Reviewer’s report

Title: Standard Set of Health Outcome Measures for Older People

Version: 0 Date: 18 Aug 2017

Reviewer: Rowan Harwood

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1. This is a description of a consensus process to develop a standard set of health outcome measures to use with older people. An international, multi-round, Delphi process was used, supported by literature reviews and focus groups with older people (in the UK). Participation in decision making, autonomy and control, mood and emotional health, loneliness and isolation, pain, ADL, frailty, time spent in hospital, overall survival, carer burden, polypharmacy, falls and place of death were agreed 'outcomes'.

2. Questions that arise are a) was it worth doing? b) was it done well? c) are the results sensible? d) is the report well written?

3. Was it worth doing? Measuring outcomes is important (as part of an important 'output' of healthcare). It allows assessment of the clinical progress of individuals, but amongst older people the inevitable ultimate trajectory is of decline, and treatment of any individual is uncontrolled ie you never know what would have happened in the absence of intervention. It allows comparison in epidemiological research and clinical trials. It allows ecological comparisons in international, regional or system-wide public health studies (albeit a weak methodology in these cases). Standardisation allows aggregation across studies, and comparison between studies. There have been many attempts over recent decades to produce standardised outcome sets, so this particular project is not unique nor wholly original. In the field of older people, it is probably true to say that they have not been particularly helpful or widely adopted. The statement (p5) 'there is a lack of robust global health outcome measures for older people) is contentious.

4. Was it well done? The study was quite ambitions, being backed by literature reviews and older people's focus groups. Participants and co-authors are from a range of countries, including Australia, Taiwan, Peru, Switzerland, Netherlands, Botswana, Canada, US and UK, with a predominance of UK authors. The focus groups were done in the UK, but were sensibly framed and appear to have been done well. Some very eminent and well-known names appear amongst the list. The provenance of authors was not always clear. Some appear to work for consultancies. Some of the affiliations are obscure, without full contact addresses (eg COBIC UK, Altarum, Sigma Theta Tau international honor society of nursing). Personal, rather than institutional email addresses were used for some co-authors. I was uncertain if the conflicts of interest statements were complete. Did all the authors read and approve the text?
P8 was a simple majority used to signify consensus - 60% or 70% is often used rather than 51%. It is surprising that experience or satisfaction with care, or proxy (carer) measures of satisfaction, suffering/distress, and mood did not emerge as themes in the literature review (table 1).

A structure or framework to guide outcome concepts might have been considered.

5. Were the results sensible? It is good to see that a broad view was taken on health outcomes, going beyond health status alone to include participation in decision making, autonomy and control, mood and emotional health, loneliness and isolation. The practicality of ascertaining these was not well addressed, in particular with respect to the large and important proportion of service users with dementia, cognitive or communication impairment. Two of the 'outcomes' were not outcomes at all - length of hospital stay and polypharmacy are process measures. Polypharmacy divides between appropriate and inappropriate polypharmacy - and whilst being a strong advocate for considered, simplified and judgement-based prescribing, fear that 'polypharmacy' alone is too crude and may lead to perverse incentives or outcomes. Place of death as an outcome is highly controversial - most evidence suggests that this is not very highly prioritised by older people (with 'not being a burden', 'having symptoms or suffering controlled' and 'being treated with dignity and respect being' more highly valued regardless of setting. Falls is also conflicted - the most effective way to prevent falls is to prevent someone from standing up, so has to be balanced against activity and autonomy. Falls ascertainment is also very difficult, and often poorly reported and recorded (do you tell your doctor every time you fall?). Frailty is of great scientific and clinical interest and importance, but I do not think constitutes an 'outcome measure' in this sense; it is more a predisposition or risk factor. Whilst it will be interesting to track 'frailty' across populations and over time, this is not a routine application; there is little evidence to suggest frailty can be reversed or prevented, although we continue to research this possibility. SF-36 is not a good measure of ADL or mood. Zarit is considered by some to be a very negative scale - especially difficult for less disabled/frail/ill populations. Table 3 'disutility of care' might be better called 'treatment burden' - but this category should not include falls (people fall during everyday activity, unrelated to healthcare).

Most importantly of all, the whole package is far too lengthy to be a viable routine measurement set to be applied across clinical populations (the objective stated on p6 was 'feasible to implement in routine clinical practice'). Some have described a 'balanced scorecard' of outcomes. At best this exercise can be considered a contribution or work in progress.

4. Was it well written up?

a. Too many unnecessary abbreviations were used (OP, WG).

b. The statement p6 that life expectancy ranges from 60 to Africa to 79 in North America is wrong - it is higher in Europe, Japan, Taiwan and Hong Kong (mid 80's).

c. p6 'there are no comprehensive international outcome measures for OP' - meaning is unclear. Mortality and disease prevalence may be insufficient but are not 'no'.
d. p7 'Application and adoption of the standard set is free of charge'. Why is this statement placed in the background?

e. p7 lines 5-20 repeats material in the previous section

f. p12 Tier 1 2 and 3 outcomes are introduced without definition (which later appears p14 discussion)

g. The discussion would benefit from better structuring (eg 'BMJ style' discussion)

h. p16 is www.johnsbopkinssolugions spelt correctly?

Are the methods appropriate and well described?
If not, please specify what is required in your comments to the authors.

Yes

Does the work include the necessary controls?
If not, please specify which controls are required in your comments to the authors.

Unable to assess

Are the conclusions drawn adequately supported by the data shown?
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No

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