

Appendix 4 – Data extraction form

Data extraction
Sample size
Mean / median age and age range (please specify if mean or median)
Number of male and female participants
Socioeconomic status of participants
Ethnicity of participants
Level of disability / activities of daily living of participants
Setting
Other participant info given
What is the purpose of the PRM?
What is its structure e.g. number of domains, subdomains, items
What aspects of treatment burden are covered? E.g. one item on info seeking, one item on medications...
Quality appraisal
Was the measure developed from concepts developed in qualitative work (in a previous study or this one)?
Was the above qualitative work done relevant to the current sample?
Did the above qualitative work include a conceptual model?
Was reliability tested?
How was reliability tested and what was the result?
Was content validity tested?
How was content validity assessed and what was the result?
Was the population that content validity was tested in similar to the current sample?
Was justification for the recall period given?
Was construct validity assessed?
How was construct validity tested and what were the results?
Was responsiveness tested?
How was responsiveness tested and what was the result?
Was interpretability of scores tested?
How was interpretability of scores measured and what was the result?
Has the measure been translated? If so into what language?
Has it been evaluated in this new language?
Has patient and investigator burden been considered?
Was this an issue?