Metrics of Success: How to Measure Adherence to PrEP and Intermittent PrEP

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Objectives
Share brief overview of self-reported adherence
Decompose self-report
Reclaiming self-report as a useful measure

Misreporting of Product Adherence in the MTN-003/VOICE Trial for HIV Prevention in Africa: Participants' Explanations for Dishonesty.

Montgomery ET[1], Mensch B[2], Musara P[3], Hartmann M[4], Woeber K[5], Etima J[6], van der Straten A[4,7].

The science of being a study participant: FEM-PrEP participants' explanations for overreporting adherence to the study pills and for the whereabouts of unused pills.

Corneli AL[1], McKenna K, Perry B, Ahmed K, Agot K, Malamatsho F, Skhosana J, Odhiambo J, Van Damme L.

first

- EDM data
  - Tends to correlate w SR
  - SR 5-15% over

- Still used as secondary outc

- High rates of adherence reported in clinical trials
- Early work signals concern with over-reporting (68% PPV, 2011)
- Series of studies show that reports by 60% or more in some studies compared to drug level

April 24, 2015

Women in Failed PrEP Trial Lied About Pill Use to Stay In Study

POZ

February 5, 2015

Failed VOICE PrEP Trial Failed to Preempt Lies About Adherence

AIDSMEDS
Your Ultimate Guide to HIV Care

CONSEQUENCES

-Social

-Tangible

-Access

Angry
Longer visit
Kicked out

Maximum Response Accuracy

Vocabulary
Comprehension
Retrieval

Validity

ASK

-Item

-Responses

The "ASK"

Cognitive and Field Testing of a New Set of Medication Adherence Self-Report Items for HIV Care

Ira B. Wilson · Floyd J. Fowler Jr. · Carol A. Cosenza · Joanne Michaud · Judy Bentkover · Aadia Rana ·

ples)

viewer

– Survey

ments

In the last 30 days, on how many **days** did you miss at least one dose of any of your HIV medicines?

Write in number of days: ____ (0 – 30)

In the last 30 days, how good a job did you do at taki

were supposed to?

- ☐ Very poor
- ☐ Poor
- ☐ Fair
- ☐ Good
- ☐ Very good
- ☐ Excellent

In the last 30 days, how often did you take your HIV medicines in the way you were supposed to?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Usually
- ☐ Almost always
- ☐ Always

Reclaiming Self-report?

- Consider context
- Evaluate demands

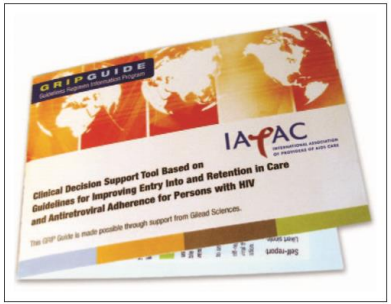

Figure 1. IAPAC Guidelines Regimen Information Program (GRIP) guide.

Stirratt et al 2015
Amico et al 2013
Williams et al 2012

Table 1 Assumptions underlying common measures of adherence

Measure	Assumptions
Self-report	Self-report participants can reasonably answer the questions (when doses were taken, how many, or provide general estimate)
	Cognitive deficits that impact memory/recall are not present.
	Immediate negative consequences (e.g., added procedures, reprimands, so on) of reporting non-adherence are absent
	The scale used to measure adherence is reliable and valid
	The scale used to measure adherence is culturally sensitive, worded clearly, and subjects know how to respond to the scaling response options with little difficulty
	Social desirability bias is minimized or it is mea

Table 1 | Ten ways to improve the validity of self-report measures

1. Do not reinvent the wheel; choose a self-report adherence measure with validation data for your target population whenever possible.
2. Define the adherence construct of interest (i.e., extent of adherence vs. reasons for nonadherence) and select a measure containing items matched to that need.
3. Administer adherence measures through computer surveys rather than face-to-face data collection to reduce social desirability concerns and improve data quality.
4. In research contexts, staff members who collect adherence data should be separate from staff members who deliver adherence support or adherence interventions.
5. Introduce the self-report adherence measure with a statement which normalizes nonadherence to help address social desirability concerns.
6. Use a question response format that asks respondents to estimate their overall adherence behavior. Response items that characterize adherence in ordinal terms (e.g., anchored Likert ratings scale) or quantitative continua (e.g., estimated percent of doses taken) may help reduce ceiling effects.
7. Use a self-report adherence measure that specifies a recall period for adherence behavior. A recall period of the last 30 days may reduce ceiling effects relative to shorter intervals. Populations characterized by cognitive impairment may require other approaches (e.g., daily text message or interactive voice response surveys).
8. Consider dichotomization of self-report adherence measures at the 100 % mark to recognize their tendency for over-reporting relative to other adherence measures.
9. Add a social desirability measure to complement analysis of self-report adherence data.
10. Research publications should include clear descriptions of any self-report adherence measure, its administration method, and descriptive data resulting from the measure (e.g., mean, median, standard deviation) to help further the science.

Table 1 Lessons learned from cognitive testing by item stem and response option

Lesson	Comment
Item stem	
Time frame	No consistent understanding of "the last week" or "the last month"; better the last 7 or 30 days
Attention to reference period	Attention to the reference period was poor overall; patients estimate rather than count
Taking "as prescribed"	Understood inconsistently
Understanding of "dose"	Understood consistently
Response option	
Visual analogue scales and percents	Both worked poorly
Use of the word "perfect"	Worked poorly
Options that express feelings	Worked poorly
Words vs. numbers	Subjects level of recall is more appropriate to verbal than numerical answers and subjects more comfortable with adjectives and adverbs than numbers as way of providing answers

Thank you

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Mixed understanding of 'Missed Dose' and 'Best Guess' in adherence self-report: Results of cognitive interviews with young women and men who have sex with men in South Africa

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KR Amico[1], M Mueller[1], E Hill[1], D Bohn[1], J Milne[1], H Brady[1], S Phakathi[2], M Mdladla[2], M Atujuna[3], T Wonxie[3], N Ngcwayi[3], T Shato[1], H Humphries[2]

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BACKGROUND

METHODS (CONT)