHS) for Syphilis, Gonorrhoea, Chlamydia Trachomatis and Trichomonas Vaginalis using self taken swabs (NAT) and syphilis serology at their first visit.

**Aims:**

1. To determine the proportion of newly diagnosed HIV positive patients who had a SHS
2. To determine the prevalence of STIs amongst patients newly diagnosed with HIV who had a SHS

**Methods:** A retrospective analysis of uptake of sexual health screening and prevalence of acute STIs amongst patients newly diagnosed with HIV at a central London hospital during 2013. Data were collected from clinical notes and the GUM database. Data were analysed using Microsoft Excel.

**Results:**

- In 2013, 318 patients were newly diagnosed HIV positive (68% MSM)
- 218/318 (68%) had a SHS at diagnosis
- Reasons for not performing a SHS were not documented
- 96/218 (44%) had an STI at HIV diagnosis with 42% from rectal samples
- 129 STIs were found in 96 patients of whom 92 were MSM
- 58 (45%) diagnoses were gonorrhoea, 38 (29%) syphilis, 30 (23%) Chlamydia, and 3 (2%) LGV.

**Conclusion:** There was a high prevalence of STIs amongst newly diagnosed patients with HIV who were asymptomatic. This has public health implications as by definition newly diagnosed patients are not yet on ART and the combination of an STI with untreated HIV may make HIV transmission more likely.

A significant proportion of patients did not have a SHS at HIV diagnosis. Furthermore, there was no accurate documentation of SHS being offered and declined so it was not possible to determine the true proportion of patients who had been offered a SHS. Measures have been put in place to improve on this and this audit will be repeated to complete the audit cycle.

These findings highlight the importance of offering and recommending SHS for newly diagnosed HIV positive patients.

## Abstract P20

**Effects of recreational drug use on sexual risk-taking behaviour**

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**Background:** Drug and alcohol use can affect an individual's judgement and may lead to increase in sexual risk taking behaviours, leading to unplanned pregnancy and STIs / HIV.

**Methods:** During the first week of December 2013 all attendees to the clinic where asked to complete an anonymous paper survey about drug use. This was done before seeing clinical staff, who did not see responses.

The survey asked about drug use in the last 6 months.

**Results:** 148 patients completed the survey, of which 32 (22%) reported using one or more recreational drugs in the last 6 months. Of the 32 responders 26 were heterosexual and 6 men who have sex with men.

Cocaine 24; Ecstasy 6; Ketamine 8; GBL/GHB 1; Crystal meth 1; Mephedrone 1; Cannabis 15.

- 4 responders reported drug use on a daily basis, with the majority using drugs one a month or a few times per month.
- Only 2 said that they did not enjoy taking drugs.
- 6 responders said they did not know how to take drugs safely, 6 responders also said they would not know where to go for support.
- 7 responders said that drug use was having a negative impact on their life.
- 11 responders said they were more likely to have unprotected sex when using drugs and a further 11 were more likely to do things sexually when taking drugs.
- Only 1 responder said they couldn't enjoy sex without drugs.

**Conclusions/Service Improvement:** This survey identified that patients using drugs were likely to make negative decisions about their sexual health, and that some users would not know where to go for support.

Asking about drug and alcohol use during a consultation should be routine to identify any potential increase in risk taking behaviour. Following this survey our service has made drug / alcohol use a mandatory question on electronic records. Any patients who see there drug use as affecting decisions they make about sexual health will be offered an appointment with the CNS for motivational interviewing, and if needed referral to clinical psychology. All patients identifying drug / alcohol use problems will be given tear of sheet with local support services details on.

**Acknowledgements:** Thank you to Jodie Scrivener, Dr Alan McOwan, David Stuart at 56 Dean Street for sharing their data and allowing me to replicate their survey.

**Abstract P21**

**How prepared are GPs to be more involved in the management of HIV?**

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**Background:** As the HIV cohort ages it is increasingly important that we develop shared care models with GPs. Better communication and involvement of GPs will improve quality of care and avoid the risk of drug-drug interactions. We undertook a survey of English GPs to assess readiness to be more involved in HIV care and to better understand the barriers that exist to this.

**Methods:** A sample of English GPs was invited to complete an on-line questionnaire, which questioned current levels of knowledge, the relationship with HIV specialist services, barriers to better involvement in the management of people living with HIV (PLWHIV) and what is required to become more involved. GPs were recruited so that respondents came from a range of practices and geographical locations, had >3 years' experience and were not also working in HIV services. In addition a 'boost' sample of GPs was recruited from areas of high HIV prevalence (>5 HIV cases /1000 population). These areas were London, Brighton and Manchester. Responses from GPs from high prevalence areas were compared with those from low prevalence areas.

**Results:** 239 GPs responded: 110 from low prevalence areas and 139 from high prevalence areas. 66% of GPs and 73% from high prevalence areas report receiving communication from HIV services but the majority did not think they worked closely with HIV services (56% and 63%). The majority of all GPs felt it was important to move the non-HIV care of patients to primary care and that GPs are best placed to provide this. Only 50% of GPs had received specific training in HIV prevention and management. GPs from high prevalence areas were significantly more likely to feel prepared to be more involved in care (63%) than those from low prevalence areas (47%). 84% of GPs and 75% of those in high prevalence areas thought there are barriers to primary care taking on more management of non-HIV issues. Lack of knowledge and training were cited as the key barriers. GPs also recognised that HIV patients have concerns about their inexperience and lack of knowledge. All GPs are looking for further training, specifically around antiretrovirals and drug-drug interactions, before they feel confident to be involved in more shared care.

**Conclusion:** The majority of GPs are willing to be more involved in the care of PLWHIV. However there are clear gaps in knowledge and confidence. Specialist services need to support primary care with training that focuses on issues of HIV management and monitoring.

**Abstract P23**

**Barriers and facilitators to recruiting patients to clinical trials in HIV clinics**

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**Background:** Research forms an integral part of HIV care. Departmental audit revealed only a minority of patients were informed of current studies with a large amount of inter-clinician variability in referrals to research. We investigate perceived barriers and facilitators to referral to studies in a large London teaching hospital.

**Methods:** An anonymous survey was circulated to all healthcare workers in the HIV clinic via email and personal communication. Free text questions investigated barriers and facilitators to research referrals and encouraged suggestions to increase recruitment to studies. Graded scale responses assessed the perceived impact of specific barriers (1=no impact; 4=great impact). Data were inputted onto a database.

**Results:** There were 25 participants: 14 doctors (43% consultant grade); 7 nurses, 3 pharmacists, 1 dietician. In the free text responses, barriers to referral were: lack of time in clinic (15/25, 60%), poor understanding of current studies (7/25, 28%) and lack of availability of research staff at time of referral (4/25, 16%). Perceived patient barriers included: lack of patient time (13/25, 52%); fear of changing medication (4/25, 16%) and increased visit frequency (7/25, 28%). Responses differed between staff group with clinicians more frequently reporting lack of time, while other groups were limited by knowledge. Facilitators to referral included email updates (9/25, 36%); pre-clinic rounds by research staff (6/25, 24%); and highlighting eligible patients in the notes and clinic lists (7/25, 28%). Suggested strategies to increase research referral included more patient information literature, pre-clinic meetings, longer clinic slots and increased availability of research team. Observational studies and studies with fewer visits were considered the easiest study type to refer patients to.

Graded scale responses were totalled and ranked in order of importance below:

Barrier to referral to research	Total score (mean average)
1. Lack of time in clinic	91(3.64)
2. Patients have no time	88 (3.5)
2. Patients declining the research referral	88 (3.5)
4. Knowledge of research studies	72 (2.9)
5. Type of studies being conducted	70 (2.8)
6. Desire to promote research	66 (2.6)

**Conclusion:** Time and knowledge represent the major barriers to referral to research. The department has proposed piloting extending clinic visit times and initiating a pre-clinic meeting to facilitate improved referral. Re-audit will assess the success of these strategies.

**Abstract P22**

**Peer mentoring – a community response to supporting self-management and well-being of people living with HIV**

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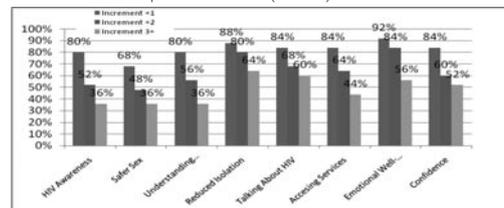
<sup>1</sup>Freelance Evaluator, London, UK and <sup>2</sup>Positively UK, London, UK

**Background:** Positively UK provides peer led support to over 1,000 people each year to improve the physical, emotional and social well-being of people living with HIV. In 2011 Positively UK established a new programme to train people living with HIV as peer mentors, with the objective of building capacity to provide peer support across London. Evaluation sought to identify benefits of the programme to mentees and volunteer mentors.

**Methods:** At evaluation the project had been operating for 18 months. Using a Star Outcome, beneficiaries were assessed their position in terms of 8 key indicators upon commencement of peer mentoring, at intervals during the support process and upon completion. An external researcher conducted interviews and focus groups with peer mentors and beneficiaries.

**Results:** Peer Mentors: A diverse group of 45 peer mentors were recruited, 58% women, 42% men; 65% heterosexual, 35% gay; 54% White British/European, 40% African, 2% Asian, 2% Caribbean. All accessed a tailored training programme, monthly supervision groups and professional development including mental health, benefits, and treatments. In rating knowledge on a 10 points scale volunteers recorded improvements in understanding of areas such as treatments (initial mean score 7, final mean score 9; and ability to advocate for others (initial mean score 6, final mean score 8). Qualitative interviews also identified personal benefits for mentors: "People have something to give – that is empowering. I'm not helpless – I'm useful"; "My consultant says I'm a new person."

Mentees: 150 people received over 1,200 hours of mentoring. The majority of mentees show progress against most of the outcomes, with a third to half recording a substantial increase of 3 points or more (table 1).



for an indicator demonstrated greatest improvements with just under 90% reported improvements in negotiating safer sex and 100% in ability to access other statutory and voluntary care services.

**Conclusion:** Peer mentoring can be a useful psycho-social tool in supporting people living with HIV with beneficial outcomes for both mentors and mentees. Further research required into long-term benefits for mentees and mentors in advocating for and managing their health are social care

**Abstract P24**

**Are SMS reminders useful to reduce DNA in routine GUM clinics?**

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**Background:** Patient non-attendance (DNA) is expensive and has a significant impact on access to care. Appointment reminders by text (SMS) have been shown to reduce DNA rates in different settings. In our service, routine sexual health appointments are bookable but despite being mostly compliant with 48 hours (h) access our DNA rate averaged 21% in 2012. We aimed to ascertain whether SMS at 24h or 48h would reduce DNA rates in sexual health clinic appointments.

**Methods:** We compared appointment outcomes (attendances, DNA, cancelled, rescheduled) in three months periods when 24h SMS (03-05/13) and 48h SMS reminders (06-08/13) were sent, with respective periods in 2012 when no SMS reminders were sent. We used unpaired 2-sample T test to determine statistical significance. A patient survey is in process to establish the acceptability of SMS reminders.

**Results:** In 2012, 18,413 patients attended the service, of which 15% booked less than 24h in advance (DNA 5%), 44% between 24-48h (DNA 22%) and 41% more than 48hrs (DNA 26%). During the period of 24h SMS reminders in 2013, 4914 patients attended the service of which 85% booked more than 24h in advance; similarly during the period of 48h SMS reminder, 4521 patients booked appointments, of which 36% booked more than 48h in advance. The table shows the mean DNA rates in 2012, 24h SMS reminder and 48h SMS reminder:

	2012 noSMS		2013 SMS		P value
	DNA% (DNA/N)	DNA % (DNA/N)	DNA % (DNA/N)	DNA % (DNA/N)	
24h SMS (Mar/Apr/ May)	All	22% (1308/6029)	19% (1145/6059)	0.1963	
	F	24% (805/3444)	20% (699/3439)	0.2827	
	M	19% (503/2585)	17% (446/2620)	0.1414	
48h SMS (Jun/ Jul/ Aug)	All	22% (1275/5782)	18% (997/5518)	0.0124	
	F	24% (786/3298)	20% (641/3219)	0.0123	
	M	20% (498/2484)	15% (356/2299)	0.0085	

Overall, DNA outcomes decreased after SMS reminders reaching statistical significance for 48h SMS and a greater impact on male than female attendances. In addition more appointments were cancelled after 48h SMS were sent, with females more likely to cancel appointments (data not shown). There was no statistically significant impact on rescheduled appointments with SMS reminders. Informal patient feedback shows that SMS are highly acceptable.

**Conclusion:** 48h SMS reminders significantly reduced DNA rates in routine sexual health clinics even in a service where most appointments are booked less than 48h in advance, and is a cost-effective strategy to increase capacity.

## Abstract P25

**Screening for depression, excessive alcohol intake, recreational drug use and adherence to antiretrovirals within an HIV outpatient clinic: a pilot service evaluation**

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**Aims:** In accordance with BHIVA and NICE guidance, we conducted a pilot service evaluation within our HIV outpatient clinic to assess the feasibility and acceptability of screening and success of onward referral for depression, excessive alcohol intake, recreational drug use and poor adherence to antiretroviral medication.

**Methods:** 100 patients were offered questionnaires, containing the following validated screening tools: PHQ-9 (depression), AUDIT (alcohol), DAST-10 (recreational drug use), and an adherence screen, enquiring about the number of missed doses of medication within the last 7 days and the patient's estimate of adherence to HIV medication within the last month, using a visual analogue scale (VAS). Patients identified with mild depression (PHQ-9 score 5-9) were offered a self-help booklet and those with moderate-severe depression (PHQ-9 score  $\geq 10$ ) were offered internal referral to the psychologist. Excessive drinkers (AUDIT score  $\geq 8$ ) were offered referral to an external specialist alcohol service, Aquarius. Patients with moderate-severe substance abuse (DAST score  $\geq 3$ ) were offered referral to an external drug service, Swanswell. Patients identified with poor adherence ( $\geq 2$  missed doses last 7 days or  $<90\%$  on VAS) were offered internal referral to the HIV pharmacist for adherence discussion.

Results (2 questionnaires were not returned)

	PHQ-9 n (%)	AUDIT n (%)	DAST-10 n (%)	Adherence n (%)
Accepted	79 (79)	77 (77)	75 (75)	83 (83)
Declined	19 (19)	21 (21)	23 (23)	15 (15)
Positive screens	5-9: 16 (20.3) $\geq 10$ : 23 (29.1)	$\geq 8$ : 8 (10.4)	Score $\geq 3$ : 3 (4)	3/83 (3.6)
Accepted referral	8/23 (34.8)	1/8 (12.5)	0/3 (0)	1/3 (33.3)

**Conclusion:** Screening was acceptable and feasible within this setting. High rates of depression were found, but internal psychology referral was not acceptable to patients. Rates of poor adherence were low. Referral to an external specialist alcohol or drug service was unacceptable to patients. Alternative strategies for managing these patients need to be researched.

## Abstract P27

**Healthcare workers knowledge of, attitudes to and practice of pre-exposure prophylaxis for HIV**

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<sup>1</sup>MRC Clinical Trials Unit at UCL, London, UK and <sup>2</sup>HIV/STI Department, Public Health England, London, UK

**Background:** Pre-exposure prophylaxis (PrEP) has proven biological efficacy to reduce the sexual acquisition of HIV. Healthcare providers knowledge of and attitudes to PrEP will be key to successful implementation. In the UK, PrEP is only widely available through the PROUD Pilot Study.

**Methods:** In September 2013 a cross-sectional survey was issued (paper or on-line) to UK healthcare providers through sexual health clinics (219), professional societies' email lists (2599), and at a sexual healthcare conference (80). The survey asked about knowledge of, attitudes to and usage of PrEP.

**Results:** Overall, 328/2898 (11%) completed the survey, 23%, 9% and 43% of the clinic, societies and conference samples respectively. The respondents were: 160 (49%) doctors, 51 (16%) health advisers (SHA), 44 (14%) nurses and 73 (22%) unspecified. A quarter (83/328) were involved in PROUD. Most respondents (260/328:79%) rated their knowledge of PrEP as medium or high, lower among nurses (27/44:61%) and SHA (36/51:71%) than doctors (144/160:90%;  $p<0.000$ ). Of these, excluding missing answers, 71% (175/247) felt that they knew enough about PrEP to have an informed discussion with patients, lower among nurses (17/33:52%) and SHA (18/33:55%) than doctors (116/131:89%;  $p<0.001$ ). Half of respondents (166/328:51%) thought PrEP should be available outside of a clinical trial, higher among nurses (29/44:66%) and SHA (37/51:73%) than doctors (66/160:41%;  $p<0.001$ ). The majority expressed concerns about prescribing PrEP without UK specific guidance (226/328:69%), higher among doctors (132/160:82%) and nurses (35/41:85%) than SHA (35/51:69%;  $p=0.002$ ). Over half supported targeted PrEP availability on the NHS (217/328:66%), and 46% (152/328) believed that PrEP would be a more effective prevention option than PEP for frequent PEP users, with only 15% disagreeing. Just under half (147/328:45%) have been asked about PrEP by patients in the past year, with no difference if they worked in a clinic not involved in the PROUD study (86/202:43%).

**Conclusion:** There was a higher level of support for PrEP availability outside of a clinical trial among nurses and SHA compared to doctors, despite a lower level of perceived knowledge and ability to discuss PrEP with patients. A large proportion of respondents have already been asked about PrEP by patients, suggesting widespread awareness of PrEP, which may or may not reflect demand. More information is needed for training all staff and to inform UK specific guidance.

## Abstract P26

**Reaching the unreachable – nurse-led STI screening at Erotica 2013**

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**Background:** Erotica, an adult lifestyle event started in 1997 providing a safe place to shop, socialise and enjoy an uninhibited venue attracting people who enjoy sex in all its forms. Our clinic has a history of novel outreach programmes and in 2013 was made aware of the event and the absence of any health promotion / sexual health presence at the event. Contact was made with the organisers and consent was given for a presence at the 2013 event within strict caveats, 20,000 tickets were sold.

**Methods:** The team were 6 senior nurses, driver & administration manager. We provided asymptomatic STI screening using self-collected sampling for Chlamydia & Gonorrhoea, bloods for HIV, Hepatitis & Syphilis, with the offer of HIV POCT. The outreach bus located near the food court was open for a total of 26 hours over 3 days. Our team actively engaged stall holders, entertainers and the venue support staff to promote the screening and health promotion material available. Our team toured the venue regularly engaging people, directing them to the bus.

**Results:** 180 screens completed, 44% female, 56% male, 5% refused HIV testing, 8% accepted or requested HIV POCT, 87% had venous sampling. Only 5% had ever tested for HIV previously, 95% stated they had not tested for a variety of reasons – access to clinic issues, not at risk, not important. As this was an adult only event the youngest person screened was 18yrs, the oldest was 71 yrs. with an average age 36 yrs. One HIV diagnosis was identified by HIV POCT in a 53 year old bisexual male swinger (last negative test early 2013). This was confirmed with the venous sample and he was referred to his local clinic in Yorkshire. We diagnosed 2 people with syphilis, 5 people with chlamydia & 1 person with gonorrhoea, all have been managed to national standards.

**Conclusion:** Testing in novel outreach settings is not new; however, focusing on those people whom we may not ever reach with specific targeted health promotion remains an issue. It is significant that 95% of those screened had never tested previously. Safer sex was not a common practice within this cohort. Seeking permission to work at events such as Erotica posed challenges for the team. The testing outcomes demonstrate the value of pursuing non-traditional clinic attendees with innovative access to sexual health screening. Timely access to STI screening, cited by many attendees, appears to be an issue of growing concern outside of large urban areas.

## Abstract P28

**"No one has God's pharmacy": Pentecostalism and divine healing in the context of HIV in migrant African communities in the UK**

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**Background:** There has been growing interest in the role UK-based African Pentecostal Christian churches play in the lives of people living with HIV. This follows well-publicised media reports of HIV-related deaths attributed to advice from pastors at a London-based church for members to eschew antiretroviral therapy in favour of divine healing. There remains little scholarly work that systematically explores HIV and Pentecostalism.

**Methods:** Our findings are drawn from interviews with 24 pregnant African women living with HIV, and ethnographic fieldwork at a London-based African Pentecostal church (referred to here as The Triumph of Christ Pentecostal Ministry, TCPM) conducted in July - September 2011. Data were analysed using grounded theory.

**Results:** The TCPM, typical of many Pentecostal churches, promulgates a belief in a universe where all misfortune (ranging from immigration concerns to illness such as HIV) is a demonic affliction necessitating spiritual warfare through a range of ritual practices including fasting, intensive prayer and healing ceremonies. The belief in divine intervention and the promise of transformation of circumstances fosters hope and self-efficacy in the face of seemingly insurmountable challenges. The church's willingness to recognise and address the social marginalisation faced by some of its members, providing the protection of a surrogate family and material assistance in times of hardship, further adds to its appeal. We found no evidence of Pentecostal beliefs acting as a barrier to engagement with HIV services. Clergy were not observed to give directives to discontinue medical treatment, and people described drawing upon their faith alongside biomedicine in a pragmatic quest to manage life with HIV.

**Conclusions:** Pentecostal beliefs in divine healing did not necessarily prevent patients from engaging with HIV services and interventions. Beliefs in divine healing of illnesses such as HIV are situated in a wider religious framework in which all types of misfortune are seen to have a spiritual aetiology. However, seeking a spiritual solution to misfortune does not preclude other approaches. Our work reveals that many patients draw upon their Pentecostal faith alongside biomedicine in a pragmatic search for outcomes. For many, Pentecostalism not only offers succour in the form of material assistance and a sense of collectivity, but is also an important resource in fostering hope and self-efficacy.

## Abstract P29

**What adherence support do patients require from an HIV service?**H Piercy<sup>1</sup>, G Bell<sup>2</sup> and C Bowman<sup>2</sup><sup>1</sup>Sheffield Hallam University, Sheffield, UK and <sup>2</sup>Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield, UK

**Background:** High levels of adherence to anti-retroviral therapies (ART) are necessary for the long term health of those with HIV and the prevention of onward transmission of infection. Lifelong adherence poses substantial challenges to many individuals for a multitude of reasons: effective support from HIV services is therefore essential. Understanding what constitutes effective support is important for service development. The aim of our study is to understand what aspects of care are important to patients in supporting their adherence to ART.

**Method:** This qualitative study involved two care centres – a sexual health clinic and an Infectious Diseases unit – in a provincial city. Semi structured interviews were conducted with a purposive sample of 23 HIV positive patients and analysed using a modified framework analysis approach.

**Results:** Four themes were identified that captured the important elements of adherence support: 1) being prepared for ART, 2) being supported to take the treatment, 3) providing a responsive service and 4) supporting engagement with the service. The relationships within which care was delivered and the impact that it had on the experience of care was an important cross cutting thread that ran through the themes. For example, collaborative decision making was an important element of being prepared for ART.

**Conclusion:** This study identified essential components of adherence support and provided insights into their importance from the perspective of the patient. Changes in commissioning will necessitate changes in the way services are delivered. These findings can be used to inform service developments to ensure optimal adherence support.

## Abstract P30

**Failure to ask about club drug use in gay men at a central London GUM clinic**

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**Background:** High levels of sexualised drug use have been reported in gay men (MSM). A previous study in our MSM service users had shown high levels of GBL, Mephedrone and Methamphetamine use and that this was associated with a greater risk of unprotected anal sex (UAI). BASHH advocate routine questioning about drug use in risk groups. We audited club drug history taking within our service.

**Methods:** The notes of all MSM attending for GUM appointments in one week were reviewed. We defined club drugs as GBL, Mephedrone and Methamphetamine.

**Results:** It was recorded that 9/144 MSM attendees were asked about drug use (6%). 100% of those asked admitted to club drug use, 8 of whom had used in the last 3 months. Only 1 user was offered onward referral for support regarding their drug use. 10.4% of MSM seen by doctors and 3.4% seen by nurses were asked about drug use. Reported recent UAI was similar in both groups 67/135 (49.6%) vs 5/9 (55.6%)

**Conclusions:** Staff, regardless of role or discipline, were poor at asking about club drug use, and there were poor rates of onward referral. There was no evidence that those asked were selected based on reported sexual risk. The opportunity to engage those with sexualised drug use in risk-reduction interventions is currently being missed. The results demonstrate a need to support clinicians to ask drug-related questions. A full-time drugs worker has been employed to act as a "champion" to meet this need. Specific questions about club drugs are being added to all proformas. This audit will be repeated in 6 months' time, with these interventions in place. It is hoped that this data and the subsequent interventions will help inform the clinic's strategy and allow for the provision of services that are better aligned to the needs of our clients.

## Abstract P31

**Key factors in the acceptability of TasP in Scotland: an exploratory qualitative study with communities affected by HIV**L Young<sup>1</sup>, P Flowers<sup>2</sup> and L McDaid<sup>1</sup><sup>1</sup>MRC/CSO Social and Public Health Sciences Unit, University of Glasgow, Glasgow, UK and <sup>2</sup>Glasgow Caledonian University, Glasgow, UK

**Background:** While the effectiveness of Treatment as Prevention (TasP) as an HIV-prevention intervention at the population-level continues to be debated, little evidence is currently available on the acceptability of TasP amongst those affected by HIV.

**Methods:** We employed consecutive, mixed qualitative methods – focus group discussion (FGDs), and one-to-one in-depth interviews (IDIs) – with HIVPositive and HIV-Negative and/or untested participants from communities most affected by HIV in Scotland (men who have sex with men (MSM) and men and women from migrant African communities). Thematic inductive data analysis focused on identifying the factors that might affect potential uptake and effective use of TasP.

**Results:** We conducted 7 FGDs (4 HIV-Positive, 3 HIV-Negative) with MSM (n=22) and African (n=11) participants and 34 IDIs (17 HIV-Positive, 17 HIV-Negative) with MSM (n=20) and male and female African (n=14) participants across Scotland. Awareness of and engagement with TasP as an HIVprevention strategy was identified as a key factor. The degree and nature of engagement with TasP was affected by HIV literacy (i.e levels of HIV-related knowledge and capacity to employ this knowledge), proximity to HIV, ethnicity and gender. A second key factor was if and how TasP might be incorporated into existing HIV risk management strategies (for example, as an alternative or complementary to existing practice). Willingness to start treatment early and use of TasP as part of combination prevention strategies was affected by perceptions of risk and the social context in which HIV risk management was practiced, including but not limited to the management of long-term serodiscordant relationships.

**Conclusion:** The acceptability of TasP at an individual level will affect how effective it is as a population-level HIV prevention intervention. Our findings demonstrate that while there is a need to increase knowledge about TasP amongst those most affected by HIV, context specific priorities, including risk perceptions and social dynamics in sexual relationships, could shape the nature of TasP uptake and use.

## Abstract P32

**Partner notification in HIV infection – closing the loop or not?**J Turner<sup>1</sup>, H White<sup>2</sup> and J Dhar<sup>1</sup><sup>1</sup>Staffordshire and Stoke-on-Trent Partnership Trust, Leicester, UK and <sup>2</sup>Leicester Royal Infirmary, Leicester, UK

**Background:** In 2007 a partner notification audit of HIV cases was performed, comparing patients diagnosed by Infectious Diseases (ID) with those diagnosed in Genitourinary Medicine (GUM). GUM were significantly more successful in initiating and achieving contact tracing than ID, identifying the need for closer working practices. Interventions included GUM placements for ID trainees and joint multidisciplinary team meetings. Until December 2013 the GUM and ID services were located in the same hospital. A joint re-audit was conducted in 2013.

**Method:** Patients newly diagnosed between 1st Jan 2009–31st Dec 2010 were audited, including 62 and 86 patients under ID and GUM respectively. Demographic data, sexually transmitted infection (STI) and hepatitis screening, and baseline CD4 counts were recorded, together with partner notification outcomes.

**Results:** In the 2013 data ID patients were older than the GUM patients (median age 42 v 35 years), and were significantly more likely to present with a CD4 count <200 (p<0.0001). 53% of ID patients had contact tracing performed by GUM.

**Conclusions:**

- Comparison between 2007 and 2013 demonstrates:
- ID achieved a marginal improvement in testing for STIs other than hepatitis/syphilis
- Both departments now have similar rates of documented partner notification discussions and an increase in the proportion of traced contacts tested
- Increased number of contacts identified and a reduction in the proportion who are successfully traced in GUM may reflect change in population dynamics (fewer black Africans and more casual, untraceable contacts)
- Approximately 50% of tested contacts were HIV positive in both groups, suggesting a large burden of undiagnosed infection in untraced contacts. Although further improvements are needed, the progress made to date highlights the continuing need for a holistic approach to HIV care, particularly in the current climate of tendering and fragmentation of GUM and HIV services.

## Abstract P33

**One forgotten child is one too many: an audit of HIV-positive female patients and their children, which resulted in an improvement to the numbers of children identified and tested for HIV**

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Royal United Hospital, Bath, UK

**Background:** "Don't forget the children" was published by BHIVA, BASHH and CHIVA in 2009 and amongst its recommendations were that:

- all new patients attending HIV services should have any children identified and tested
- all units should perform a look back exercise to establish the HIV status of any children whose parents attend the service

In response to these recommendations, an audit of all female patients attending the HIV service in Bath took place in 2009 and a re-audit in 2013.

**Methods:** The audit involved a case note review looking at 2 groups:

- "New patients" or patients at the point at which they were diagnosed or transferred into the service (the children they brought with them): 34 female patients in 2009, 57 in 2013
- "Existing patients" or patients who were under the care of the clinic at the time their children were born (the children born since): 5 infants in 2009, further 5 in 2013.

Standards included a discussion about HIV testing all children identified and referral to community paediatrics in situations where there is refusal to test.

**Results:** All infants born to "existing patients" under current follow up, were tested for HIV or referred to community paediatrics where this was appropriate. However only 80% (24/30) of "new patients" in 2009 were asked if they had children and in only 22% (4/18) of cases, was there documentary evidence that a discussion about HIV testing the children had taken place. The re-audit in 2013 showed this had improved to 93% (53/57) being asked if they had children with a discussion about testing in 82% (28/34).

**Conclusions:** Patients new to the clinic were not consistently being asked about whether they had children or whether these children were had been tested for HIV (2009). Discussions within the MDT, following the original audit, led to appropriate retrospective follow up of all patients who had not met the audit criteria and the establishment of a mechanism to collect this data for the future. A new patient pro forma introduced in 2011 has improved the recording of this information for patients new to the service, as evidenced by the results of the re-audit. Management of children of female HIV patients has improved as a result.

## Abstract P35

**Acceptability of home HIV sampling and testing: a user survey**M Brady<sup>1</sup>, A Nardone<sup>2</sup>, E Buenaventura<sup>1</sup>, P Kelly<sup>1</sup>, D Edwardes<sup>1</sup>, F Qureshi<sup>1</sup>, K Mutton<sup>3</sup>, D Ellis<sup>3</sup>, P Ward<sup>1</sup> and N Gill<sup>2</sup>

<sup>1</sup>Terrence Higgins Trust, London, UK and <sup>2</sup>Public Health England, London, UK and <sup>3</sup>Public Health England Laboratory, Manchester, UK

**Background:** Home HIV sampling has been shown to be both feasible and acceptable and offers another strategy to reduce undiagnosed HIV and late diagnosis. In addition, home HIV testing will be legal in the UK from April 2014. We undertook a survey of users of a home sampling service to assess their experience and to gauge acceptability of home testing.

**Methods:** From Jan – Sept 2013 we piloted a national home HIV sampling service. Clients request a 4th generation HIV dried blood spot test on-line. The completed test is posted back to the laboratory. Negative results are communicated by text and positive results are given by phone with support and the offer of referral to HIV services. We contacted those who had given consent to ask them to complete an on-line survey to assess their experience of the ordering and results management process and to ask about the acceptability of home testing. Those who had ordered but not returned a test were contacted to ascertain why.

**Results:** 9,868 tests were requested and 6,230 (63.1%) were returned. 925 (14.8%) of those who returned a test completed the survey. 92.7% were MSM, 82.0% were white British and the peak age range was 25–39 (48.7%). 32.1% had never tested before and 25.1% had not tested in the last year. Most heard about the service via social media sites (32.8%) or word of mouth (20.8%). The commonest reasons for using the service were "didn't want to attend an STI service" (52.0%) and "clinic opening times are inconvenient" (47.7%). Responses to questions about acceptability of the service are given in Table 1. 138 of those who ordered but didn't return a kit responded to the survey (3.7%). The main reasons for not returning the kit were "not important enough for me to test immediately" (25.9%), "didn't like the testing method" (25.9%) and "I was worried the test might be positive (22.2%). Despite this 89% would use the service again.

Question	Testers	Non-Testers
I would use the service again	97.0%	89.0%
Would you recommend the service to a friend you expected to test <b>negative</b> ?	Yes = 96.6%	Yes = 88.3%
Would you recommend the service to a friend you expected to test <b>positive</b> ?	Yes = 65.8%	Yes = 67.7%
I would prefer a home test with immediate results	68.7%	69.6%

**Conclusions:** We have demonstrated the acceptability of home HIV sampling and high levels of user satisfaction. This cohort showed high levels of acceptability of home HIV testing, which suggests there may be reasonable demand for this when the legislation is changed.

## Abstract P34

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

J Bennett and M Croston

NHIVNA, UK

**Background:** There is now strong evidence supporting the use of TasP and current British HIV Association treatment guidelines recommend that clinicians should discuss the evidence for the effectiveness of antiretroviral treatment as prevention with all patients with HIV. Nurses are involved in all aspects of service delivery 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. The study aimed 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. A mixed methods research design was adopted comprising 2 phases: an on-line survey followed by in-depth telephone interviews. The on-line survey was disseminated to the NHIVNA membership ( $n=244$ ) via email. The response rate was 33% ( $n=81$ ). Ten interviewees were then purposively selected from those who volunteered, to represent the diversity of the NHIVNA membership. The interview schedule was designed to follow up on key findings emerging from the survey and to enable complex topics to be explored in more depth. The survey was analysed using descriptive statistics. The interview data was analysed thematically.

**Results:** The study revealed considerable diversity and lack of clarity in nurses' understanding of the scope of the term 'TasP'. Overall, nurses saw it as their role to facilitate discussion with patients around TasP, as part of a multidisciplinary and partnership approach to care provision. Nurses feel skilled and competent in terms of general communication around sexual health and risk behaviour, but less confident to discuss TasP in the context of more complex patient scenarios. Many potential benefits of TasP were identified, including as a possible empowering and motivational tool, but several concerns were also expressed about the possible negative consequences of TasP, e.g. challenges with long term treatment adherence and the potential for changes in sexual risk taking.

**Conclusion:** Deficits in nurses' knowledge and confidence regarding TasP were identified and need to be addressed proactively at national level, with opportunities for continuing professional development made readily accessible. Further discussion and recommendations will be made on presentation.

**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 NHIVNA with support from a grant from Gilead Sciences.

## Abstract P36

**Emergency care for HIV patients: remodelling a 'walk-in' service at a specialist HIV centre**

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**Background:** BHIVA Standards of Care for People Living with HIV outline that HIV services should have pathways in place to provide equity of access to emergency treatment and advice. An audit of the emergency outpatient care pathway at a busy HIV clinic was performed and following this changes were implemented. The service was then re-evaluated to assess the impact of these changes.

**Methods:** The original care pathway, an open access all-day Emergency clinic (EC), was retrospectively audited over a 2-week period using case notes review with a standard proforma. After service remodelling all encounters (telephone triage or EC visit) were audited over a 4-week period. Data collected: demographics; GP registration status; antiretroviral therapy (ART) status; CD4 count; HIV viral load; reason for encounter; number of encounters/day; triage outcome.

**Results:** The emergency service was remodelled, changing from an all-day doctor-led 'walk-in' service to a doctor-led afternoon booked clinic with morning telephone triage. Triage patients were directed to the appropriate service (EC, pharmacy, regular HIV clinic, GP, A&E, 999 services). The majority of patients using the service were white MSM. 174/244 (71%) patients were on suppressive ART, and 210/244 (86%) had a CD4 count >200 cells/L. The demographics and HIV parameters of attenders were similar in both audits. Before remodelling there were 87 attendances in total, mean 9.6 (5–17) per day. The commonest presentations were ART prescriptions (32%), gastrointestinal (29%), respiratory (19%). 41% required review and advice only. 85% of attenders were registered with a GP. After service remodelling there were 157 encounters in total, mean 8.3 (5–13) per day, of which 7.6 (2–9) were clinic visits. The commonest presentations were gastrointestinal (20%), ART prescriptions (18%), respiratory (13%). 14% of attenders required review and advice only, 32% were referred to non-HIV services. 81% of attenders were registered with a GP. Of the 54 calls to the telephone triage service, 76% were booked into the EC and 24% were redirected to other services.

**Conclusion:** Telephone triage enabled patients to access advice and be signposted to appropriate services early in their care pathway. The redesign of the service resulted in a reduced number of face-to-face and prescription related attendances, allowing better use of staff resources whilst retaining patient-centred and accessible specialist HIV emergency care.

**Abstract P37**

**Management of patients lost to follow-up; early results of a new approach**

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University Hospitals Birmingham, UK

**Background:** At present, HIV care requires long term engagement between patients and treatment centres. Failure to attend clinic appointments is a common observation in HIV clinics. We investigated the impact of an enhanced protocol for follow up of patients who failed to attend their HIV clinic appointments.

**Methods:** In our centre, patients are routinely invited to attend the clinic every 4 months. The appointments are booked in advance to permit for necessary arrangements patients may require. Failure to attend a booked appointment is followed by three attempts to contact the patient on the phone within one week. A letter is then sent to the home address of patients who can not be reached. The letter states the number of attempts made to reach the patient and that no further attempt would be made to contact them. After two weeks and if the patient failed to contact the department, a letter is sent to their general practitioner (GP) to inform them of the patients' default from clinic where permission to write to GPs is granted. All patients defaulting from the clinic are discussed in monthly "Did Not Attend" (DNA) meetings. Their antiretroviral treatment, the number of days of available medicines according to our records, last CD4 and viral load counts, social issues, pending issues for partner notification and children testing, and any clinical issues from their last visit are discussed. A structured "final clinical summary" (FCS) letter containing the above information is dictated. It highlights patients' clinical and social issues and the consequences of interruption in HIV care. They are saved in patients' electronic records. A copy of the letter is sent to their GP where permission is given.

**Results:** Between September and December 2013, FCS letters were issued for 54 patients (33 men, 19 MSM) who were lost to follow up. They had a median CD4 count of 577 (IQR 364, 764) cells/mm<sup>3</sup>; 11 had CD4 count of less than 350 cells/mm<sup>3</sup>. After a median of 24 (IQR 9.5, 64.5) days, 26 (48%) patients re-attended the clinic. All of the 9 patients who had not permitted to contact their GPs attended the clinic after receipt of the final written letter. Of the 45 patients whose GPs were contacted with the FCS, 17 (37%) re-attended the clinic.

**Conclusion:** Our new enhanced policy for management of DNA patients has resulted in re-attendance of 48% of patients who would have otherwise been lost to follow up. Early results suggest that GPs may play a significant role in convincing those patients to re-attend. Follow up of patients defaulted from HIV clinics should be pursued jointly with their GPs.

**Abstract P38**

**Expand your option(e)s!**

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Chelsea and Westminster Hospital NHS Foundation Trust, London, UK

**Background:** In our service stable HIV+ve patients are seen 6 monthly for standard HIV monitoring with additional assessments according to clinical need. Annually, patients have full haematology and biochemistry profiles, as well as hepatitis C serology, assessment of hepatitis B immunity, cervical cytology, measurement of cardiovascular risk and STI screening if appropriate. Stable patients may elect to be managed by a nurse in Option E and receive results by email. Patients are encouraged to receive their medication by home delivery.

**Methods:** We reviewed a random selection of 50 Option E (nurse-managed) and 50 non-Option E (doctor-managed) patients who attended our service from 1 December 2012–30 November 2013.

**Results:** No of patients in clinic cohort = 2757; no of patients in Option E 1244 (45%). Below are presented results of random selection of 50 patients from each group. There was no difference in number of clinic visits, referrals to Daycare/A&E or hospital admissions between Option E and general HIV clinic patients.

Characteristic	Option E n=50	Gen HIV clinic n=50
Median age (yrs)	41 (IQR 34-47)	49 (IQR 46-55)
Median time since diagnosis (yrs)	7 (IQR 6-11)	16 (IQR 14-19)
Undetectable VL on treatment	47 (94%)	48 (96%)
No of previous regimens	1 (IQR 1-2)	4 (IQR 3-8)
Home delivery	37 (74%)	30 (60%)
Annual review	50 (100%)	47 (94%)
Cardiovascular risk assessment	20/47 (43%)	16/49 (32.7%)
STI screen	23 (46%)	19 (38%)
Hepatitis C screen	50 (100%)	44 (88%)

**Conclusion:** Patients managed by nurses in Option E have similar outcomes to those managed by doctors in the general clinic. Younger, more recently diagnosed patients may be more accepting of new patient management initiatives than older, less recently diagnosed patients.

**Abstract P39**

**A qualitative survey of attitudes towards HIV among providers of community care**

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**Introduction:** The majority of those infected with HIV are now expected to reach older age. Aging is associated with illness and disability. Dependence on others to provide care in older age raises concerns regarding discrimination and isolation. There is a need for preparedness of community services to provide care.

**Aims:** The survey sought to describe the feelings and concerns of potential carers of older people living with HIV in a community care setting; understand the extent to which these may impact care provision; assess basic knowledge regarding HIV transmission and treatment; and identify specific areas where intervention may help improve practice.

**Methodology:** A mixed-methods survey, by interviews and questionnaires, of attitudes and knowledge towards people living with HIV (PLWH), was conducted among healthcare workers from care home and domiciliary services from May to July 2013.

**Results:** 18 care home and 7 domiciliary supervisory staff were interviewed; 104 care home and 13 domiciliary staff completed the questionnaire. Only 22/117 (18%) answered correctly all questions about transmission by sexual and household contact. While the majority of services and respondents said that they would agree to care for people with HIV, concerns were expressed regarding the ability to care adequately for the emotional and physical needs, and of HIV transmission from carer contact.

**Conclusion:** This study, the first in the UK to explore attitudes among providers of community nursing care to PLWH, highlights varied levels of knowledge about HIV and mixed attitudes towards care provision. The majority of respondents were willing to provide care, but a minority had serious misgivings. A training intervention to provide more up-to-date information on risk, treatment and attitude shift strategies is planned.