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Value in Health

DOI:
10.1016/j.jval.2017.06.011

Published: 01/06/2018

Peer reviewed version

Cyswllt i'r cyhoeddiad / Link to publication

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):
Thom, J., Brookes, S. T., Ridyard, C., Riley, R., Hughes, D., Wordsworth, S., Noble, S., Thornton, G., & Hollingworth, W. (2018). Core items for a standardized resource-use measure (ISRUM): expert Delphi consensus survey. *Value in Health*, *21*(6), 640-649. https://doi.org/10.1016/j.jval.2017.06.011

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19. Sept. 2024

Core items for a standardized resource-use measure (ISRUM): expert Delphi consensus survey

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Acknowledgments

We would like to thank the health economists who responded to the Delphi survey, whose expert participation enabled us to conduct this study, and Ed Wilson in particular. We also thank Mai Baquedano for help with setting up the REDCap survey software and Leila Rooshenas for guidance with the qualitative content analysis. An earlier version of the paper was discussed at the Health Economists' Study Group meeting in Gran Canaria, June 2016; we thank Rachael Hunter and other attendees for useful comments. This work was undertaken with the support of the MRC ConDuCT-II Hub (Collaboration and innovation for Difficult and Complex randomized controlled Trials In Invasive procedures - MR/K025643/1), the MRC NWHTMR (North West Hub for Trials Methodology Research - MR/K025635/1) and the MRC Network of Hubs for Trials Methodology Research (MR/L004933/1-N57).

Statement of contributions

WH initially conceived the idea for the project and JCT led the work. STB provided expert advice on the Delphi survey methodology. CR and JCT extracted data for the 'long list', and RR developed and tested the Delphi survey. DH, SW, SMN, WH, CR, STB and JCT contributed to the design, implementation and analysis of the study. DH, SW, SMN, WH, CR and JCT finalised the 'long list' and contributed to the final selection of items from a health economics perspective. GT provided input from a patient and public point of view. JCT and STB wrote the first draft of the paper; all authors commented on final drafts of the manuscript.

Keywords

Resource use; patient-reported; randomized clinical trial; cost measurement

Running title

Items for a standardized resource-use measure

Highlights

- There is considerable variation in the methods used to collect resource-use data in economic evaluations alongside randomized controlled trials. We aim to improve the methods by which patient-reported resource use is measured.
- A consensus process among health economists has shown that it is possible to identify a 'core set' of 10 resource-use items that should be measured in almost all economic evaluations conducted alongside randomized controlled trials in the UK
- The results imply that it may be feasible to develop a short, standardized resource-use instrument that reduces patient and researcher burden and improves comparability across trials, supplying healthcare decision makers with more consistent evidence on comparative cost-effectiveness.

Abstract

Background: Resource-use measurement by patient recall is characterized by inconsistent methods and a lack of validation. A validated standardized resource-use measure could increase data quality, improve comparability between studies and reduce research burden.

Aim: To identify a minimum set of core resource-use items that should be included in a standardized adult instrument for UK health economic evaluation from a provider perspective.

Methods: Health economists with experience of UK-based economic evaluations were recruited to participate in an electronic Delphi survey. Respondents were asked to rate 60 resource-use items (*e.g.* medication names) on a scale of 1 to 9 according to the importance of the item in a generic context. Items considered less important according to predefined consensus criteria were dropped and a second survey was developed. In the second round, respondents received the median score and their own score from round 1 for each item alongside summarized comments and were asked to re-rate items. A final project team meeting was held to determine the recommended core set.

Results: 45 participants completed round 1. 26 items were considered less important and dropped, 34 items were retained for the second round and no new items were added. 42 respondents completed round 2 (93.3%), and greater consensus was observed. Following the final meeting, a list of 10 core items was selected with further items identified as suitable for 'bolt-on' questionnaire modules.

Conclusions: The consensus on 10 items considered important in a generic context suggests that a standardized instrument for core resource-use items is feasible.

Introduction

For cost-effectiveness analyses to be optimal, resource-use measurement in randomized controlled trials (RCTs) must be accurate. However, to date, considerably more research has been directed at improving outcome measurement methodologies (*e.g.* utilities) [1]. The methods used to measure costs are poorly reported [2], and instruments to collect data directly from patients are commonly not validated [3] (although there are studies in which the reliability/validity of self-report is considered [4]). Where available, routine data sources (*e.g.* electronic hospital records) might reduce attrition bias, be more accurate, and minimise the burden on trial participants. However, routine data may not be readily available, consistent or suitable for costing purposes [5]. Electronic systems may also be costly to access, and lack information on personal costs incurred by patients. It is therefore likely that researchers will continue to be reliant on instruments based on patient recall (*e.g.* diaries, logs, questionnaires [6]) for some time, despite the fact that self-reported data on healthcare use are of variable accuracy [7].

A significant amount of work in recent years has focused on developing core outcome sets (COS): agreed minimum sets of outcomes (often health related) to be measured and reported in all trials for a specific condition/treatment [8]. Standardization counteracts problems with researchers selecting outcomes based on their own expertise or the statistical significance of results. A standard set of outcomes also reduces heterogeneity and improves comparability across trials [9]. Although developing a core set of resource-use items has much in common with COS development, there are also some important differences. A fundamental consideration of an economic analysis is the perspective, which leads to the inclusion of different types of resource use. Whereas COS are specific to clinical conditions or treatments and are therefore different across trials, a core set of resource use is specific to the perspective, but could potentially be generalizable across trials. Separate measurement instruments may be required for outcomes identified in COS (*e.g.* the EQ-5D for quality of life, or the modified Health Assessment Questionnaire (HAQ) for patient satisfaction with activities of daily living [10]); in contrast, a core set of resource-use items would generally form a single instrument.

Standardization of resource-use measurement is potentially controversial amongst health economists. Legitimate concerns about the study perspective, nature of the intervention and type of analysis planned may suggest that standardization is too limiting. There is a trade-off between gathering as

much information as possible (with increased patient burden and possible poor response rates) and gathering less information (which may not allow an accurate analysis to be conducted). As Drummond *et al* point out, "The skill in costing is to match the level of precision (and effort) to the importance (in quantitative terms) of the cost item." [11](p253). However, standardizing outcomes using the EQ-5D instrument is accepted in the UK (and indeed required by NICE [12]), despite the inevitable limitation on the flexibility of the instrument. In contrast, health economists typically generate new, or revise existing, resource-use instruments for RCTs on a case-by-case basis; some standardization of cost measurement (albeit with 'bolt-ons' to ensure more complete coverage of resources) would allow greater comparability between trials, and would reduce the research effort required. The significant overlap between questions in instruments held in the Database of Instruments for Resource-Use Measurement (www.dirum.org) [13] suggests that defining a core set may be feasible [14].

In our study, we aim to identify core items of resource use that should be included in any economic evaluation of a healthcare intervention conducted in the UK. We aim to identify a minimum set of items that should be measured, and not a complete set; we anticipate health economists may measure additional items according to the particular nature of the RCT and perspective of the analysis. We use a Delphi survey to seek consensus expert opinion.

Methods

Approval for the study was granted by the Faculty of Health Sciences Research Ethics Committee of the University of Bristol. A patient and public involvement (PPI) representative was recruited to the study team via the People in Health West of England (http://www.phwe.org.uk/) mailing list.

Phase 1: Identification of 'long list' and development of survey

The identification of a 'long list' of resource-use items is described in detail elsewhere [14]. In brief, a review of measurement instruments currently used in RCTs of health interventions was undertaken; individual items were extracted by two researchers (JT/CR) and disagreements were resolved by discussion. Items were scrutinized by a single researcher (RR) and overlapping items merged. Similar types of items were combined; for example, doctor, nurse and allied health professional were

collapsed into 'professional seen'. Items not relevant to an NHS and personal social services (PSS) perspective (commonly taken in UK studies) were dropped. Remaining items were formulated as individual questions for a Delphi survey. The Delphi method is employed increasingly for consensus in core sets of outcomes [15]. It requires expert participants to provide their opinions in sequential questionnaires (rounds), with each round presenting group feedback from the previous round. Anonymity of the responses is maintained to ensure that no individual dominates the process [16]. A web-administered 'eDelphi' survey was developed using REDCap electronic data capture tools hosted at the University of Bristol [17]; items were grouped according to the location in which the care took place (*e.g.* hospital). The survey was piloted amongst the study team, and a think-aloud web usability study (in which participants were asked to talk through their responses) was conducted with a convenience sample to ensure it was comprehensible and manageable [18].

Phase 2: Prioritization of resource-use items

Stakeholders

Practising health economists with experience of RCTs in the UK were recruited to the Delphi panel. A generic email was sent to the Health Economists' Study Group mailing list describing the preparatory work and purpose of the study and inviting participation by following a web link. Health economists who had recently contributed to NIHR Health Technology Assessment reports (http://www.journalslibrary.nihr.ac.uk/hta) or attended relevant workshops were approached directly. One reminder email was sent. Completion of the first questionnaire was deemed to represent informed consent to participate. Demographic details were requested within the survey including subgroups describing experience with different types of patient care (physical, mental and public health, older adults, primary and secondary care), length of experience and professional background.

Survey round 1

In round 1 of the survey, participants were asked to rate the importance of retaining each item in the core standardized resource-use set on a scale of 1 (not important) to 9 (very important). Participants were asked to think in terms of resource use relevant to an NHS and PSS perspective for adult patients of any age, living with wide-ranging physical and/or mental health conditions of variable

severity (appendix 1). They were asked to assume that there may be differences between trial arms in any item and that they have no access to any other source of resource-use data (such as medical records). Participants were encouraged to comment on their ratings and suggest additional items. After completion of the questionnaire, items that the participant had scored 7-9 were presented back to them, with a request to select their 'top 10' items for the core set. Round 1 item scores were summarized across participants and items to retain for round 2 were identified using pre-specified criteria; items suggested by participants were added if they met pre-specified criteria (see analysis section).

Survey round 2

All participants who had completed round 1 of the survey were emailed a web link to the round 2 questionnaire. Feedback from round 1 was presented for each round 2 item in the form of the median score along with a reminder of the individual's own score. Comments in round 1 that were relevant to selection choice were also summarized and presented, and changes were made to the wording for a small number of items based on some of the comments. Participants were asked to re-rate each item (appendix 1), and were given further opportunity to comment on their choices. A reminder invitation was sent after two weeks, and a further reminder specifying a closing date was issued one week later. Shortly after the closing date, non-responders were contacted by telephone to request reasons for non-completion.

Analyses

Statistical analyses were carried out in Stata 14 (Statacorp, TX) [19], and were conducted according to a pre-specified analysis plan.

Criteria for retaining items: At the end of round 1, the percentage of participants scoring 7-9 (high priority) and 1-3 (low priority) was calculated for each item, both for participants overall and for each of the 'type of experience' subgroups separately. Items were retained if scored 7-9 by >50% and 1-3 by <15% by participants overall or within two or more subgroups of participants; these pre-specified criteria were deliberately inclusive. Items were also retained if ≥15% of participants prioritized the item in their 'top 10' list. Items not meeting any of these criteria were closely examined for overlap with retained items; if there was no overlap, the item was further considered for retention. New items were added to round 2 if suggested by >10% of participants.

Following round 2, items were retained if scored 7-9 by >70% and 1-3 by <15% of all participants. Since further Delphi rounds were beyond the scope of this study, more stringent criteria were also set (>70% scoring an item 8 or 9 and <15% scoring 1-3) to aid discussions in a final item selection meeting so that a pragmatic core set could be identified.

Attrition: Non-responders to round 2 were examined in terms of years of experience; mean scores were compared with those from round 2 responders.

Assessment of consensus: It is not a requirement of the Delphi process to achieve consensus for all items (*e.g.* where all participants agreed on the high/low priority grouping); however, it is essential that participants agree a reduced number of items to be most important. It is therefore informative to consider the level of agreement across participants in both rounds and the degree of stability in scores.

For each round, the percentage of participants scoring 7-9 and 1-3 was examined for evidence of bimodality (defined as >40% rating an item 7-9 and >40% rating it 1-3) for each item, as this could indicate an irreconcilable difference of opinion. The intraclass correlation coefficient (ICC, two-way random effects model) was calculated for both rounds, to give an indication of agreement within the survey. [20]

For each item, the mean absolute change in score between rounds was also calculated; a large change (defined as ≥3 points) could indicate instability. The percentage of people changing their

score by a small amount (1 or 2 points) and a large amount (≥3 points) was calculated for each item to give an indication of the stability of the results. Variation in changes to scores with length of experience (categorized as <5 years, 5-10 years, 10-20 years and >20 years) was explored through linear regression. Finally, the standard deviation of scores was calculated for each item (separately for each round) as a measure of the spread in responses across participants (and degree of agreement), and used to calculate the change in each item's variability between rounds [21].

Analysis of comments: Content analysis (a systematic approach to studying text that aims to categorize and quantify content) was conducted for comments using nVivo software [22,23]. Suggestions in round 1 for new items were extracted, and broad themes were identified for both rounds.

Phase 3: Final item selection meeting

The project team met to determine the final core items to include in a standardized 'short form' resource-use measure. Participants who had commented extensively during the Delphi process or were associated with the MRC Network of Hubs for Trials Methodology Research were invited to attend the meeting. Each item included in round 2 was discussed in detail. The two pre-specified criteria were applied to the round 2 data to identify the items considered most crucial (more stringent criteria) and very important (less stringent criteria) for inclusion in the final core set. Items reaching the more stringent criteria were included in the final set if considered relevant, by the team, to all trials and patient populations. If relevant only to specific settings, items were included in suggested bolt-on modules. Items reaching the less stringent criteria were then discussed and merged with those already in the final set where appropriate, or considered as separate items for the core set or as items within bolt-on modules. Remaining items were examined to ensure that nothing vital was overlooked.

Results

Phase 1

Items were extracted from 59 resource-use instruments. Following the deduplication and merging processes, the 'long list' contained 60 items, categorized as hospital care (*n*=15), emergency care (*n*=5), care at a GP surgery or health clinic (*n*=7), care at home (*n*=7), remote access care (*n*=4), other community care (*n*=6), residential care (*n*=10) and medication (*n*=6). Usability studies with both a native and a non-native English speaker indicated that the Delphi survey was comprehensible, and completion was manageable.

Phase 2

45 participants provided usable responses to round 1; 41 completed the whole survey, while 4 supplied ratings for all items, but did not select their 'top 10' (figure 1). Participants with a range of experience were represented (table 1), although almost all were working in academia (*n*=42/45). Applying the predefined consensus criteria identified 27 items to be retained for round 2, considered to be of high priority by participants overall. Four additional items were considered important by ≥2 subgroups: minor surgery (important to participants with experience of primary care, physical health, public health or older adults), living in either a residential home or supported accommodation (rated highly by participants with experience of primary care, mental health or older adults), and the period over which medication is taken (important to respondents with experience in primary care and public health). Type of ward and scans were added because >15% of respondents cited it in their top 10. Finally, equipment was identified as a suitable addition because it came close to meeting several of the above criteria and no other similar items were included. No new items met the inclusion criteria. 34 items were therefore included for round 2 (table 2a) and 26 were dropped (table 2b). Engagement with the project in round 1 was good, with broadly positive comments indicating that achieving consensus was feasible.

42/45 participants (93.3%) responded to round 2 (figure 1). The three non-responders each came from a different level of experience. Non-responders had a mean(SD) score of 8.53(0.33) in round 1 compared with 7.13(1.09) for responders (*p*=0.03). There was no evidence of bimodality for any item in either round. All responding participants changed at least one rating between rounds, and all items

were changed by at least one participant. Participants changed their scores by a mean(SD) of 0.70(0.36) points between rounds.

The ICC (95% CI) increased from 0.85 (0.77-0.91) in round 1 to 0.93 (0.89-0.96) in round 2, suggesting increased consensus in round 2. Between rounds, standard deviations reduced for all individual items except hospital admission items and prescribed medication (table 3), again suggesting movement towards increased consensus in round 2. As anticipated, 100% concordance on the priority group (high/low) was not achieved for any item in either round. No relationship was observed between changes to mean scores and length of experience.

28 respondents commented in round 1, with two not completing the survey. The content analysis showed that the hospital and home care categories attracted the highest number of comments (15 and 11, respectively). Some comments indicated that the task was cognitively challenging. The most common theme was that the inclusion of a particular item depended on another factor including perspective, intervention, setting, condition, patient group, level of detail, recall period, time horizon and comparator. Potential issues with patient recall and practical aspects of administering a resource-use questionnaire were also raised. 17 respondents commented in round 2; comments largely focused on useful suggestions for developing an instrument, with 7 individuals suggesting a modular approach.

Phase 3

In addition to the project team, three Delphi participants were invited to attend the final item selection meeting; owing to other commitments, only one was available. The selection group identified community healthcare questions that could be combined with GP questions for consistency. Items asking about details of hospital operations or procedures were considered less important by the more stringent set of consensus rules, and were rejected for the core set of items for the 'short form' (table 4). These items could be included in an extended hospital care module for trials where admissions (or re-admissions) for procedures are prevalent. Similarly, most residential care items (with the exception of hospice stays) did not meet the stringent consensus rules. While residential care was thought to be extremely important in some trials, it was judged by the selection meeting group to be not relevant in the majority, and was therefore identified as a suitable candidate for a bolt-on module. Items on social

care did not meet the more stringent consensus rules, potentially because they were considered to be more relevant to particular groups, such as older adults; these items could therefore be included in a bolt-on social care module. Perhaps surprisingly, items on medication use were not identified as important by the more stringent criterion rules. The selection committee group felt that medication use was relevant to participants in the majority of trials, and should therefore remain on the included list; however, future work will look at the practical aspects of collecting medication data, and medication may form a separate module in the future.

Discussion

Based on consensus amongst health economists, we have identified a minimum core set of 10 resource-use items that should be considered for inclusion in a standardized questionnaire for patients (table 5). We have identified additional items that are suitable for inclusion as 'bolt-on' or extended modules covering further details about hospital procedures, residential care and social care. Agreement amongst participants was excellent [24] and moved towards consensus in the second round. Results were reasonably stable, suggesting that a third round would not have significantly altered the outcome. Although the survey was conducted from the viewpoint of the NHS and PSS, the key inclusions are all items commonly provided by the NHS. Social services care could therefore form a separate bolt-on module for trial populations where it is thought to be prevalent.

Knapp and Beecham [25] identified 'reduced lists' of key services that could be measured to capture over 90% of the total costs of health and social care in patient groups with mental health conditions. The study indicated that, in principle, capturing a fairly small number of key items of resource use can lead to adequate cost information, with diminishing returns gained by further data collection. However, while there was some overlap with the items we identified in this study (hospital inpatient and outpatient, residential care and GP care), the nature of the patient group meant that social services played a considerably more prominent role.

Generic resource-use measures developed to date include the Annotated Patient Cost Questionnaire (APCQ) [26], and the Client Service Receipt Inventory (CSRI) [27]. The APCQ was designed as a generic

patient-reported instrument. Although empirical evidence suggests the questionnaire performs well [28], it has not been widely adopted (possibly due to the length of the questionnaire necessitating substantial work to generate an instrument for a trial). The CSRI has been tested extensively, demonstrating good consistency, reliability and validity [29-32] and is well used. However, it was developed in the context of psychiatric care, was designed for interview administration rather than patient self-completion and has been subject to uncontrolled modification over the years. Standardization of data collection has also been attempted in the context of cancer care [33], and a generic Dutch-language instrument has been developed [34]. However, neither implementation combines full standardization across all disease areas with a concise instrument, and neither attempted to determine relevant content through a documented consensus process involving health economists.

Strengths of the study include the recruitment of the panel of expert participants, who were representative of a wide range of experience and had extensive NHS research experience. The stability of the panel was good with less than 10% attrition, and the study benefited from patient involvement in the study team. Established methods for conducting Delphi surveys were followed, with consensus criteria defined in advance of conducting each round. There was clear consensus for items ultimately included in the core set. However, there may also be some limitations. Almost all of the respondents came from an academic background; wider participation from industry representatives may have been beneficial in terms of generalizability, although their experience of NHS research would have been more limited. A larger sample participating in the Delphi survey would have been preferable; however, there is no statistical basis on which to determine necessary sample size for a Delphi survey and previous studies including fewer participants have been shown to produce reliable results [35]. Respondents were asked to rate both type of resource use (e.g. hospital or GP care) and measurement information (such as the number of nights or appointments) simultaneously. The task was therefore cognitively challenging, with a large set of factors to bear in mind while responding; it is possible that participants may not have taken everything relevant into account.

The items identified are those considered most important by professional health economists for inclusion in a core set of resource-use items. Work is now needed to identify the most appropriate way to measure these items to ensure patient acceptability and comprehensibility. There was evidence from the comments that some participants were considering patient ability to respond to questions. For example, one respondent commented that "…many patient groups are very confused about which services and professionals have visited them at home". This requires further investigation with patient groups. Patients were not recruited to the Delphi panel, as the task was not meaningful in the context of the UK healthcare system in which patients do not pay for services at the point of use. However, the patient perspective was represented during the study by the PPI member of the project team. Translation of the questionnaire to other languages (and other healthcare systems) also requires further investigation; given the common nature of the items included, it is possible that it will extend readily to other healthcare systems.

In this project, we have focused on an NHS and PSS perspective. There will commonly be requirements for additional data to be collected; any future instrument should take this into account through modularization, allowing modifications in a controlled fashion only, with alterations recorded. It is also likely that the resource use associated with the intervention itself will need to be collected separately. The developed instrument should be reviewed regularly to ensure that it remains current; for example, remote-access care does not feature in our short form, but may become more pertinent in future if online consultations become common. We plan to develop a core module based on the 10 items identified in this study, working with PPI representatives to convert the items into questions that are meaningful and straightforward to answer.

Conclusions

The consensus on which items are important to health economists working on clinical trials in a generic context suggests that a standardized instrument for core items is feasible. The list of items identified forms a coherent set that is potentially relevant to most trials, conditions and patient groups; it is therefore suitable for further development into a flexible instrument with additional extended and 'bolt-on' modules. Collecting cost data in a manner that is simultaneously concise, understandable for

patients, valid, precise, consistent between trials, and generalizable is challenging. We have provided much needed evidence that it may be possible to develop a standardized instrument that goes some way to meeting those challenges, based on the most important cost items.

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Table 1. Characteristics of 45 Delphi participants from round 1.

	N (%)
Years of experience	
<5 years	11 (24.4%)
5-10 years	12 (26.7%)
10-20 years	11 (24.4%)
>20 years	11 (24.4%)
Trial experience	
Adults	44 (97.8%)
Children	21 (46.7%)
Older adults	26 (57.8%)
Physical health conditions	38 (84.4%)
Mental health conditions	28 (62.2%)
Public health interventions	20 (44.4%)
Primary care	33 (73.3%)
Secondary care	39 (86.7%)
Background	
Academia	42 (93.3%)
Other	3 (6.7%)

Table 2a. Items retained at the end of round 1.

Item description	% rating 7-9	% rating 1-3	Median (IQR)	Inclusion reason
HOSPITAL CARE:				
(1) Number of hospital admissions (inpatient stay or day case)	95.56	0.00	9(9-9)	consensus
(2) Number of hospital outpatient appointments	91.11	2.22	9(8-9)	consensus
(3) Length of stay (e.g. dates or number of nights)	84.44	0.00	9(8-9)	consensus
(4) Number of operations/procedures undergone	64.44	4.44	8(6-9)	consensus
(5) Type of operation/procedure undergone	64.44	4.44	8(6-9)	consensus
(6) Type of professional seen (e.g. consultant/nurse)	53.33	13.33	7(5-8)	consensus
(7) Number of imaging scans undergone (e.g. X-ray/MRI)	42.22	13.33	6(5-8)	top 10 [a]
(8) Type of ward stayed in	37.78	11.11	6(5-8)	top 10 [a]
EMERGENCY CARE:				
(9) Number of visits to accident and emergency	91.11	0.00	9(7-9)	consensus
(10) Number of admissions to hospital, after A&E	80.00	2.22	9(7-9)	consensus
(11) Number of times paramedic care received	53.33	4.44	7(5-9)	consensus
CARE AT A GP SURGERY or HEALTH CLINIC:				
(12) Number of appointments at GP surgery or health clinic	95.56	2.22	9(9-9)	consensus
(13) Type of professional seen (e.g. GP/nurse/counsellor)	80.00	0.00	9(7-9)	consensus
(14) Number of minor surgery/procedures/treatments undergone	46.67	6.67	6(5-9)	subgroup [b]
CARE AT HOME:				
(15) Number of healthcare or social care professional visits at home (e.g. health visitor/GP)	86.67	2.22	9(8-9)	consensus
(16) Type of professional seen at home	80.00	0.00	9(7-9)	consensus
(17) Number of professional visits for help with daily activities (e.g. washing/dressing)	55.56	6.67	7(5-9)	consensus

(18) Equipment (e.g. wheelchairs/portable oxygen/specialist clothing) or home adaptation (e.g. grab rails/ramp) supplied	44.44	13.33	6(5-8)	close [c]
REMOTE ACCESS CARE:				
(19) Number of real time telephone/computer contacts with health or social care professional (e.g. with GP or telephone helpline)	68.89	4.44	7(6-9)	consensus
(20)Type of professional contacted (e.g. doctor/nurse/social worker)	53.33	6.67	7(5-9)	consensus
OTHER COMMUNITY CARE:				
(21) Number of visits to healthcare professional in the community (e.g. dentist, pharmacist, nurse, counsellor, therapist)	80.00	2.22	9(7-9)	consensus
(22) Number of visits to social care professional in the community (e.g. social worker/housing worker/drug and alcohol worker)	75.56	2.22	9(7-9)	consensus
(23) Type of healthcare professional seen	71.11	4.44	8(5-9)	consensus
(24) Type of social care professional seen in the community	62.22	4.44	8(5-9)	consensus
RESIDENTIAL CARE:				
(25) Stay in hospice	77.78	6.67	9(7-9)	consensus
(26) Length of time spent in the hospice	75.56	8.89	8(7-9)	consensus
(27) Use of short-term respite or rehabilitation care	66.67	6.67	7(5-9)	consensus
(28) Length of stay in short term respite or rehabilitation care	62.22	8.89	7(5-9)	consensus
(29) Living in a nursing home	53.33	11.11	7(5-9)	consensus
(30) Living in a residential home	48.89	11.11	6(5-9)	subgroup [b]
(31) Living in supported accommodation/sheltered housing	46.67	11.11	6(5-9)	subgroup [b]

MEDICATION:				
(32) Number of prescribed medications	68.89	6.67	8(5-9)	consensus
(33) Name of medication	64.44	4.44	8(5-9)	consensus
(34) Period taken for (e.g. dates or number of days)	46.67	11.11	6(5-9)	subgroup [b]

[a] Item included because >15% of participants listed it in their 'top 10' choice. [b] Item included because >1 subgroup rated it highly. [c] Item included because it came close to meeting several criteria.

Table 2b. Items dropped at the end of round 1.

Item description	**% rating 7-9**	**% rating 1-3**	**Median (IQR)**
HOSPITAL CARE:			
Number of other procedures undergone	35.56	20.00	6(4-7)
Number of laboratory tests undergone	35.56	24.44	5(4-7)
Type of imaging scans undergone	31.11	15.56	6(5-8)
Type of other procedures undergone	26.67	17.78	5(4-7)
Type of laboratory tests undergone	22.22	26.67	5(3-6)
Length of outpatient appointment	15.56	55.56	3(2-5)
Number of hospital transport journeys (non-emergency)	13.33	42.22	5(2-5)
EMERGENCY CARE:			
Number of ambulance journeys	28.89	17.78	5(4-7)
Time spent in accident and emergency	15.56	46.67	4(3-5)
CARE AT A GP SURGERY or HEALTH CLINIC:			
Number of laboratory tests undergone	40.00	22.22	5(4-7)
Type of minor surgery/procedures/treatments undergone	33.33	11.11	5(5-7)
Timing of appointments (office hours or out of hours)	33.33	31.11	5(3-9)

Type of laboratory tests undergone	26.67	28.89	5(3-7)
CARE AT HOME:			
Type of equipment or adaptation supplied	35.56	22.22	5(4-7)
Time spent with professional at home	33.33	22.22	5(4-7)
Time spent by professional for help with daily activities	31.11	15.56	5(5-7)
REMOTE ACCESS CARE:			
Duration of contact with professional	24.44	33.33	5(3-6)
Number of email or SMS (Text) communications with healthcare professional	13.33	42.22	4(3-5)
OTHER COMMUNITY CARE:			
Use of patient support services in the community (e.g. self-help groups/lunch clubs/day centre)	28.89	15.56	5(4-7)
Type of support service used	24.44	22.22	5(4-6)
RESIDENTIAL CARE:			
Date moved to nursing home	46.67	13.33	6(5-9)
Date moved to residential home	42.22	13.33	6(5-9)
Date moved to supported accommodation/sheltered housing	40.00	13.33	5(5-9)
MEDICATION:			
Frequency taken	42.22	15.56	6(5-9)
Dose taken	42.22	15.56	5(5-9)
Route taken (e.g. oral/suppository/intravenous)	24.44	35.56	5(3-6)

Table 3. Indicators of response to feedback from round 1.

	Mean (SD)		Round 2 minus Round 1		% rating an item 7-9		% changing score by	
Item description	**Round 1**	**Round 2**	**Change in mean**	**Change in SD**	**Round 1**	**Round 2**	**1 or 2**	**>=3**
GP appointments	8.5(1.1)	8.7(0.9)	0.13	-0.23	95.56	97.62	21.43	0.00
GP surgery/procedure	6.3(2.1)	5.8(1.9)	-0.52	-0.25	46.67	35.71	52.38	2.38
GP prof. seen	7.9(1.5)	8.2(1.2)	0.30	-0.35	80.00	92.86	23.81	2.38
Equipment	6.1(2.2)	6.0(1.7)	-0.13	-0.48	44.44	33.33	45.24	4.76
Home visits	8.3(1.3)	8.5(0.8)	0.19	-0.49	86.67	97.62	11.90	2.38
Help with activities	6.9(2.1)	6.8(1.5)	-0.13	-0.58	55.56	59.52	59.52	4.76
Prof. seen at home	7.8(1.6)	8.0(1.4)	0.20	-0.23	80.00	88.10	21.43	7.14
Admissions after A&E	7.8(1.7)	7.9(1.8)	0.06	0.06	80.00	88.10	21.43	16.67
Paramedic care	6.8(2.0)	6.7(1.3)	-0.07	-0.68	53.33	50.00	52.38	7.14
A&E	8.2(1.2)	8.5(0.8)	0.25	-0.40	91.11	95.24	26.19	2.38
Length of stay	8.2(1.5)	8.4(1.4)	0.20	-0.02	84.44	92.86	23.81	2.38
Hospital admissions	8.7(0.8)	8.6(1.2)	-0.14	0.38	95.56	97.62	9.52	2.38
Hospital outpatients	8.2(1.5)	8.5(0.9)	0.21	-0.52	91.11	97.62	26.19	2.38
Imaging scans	6.2(2.3)	5.6(1.8)	-0.58	-0.51	42.22	23.81	33.33	9.52
Operation/procedure	7.2(2.1)	7.5(1.4)	0.28	-0.75	64.44	78.57	45.24	7.14
Speciality/ward	6.2(2.0)	6.1(1.7)	-0.08	-0.26	37.78	38.10	45.24	7.14
Operation type	7.1(2.0)	7.3(1.4)	0.17	-0.59	64.44	71.43	35.71	7.14
Prof. seen outpatient	6.2(2.2)	6.4(1.7)	0.16	-0.49	53.33	57.14	47.62	7.14
Name of medication	7.1(2.1)	7.3(1.9)	0.17	-0.20	64.44	73.81	42.86	14.29
Prescribed medication	7.2(2.3)	6.7(2.3)	-0.51	0.03	68.89	64.29	35.71	9.52

Period taken for	6.4(2.3)	6.3(1.8)	-0.09	-0.41	46.67	40.48	42.86	9.52
Community healthcare	7.8(1.7)	8.1(1.3)	0.29	-0.41	80.00	88.10	33.33	4.76
Community social care	7.7(1.8)	8.0(1.2)	0.22	-0.55	75.56	85.71	35.71	4.76
Health prof. seen	7.2(2.0)	7.5(1.5)	0.30	-0.56	71.11	78.57	33.33	7.14
Social care prof. seen	7.0(2.2)	7.4(1.6)	0.38	-0.56	62.22	73.81	35.71	9.52
Tel/computer contacts	7.2(1.9)	7.0(1.5)	-0.27	-0.43	68.89	64.29	50.00	2.38
Professional contacted	6.6(2.0)	6.8(1.5)	0.16	-0.51	53.33	54.76	52.38	2.38
Respite length of stay	6.9(2.3)	6.7(1.9)	-0.24	-0.36	62.22	64.29	57.14	2.38
Hospice length of stay	7.4(2.1)	7.4(2.1)	-0.02	-0.02	75.56	78.57	33.33	7.14
Nursing home	6.8(2.4)	6.6(2.0)	-0.14	-0.42	53.33	57.14	57.14	4.76
Residential home	6.7(2.4)	6.2(2.1)	-0.50	-0.28	48.89	40.48	42.86	11.90
Supported accommodation	6.4(2.5)	5.9(2.0)	-0.52	-0.52	46.67	30.95	40.48	9.52
Stay in hospice	7.5(2.1)	7.6(2.1)	0.13	-0.05	77.78	80.95	19.05	11.90
Respite care	7.0(2.2)	6.9(1.9)	-0.16	-0.32	66.67	73.81	47.62	7.14

Table 4. Final outcomes for items following round 2.

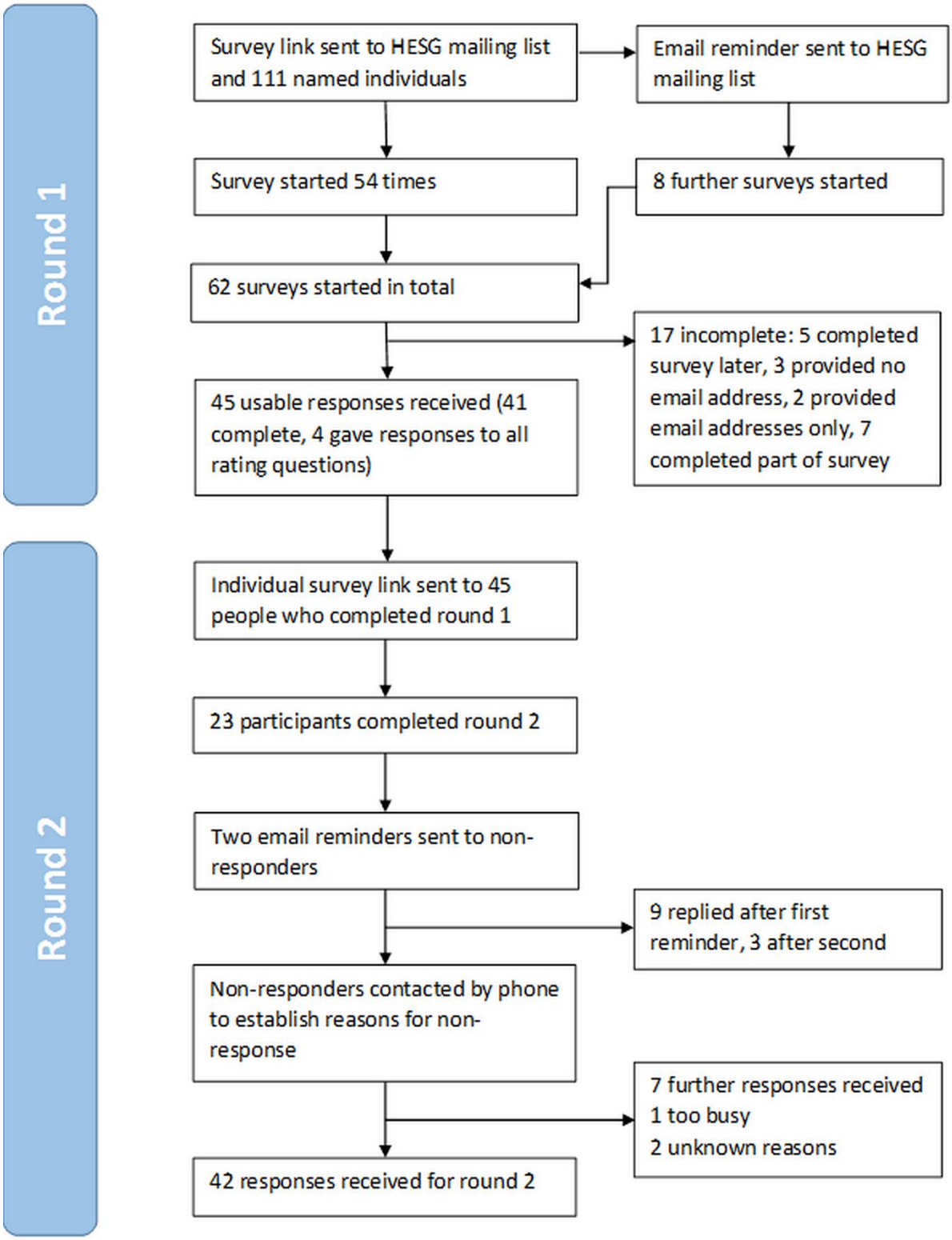
Item description	% rating 7-9	% rating 8 or 9	% rating 1-3	Outcome: pre-agreed rules	Outcome: more stringent rules	Final outcome following item selection meeting
Hospital outpatients	97.62	80.95	0.00	include	include	Short form
Hospital admissions	97.62	90.48	2.38	include	include	Short form
Length of stay	92.86	85.71	2.38	include	include	Short form
Operation/procedure	78.57	61.90	0.00	include	exclude	Extended hospital care module
Operation type	71.43	54.76	0.00	include	exclude	Extended hospital care module
A&E	95.24	88.10	0.00	include	include	Short form
Admissions after A&E	88.10	76.19	7.14	include	include	Short form
GP appointments	97.62	95.24	0.00	include	include	Short form
GP prof. seen	92.86	78.57	0.00	include	include	Short form
Home visits	97.62	85.71	0.00	include	include	Short form
Prof. seen at home	88.10	69.05	2.38	include	exclude	Short form
Community healthcare	88.10	78.57	2.38	include	include	Combined with GP appointments in short form
Community social care	85.71	69.05	0.00	include	exclude	Social care module
Health prof. seen	78.57	57.14	2.38	include	exclude	Combined with GP appointments in short form
Social care prof. seen	73.81	52.38	2.38	include	exclude	Social care module

Stay in hospice	80.95	73.81	9.52	include	include	Residential care module
Hospice length of stay	78.57	66.67	11.90	include	exclude	Residential care module
Respite care	73.81	40.48	7.14	include	exclude	Residential care module
Name of medication	73.81	59.52	4.76	include	exclude	Short form
Prof. seen outpatient	57.14	26.19	4.76	exclude	exclude	
Speciality/ward	38.10	16.67	9.52	exclude	exclude	
Imaging scans	23.81	11.90	9.52	exclude	exclude	
Paramedic care	50.00	23.81	0.00	exclude	exclude	
GP surgery/procedure	35.71	16.67	9.52	exclude	exclude	
Help with activities	59.52	30.95	2.38	exclude	exclude	
Equipment	33.33	21.43	2.38	exclude	exclude	
Tel/computer contacts	64.29	38.10	2.38	exclude	exclude	
Professional contacted	54.76	35.71	2.38	exclude	exclude	
Respite length of stay	64.29	40.48	7.14	exclude	exclude	
Nursing home	57.14	35.71	9.52	exclude	exclude	
Residential home	40.48	28.57	11.90	exclude	exclude	
Supported accommodation	30.95	19.05	11.90	exclude	exclude	
Prescribed medication	64.29	47.62	14.29	exclude	exclude	
Period taken for	40.48	28.57	4.76	exclude	exclude	

Table 5. Items included in final core set.

	Type of care	**Item**
1	HOSPITAL CARE	Number of hospital admissions (inpatient stay or day case)
2	HOSPITAL CARE	Length of stay (*e.g.* dates or number of nights)
3	HOSPITAL CARE	Number of hospital outpatient appointments
4	EMERGENCY CARE	Number of visits to accident and emergency
5	EMERGENCY CARE	Number of admissions to hospital, after accident and emergency
6	CARE AT A GP SURGERY OR HEALTH CLINIC OR OTHER COMMUNITY SETTING	Number of appointments
7	CARE AT A GP SURGERY OR HEALTH CLINIC OR OTHER COMMUNITY SETTING	Type of professional seen
8	HEALTHCARE AT HOME	Number of healthcare professional visits at home
9	HEALTHCARE AT HOME	Type of healthcare professional seen at home
10	MEDICATION	Name/class of medication

Figure 1. Flow of Delphi study participants through study.



Appendix 1. Delphi survey instructions

Figure A1. Instructions for round 1.

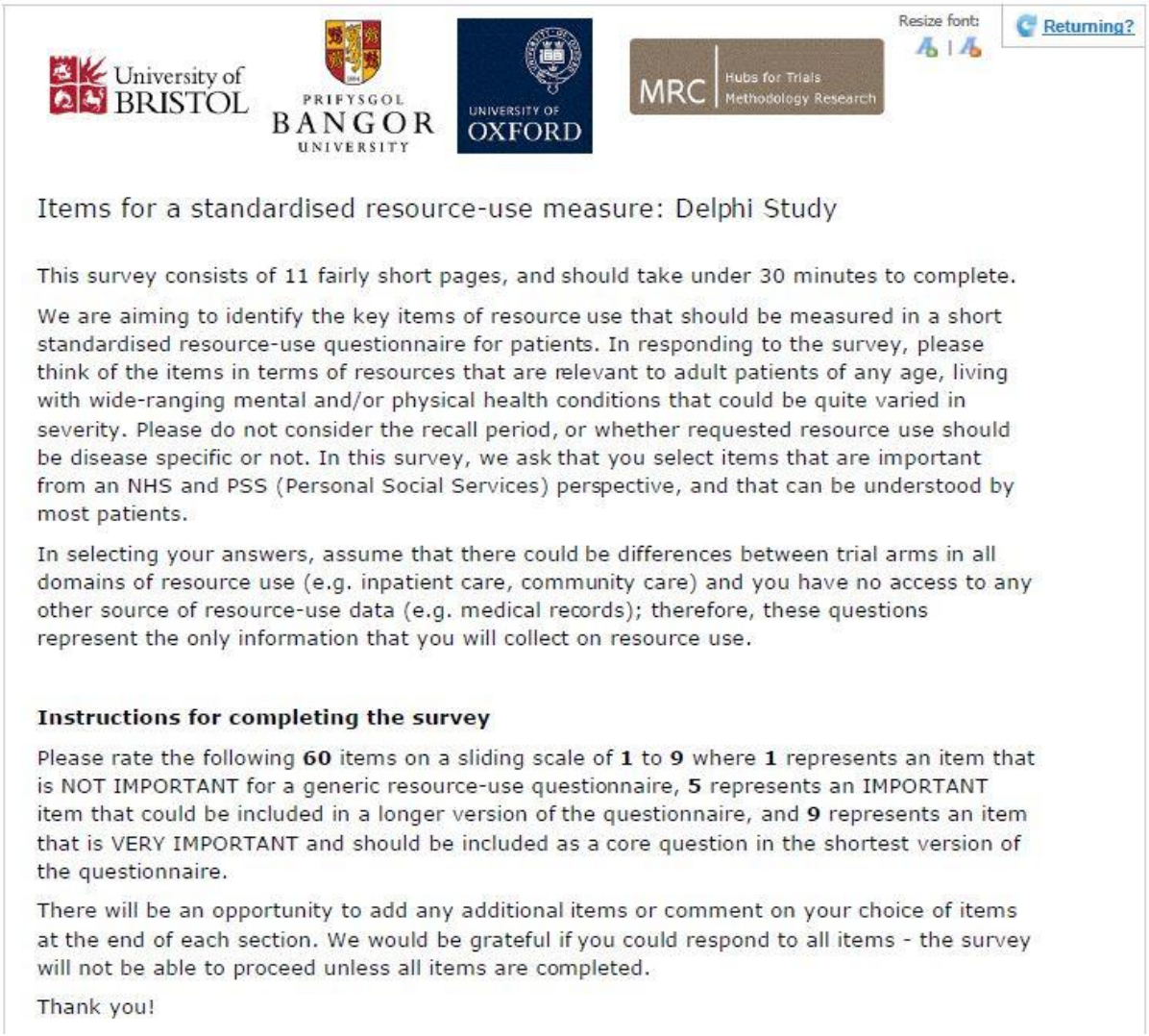


Figure A2. Instructions for round 2.

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Items for a standardised resource-use measure: Delphi Study Round 2

Instructions for completing the survey

Thank you for completing round 1 of the Delphi survey. We are aiming to identify the core items of resource use that should be measured in a short standardised patient-reported resource-use questionnaire. However, we do not envisage that these will be the only items collected in a trial; we anticipate that additional 'bolt-on' questions may be necessary in some trials.

In responding to round 2, please think of the essential items in terms of resources that are relevant to

- an NHS and PSS perspective
- adult patients of any age
- patients living with wide-ranging mental and/or physical health conditions that could be quite varied in severity

Please also assume

- there may be differences between trial arms in any item
- you have no access to any other source of resource-use data (*e.g.* medical records)
- no item is particularly associated with the trial intervention

Please do not consider the recall period, or whether requested resource use should be disease specific or not.

Thank you!

Please rate the following items on a sliding scale of 1 to 9 where:

1 = An item that is NOT IMPORTANT for a short core questionnaire
9 = An item that is VERY IMPORTANT for a short core questionnaire