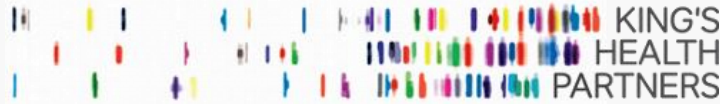




WHO Collaborating Centre for Palliative Care and Rehabilitation



POSITIVE OUTCOMES: properties of a novel brief tool to measure and improve person-centred outcomes in routine HIV care

Richard Harding, Katherine Bristowe, Brian West, Chris Jones, Stephen Bremner, Jenny Whetham, EMERGE Team, POSITIVE OUTCOMES



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HIV TREATMENT ADVOCATES NETWORK

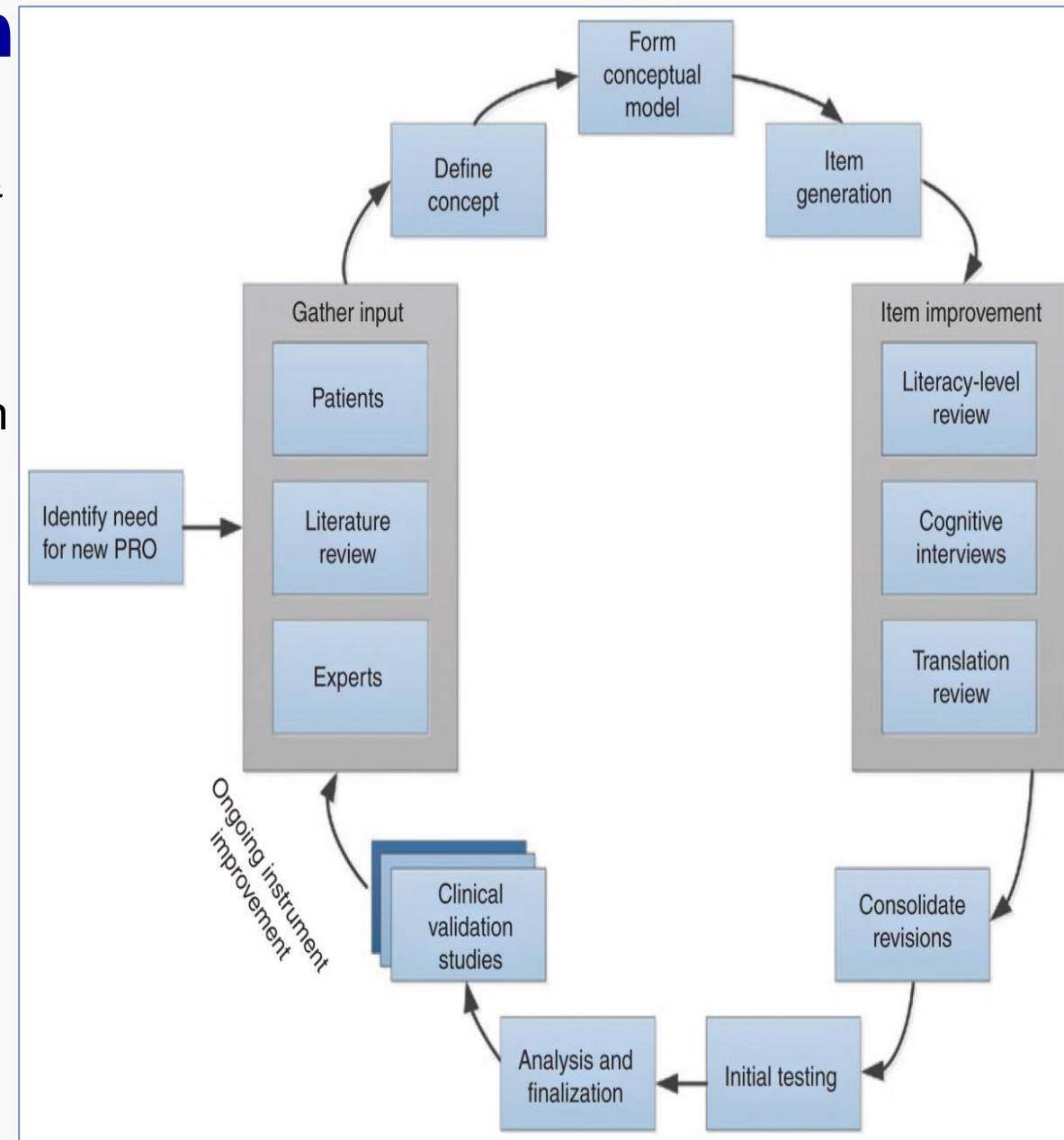


Background: the challenge

- Health Related Quality of Life (HRQoL) on ART poorer than UK general population (May et al. 2011; Miners et al. 2014)
- High symptom burden, emerging comorbidities (Sabin 2018, Simms et al. 2011; Harding et al. 2010; Harding et al. 2011)
- Contribution of physical and mental health to HRQoL is current “*critical challenge*” in HIV medicine (Buscher et al. 2010)
- UK outpatient attendees perceive care does not address issues of physical, mental & social wellbeing that matter (Harding et al. 2008)
- Self-reported outcomes are clinically important (Lampe et al. JAIDS 2010 JAIDS 2010, Merlin JAIDS 2018)
- HIV practitioners often miss patients’ needs and symptoms (Justice et al. 2001)

Background: potential solution

- PROMs identify problems/concerns & improves outcomes for patients (*Greenhalgh et al. 2009; Boyce & Brown 2013*)
- In HIV
 - “Challenges remain in the collection, interpretation and use of PRO data”
 - “Patient involvement in the development of PROMs is vital to ensure their usability & acceptability in the population of interest” (*Kall et al. Lancet HIV 2020*)
- Prior phases completed:
 - Primary evidence for face and content validity (*Bristowe et al. HIV Medicine 2019*)
 - Item generation & cognitive interviewing (*Bristowe et al. HQLO 2020*)



Aim+ methods



- **Aim:** to determine the psychometric properties of the novel PROM
- PROM purpose:
 - clinical: improve person-centredness of care and quality improvement
 - Research: as valid measure
- Construct: symptoms & concerns (WHO “*physical, mental and social well-being*”)
- Patient complete self-report & linked to electronic records

Validation: N=1392 one



completion, N=313 twice

- UK (*Brighton & Sussex*



University Hospitals) n=358

- Belgium (*Institute of Tropical*



Medicine Antwerp) n=226

- Spain (*Fundacio Privada*

Clinic Per A La Recerca

Biomedica) n=387



- Croatia n=234 (*Klinika Za*

Infektivne Bolesti)



- Portugal (*Centro Hospitalar*

De Lisboa Central) n=187

Results 1

Sample characteristics

- Age: median 45 (IQR 38-52)
 - >50 67.2%
- CD4: 753 (IQR 589-939)
- Gender: 92.4% male
- Ethnicity: 77.1% Caucasian
- Non-national: 20.2%
- MSM: 77.7%
- Frailty: 73.6% robust

Completeness

Average = 97.3%

Validity

- Factor analysis (EFA) promax rotation loadings >0.3
 - 5 factor structure
 - I. Feelings (*anxious, depressed, felt good, at peace, supported*)
 - II. Relationships (*safety, drugs, sex/intimacy, sexual health, contraception, starting family*)
 - III. Finances (*money, housing*)
 - IV. Health problems (*pain, GI, memory, sleep*)
 - V. Social stability (*information, disclosure, immigration, support, starting family*)
 - No loading: “*able to perform usual activities*”

Results 2

- Convergent validity
 - Correlation to PAM n=1295 (Cooper et al. 2002) weak
rho = -0.295, $p < 0.001$
 - Correlation to PROQOL n=1280 strong
 - rho = 0.678, $p < 0.001$
- Discriminatory validity
 - Known groups comparison logistic regression:
 - Robust vs frail/pre-frail
 - OR 4.81 (95% CI 3.74, 6.19), $p < 0.001$
 - PAM level 1/2 vs 3/4
 - OR 2.28 (95% CI 1.79, 2.90), $p < 0.001$

Results

Reliability

- Internal consistency
 - Total Alpha=0.879
 - Factor 1 0.874
 - Factor 2 0.788
 - Factor 3 0.770
 - Factor 4 0.763
 - Factor 5 0.545

Threshold 0.6 for non-redundant multidimensional measures (Measurement in Medicine 2011)

- Test-retest

Defined: *consistent on PAM, frailty status, viral load detectable* n=115

Median difference in PROM 0.00 (IQR: -0.20, 0.23)

Responsiveness

Defined: *change in PROQOL, clinic visits (n=242) and change in PROM (n=247)*

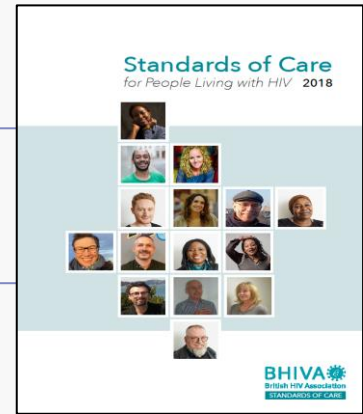
Moderate association

Pearson's= -0.44, p<0.001)

Conclusions

- POSITIVE Outcomes has completed the required stages of development and validation
- Collaborative process to optimise relevance and uptake
- Question: “medically stable” limitation & opportunity?
- Data use cycle is crucial
 - Community & HCP view is that it offers improved communication, assessment, empowerment, decision-making (HIV Medicine 2019)
 - Implementation strategies are key in PROM success

Standard 2:
“Person-centred care”



Positive Outcomes: HIV PROM (Version 1: 30.1.18)

Please answer the following questions about any problems or worries that you have had over the past 4 weeks. Your answers are really important to us. They will help us to improve your HIV care by making sure that we can focus on the things that are most important to you.

1. What have been your **main problems and worries over the past 4 weeks** that you would like to be addressed?

a. _____

b. _____

c. _____

2. In general, how would you rate your **health and wellbeing** over the past 4 weeks? *Please think about both physical and emotional wellbeing.*

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| Excellent | Good | Average | Poor | Very poor |
| <input type="checkbox"/> ⁰ | <input type="checkbox"/> ¹ | <input type="checkbox"/> ² | <input type="checkbox"/> ³ | <input type="checkbox"/> ⁴ |

3. Do you feel you have **enough information** to manage your HIV?

| | | | | |
|---|--|---|--|---|
| Enough information, The right amount for me | Information received, but hard to understand | Information received, but would like more | Very little information, and would like more | No information received, and would like information |
| <input type="checkbox"/> ⁰ | <input type="checkbox"/> ¹ | <input type="checkbox"/> ² | <input type="checkbox"/> ³ | <input type="checkbox"/> ⁴ |

*The next few questions ask you more about your **physical** health and wellbeing.*

4. Over the past 4 weeks, how much have you been affected by **pain**? *This could include headache, joint pain, neuropathy (which might include pins and needles or burning pain) or any other pain in your body*

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| 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 |

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 |

6. Over the past 4 weeks, how much have you been affected by problems with your **memory or concentration**?

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| 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 |

7. Over the past 4 weeks, how much have you been affected by problems with your **sleep**?

| | | | | |
|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|---------------------------------------|
| 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 |

The EmERGE Consortium



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- Zagreb
- Antwerp
- Barcelona
- Lisbon
- Brighton



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Prof Martin Fisher
1964 - 2015

EmERGE Consortium

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www.emergeproject.eu

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