

## Measuring empowerment among people living with HIV: a systematic review of available measures and their properties

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### Background

- Patient empowerment is increasingly recognised as an important outcome of healthcare interventions and policy [1]
- Empowered patients are believed to make more rational decisions about their health, be more adherent and less dependent on healthcare services [2]
- The aim of this study was to identify and appraise measures of empowerment used in peer-reviewed research with people living with HIV (PLWH)

### Method

- Papers identified through searching
  - online databases
  - reference lists
  - citation search of the primary validation paper of each empowerment measure
- **Databases** (Medline, Embase, PsycINFO, Cochrane, CINAHL, Web of Science)
- **Search terms** (HIV OR human immunodeficiency virus OR antiretroviral) AND empower\* OR patient activation OR enablement OR perceived control OR capability OR independence OR (self-efficacy and manage\*) AND (measure\* OR invento\* OR scale\* OR questionnaire\* OR self-report\* OR assessment\* OR survey)

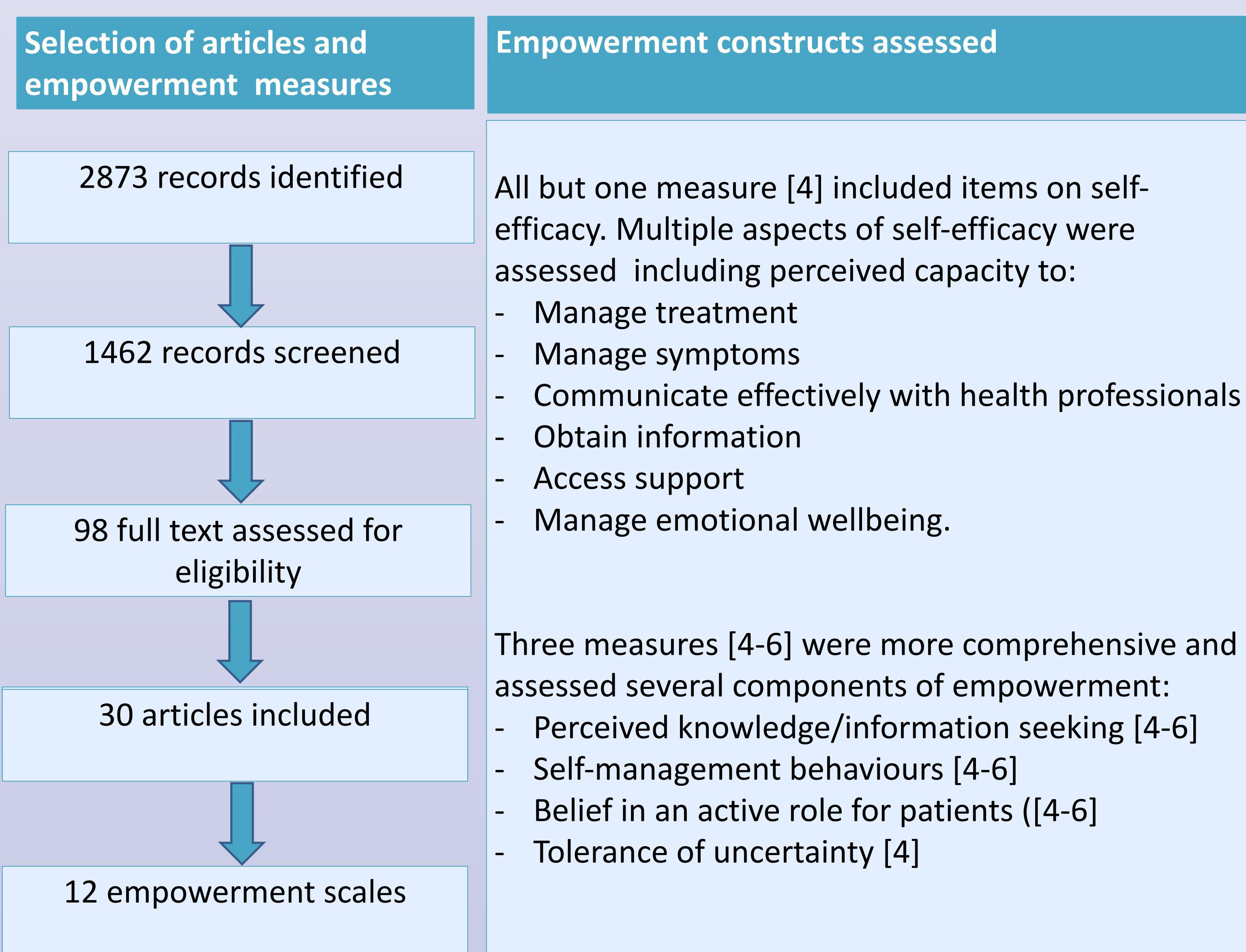
#### Inclusion criteria

- Study measured patient empowerment or an overlapping construct (e.g. patient activation, self-management self-efficacy)
- Sample consisted of >50% PLWH

#### Exclusion criteria

- Study focused on children
- Unpublished thesis
- Empowerment assessed in relation to a single behavior (e.g. adherence)
- Two researchers independently extracted data from identified papers and the primary validation paper for each empowerment measure
- Psychometric quality criteria [3] were applied to the primary validation papers

### Results



#### Psychometric quality of measures (Terwee criteria) [3]

	Number of items	Content validity	Internal consistency	Criterion validity	Construct validity	Agreement	Reliability	Responsiveness	Floor/ceiling effects	Interpretability
Chronic Disease Self-Efficacy Scales	33	+	?	0	+	?	0	0	+	0
Health Care Empowerment Inventory (HCEI)	8	-	+	0	+	0	0	0	0	?
HIV Symptom Management Self-Efficacy Scale	34	-	?	0	?	0	0	0	0	0
HIV Self Efficacy Questionnaire	9	+	-	0	+	0	0	0	0	0
HIV Symptoms Management Self-Efficacy for Women Scale	10	-	?	0	-	0	0	?	0	0
Patient Activation Measure (13-items) (PAM-13)	13	+	?	0	+	0	0	0	0	0
Patient Activation Measure (22-items) (PAM-22)	22	+	+	+	+	?	0	0	0	0
Perceived HIV Self-Management Scale	8	0	?	0	?	0	0	0	0	0
Self-Efficacy Inventory	8	0	?	0	?	0	0	?	0	0
Self-Efficacy to Manage Chronic Disease Scale	6	+	+	0	+	0	0	?	+	0
Strategies Used by Patients to Promote Health	29	+	+	0	+	?	?	0	0	0
Treatment Self-Efficacy	20	0	?	0	?	0	0	0	?	?

Rating: + clear description/met design/evidence criteria; ? indeterminate (doubtful design/method or lack of clear description); - lack of evidence; 0 no information

### Conclusions



- Empowerment questionnaires captured a variety of different constructs
- The majority of questionnaires focused on self-efficacy which is only one component of empowerment [2]
- Three questionnaires were broader in scope, each addressing three additional constructs [4-6]
- Most scales had acceptable construct validity but further into reliability and responsiveness is needed
- The choice of measure is likely to be influenced by the purpose of the assessment and empowerment domains relevant to the research questions

#### References

- 1 Bravo et al. (2015) Conceptualising patient empowerment: A mixed methods study. *BMC Health Serv Res*, 15, 252.
- 2 McAllister et al. (2012) Patient empowerment: The need to consider it as a measurable patient-reported outcome for chronic conditions. *BMC Health Serv Res*, 12, 157.
- 3 Terwee et al. (2007) Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol*, 60 (1), 34-42.
- 4 Johnson, M. O., Rose, C. D., Dilworth, S. E., & Neilands, T. B. (2012). Advances in the conceptualization and measurement of health care empowerment: Development and validation of the health care empowerment inventory. *PLoS One*, 7(9).
5. Hibbard, J. H., Stockard, J., Mahoney, E. R., & Tusler, M. (2004). Development of the patient activation measure (pam): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res*, 39(4 Pt 1), 1005-1026.
6. Hibbard, J. H., Mahoney, E. R., Stockard, J., & Tusler, M. (2005). Development and testing of a short form of the patient activation measure. *Health Serv Res*, 40(6 Pt 1), 1918-1930