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Lack of implementation of PROMS

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Lack of Implementation of PROMs

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Conflict of Interest

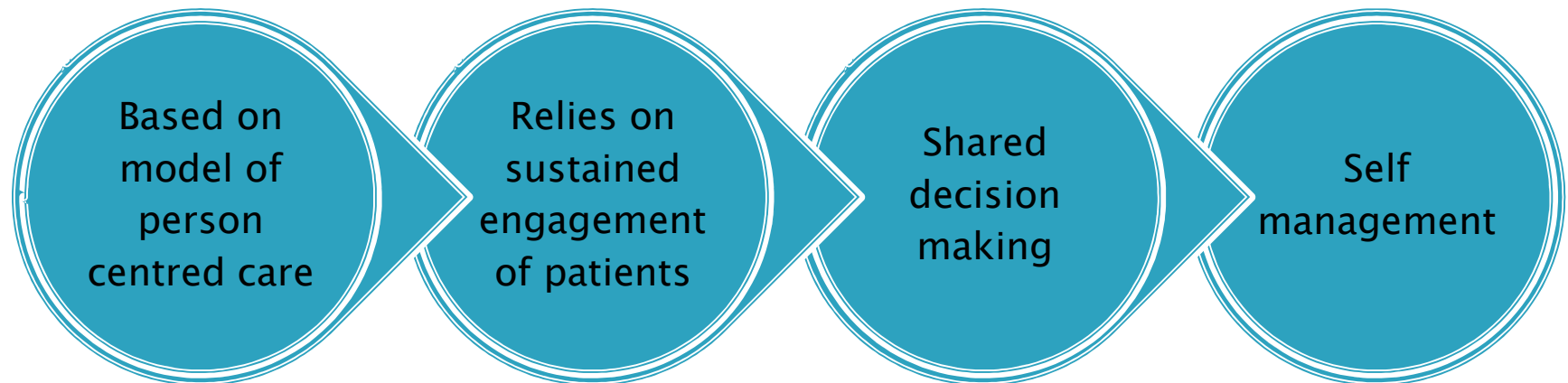
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Virology education

Set the scene

- ▶ NHS Plan and HIV Action Plan
 - ▶ Background: Concerns and PROMs in HIV
 - ▶ PROMs tools
 - ▶ Priority PROMs Areas for inclusion
 - ▶ Implementation questions
 - ▶ Possible barriers of HIV PROMs implementation
 - ▶ Benefits of HIV PROMs
 - ▶ Factors that would facilitate effective use of PROMs
 - ▶ What next?
 - ▶ Summary
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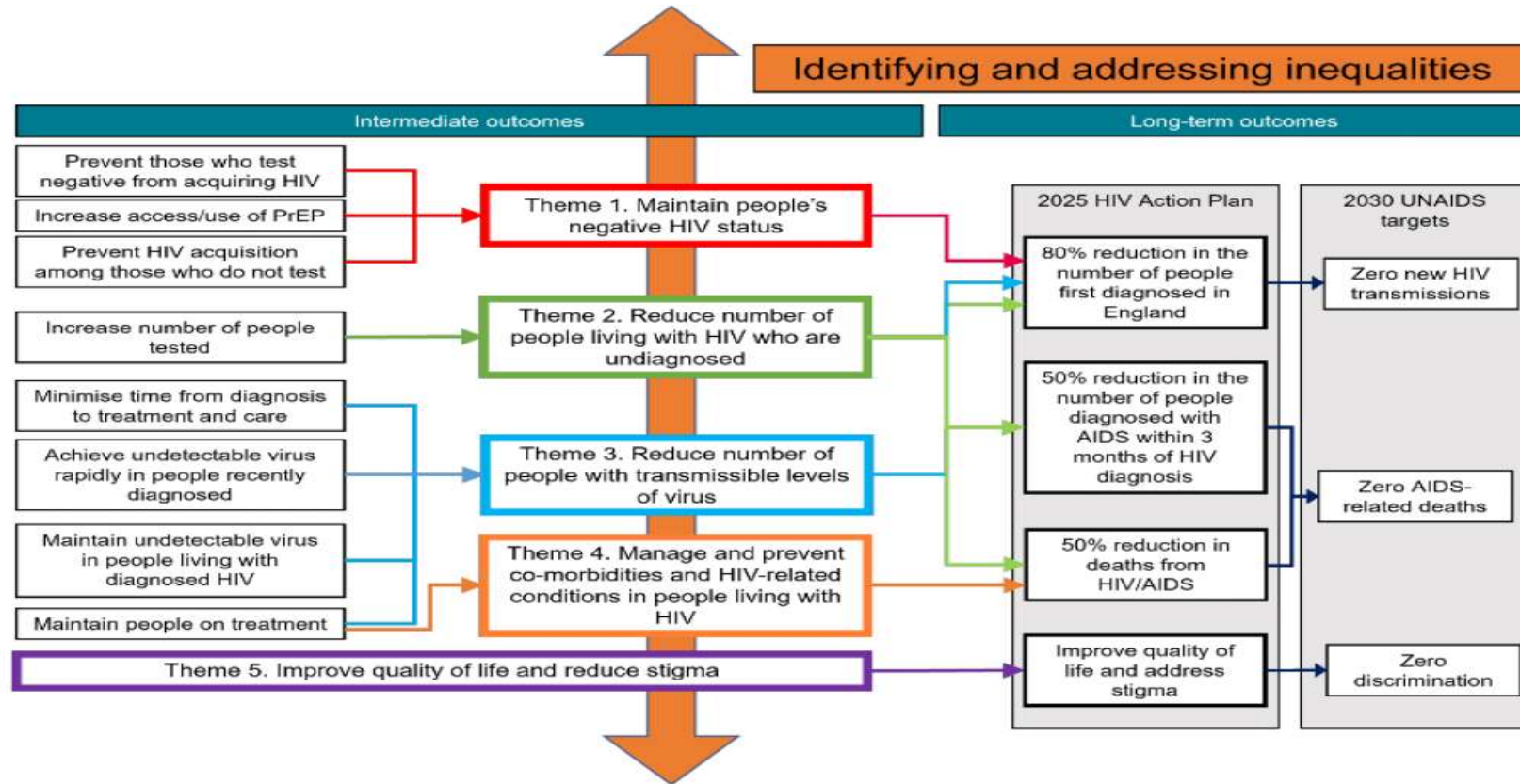
PROMs and HIV

NHS Long term plan – 2019



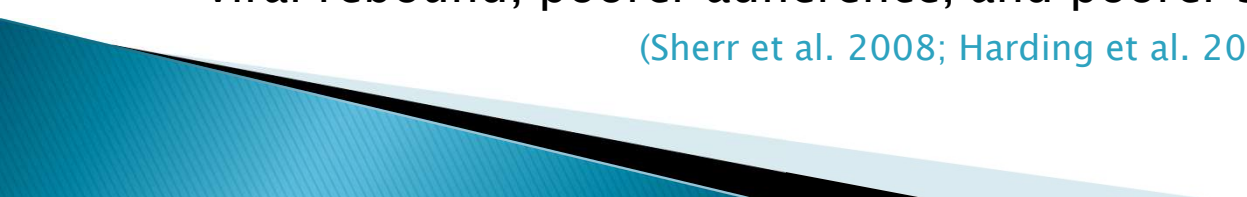
PROMs and HIV

The HIV Action Plan for England, 2022



PROMs and HIV

Background: Concerns

- ▶ UK outpatients attendees perceived care does not address issues of physical, mental & social wellbeing that matter
(Harding et al. 2008)
 - ▶ Contribution of physical and mental health to Health Related Quality of Life is currently a “critical challenge” in HIV medicine
(Buscher et al. 2010)
 - ▶ High symptom burden: physical, psychological, social and spiritual concerns and emerging physical complications (e.g. bone density, cardiovascular, renal, liver, malignancies)
(Simms et al. 2011; Harding et al. 2010; Harding et al. 2011)
 - ▶ Physical and psychological symptoms are associated with sexual risk taking, viral rebound, poorer adherence, and poorer self-rating of health
(Sherr et al. 2008; Harding et al. 2010; Lampe et al. 2010; Harding et al. 2012)
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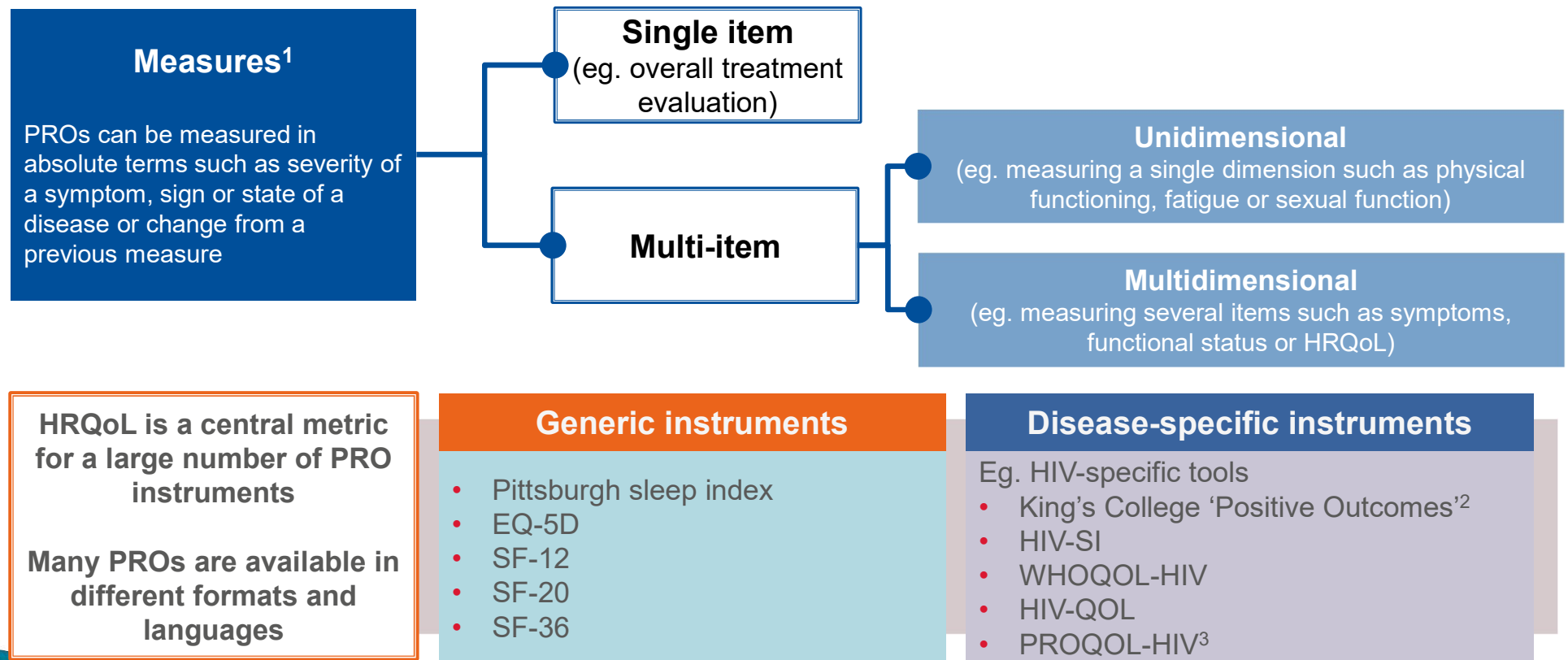
PROMs and HIV

Background: PROMs in HIV

- ▶ HIV practitioners often miss patients' needs and symptoms, especially non-physical ones
(Justice et al.2001)
- ▶ PROMS are used in clinical trials, but not in routine HIV care
(Simpson et al. 2013)
- ▶ Routine use of PROMs helps identify problems/concerns & improves outcomes for patients
(Greenhalgh et al. 2009; Boyce & Brown 2013)
(Engelhard et al. 2017; Boyd et al. 2014)
- ▶ The Wellness Thermometer: healthcare professionals' experiences of using the tool in practice
(Croston et al. 2015. 17th Annual Conference of NHIVNA)

PROMs and HIV

PROs may be assessed using a variety of available tools tailored to different clinical scenarios



PROMs and HIV

Several PRO tools developed for the HIV setting

There is a need for valid PRO tools for assessing impact of long-term AEs (ie. metabolic, CV and skeletal effects)^{1,2}

Examples of several HIV-specific PRO tools at various stages of development:

- **PROQOL-HIV**
 - Uses multiple languages and accounts for HAART treatment and AEs
 - 70 items (67 items across 11 themes and 3 independent items)³

- **King's College London's HIV-specific PRO tool 'Positive Outcomes'**⁴
 - Reflects outcomes based on insights from PLHIV and HIV specialists
 - Six domains of need: physical, cognitive, psychological, welfare, social and information
 - Developed to drive routine HIV care

- **HIV Stigma Scale**
 - Patient stigma has been historically associated with depression, non-disclosure, contributing to higher morbidity and transmission of HIV⁵
 - A shorter HIV Stigma Scale PRO tool may facilitate more widespread assessment of HIV stigma⁶

PROQOL-HIV item examples by theme

Theme	Example Item
General health perception	... my overall health (both HIV and non-HIV related) has been
Social relationships	I have felt restricted in my relationships with my family or friends
Emotional distress	I have felt ashamed
Energy/fatigue	I have felt tired
Sleep	I have had difficulty sleeping
Cognitive functioning	I have had problems with my memory
Physical activity	I have had difficulty with daily activities
Coping	HIV has prevented me from living a normal life
Future	I have had difficulty making long-term plans
Impact on symptoms and side effects	I have been bothered by pain
Treatment	I have had to hide to take my HIV medicine

AE, adverse events; ART, antiretroviral therapy; CV, cardiovascular; HAART, highly active antiretroviral therapy; HRQoL, health-related quality of life; PLHIV, people living with HIV; PRO, patient reported outcome; PROQOL-HIV, PRO quality of life-HIV.

1. Simpson N, et al. *Health Qual Life Outcomes* 2013;11:164; 2. Sekhar H, et al. *Drugs* 2013;73:651–72; 3. Duracinsky M, et al. *J Acquir Immune Defic Syndr* 2012;59:498–505; 4. Bristowe K. A novel patient reported outcome measure for people living with HIV: development, face and content validity and stakeholder views on implementation. Available at: www.bhiva.org/file/xRtasJbTvYFkh/KatherineBristowe.pdf. Last accessed: August 2019; 5. Simbayi LC, et al. *Soc Sci Med* 2007;64:1826–31; 6. Hamus M, et al. *Health Qual Life Outcomes* 2017;15:115.

PROMs and HIV

4th 90 – Health Reported Quality of Life

- ▶ PROMs are multidimensional – measuring several items such as symptoms & functional status
- ▶ PROMs improve communication and awareness of unmet needs in the patient care pathway among HCPs.
 - Positive impact on communication and patient satisfaction¹ (strong evidence)
 - Positive impact on communication² (strong evidence)
 - Improves awareness of unmet need³ (moderate evidence)
 - Supports professionals to better address patients' needs³ (moderate evidence)

^aData generated in oncology patients and palliative care.

HCP, healthcare professional; PRO, patient-reported outcome.

1. Chen J, et al. *BMC Health Serv Res* 2013;13:211; 2. Lockett T, et al. *Psycho-oncology* 2009;18:1129–38; 3. Etkind SN, et al. *J Pain Symptom Manage* 2015;49:611–24.

PROMs and HIV

Priority PROMs Areas for inclusion

Physical

Cognitive

Psychological

Welfare

Social

Information
needs

PROMs and HIV

Implementation questions

For which reason do we use PROMS?

- Screening, Diagnosis, Monitoring, Shared decision making – End of life care, care plans

Are there any standard set of PROMs being used?

Any recommended tool?

How frequent we should use them?

Any group of patients that could be more effective on?

How do they inform care?

Resources needed and who needs to be involved and how?

PROMs and HIV

Possible barriers of HIV PROMS implementation

Diversity of the HIV population

Diversity of need depending on the time since diagnosis

Health literacy– ability to read

Asking about areas we can not help with

Measurable outcomes and not “tick box exercise”

Reliability of a single tool

Awareness of coordinated implementation strategy

Lack of outcome data to evidence the benefits in HIV

PROMs and HIV

Benefits of HIV PROMs

People living with HIV

- ▶ Patient centeredness and empowerment
- ▶ Help raise concerns, feel heard, valued and share sensitive information
- ▶ Build resilience and self confidence
- ▶ Encourage referrals for additional support
- ▶ Reduce assumptions and monitor changes over time
- ▶ Ability to encourage engagement
- ▶ Get to know your patients better
- ▶ Help clinicians go beyond viral suppression and adherence.

Services

- ▶ Plan service according to patients needs
- ▶ Helps understand the changes in HIV care
- ▶ Efficiencies
- ▶ Reassurance and confidence in clinicians
- ▶ Provides good evidence for new spending needs

NHS England. Comprehensive model of personalised care. 2019; <https://www.england.nhs.uk/personalisedcare/comprehensive-model-of-personalised-care>

Wheat H, Horrell J, Valderas JM, *et al.* Can practitioners use patient reported measures to enhance person centred coordinated care in practice? A qualitative study. *Health Qual Life Outcomes* 2018; 16(1): 223. DOI: <https://doi.org/10.1186/s12955-018-1045-1>

PROMs and HIV

HCP's Perspective on PROMs



Reflect the range of outcomes for people living with HIV



Drive, evaluate and improve quality of care



Find a tool that would enable patients to discuss all areas that impacts on their quality of life



People living with HIV are at the heart of everything we do



Engage in a dynamic way that reflects the diverse needs of people living with HIV



Develop a culture which proactively takes steps to build collaborative relationships:- listen to, and respond to, their concerns and preferences; give information in the way they understand

PROMs and HIV

Factors that would facilitate effective use of PROMs

Integration with current processes or systems

Integration with electronic health records

Automatically generated and distributed questionnaire to patients

Timing of completion

Validated and approved tool – simplicity

Attitude or motivation to the implementation

External policies and incentive – mandatory

Multimorbidity tool

Seen as a priority

Start on ad hoc basis

Training

Patient Engagement – e.g. Positive Voices, 2017

PROMs and HIV

What next?



Create and communicate a compelling body of evidence of their efficacy and benefits.



Embed in clinic processes and becomes business as usual.



Consensus on which tool to use and support with implementation.



The use of technology to support the role out is key.



Tools to be in different languages considering the demographics.



Annual health review to incorporate this.



Wider team engagement and links with other NGO for support.

PROMs and HIV

Summary

Focus on what matters most to people living with HIV to ensure personalised effective quality of life

Ensure equality, equity and inclusion principles are embedded in the way we deliver patient engagement

People living with HIV to have access to high quality care when they need it

People living with HIV should feel valued and always supported and receive excellent HIV care

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- ▶ Greenhalgh J, Dalkin S, Gibbons E, *et al.* How do aggregated patient-reported outcome measures data stimulate health care improvement? A realist synthesis. *J Health Serv Res Policy* 2018; 23(1): 57–65. DOI: [https:// doi. org/ 10.1177/ 1355819617740925](https://doi.org/10.1177/1355819617740925)



Any Questions

Thank You

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