

# Outcomes in HIV

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speaking in personal capacity

# Background

- NHS Choices website
- Transparency in Outcomes/NHS Outcomes Framework
- Broader outcomes agenda

# Transparency in Outcomes

“All too often, the NHS has been hamstrung by a focus on nationally determined process targets which have had a distorting effect on clinical priorities, disempowered healthcare professionals and stifled innovation. We therefore need to recalibrate the whole of the NHS system so it focuses on what really matters to patients and carers and what we know motivates healthcare professionals - the delivery of better health outcomes.”

# Process or outcome?

## Outcome:

- Actual health/well-being
- Comparison needs poor outcomes
- Measurement issues
- Time delay
- Low variability
- No clue to action needed.

## Process:

- Needs validation
- Often measurable
- Large variability
- Identifies *how* to improve

If valid, may be re-defined as outcome, eg % baseline tested for HIV resistance or involved in care decisions.

# NHS Next Stage Review

Identified quality as:

- the **effectiveness** of the treatment and care provided to patients;
- the **safety** of the treatment and care provided to patients; and
- the broader **experience** patients and their carers have of the treatment and care they receive.

# NHS Outcomes Framework

To be made up of a focussed set of national outcome goals that will provide an indication of the overall performance of the NHS.

NHS Commissioning Board will work with clinicians, patients and the public to develop the set of indicators it will use to operationalise the national outcome goals.

# Outcome domains

Preventing people from dying prematurely

Enhancing quality of life for people with long-term conditions

Helping people to recover from episodes of ill health or following injury

Ensuring people have a positive experience of care

Treating and caring for people in a safe environment and protecting them from avoidable harm

# Within each domain

- An overarching outcome indicator or indicators to measure progress across the breadth of NHS activity covered by the domain
- Approximately five, more specific, improvement areas with supporting outcome indicators
- A suite of supporting Quality Standards developed by NICE setting out the structures and processes of care most likely to deliver improved outcomes for the overall domain as well as the specific improvement areas

# HIV-relevant

- Long term conditions: feel confident and supported to self-manage
- Long term conditions generic PROM
- Emergency admissions
- ???Patient experience

# Existing HIV outcomes

London Commissioners' Consortium baseline:

- Time from HIV diagnosis to first CD4 count at same centre (100% within 28 days)
- VL <50 and still on ART 1 year after first started (85% of patients with available VL)
- CD4  $\geq$ 200 after 1 year or more at centre (90% of patients still in care)
- Proportion still alive by 1, 2, 3 years from HIV diagnosis, stratified by CD4 count at diagnosis (no standard).

# HIV CQINS/QIPP

- 80% confirm involved in care decisions, given access to information, supported to self manage
- 80% without resistance on NNRTI
- 95% sustain undetectable VL and avoid resistance
- 95% with CD4<200 on therapy
- 90% with STI have support and advice around behaviour change
- 80% notified for TB tested for HIV
- Baseline partner notification / promotion of testing for partners / family members at risk
- Of patients disclosed to GP, letter sent to the GP in last 12 months for 80%

# Why do outcomes vary?

- Random fluctuation
- Reporting/recording bias
- Data error
- Casemix
- Quality of care.

# Which outcomes matter?

In HIV, personally speaking:

- Excellence in managing complex disease/co-morbidity (one-offs, networks)
- VL suppression (small variability, may be largely casemix)
- Retention in care (perverse incentives)
- Patient experience.

# BHIVA Audit 2011

Patients in care in 2009:

- VL among those ever started on HAART
- CD4, to identify those who *should* have started
- BP, lipids measured, possibly also vaccinations

Survey of psychosocial support, enabling attendance/adherence.

# What information matters to you?

To assist patients and commissioners in choosing providers – need not be measure of quality

To facilitate change and improvement:

- Robust indicators
- Reflect quality – effectiveness, patient experience, safety
- What matters, not just what's measurable.