Challenges in expanding routine use to new clinical areas

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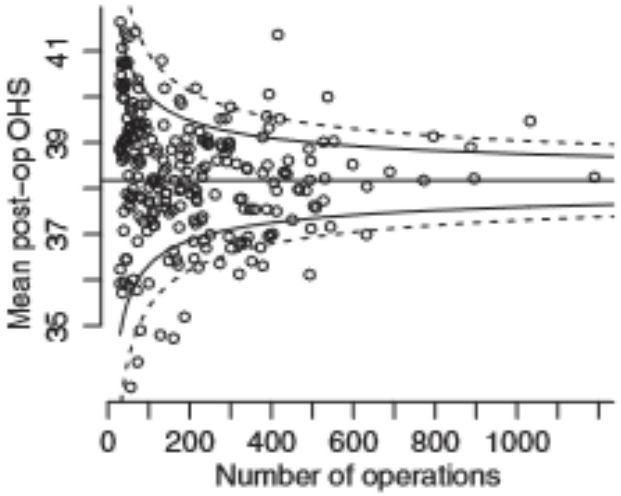
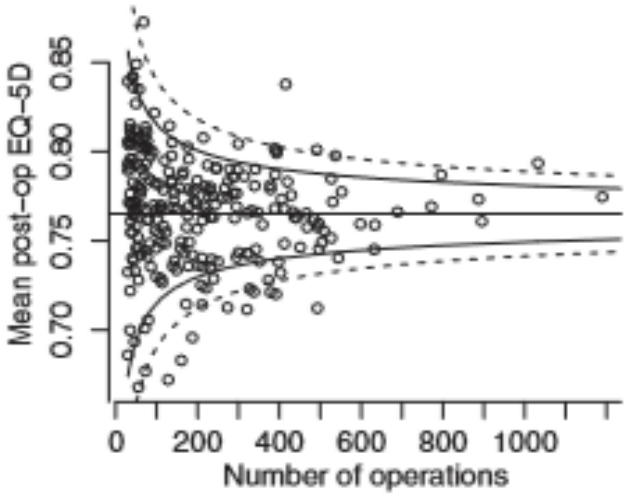
Story so far…

- Routine use of PROMs for comparing providers
  - focused on elective surgery
  - shown to be feasible
  - policy rather than methodological challenges

Comparison of outcome of hip replacement for 243 providers





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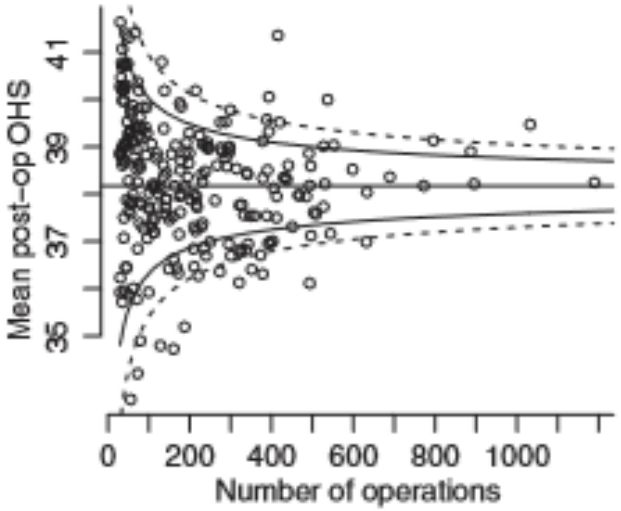

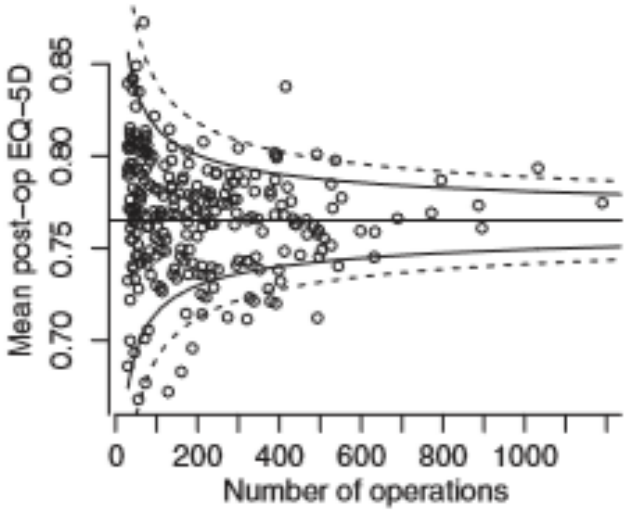

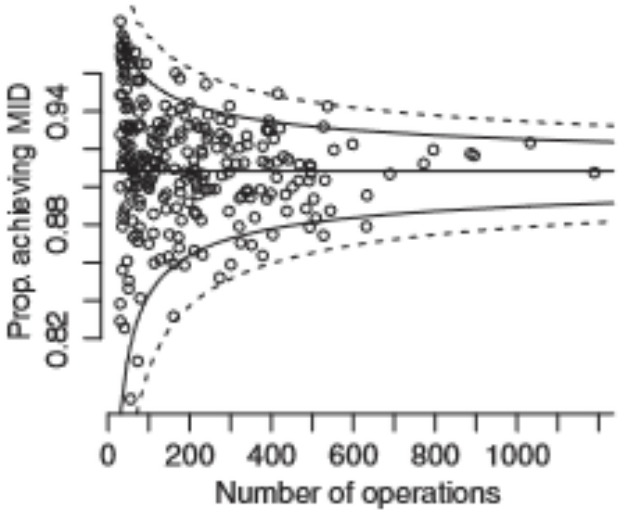

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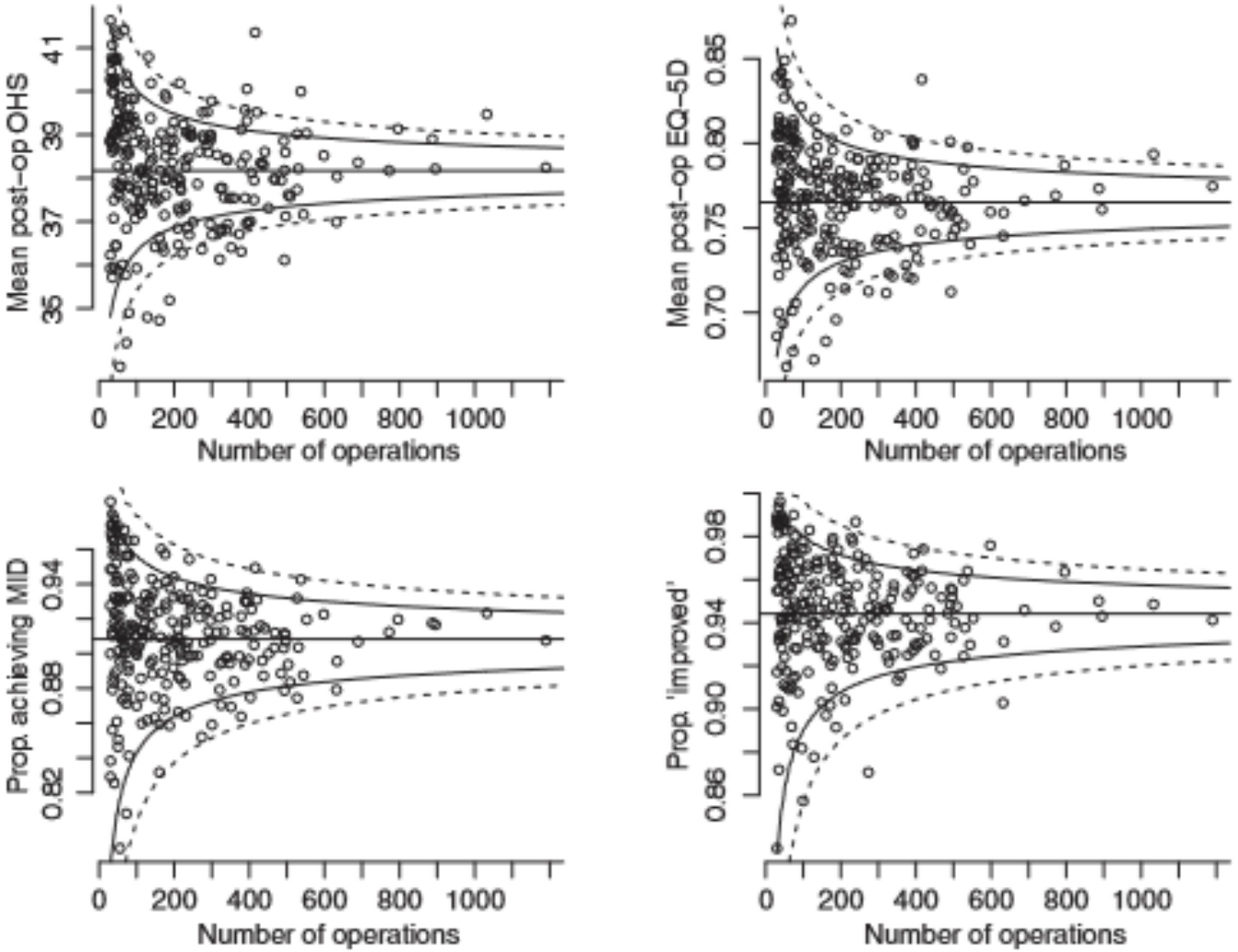


- Proportion of providers rated as ‘outliers’ (>2SDs) differs between metrics (eg hip replacement)
  - Mean post-op OHS: 25%
  - Mean post-op EQ-5D: 16%
  - % achieving OHS MID: 12%
- Choice depends on policy priority
  - avoid missing ‘poor’ providers (use mean post-op OHS)
  - avoid mislabelling providers as poor (use % ‘improved’)

Uncertain value given lack of variation between providers in performance

Areas of concern about quality of care

- Emergency admissions to hospital
- Management of long-term conditions
- Primary care
- Social care
- Mental health services

Unexpected emergency admissions

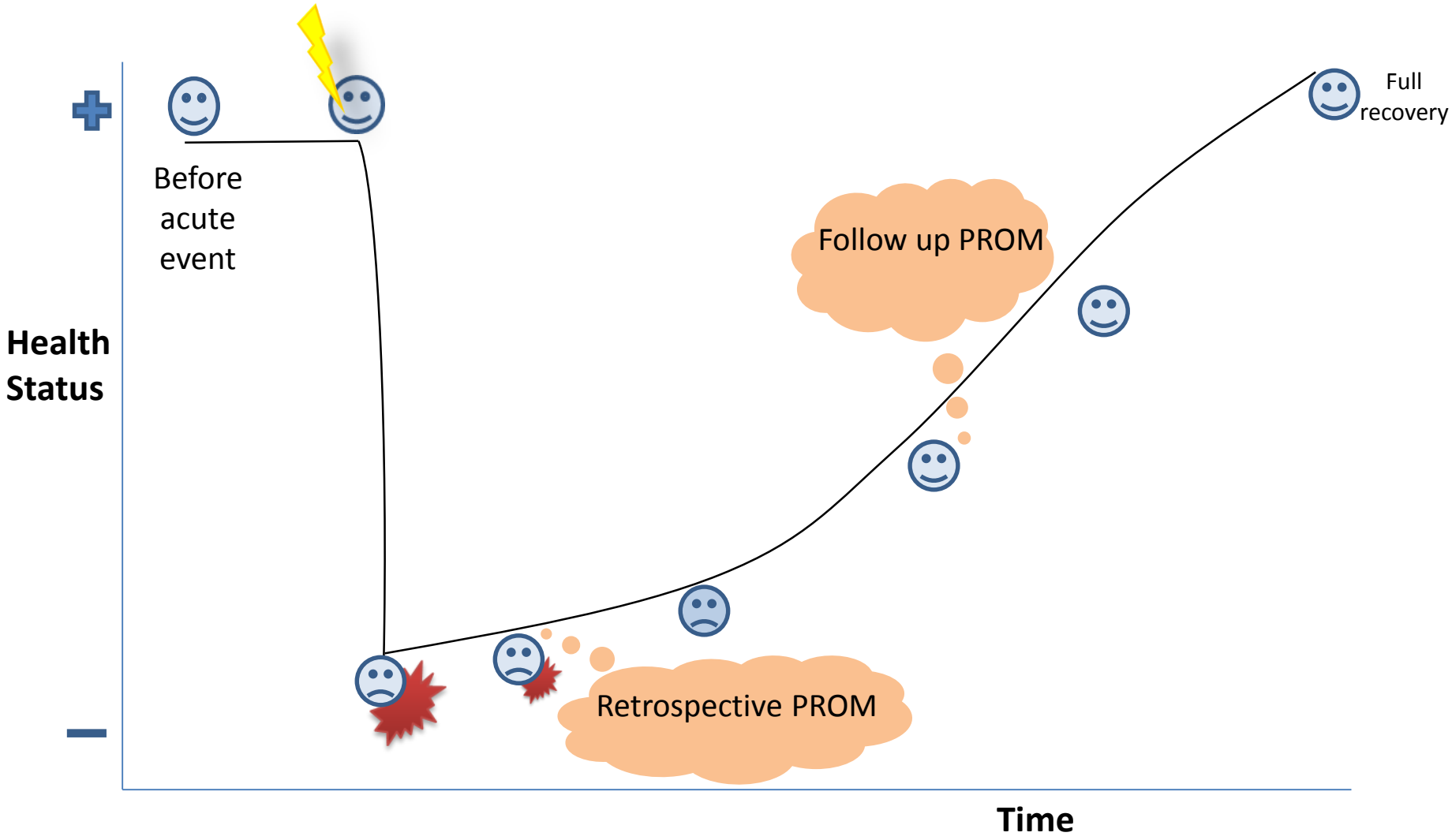
Dementia care

Unexpected emergency admissions

Challenge

- no information on health status before event

Use of retrospective PROMs?



What's known about 'accuracy' of retrospective PROMs?

- Comparison with contemporary PROMs
  - Inevitably limited to elective admissions
    - hip and knee arthroplasty (5 studies in N America)
    - benign prostatic hypertrophy (1 study in UK)
- Association
  - strong (correlation coefficient 0.68)
- Agreement
  - continuous measures strong (intraclass coefficient 0.75)
  - categorical measures moderate (kappa 0.3-0.6)
- Stronger: indices; shorter time intervals

What is the ‘accuracy’ in the UK?

- Hip and knee arthroplasty in 4 hospitals
- Retrospective PROM completed by 60%
  - Representative sample
  - Oxford Hip/Knee Score; EQ-5D-3L
- Agreement (intraclass correlation coefficient) with contemporaneous PROM
  - OHS/OKS: 0.82
  - EQ-5D-3L: 0.61
  - No influence of severity, age, SES
- Conclusion: At group level, retrospective PROMs reliably predict contemporary

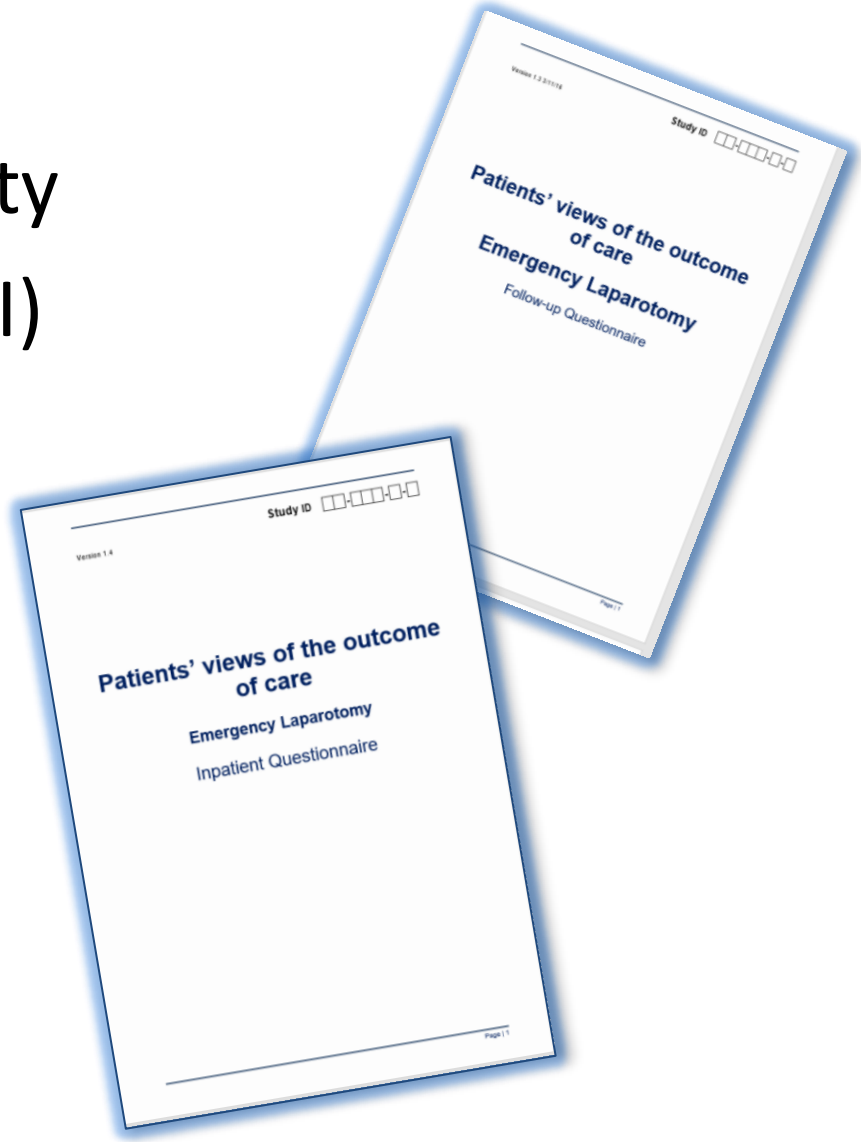
Is it feasible to collect retrospective PROMs in emergency admissions?

- Two conditions selected
  - Medical (*acute myocardial infarction requiring primary coronary angioplasty*)
  - Surgical (*gastrointestinal conditions requiring laparotomy, excluding appendicitis*)
- Feasibility of recruitment during admission
  - Proportion patients eligible
  - Proportion eligible invited
  - Proportion invited completing questionnaire
- Feasibility of follow-up
  - Response rate at 3 months

PROMs for emergency laparotomy

- Gastrointestinal Quality of Life Index (GIQLI)
  - 36 items; 5 subscales

- EQ-5D-3L



Feasibility of patient recruitment

	Hospital											
	A	B	C	D	E	F	G	H	J	K	L	Overall
Proportion of admissions deemed eligible												85
Proportion of eligible patients invited												85
Proportion of invited patients participating.												72

Feasibility of patient recruitment

	Hospital											
	A	**B**	**C**	**D**	**E**	**F**	**G**	**H**	**J**	**K**	**L**	**Overall**
Proportion of admissions deemed eligible	72	78	82	92	86	82	86	86	83	88	97	**85**
Proportion of eligible patients invited	92	86	93	75	83	91	89	84	60	86	74	**85**
Proportion of invited patients participating.	92	65	68	74	73	55	61	63	77	79	85	**72**

Feasibility of follow-up

- Mailed questionnaire; one reminder
- Response rate 74%
- Responders v non-responders
  - No difference for comorbidities; overall health status (EQ-5D); pre-operative severity (GIQLI)
  - Responders: older, female, more affluent
- Response bias: improvement in health slightly over-estimated
  - EQ-5D improvement 0.055 instead of 0.060

Implications

- Routine collection of PROMs in emergency admissions is feasible using retrospective PROMs
  - Recruitment
    - 85% of eligible invited; **3 of 11 sites achieved over 90%**
    - 72% invited patients participated; **one site achieved 92%**
  - 74% response rate at follow-up
    - Need to adjust for patients' age, sex and SES when comparing providers

- Need for a larger developmental study to
  - Obtain high recruitment rates (80%) – learn from the best sites
  - Take clinical characteristics (eg diagnosis, severity) into account
  - Determine if suspected variation in outcomes between providers actually exists

Dementia

Challenges

- people with dementia have limited ability to respond
- informal care-giver-reported PROMs need interviewer
- view of informal care-giver different from person with dementia

DEMQOL and DEMQOL-Proxy

DEMQOL

- patient's self-report of HRQL
- 28 items
- overall HRQL

DEMQOL-Proxy

- informal care-giver's report of patient's HRQL
- 31 items
- overall HRQL

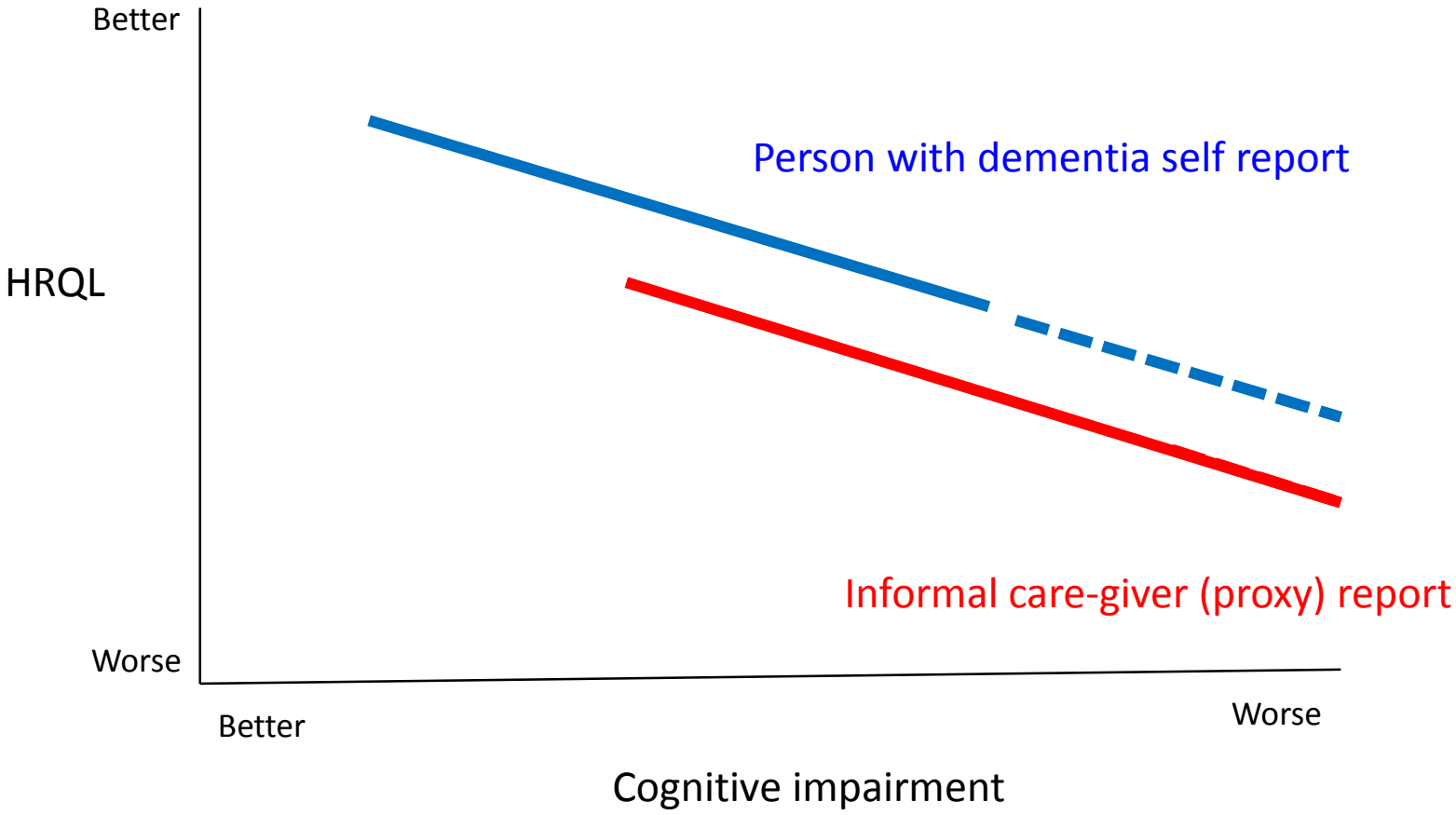
Five domains

Health & wellbeing
Cognitive functioning
Daily activities
Social relationships
Self-concept

Can proxies report without interviewer?

- Self-administered comparable to interviewer administered
  - Acceptability (3.5% missing data; 0% scores at floor or ceiling)
  - Reliability (Cronbach's alpha 0.93)
  - Validity (convergent and discriminant)
- Conclusion: DEMQOL-Proxy can be obtained without an interviewer

Can proxy scores predict patients' score?



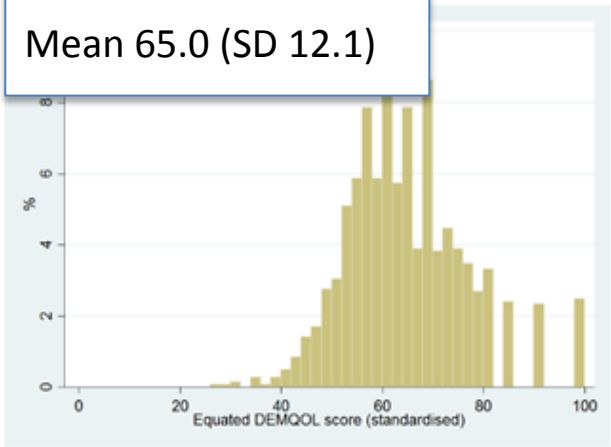
Can DEMQOL and DEMQOL-Proxy be equated/cross-walked?

- Require interval scales
  - Need modern psychometric methods (based on the Rasch model)
- Successfully transformed both PROMs
  - DEMQOL – used 23 (of the 28 items)
  - DEMQOL-Proxy – used 26 (of the 31 items)

Direct comparisons

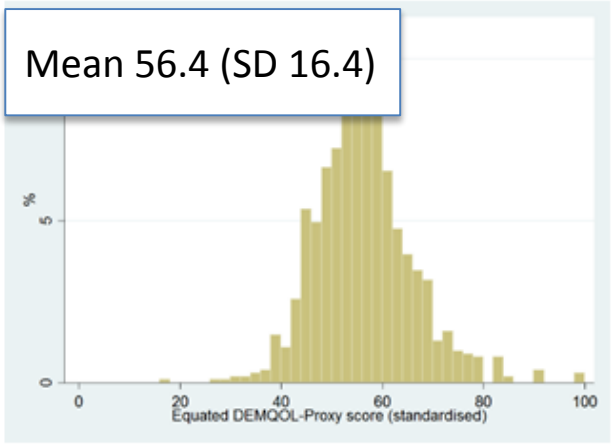
a) DEMQOL equated score* (n=1,425)

Mean 65.0 (SD 12.1)



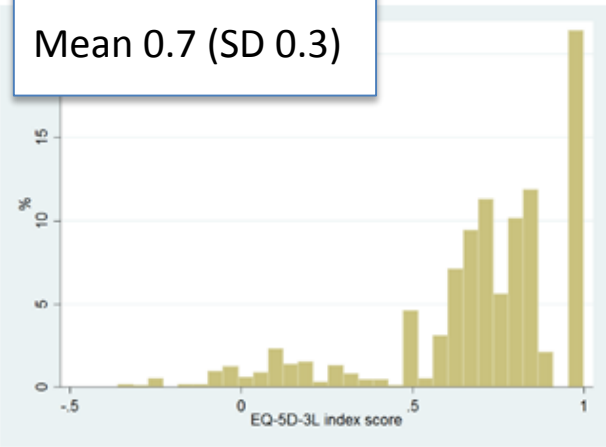
b) DEMQOL-Proxy equated score* (n=1,011)

Mean 56.4 (SD 16.4)



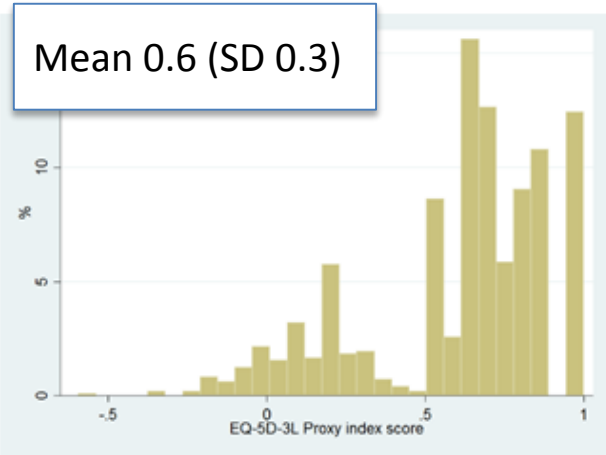
c) Self-reported EQ-5D-3L index score (n=1,394)

Mean 0.7 (SD 0.3)



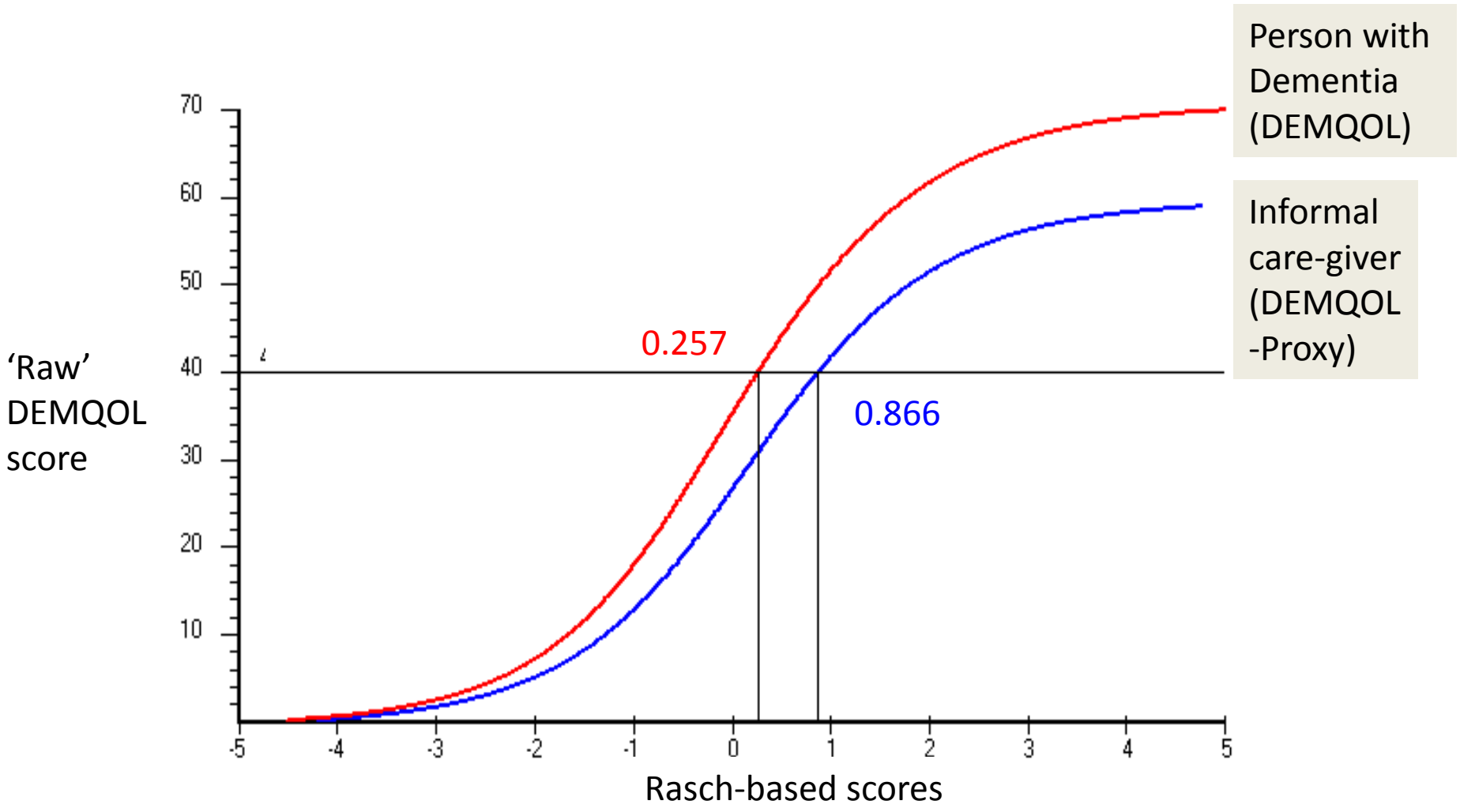
d) Proxy-reported EQ-5D-3L index score (n=975)

Mean 0.6 (SD 0.3)



Proxy-reported HRQL lower than self-reported HRQL for dementia-specific and generic measures

Can cross walk from DEMQOL-Proxy to DEMQOL



Conclusions

Given that

- proxy reports of HRQL can be obtained by self-administered questionnaires
- patient's view of their HRQL can be based on the responses of their proxy

Possible now to

- estimate HRQL of people with moderate/severe dementia
  - Include in clinical research, HTA, routine audit of care
- determine the trajectory/natural history of cognitive decline
- evaluate impact of social and health care policies to maintain and improve HRQL of people with dementia

Exciting new opportunities for PROMs

- If further developmental testing demonstrates feasibility
  - will allow widening in routine use of PROMs
  - enable attention to focus on clinical areas of greatest concern