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International
Better care at the end of life

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Quality of life: why, what and how to measure?



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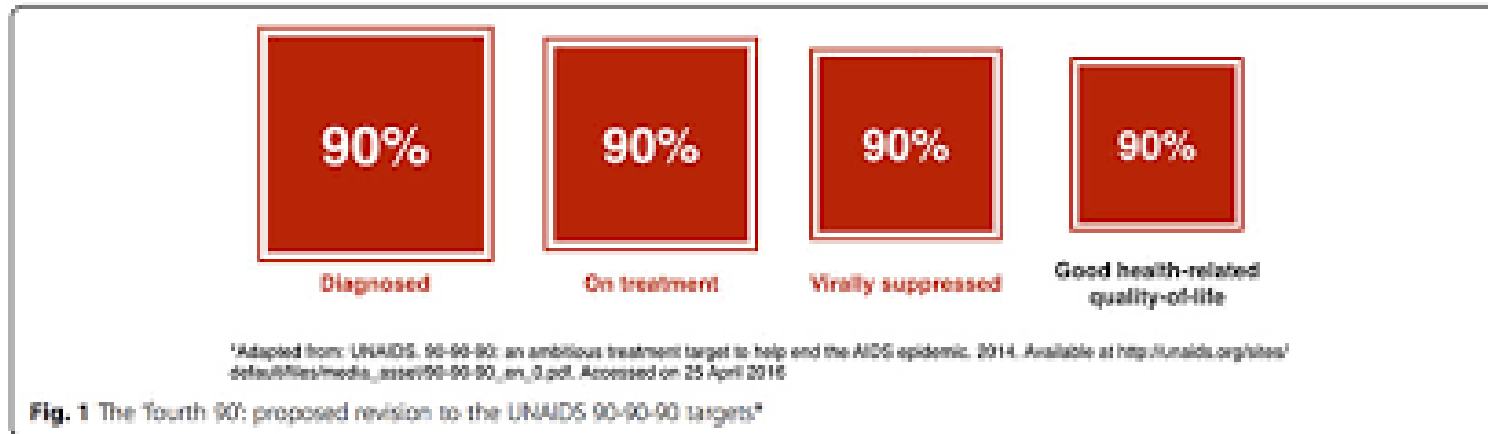


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The 4th 90: quality of life



- High level of consensus
- Underpinned by a holistic understanding of “health”
 - *“State of complete physical, mental, and social well being, and not merely the absence of disease or infirmity.”* WHO 1948
 - *“Health-related quality of life is an assessment of how the individual's well-being may be affected over time by a disease, disability or disorder”* CDC

Key questions to achieve this “90”:

- WHY do we need to measure?
- HOW do we measure this construct?
- WHAT do we do with the data?

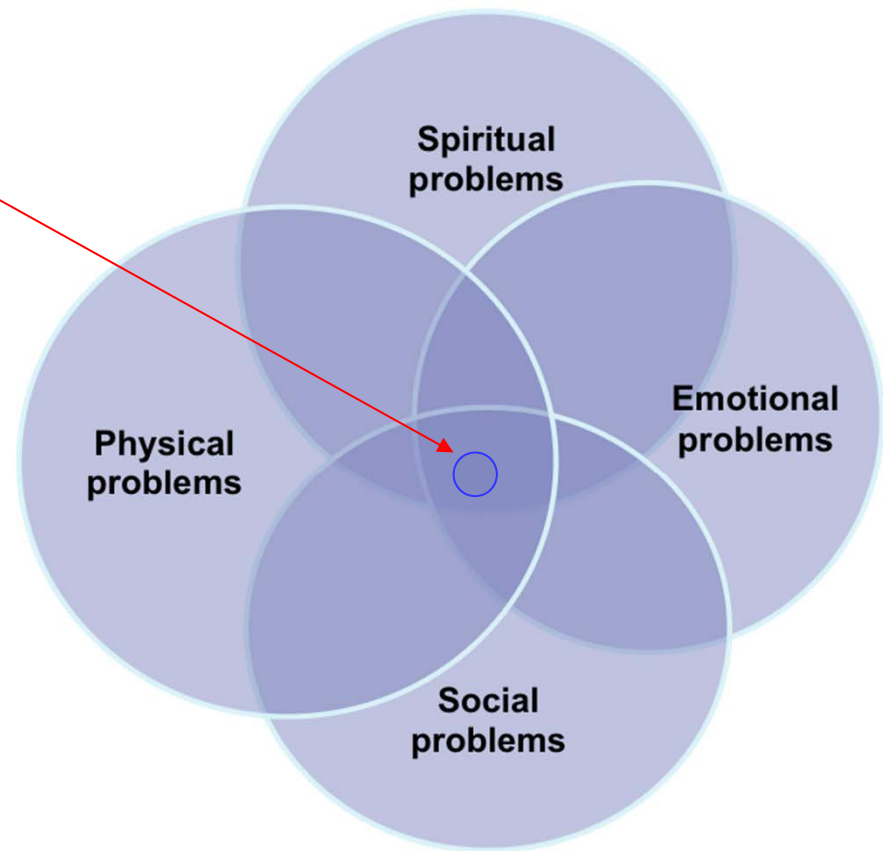
1) Why measure quality of life?

- HIV now cast as “chronic” condition (Lohse et al 2007 *Arch Int Med*)
- Improved morbidity & policy shift to social participation
- Optimal quality of life is an important clinical outcome alongside viral suppression
- Contribution of physical and mental health to QoL is current “critical challenge” in HIV medicine (Buscher *JAMA* 2010)
- Evidence of high symptom burden (Harding et al *STI* 2010) and emerging physical complications (e.g. bone density, cardiovascular, renal, liver, malignancies) (Harding et al *CID* 2011)
- Depression prevalence among those on ART (45%) higher than cancer pts (10-25%) (Lowther *Int J Nurs Studies* 2014)

Person-centredness

*“From the life of the virus
to the life of the host”*

(Carla Alexander)



Community HIV care in Ghana: Mary Abboah-Offei

- “staff don’t really ask me about what matters to me because their questions are always about my medication”

(female 38 years)

“I am not involved in my care and staff don’t ask me my opinion about my care and I don’t know if I have a role to play in my care and staff don’t ask what matters to me”

(male 35 years)

“POSITIVE OUTCOMES” (Bristowe)

- “I think in general terms I would like to hear them say ‘How is your physical health? How is your weight? How is your mobility? Is there anything going on there?’ ” (PLWH)
- “I’d expect adherence to be discussed in their clinic appointment. I’d expect them to be updated on their latest blood results. I’d expect partner notification” (Commissioner)

We measure because we risk not assessing

- E.g. pain & symptoms
 - Highly prevalent
 - assoc with poorer QoL, viral rebound, risk taking, poor adherence, treatment switching, suicidal ideation (Harding: AIDS Care, AIDS, JPSM, AIDS Care, JAIDS, HIV Med)
 - Clinicians detect around 1/3 of patient problems (Justice 2001, 2011)
 - UK HIV outpatient attendees perceive clinical care does not address issues of physical, mental and social wellbeing that matter to the patient (Harding et al. 2008)

2. How should we measure?

- Detailed clinical assessment is “gold standard”
 - but no guarantee that all areas of concern *to the patient* covered
 - not consistent
 - doesn't allow longitudinal monitoring, comparison at pt, service, system, cross-national levels

The risks of the wrong measure

- You measure the wrong things- or the right things badly!
- Measurement is complex and evolving science
 - Is your construct the right one?
 - Do your items address all the things that matter?
 - Is it interpretable?
 - Can you detect change?

Crucial aspects of a measure

- Validity (*“does it measure what it intends to measure?”*):
 - Face (*Does it seem to address the concept you’re interested in?*)
 - Content (*Does it measure it comprehensively?*)
 - *NOTE: The patient is the **expert!***
- Reliability (*“does it measure accurately?”*)
 - *Construct*
 - *Internal*
 - *Test-retest*
- Responsiveness
- Acceptability & interpretability

Disease generic vs specific

- A “general” measure of QoL
 - Widely applicable, sound properties, easy comparison
- A “specific” measure of QoL
 - Captures aspects of a specific condition, best face and content validity
 - HIV & hepatitis are good examples of specific “lived experience” which is MULTIDIMENSIONAL
- Solution?
 - Generic + disease specific

A systematic review of systematic reviews: QoL measures used in HIV research

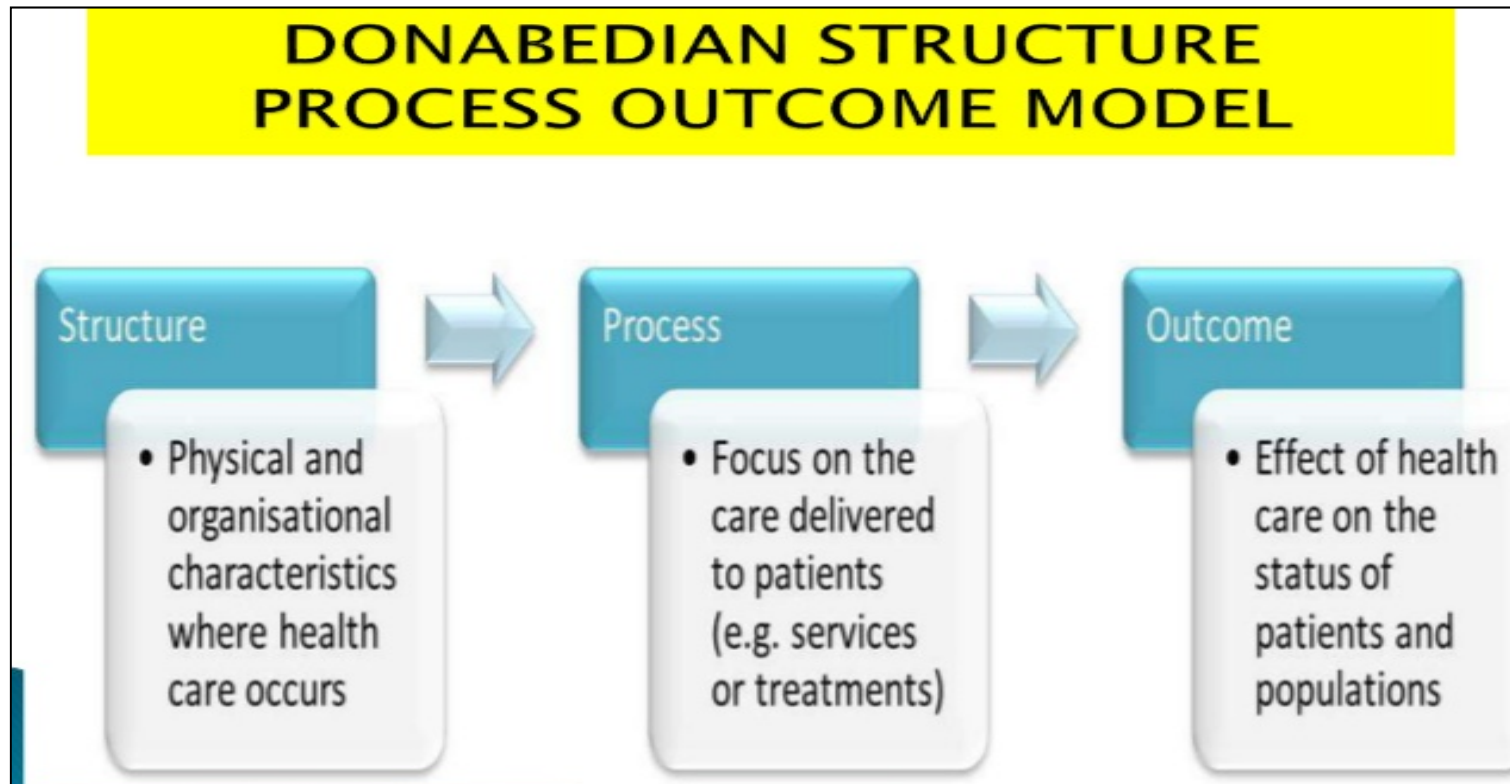
- n=9 generic scales:
 - EQ-5D*; Health Utilities Index; McGill Short SF-12; SF-36*; WHOQOL- BREF, of Life Satisfaction (FLZM); SF-20
- n=7 HIV-specific scales
 - AIDS Clinical Trials Group (ACTG)-21; HIV-QL-31; MOS-HIV*; Multidimensional Quality of Life Questionnaire for Persons with HIV/AIDS (MQOL-HIV), PROQOL-HIV*, Symptom Quality of Life Adherence (HIV-SQUAD) and the WHOQOL-HIV BREF



3. What do we DO with the data?

- Patient Reported Outcome Measures (PROMs) ensure that care is quality, accessible, and reflect what matters to the patient (Dawson 2007)
- Should be simple, valid & reliable
 - address the self-reported, subjective aspects of health
- Can:
 - guide comprehensive assessment
 - highlight main concern
 - empower patients to guide clinical care
 - assist monitoring of response to care
 - underpin audit & research

What is an outcome?



More specifically *“A change in health status”*

PROMs driving health services?

- Current NHS policy drive for use of PROMs
- PROMs improve outcomes for patients
(Greenhalgh, Etkind, Boyce, Brown)
 - improve communication
 - raise awareness of need among professionals
 - improve outcomes for patients & families
- To be taken up in routine care end-users
MUST be involved in development (Antunes 2014)
- Data usage is crucial to PROM effectiveness

“POSITIVE OUTCOMES”

- Novel PROM for PLWH (Bristowe)
- Designed to DRIVE patient-centredness and quality improvement in routine practice
 - i.e. a core measure with items that can be responded to within routine care, reflecting patient priorities
- Development, face and content validity and stakeholder views on implementation



Aims

- Determine the priorities of adults living with HIV in terms of measurement of outcomes from their NHS care
- Develop a patient-reported outcome measure (PROM)
- Establish how the novel PROM should be implemented to improve the person-centredness of healthcare and maximise benefit for PLWH, clinicians and commissioners

Design

Observational qualitative study following the COSMIN taxonomy and guidance for relevance, comprehensiveness and comprehension of PROMs, and Rothrock guidance on the development of a valid PROM

(Mokkink et al. 2010; Terwee et al. 2018; Rothrock et al. 2011)

Methods

Gather Input

Qualitative interviews to establish face/ content validity

- PLWH (n=28); HIV Professionals (n=21); HIV Commissioners (n=8)

Conceptual model and item generation

Thematic & framework analysis

Existing literature & interview findings :

- define the concepts (priorities or concerns) for PLWH
- inform a conceptual model (key domains for inclusion within HIV PROM)
- inform item generation (individual items within each domain)

Item generation meeting where items were selected & refined

- PLWH (n=4)
- health services researchers (n=4)
- HIV professionals (n=5)

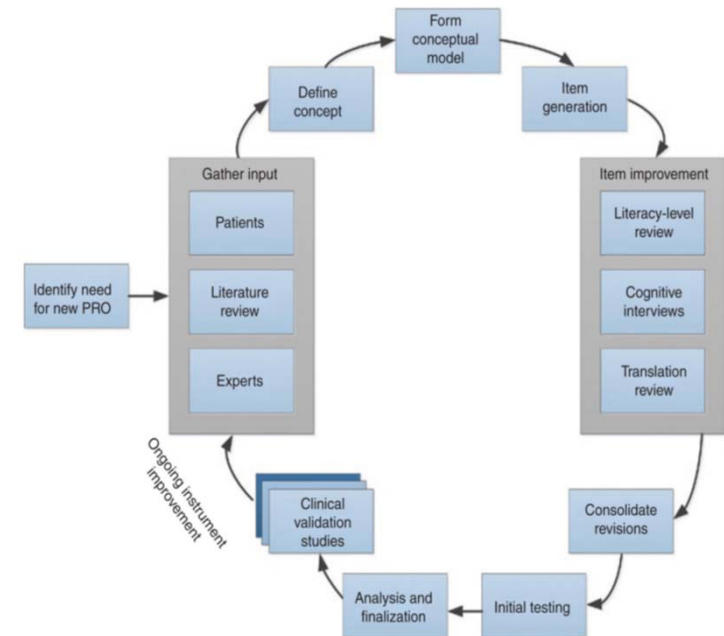
Second round of revisions to refine items

Item improvement

Cognitive interviews with maximum variation sample of PLWH (n=6) to assess:

- acceptability and accessibility of the format and structure
- interpretation of items
- how responses are formulated
- whether any key concepts have been missed

PROM refined further informed by findings from cognitive interviews



(Rothrock et al. 2011)

Results: findings

- Participants described **diverse** but **interrelated** problems and concerns
- Priority areas for inclusion within the PROM emerged under six domains:
 - **Physical**
 - **Cognitive**
 - **Psychological**
 - **Welfare**
 - **Social**
 - **Information needs**
- Participants requested inclusion of:
 - **global assessment** of wellbeing
 - **freetext** opportunities

*"I think, living with HIV is a bit hard and tricky. Sometimes, you just feel **down**, you feel **lethargic, tired**. The **aches and pains** in your body, **physical**... Yes, so it's all **physical, mental**... Most of the people I talk to kind of feel the same. Especially with **lethargy and tiredness, low mood**...Yes, I know everyone gets **stressed and depressed**, but if you are on the medication, it's a **different feeling** that you're feeling in your body...Sometimes, it's the time. If you take them late, which means in the day time, you still have the **hangover effect**. That's the difficult bit. You just move, but you still have the kind of hangover...Sometimes, for me, I get **foggy and forgetful, muddled**. Like, I was going to college. I **stopped going to college** because I could hear the teacher talking, but I **couldn't process** what she was saying or what was going on. It was just useless for me to keep going to college." PLWH:5*

Results: benefits of HIV PROM

For PLWH:

- Enable **patient centeredness** and **empower** PLWH
- Help PLWH **raise concerns**, and **feel heard** and **valued**, and **share sensitive information**
- Help PLWHIV to build **resilience** and **self confidence**
- Encourage **referrals** for additional **support**
- Reduce **assumptions**, establish an **individual baseline** and monitor **changes over time**
- Help get to know **new patients**
- Go **beyond adherence and viral load**

For services:

- Tailor service to **specific needs** of population
- Understand **changing picture** of HIV
- Improve **efficiency** and reduce inappropriate service use
- **Reassure** and **build confidence** in clinicians
- **Justify** current spending

*“Undoubtedly HIV has an impact on the psychological status of the individual. And so many people will require a greater level of support than others. So yes, it is a **key early indicator**, and it could **help the clinicians identify the need in the patients**, but it could also **help the commissioner identify the need of either developing pathways between clinical care and psychological and mental health care...The single tool needs to be voiced in a way that it is relevant for people at different stages of their disease pathway. So it needs to be sensitive enough and... It is complex. It is not “flexible”, the word I am trying to find, but it needs to, it needs to relate to people at different stages ...”***

HIV Commissioner: 3

Results: challenges of HIV PROM

- **Heterogeneity** of HIV population
- Heterogeneity of need depending on **time since diagnosis**
- **Literacy**
- Utility for those who struggle to **engage**
Highlighting symptoms **may cause anxiety**
- Asking about areas that we **cannot help with**
- Data **must be used** – not ‘tick box exercise’

HIV Professional: 7: “I suppose it might make the **consultation longer**, because it might bring up **things that haven’t been discussed before**, but hopefully that will be **worth investing that time**. If there are **things that are out of our hands**, that would be frustrating. I wouldn’t want to **give false hope** that you can tell us these things and we can cure or whatever.”

Interviewer: “Yes, opening a can of worms?”

HIV Professional: 7: “Yes. Yes, but **it’s better to open it, have a look inside and check it and see what you can do.**” **HIV**

Professional:7

Positive Outcomes HIV PROM

- 23 item person-centred PROM developed
- Items across the 6 domains of need described by PLWH:
 - **Physical, Cognitive, Psychological, Welfare, Social, and Information** needs
- Includes single item for **global assessment** of wellbeing
- Includes a **freetext** option to list main problems and concerns
- Example question:

5. Over the past 4 weeks, how much have you been affected by **stomach or bowel problems**? *This could include sickness, diarrhoea, bloating, feeling sick or other stomach or bowel problems*

Not at all	Slightly	Moderately	Severely	Overwhelmingly
<input type="checkbox"/> ⁰	<input type="checkbox"/> ¹	<input type="checkbox"/> ²	<input type="checkbox"/> ³	<input type="checkbox"/> ⁴

- PROM was refined following cognitive interviews PLWH (n=6)



Conclusions

- Attention to person-centred outcomes is essential to 90x90x90
 - the psychosocial is not “optional” (Harding JAIDS)
- PLWH, clinicians welcome the implementation of a clinically relevant, brief PROM to **drive, evaluate and improve care**
- Selection of a valid and reliable PROM is essential
- Careful plans must be laid to ensure that data DRIVE care
 - wise allocation of limited resources
 - whose data?
 - embed into your standards (e.g. BHIVA)
- Testing, entry, retention are dominant discussions
 - Whose perspective drives our health systems planning?
 - Do we provide treatment, care and support that truly reflect what matter?
 - Are we measuring the outcomes that motivate people to enter and remain in care?

