15th Annual Conference of the
National HIV Nurses Association (NHIVNA)

National HIV Nurses Association

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Barking Community Hospital

27-28 June 2013- The International Convention Centre, Birmingham

Lost to Follow-up: Identification of Strategies to Assist with Patient Engagement in Service

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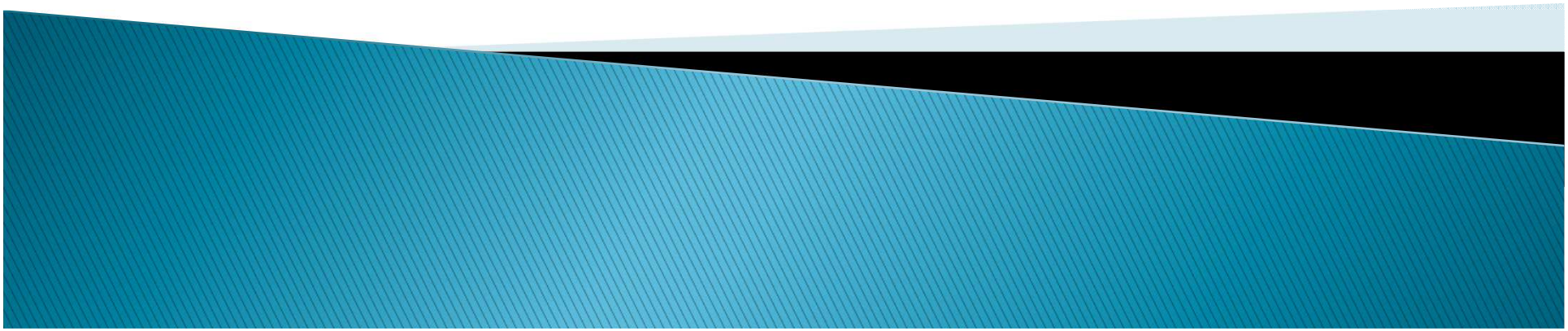
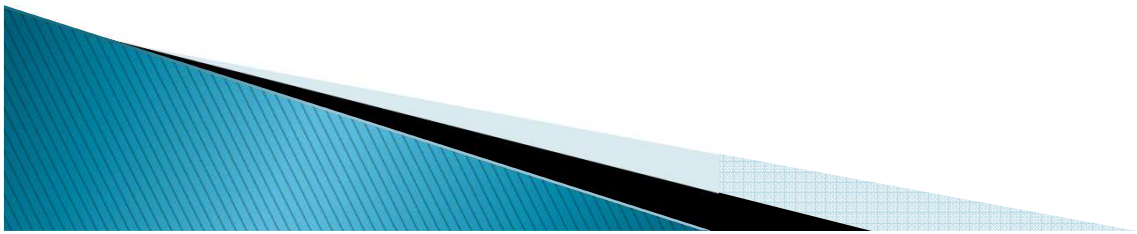


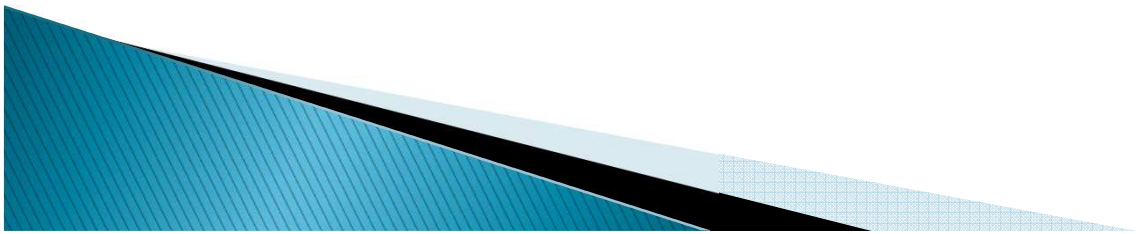
What's the problem?

- Lost to follow up – do we know where our patients are and do we need to know?
- How well are we doing?
- How could we do better?



Mental Capacity Act, 2005

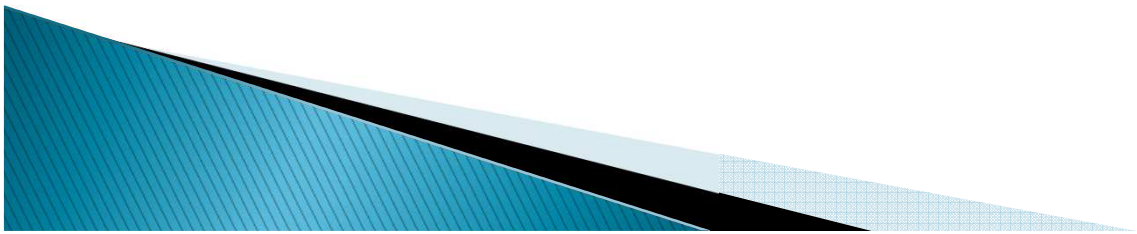
‘A person is not to be treated as unable to make a decision merely because he makes an unwise decision’

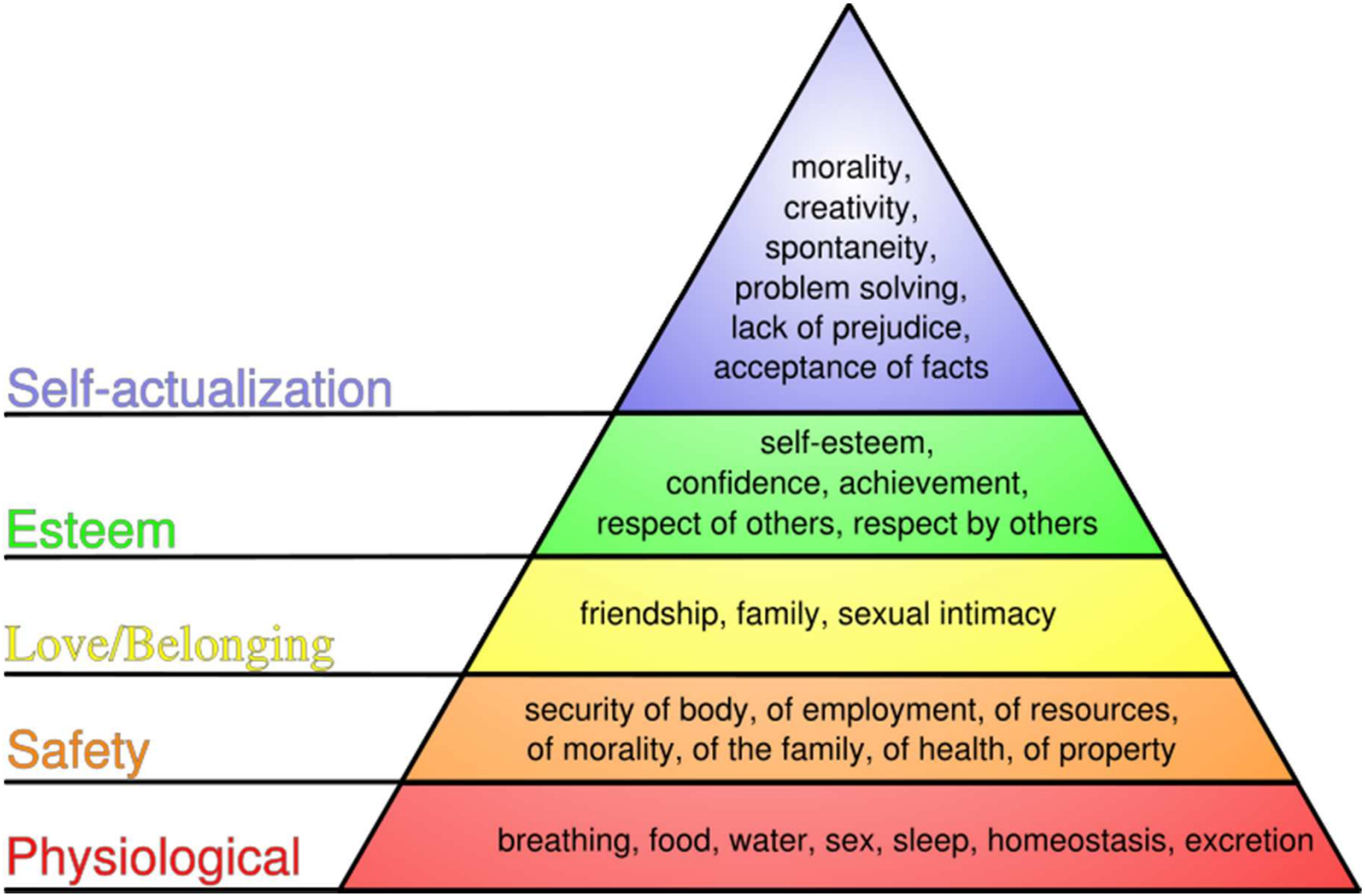


Who is responsible for my health and wellbeing?

Reasons for Disengagement

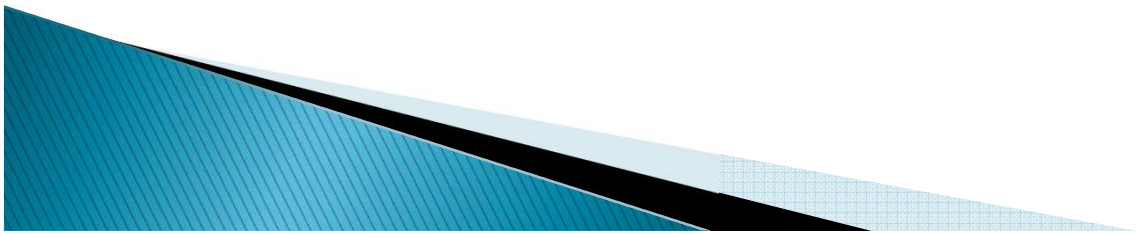
- Stigma, shame, denial
- Fears around confidentiality
- Other priorities, e.g., immigration, housing, family, work
- Detention/incarceration/relocation
- Travel/financial constraints
- Lack of understanding of illness
- Bad experiences




Self-actualization
morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts
Esteem
self-esteem, confidence, achievement, respect of others, respect by others
Love/Belonging
friendship, family, sexual intimacy
Safety
security of body, of employment, of resources, of morality, of the family, of health, of property
Physiological
breathing, food, water, sex, sleep, homeostasis, excretion

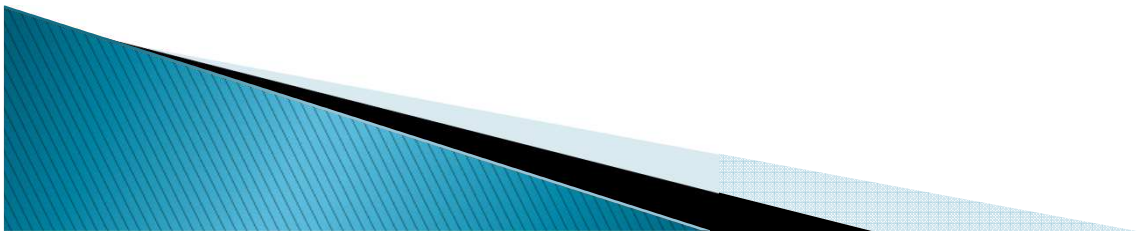
A Problem for the Patient…

- Lack of monitoring may put person at risk of opportunistic illness and death
- Lack of psychological/emotional support may result in mental distress, anxiety, depression
- Beliefs around HIV may prevent person from living happy and healthy life



A Problem for Society

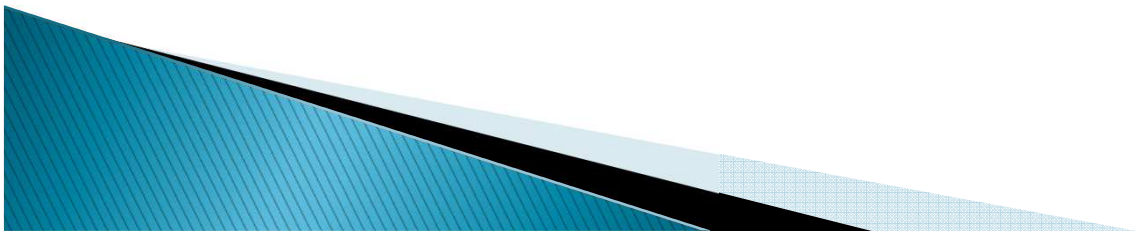
- Untreated patients more at risk of passing on infection
- Non-disclosure to sexual partners/children may put them at risk of late diagnosis and associated morbidity and mortality
- Patients admitted to hospital due to opportunistic disease and other morbidities cost money – hospital/ITU bed days, high cost treatments, care packages



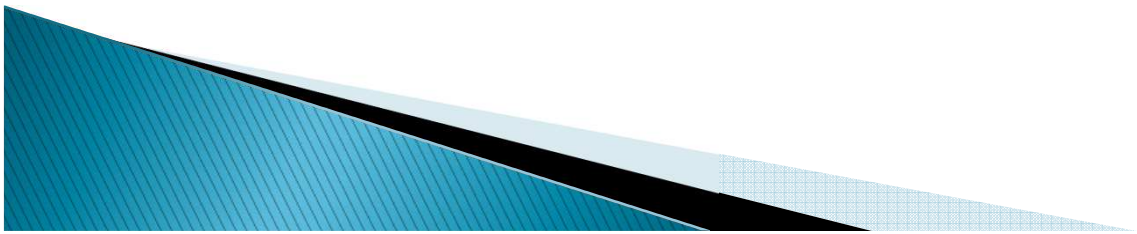
BHIVA Standard 2: Access to and retention in treatment and care

‘Services must have mechanisms in place for those who miss appointments or who transfer care to another centre, to ensure people with HIV are retained in specialist care’

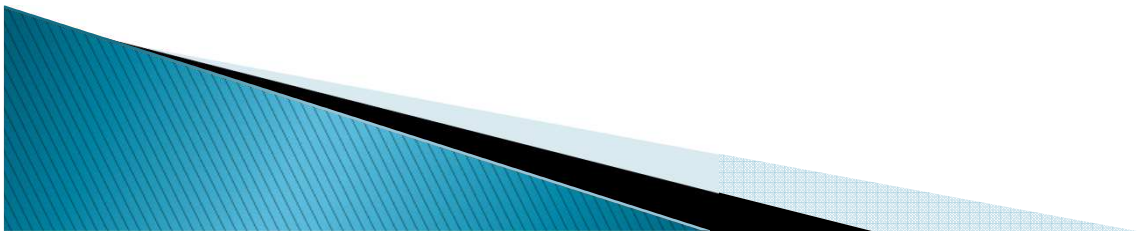
BHIVA Standards of Care for People Living with HIV, 2013



- All HIV services must have mechanisms to identify people with HIV, registered with their service, who become disengaged from care
- Clinical HIV services must have mechanisms in place to follow up people with HIV who miss appointments, monitoring tests or run low on supplies of medication

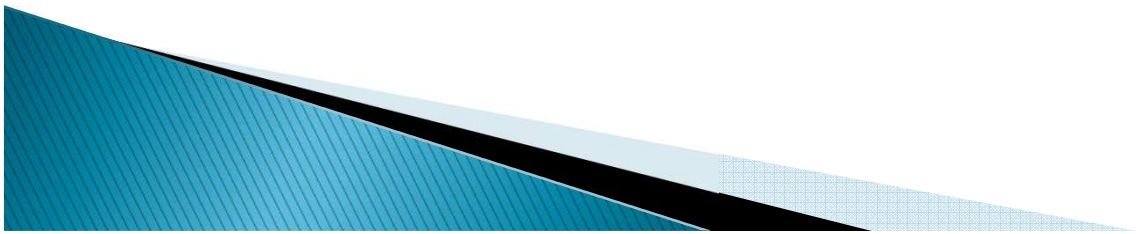


- If a patient is unhappy with the care provided by an individual clinician, an alternative should be offered (including referral to another centre if necessary) after exploration of the basis for concerns and addressing as appropriate.
- HIV services must have defined pathways for the safe transition of care



Auditable and Measurable Outcomes

- The proportion of people with known HIV infection who have accessed HIV clinical services within the past 12 months (target: >95%)
- Patients attending HIV services 1 year ago who have not been lost to follow up – all patients
- Patients attending HIV services 1 year ago who have not been lost to follow up – new diagnoses



How are we doing?

- BHIVA/HPA audit – 'People with diagnosed HIV infection apparently not in care'

  Aims:

- Estimate numbers of people with diagnosed HIV living within the UK but not receiving care
- Explore factors associated with non-retention in care
- Work towards good practice guidance on retention.

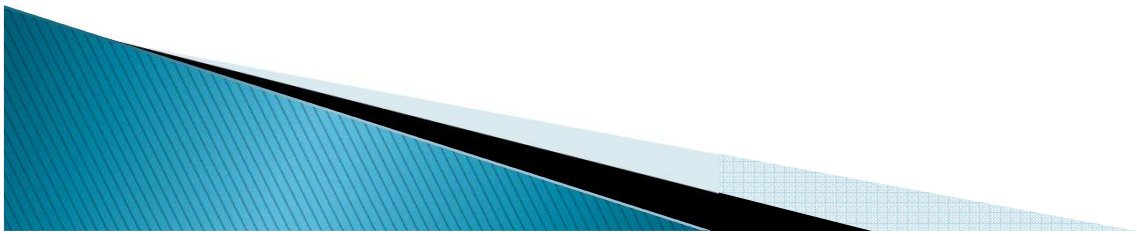
England, Wales, NI: HPA used surveillance data to identify:

- Patients seen for HIV care in 2010 with no linked care report from any site in 2011 and no linked death report
- New diagnoses in 2010 with no linked care report from any site in 2010 or 2011 and no linked death report.

Scotland:

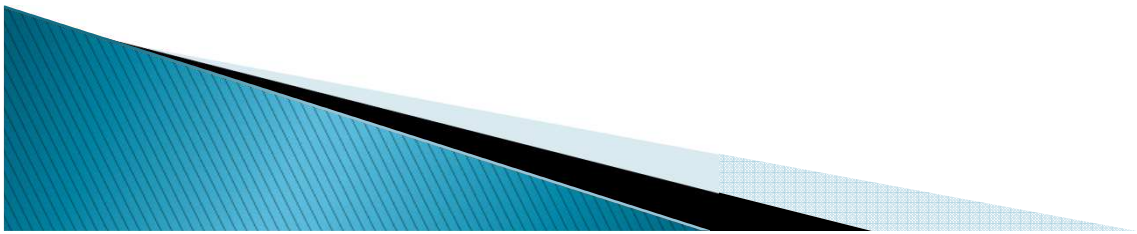
- Clinics identified patients seen for care in 2010 and not known to have been seen there or elsewhere in 2011.

- Case note review of all above patients – with extended version for first 5 or 10 per site
- Survey of policy and practice on retention in care.

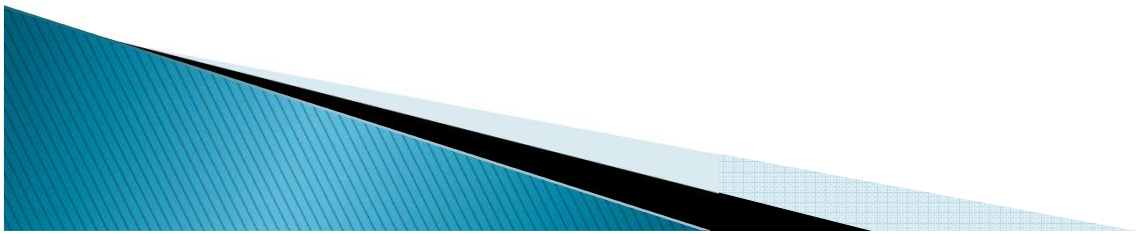


Outcomes

- Out of 2,255 patients:
  50 (2.2%) not identified
  964 (42.7%) probably in UK
  578 (25.6%) status unknown
  590 (26.2%) probably left UK
  73 (3.2%) died



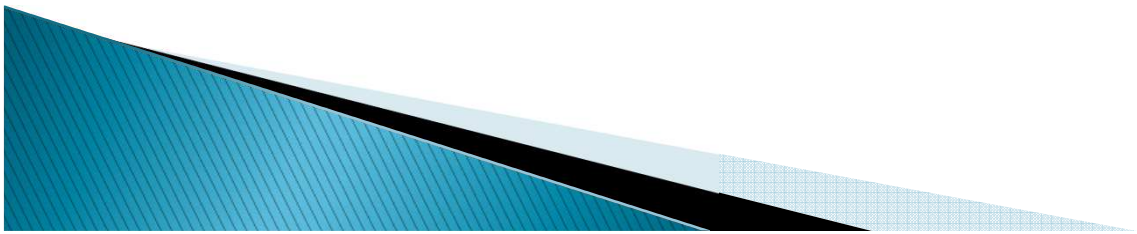
- Of 964 probably in UK
  508 (22.6%) in care/presumed in care
  262 (11.6%) out of care
  194 (8.6%) not known/answered
- Status in 2011 not known for 822 (36.5%) patients
- 456 (20.2%) presumed out of care



- Being out of care associated with being:
  - Younger (<40yrs)
  - Male
  - Black African
  - ARV naïve
  - CD4 >200
  - Previously an irregular attender

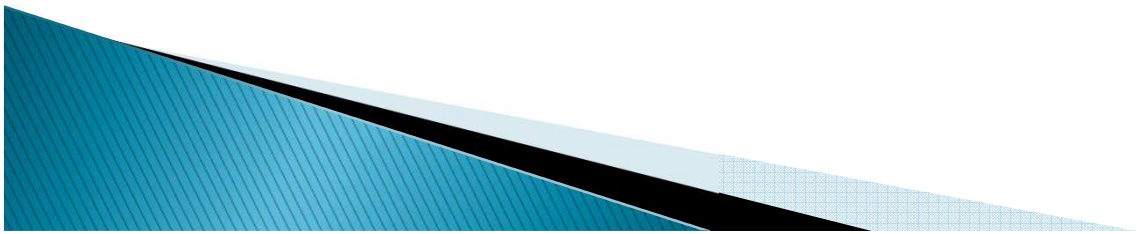
- No statistically significant differences found between those in or out of care for factors including:

  Stigma, poverty, immigration status, mental illness, childcare responsibilities, alcohol/drug dependence, shift work/employment issues, HIV symptoms, poor ART tolerability



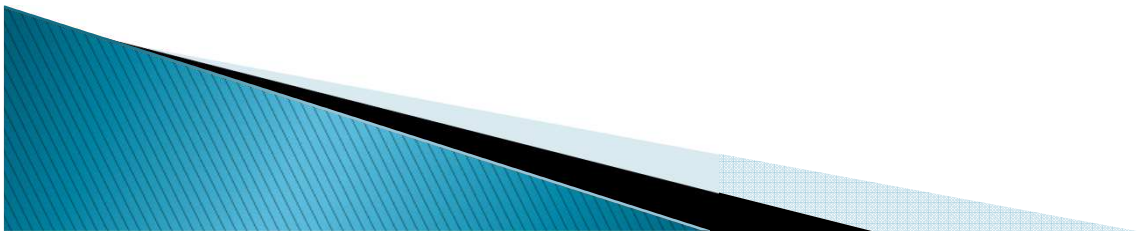
Policies on non-retention

- 134 sites completed the survey
- 17 (13%) had a written and 106 (79%) an unwritten or informal policy on retention
- 90 (67%) routinely discuss non-attenders in MDT, but 23 (17%) only for vulnerable patients
- 40 (30%) have a written policy or template for information for patients transferring out



Conclusions of audit

- Leaving the UK accounts for over a quarter of cases of apparent non-retention
- The outcome for many patients was unclear.
- However, auditors estimated that at most 2.6% of people seen for care in 2010 remained in the UK and out of care during 2011



Examples of strategies to retain patients in care

- BHRUT Outpatients East – Virtual Recall Clinic
- 1 dedicated session per week run by HIV health advisor
- Patients referred to VRC if not attended for 6 months
- HA tries to contact by all details given, through referrer, ward, Positive East etc.
- Last resort writes to patient informing GP will be informed if no contact made

- Clinic started Dec 2012
- 41 patients for recall
- 3 transferred care to other clinics
- 3 traced but not accessing care anywhere
- 12 returned to treatment at BHRUT
- Questionnaire completed with patients on return to care to help identify how we can avoid disengagement in future

Barking, Havering and Redbridge NHS
University Hospitals
NHS Trust

Returning to Treatment Assessment

Completed by:
Date:

Patient Identifier:

When was the last time you attended this clinic?

Was there a reason why you didn't /couldn't attend?

Were you receiving treatment somewhere else?

When was your last prescription for ARVs?

What was the prescription for?

Who provided the prescription?

Any other medication?

How do you feel your general health is?

Have you been admitted to hospital since we last saw you?

Have you been seen by your GP since we last saw you?

Have any of your contact details changed?

New address: Can we write to this address? Y/N

Any problems with this accommodation?

New Phone number:

New GP: Can we contact your GP? Y/N

Next of Kin: Can we contact your NOK? Y/N

Can the CNS contact you? Y/N

Have any other of your circumstances changed?

Occupation:

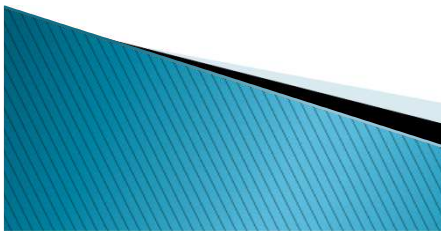
Immigration status:

Any problems at home?

New Partner:
Tested/needs testing

Pregnant/Children:

Financial:



Other agency involvement:
Social services/health visitor/mental health team/voluntary agencies

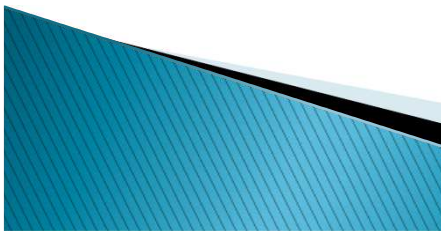
Emotional Health:

How do you feel about returning for HIV treatment?

On a scale of 1 – 10 (1 being least ready and 10 being fully committed) how ready do you feel to engage with the clinic?

On the same scale – how ready do you feel to commit to taking ARV treatment again?

Is there anything else you need help with/support for/information about?



Actions/Follow Up

Referrals made		**Contact details**
Social services – Adult disabilities team	□	
Social Services – Children and families team	□	
Occupational Therapy	□	
District nursing	□	
Specialist Midwife	□	
Health visitor	□	
Community CNS	□	
CMHT	□	
Psychology	□	
Health advisor	□	
Positive East	□	
Dietician	□	
Alcohol/Drug Service	□	

Bloods taken today: CD4, Viral Load, Resistence Study, STS, Heps A B C, LFT, U&E, Ca (Bone/Phosphate), Lipids, LDL (Cholesterol) HDL (triglycerides) RBS, FBC, Glucose, Vitamin D

Taken by:

Urine:

Albumin Creatine Ratio	□	
NAATS:	□	
Pregnancy test:	□	POS/NEG
NAATS (self taken HVS)	□	

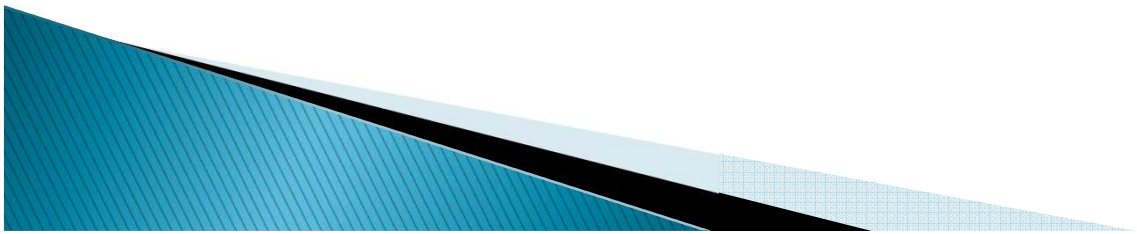
Doctor's appointment made for:

Medical Summary requested (if applicable) Date of letter:

GP informed of attendance (if referred by GP) Date of letter:

Role of Community Nurses

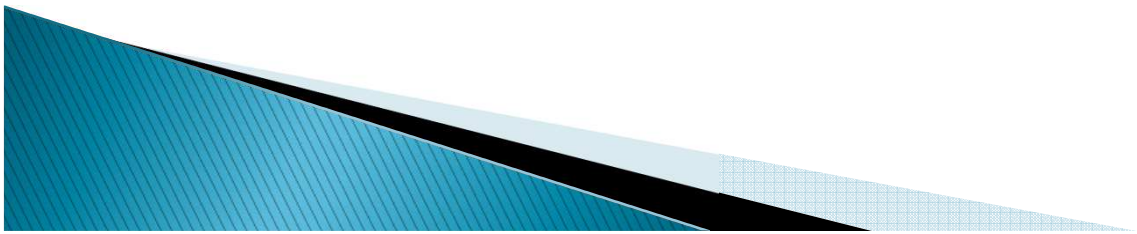
- Unannounced visits to patients problematic for reasons of security and confidentiality
- Patients also have right to choose not to attend…think back to Mental Capacity Act
- Potentially damaging to relationship with clinic/nursing team if patient's feel privacy/confidentiality has been compromised



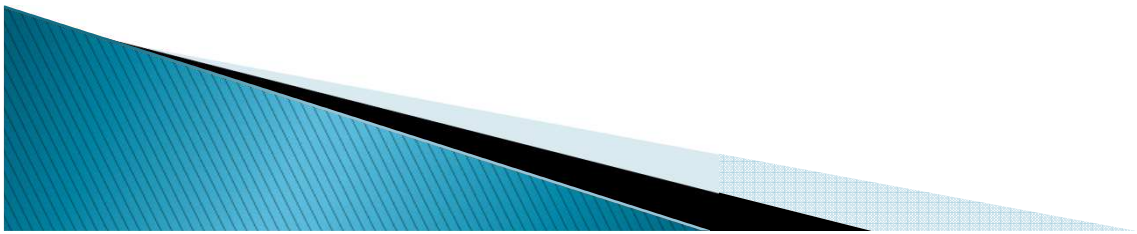
Case Study – Michael

- 36 year old Nigerian born man, lived most of life in UK
- Referred to community nursing team in November 2009 by his outpatient HIV clinic in north-west London
- Recently released from prison
- CD4 3, VL 250,000c/ml
- Multi-drug resistant virus and history of multiple adherence problems.
- Not attended treatment centre since release from prison – clinic very keen to re-engage him

- CNS contacted Michael by letter after 3 attempts and met with him in a community clinic
- He reported a chaotic lifestyle since release from prison; partner recently had a baby; trying to find work
- He reported difficulty in attending outpatient clinic appointments so far away from where he lived

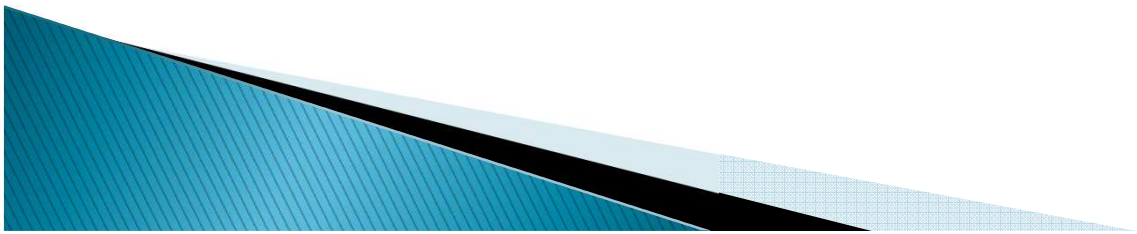


- CNS linked him into local treatment centre and he was recommenced on antiretroviral medication and given a course of hepatitis B vaccination
- He declined community support at this time as he felt he needed to try and get his life in order by himself

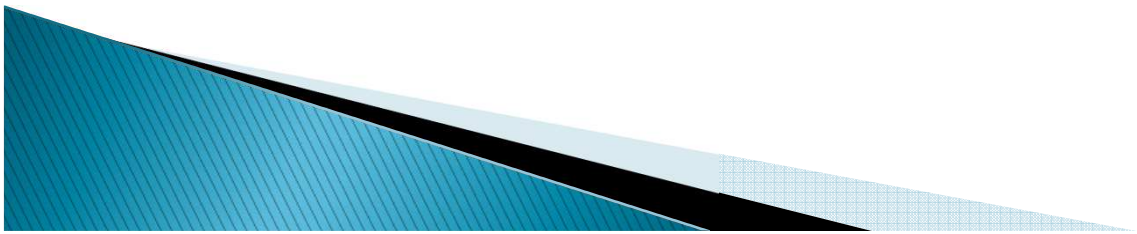


- April 2010 CNS noticed Michael had not attended most recent clinic appointments and would soon be running out of medication
- When CNS called Michael he reported erratic adherence – brother recently died in Africa and he and his partner were having problems in their relationship

- CNS re-engaged with Michael and provided adherence support, including practical support around dose timing and remembering doses, emotional support around coming to terms with HIV diagnosis, which was very linked to his adherence, as well as support around managing problems in his life



- Michael needed frequent prompting to attend appointments and also required support in accessing his GP regarding some other health issues
- Michael declined referral to psychology but agreed to see CNS on weekly/two weekly basis
- As well as adherence support CNS also provided information and advice around safer sex and disclosure of multi-drug resistant status to partners, and PEP



- By January 2011 Michael's CD4 count had risen to 160, his viral load had fallen to 250 and he was attending most of his outpatient clinic appointments
- He told the CNS that if she had not persisted in keeping in contact with him he would no longer be attending his treatment centre or taking his medication as he had not previously seen the point

In Summary

- Structures for monitoring clinic attendance and pathways for following up patients who disengage from care essential
- Multidisciplinary team approach helpful – appropriate utilisation of community nursing teams can be of great value in retaining patients in care
- Role of the GP?

Thank you