Treatment Cascade:
Challenges of retaining people in care

Eileen Nixon
Brighton and Sussex University Hospitals

Odd one out in Leeds?

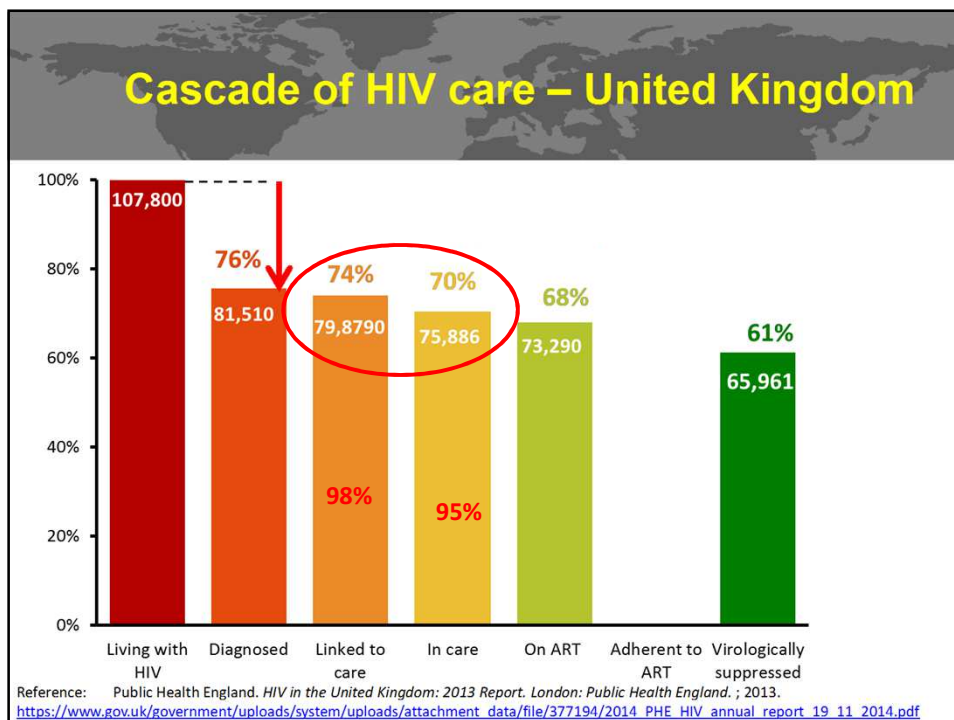# Odd one out in Leeds?

Odd one out in Leeds?

Plan for session

Why is it important to retain people in care

How do we identify who is lost to follow-up

What frameworks and preventative strategies can we use in practice?

Cascade of HIV care – United Kingdom

Reference: Public Health England. *HIV in the United Kingdom: 2013 Report. London: Public Health England.* ; 2013.
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/377194/2014_PHE_HIV_annual_report_19_11_2014.pdf

Fine Tuning OR Essential Maintenance?

Biomedical, Public Health and Economic Perspective

Poor retention in HIV care has been associated with:

- Reduced adherence to ARVs
- Increased morbidity
- Increased hospital admission
- Potential for onward transmission

Bakken, Holzemer and Brown et al, 2000; Mugavero, Davila and Nevin et al, 2010; Mugavero, Norton and Saag, 2011; Gardner, McLees and Steiner et al, 2011; Lee, Rayment, Scourfileld et al, 2012; Estill, Tweya and Egger et al, 2014

Reach Study

Higher engagement in-care is associated with improved clinical outcomes, at least one year into the future as well as among those on ART

Largely explained by poorer CD4 profiles in those with sub-optimal engagement in-care

REACH

Slide Source: Caroline Sabin (adapted)

Other disease areas?

- Joint replacement
  - Murray, Britton and Bulstrode 1997
- Diabetes
  - Griffin 1998
- Adult Congential Heart Disease
  - Norris, Webb and Drotar et al 2012
- Glaucoma
  - RNIB 2014
- TB
  - Active case finding, finding lost to follow-up and case management

UK targets and standards

HIV Service Specification: Key Performance Indicators

– Reduction in the proportion of patients lost to follow up and in do not attend rates
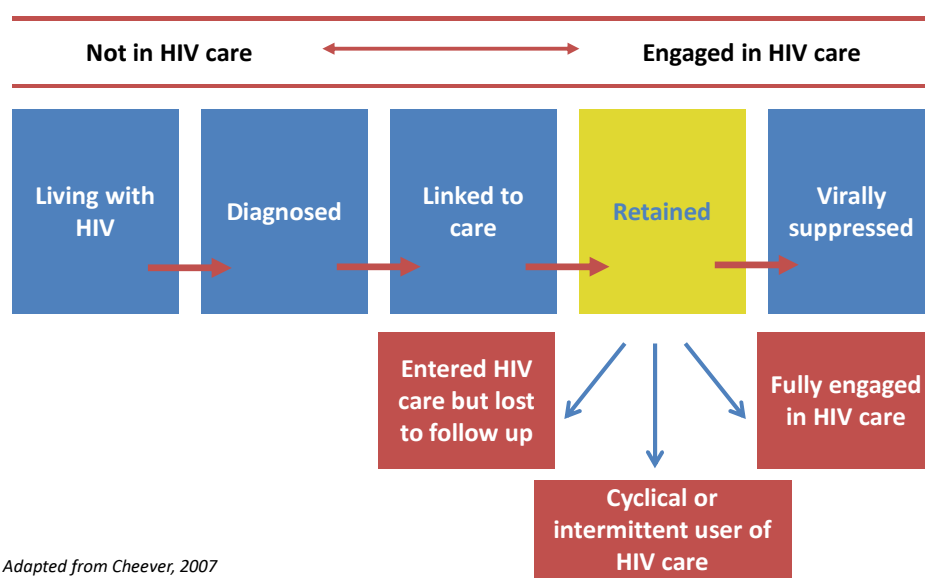
HIV Service Specification: Available at:

http://www.england.nhs.uk/wp-content/uploads/2013/06/b06-spec-hiv-serv.pdf

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'

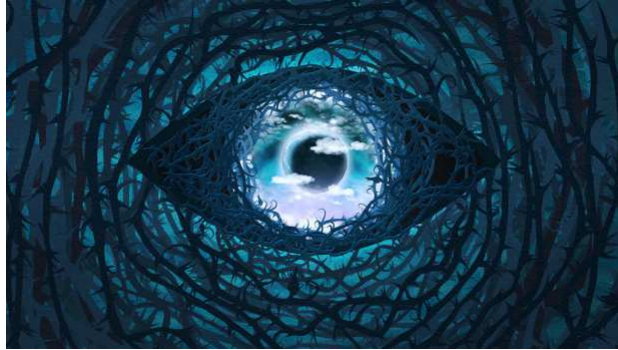*BHIVA Standards of Care for People Living with HIV, 2013*

Continuum of HIV care

Not in HIV care ←——————→ **Engaged in HIV care**

| Living with HIV | Diagnosed | Linked to care | Retained | Virally suppressed |

Entered HIV care but lost to follow up

Cyclical or intermittent user of HIV care

Fully engaged in HIV care

Adapted from Cheever, 2007

Lost to follow-up

HAVE YOU ATTENDED YOUR HIV APPOINTMENT?

BIG BROTHER IS WATCHING

Tory plans to deny patients the right to refuse treatment are an assault on human rights
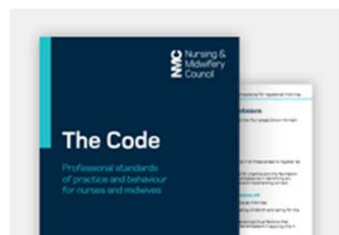
Peter Kinderman 18 April 2015

"People who might benefit from treatment should get the medical help they need so they can return to work. If they refuse a recommended treatment, we will review whether their benefits should be reduced."

Conservative Party Manifesto, pg 28

https://www.opendemocracy.net/ournhs/peter-kinderman/tory-plans-to-deny-patients-right-to-refuse-treatment-are-assault-on-human-ri.

Professional Guidance

General Medical Council

The Code
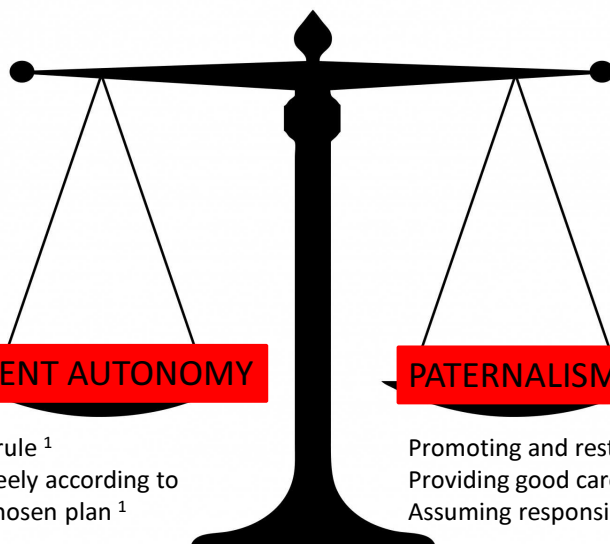Professional standards of practice and behaviour for nurses and midwives

Patients who refuse treatment
24. You must **respect a competent patient's decision to refuse an investigation or treatment, even if you think their decision is wrong or irrational.**

http://www.gmc-uk.org/guidance/ethical_guidance/21181.asp.

4.1 balance the need to act in the best interests of people at all times **with the requirement to respect a person's right to accept or refuse treatment**

http://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/revised-new-nmc-code.pdf.

PATIENT AUTONOMY

PATERNALISM

Self –rule [1]
Act freely according to self-chosen plan [1]

Promoting and restoring health [2]
Providing good care [2]
Assuming responsibility [2]

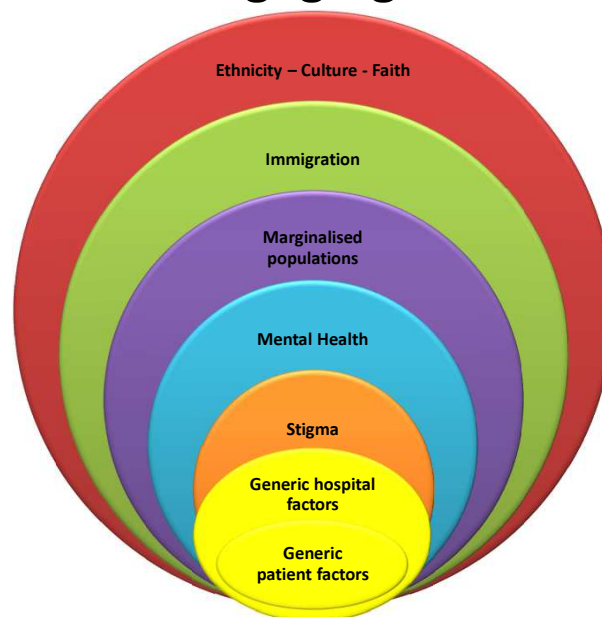[1] Varelius, J. (2006) The value of autonomy in medical ethics. Medicine, Health Care and Philosophy 9:377–388
[2] Pelto-Piri,V., K. Engström and I. Engström. 2013. Paternalism, autonomy and reciprocity: BMC Medical Ethics 14:49
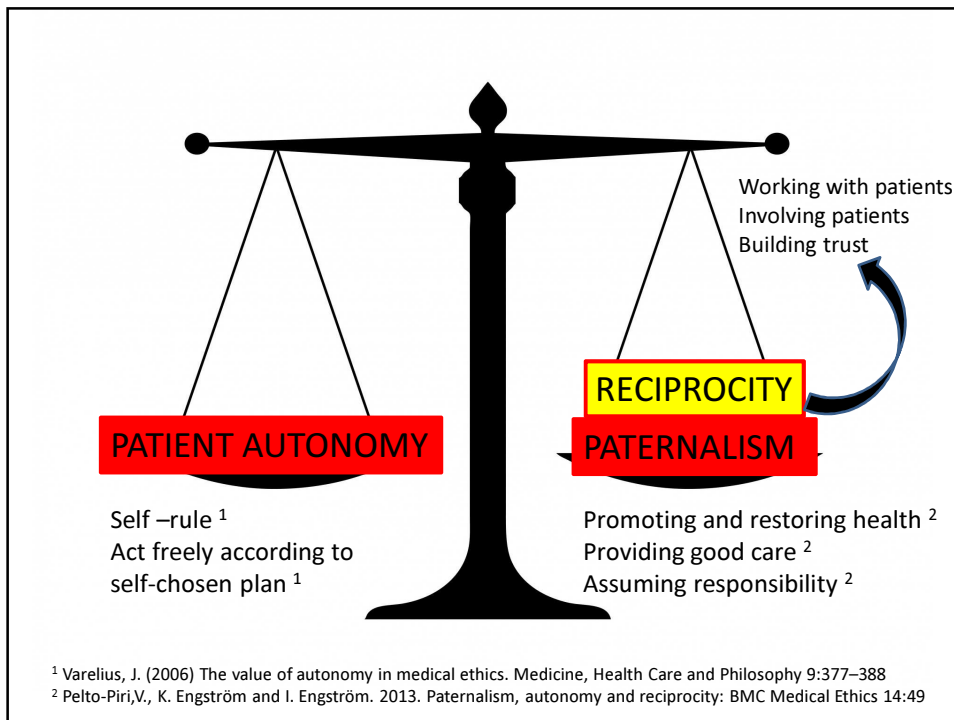
Autonomy and Decision-making Capacity

- Levels of autonomy
- Affected by
  - Degree of self-congruence[1]
  - Susceptibility to control[1]
  - Interest in own actions[1]
  - Compulsive behaviour[2]
  - Coercion[2]

Decision-making capacity

- **Decision specific**
- Understand information
- Retain information
- Weigh or use information

[1]Weinstein N., A Przybylski and R. Ryan. The index of autonomous functioning: *Journal of Research in Personality* 46 (2012) 397–413. [2]Varelius, J. (2006) The value of autonomy in medical ethics. Medicine, Health Care and Philosophy 9:377–388

Barriers to engaging in HIV care

Ethnicity – Culture - Faith

Immigration

Marginalised populations

Mental Health

Stigma

Generic hospital factors

Generic patient factors

Stigma (*Naar-King et al, 2007*); Mental Health (*Tobias et al, 2007*); Marginalised populations (*Rajabiun et al, 2007*); Morrison et al, 2011
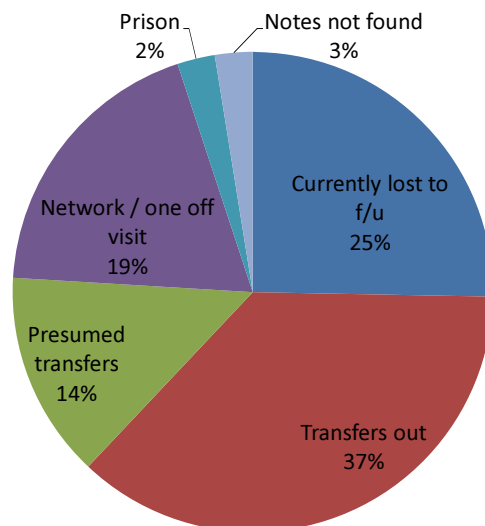
Working with patients
Involving patients
Building trust

RECIPROCITY

PATIENT AUTONOMY

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Identifying lost to follow-up

How do we know who is lost to follow-up

Data capture of people not seen for 8 and 12 months

Pharmacy systems and medication pick-ups

Multidisciplinary teams

Data breakdown of reported LFU data

Prison
2%

Notes not found
3%

Network / one off visit
19%

Presumed transfers
14%

Currently lost to f/u
25%

Transfers out
37%

81 patients reported as LFU 2012, Lawson Unit , Brighton

How do we find patients?

Home visits

Other healthcare teams

Letters and registered mail

Outreach

Community groups

Social media

Phone calls

Significant others

Standard versus individualised letters

WHERE, WHO AND HOW

WHAT TO EXPECT

NAMED CONTACT

Considerations for tracking patients

Does it work?
- Mc Mahon, Elliott and Hong et al. 2013

When do we stop?

Engaged with any service?

Do we actively discharge patients?
- Grant, Bowen and Sivia et al 2014

What do we do when we find patients?

| DO's	DON'Ts
• Individual plans of care with the patient	• Throw the kitchen sink at them
• Case management (?enhanced)	• Rush decisions
• Building trust	• Immediately restart ARVs

Tools for assessing priority needs

HOSPITAL NO: NAME: DOB:

We would like to know about your worries and concerns today. Please circle a number on the thermometer below and tick any boxes that are relevant to you.

10 Many Worries

10
9
8
7
6
5
4
3
2
1
0

0 No Worries
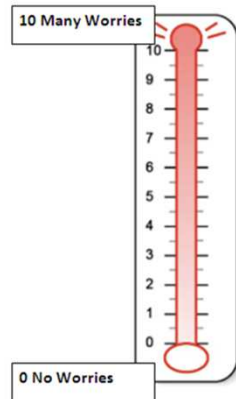
PRACTICAL PROBLEMS
- ☐ Housing
- ☐ Financial
- ☐ Benefits
- ☐ Immigration
- ☐ Employment
- ☐ Childcare
- ☐ Transport

SOCIAL PROBLEMS
- ☐ Relationships (family, friends, partner)
- ☐ Difficulty telling others about your diagnosis

MEDICATION PROBLEMS
- ☐ Side effects of medication
- ☐ Difficulty remembering medication

PSYCHOLOGICAL PROBLEMS
- ☐ Loneliness or isolation
- ☐ Depressions or sadness
- ☐ Worries about the future
- ☐ Difficulty accepting your diagnosis
- ☐ Concerns about stigma/confidentiality

SPIRITUAL/RELIGIOUS ISSUES
- ☐ Questioning beliefs and values
- ☐ Conflicts between faith and HIV

OTHER
- ☐

Preventative Strategies

Patient factors associated with disengagement

BHIVA Audit
- – Younger
- – More recently diagnosed
- – Black-African ethnicity
- – Being ART naïve
- – Poor attendance
- – Poor adherence

In collaboration with the Health Protection Agency 2013.
Source: Hilary Curtis, Audit co-ordinator

Health Beliefs

- – Avoidance / disbelief of HIV diagnosis
- – Conceptions of illness
- – Negative experiences and distrust

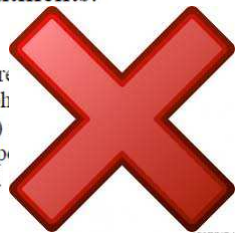*Beer, Fagan and Valverde et al, 2009*

Promoting appointment attendance

Number of patients who didn't attend their appointments

Week commencing:

Over this week we had _____ patients who didn't attend for nurse appointments and _____ who didn't attend for doctor appointments.

If you are _____ ointment please ph _____ am – 4.30pm) _____ n offer your app _____ nt who needs it.

Lawson Unit
LEADING HIV CARE FOR BRIGHTON

Goldstein, Martin and Cialdini. 2007

The Lawson Unit
LEADING HIV CARE FOR BRIGHTON

Attending your clinic appointment

If, for any reason, you are unable to attend your appointment at the clinic, will you please phone us to let us know?

Telephone 01273 664722: Option 3
(9.30am – 4.30pm)

Appointment reminders?

Systematic review of telephone and SMS appointment reminders [1]

- 34% increase in attendance with any reminder
- Automated reminders less effective
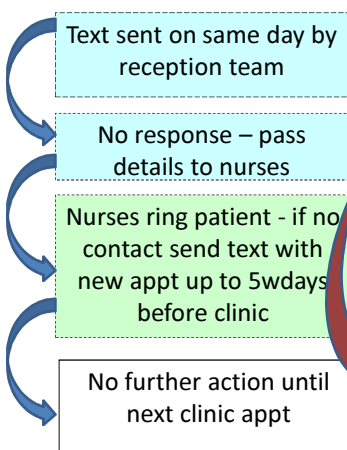
Cochrane Review of text messages [2]

- Moderate evidence that SMS reminders better than no reminders and as good as phone reminders
- Low grade evidence that texting plus letter better than letter alone
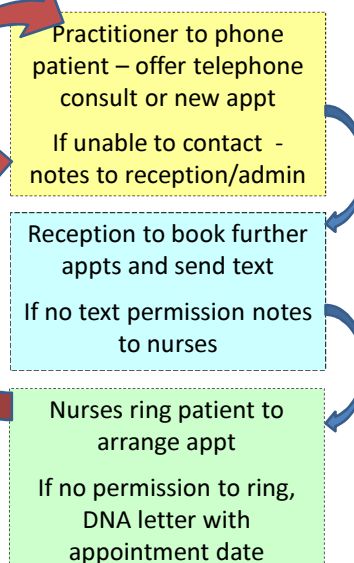
[1] *Hasvold and Wooton, 2011*
[2] *Car, Gurol-Urganci and de Jongh et al, 2012*

Managing DNAs

Routine blood appointments

- Text sent on same day by reception team
- No response – pass details to nurses
- Nurses ring patient - if no contact send text with new appt up to 5wdays before clinic
- No further action until next clinic appt

If persistent DNA identify at risk of LFU

Clinic appointments

- Practitioner to phone patient – offer telephone consult or new appt

  If unable to contact - notes to reception/admin
- Reception to book further appts and send text

  If no text permission notes to nurses
- Nurses ring patient to arrange appt

  If no permission to ring, DNA letter with appointment date

Provider Factors

Facilitators

Connecting

Validating

Partnering

Trust / Knowing

Barriers

Patronising response

Power differential

Mallinson, Rajabuin and Coleman et al. 2007;
Graham, Giordano and Grimes et al. 2010; Flickinger, Saha and Moore et al. 2013

Conclusions

Maintain respect for autonomy

BUT consider factors that may impact on decision-making capacity

Sustain a model of care that enables patients to remain in care and return to care