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RESEARCH

The Development of a Core Outcome Set for Trials and Evaluative Studies in Adult Social Care

Thavapriya Sugavanam*, James Caiels†, Michele Peters* and Ray Fitzpatrick*

Context: Core outcome sets that help to harmonise results across studies have had a major impact on clinical research and policymaking. However, it is less developed in social care research.

Objectives: We aimed to explore feasibility and identify a set of domains that would comprise a core outcome set for adult social care research and specific measures to assess these domains.

Methods: We identified core domains through a scoping review. A panel was recruited to participate in two surveys. In the first survey, participants scrutinised the approach and the proposed domains; based on which, domains were refined. Outcome measures were then identified for each domain. In the second survey, the panel provided their views on domains and measures.

Findings: Of 30 individuals approached, 25 participated in the first survey and 19 in the second. The first survey revealed that the majority (20/25) were supportive of the overall approach. Of seven domains proposed initially, six (well-being, health-related quality of life, functional ability, experience with services, service use and costs, and carers' perspectives) were retained and one (psychological well-being) was merged with the well-being domain. Based on available evidence, we recommended specific measures for four domains and highlighted potentially relevant resources for the other two domains. In the second survey, majority of the panel (i.e. over 70%) agreed with the domains and recommendations on measures.

Implications: This study has shown that it is feasible to progress the idea of a core outcome set that might inform and guide future social care research.

Keywords: Social care; core outcome sets; well-being; health-related quality of life; functional ability; experience with services; carers' perspective

Background/Rationale

Systematic reviews of the effectiveness of interventions are a vital element of evidence-based policy, with well-established processes for assessing and synthesising evidence from all relevant primary research. However, a major challenge in the conduct of such reviews arises from the wide diversity of outcome measures used in trials and evaluative studies and the difficulties of combining and comparing findings from such diverse measures. A solution has emerged in the form of a process of agreeing a shared core outcome set for any given areas of research that researchers are encouraged to use in order to harmonise results across studies (Clarke and Williamson, 2016). Agreement to use a pre-specified set of outcome measures does not stop investigators using additional measures deemed critical to any given study. This approach has had a major impact on clinical research with widespread

identification of core outcome sets across areas of health; impact being most visible in terms of growing numbers of applicants to research funders using core outcome sets and increasing use in the conduct of systematic reviews (Hughes *et al.*, 2019; Williamson *et al.*, 2020). Core outcome sets appear to be a far less influential development in social care research, with a few notable exceptions (Reilly *et al.*, 2020). We should firstly acknowledge that adult social care includes a broad and disparate range of services, with considerable diversity of providers. In the United Kingdom (UK), social care services include various community-based services such as home care, day centres, equipment, home adaptations or assistance aid, community groups and social worker support, as well as the complete range of support provided by institutional residential care. This broad understanding of adult social care was used to define the scope of this study.

One major reason for the relative absence of core outcome sets in social care research is the dearth of randomised controlled trials (RCTs). A range of reasons for this have been proposed. It has been suggested that the social care profession is sceptical about the scientific basis of trials and considers the approach 'too positivist'

* University of Oxford, GB

† University of Kent, GB

Corresponding author: Thavapriya Sugavanam
(priya.sugavanam@ndph.ox.ac.uk)

(Trinder, 1996; Oakley *et al.*, 2003; Mezey *et al.*, 2015). There are also ethical concerns about withdrawing access to potential benefits (Dickson *et al.*, 2017; Oakley *et al.*, 2003). Historically, research methods and the principles of evidence-based practice have had a modest impact on social care training (McCrystal and Wilson, 2009; Rubin and Parrish, 2007). One other suggestion is that RCTs are not feasible (or as feasible) in social care (Mezey *et al.*, 2015). To date, the question of whether there is expert support for a core outcome set for social care has yet to be examined, and therefore what such a core outcome set might include has not been explored. The potential benefits of core outcome sets are relevant given that funding and guiding organisations such as the National Institute for Health Research (NIHR) and the National Institute for Health and Care Excellence (NICE) respectively are becoming increasingly committed to fund and guide social care research and practice, with a strong emphasis upon evaluative studies (Dodd *et al.*, 2020).

At the heart of core outcome sets is establishing consensus about two issues: (1) the domains or areas of life that should be assessed in trials or evaluative studies of interventions and (2) the specific, optimal measures that should be used to assess core domains identified from the first issue. Although there is substantial diversity in the details of how such studies are conducted, there are some commonalities (Williamson *et al.*, 2012). The scope, focus and need for the core outcome set has to be agreed. Then, a review of relevant literature is carried out, particularly of relevant trials, to identify currently-used outcome measures. Finally, consensus methods are used to address and resolve by agreement the recommended measures (Kirkham *et al.*, 2017).

This paper reports research with two aims:

- (1) To explore the feasibility of the development of a core outcome set for research in adult social care and
- (2) To identify a set of specific recommendations of domains that should comprise a core outcome set and specific measures that could be recommended to assess domains.

Methods

The study followed the key stages of development of a core outcome set: defining the scope of the project, identifying the need for a core outcome set, determining what to measure, determining how to measure (Williamson *et al.*, 2012). In relation to the first two stages, the project was to focus on outcomes in adult social care and no comparable existing initiative was found. The following steps were taken to determine what to measure, and how to measure:

- (1) A scoping literature review and initial mapping of domains of outcome was carried out by the authors.
- (2) Recruitment of a panel to whom the scoping review of domains was sent with a first survey asking for views about a set of core domains for research in adult social care.

- (3) The proposed domains were revised in light of the first survey and a review of literature was undertaken to recommend specific measures for the measurement of each domain.
- (4) A second document was sent to the same panel containing the revised domains and recommended measures for some domains, with a survey to elicit views of domains and measures.

These elements are now briefly summarised.

Firstly, a paper was written in the form of a scoping review of literature regarding domains of outcomes relevant to research in adult social care. Normally, the literature review informing the development of a core outcome set would focus particularly on outcomes used in relevant trials. A preliminary search carried out on Pubmed, PsycInfo and Social Care online to scope the current project using keywords 'social care' and 'core outcomes'/'outcome sets' and 'social care' and 'randomised controlled trials' identified four trials. This small number can be compared with 38, 54 and 129 trials respectively informing the literature reviews of three recently published core outcome sets in various areas of health (Andersen *et al.*, 2019; Hirsch *et al.*, 2016; O'Reilly *et al.*, 2020). Although more exhaustive searches might have uncovered some more trials, the decision was taken that our preliminary search was consistent with conventional wisdom: that trials in social care are uncommon and would not therefore substantially inform the current project.

One recent meta-review that summarised systematic review-level evidence on the effectiveness of social care interventions did identify a larger number of reviews/trials in social care (Dickson *et al.*, 2017). However, as the authors themselves acknowledge, the majority of these studies focussed on physical activity and occupational therapy interventions, rather than addressing core social care services in the UK such as assisted living, community support and home help. Instead of a focus on trials therefore, we drew on a wide range of literature reviewing or discussing the evaluation of outcomes of social care (Netten, 2011; Forder *et al.*, 2012). The purpose of scoping was to descriptively map the field and to identify as many as possible domains from the literature. The databases described above were again used but removing search terms for trials and focusing on reviews, supplemented by searching backwards from key reviews. Based on our reading of that literature, and judgements of whether we reached saturation of description of domains, a manageable and coherent set of potential domains was proposed and discussed by the authors, resulting in a scoping review containing a list of domains (areas of life).

The **second** step was recruitment of a panel and a first survey to obtain a range of views and feedback on the scoping review of domains. Sampling to recruit a panel was pragmatic but with an effort to reach a diversity of respondents, ideally, according to guidelines, to include service users and members of the public, researchers, professionals/providers, commissioners (Williamson *et al.*, 2012). Two main sources were used. Firstly, members

of a recently formed NIHR national collaborative group to address research in adult social care was approached; this collaboration included practitioners and providers as well as researchers. Secondly, members of a network of Department of Health and Social Care (DHSC) Policy Research Units¹ with an interest in adult social care were approached. This second route included a Patient and Public Involvement (PPI) network as well as researchers. Ethics approval was not obtained for this study as only opinions and not reports of personal experience were sought from the panel. Informed consent was obtained from participants prior to participation.

In the survey, respondents were invited to read our scoping review that summarised relevant evidence, and discussed and defined key domains that should be included for research in adult social care. The respondents were also asked to give general views about the feasibility and meaningfulness of aiming to reach agreement about a core outcome set for adult social care research. They were asked whether they agreed with the proposed core set of domains. In addition, respondents were asked about duplication or significant overlap in suggested domains, and invited to suggest domains not included in the proposed list. The survey was conducted via email and Microsoft Forms. One reminder was sent approximately one month after the initial survey.

In the **third step**, data from the first survey was analysed. The numbers and percentage of agreement for each question were calculated. The conventional threshold of 70% agreement was used to define agreement throughout the study (Williamson *et al.*, 2017). Based on these results, a revised core set of domains was proposed. In addition, the authors conducted another review of the published literature to identify specific outcome measures for the measurement of each domain. Based on the available evidence from this review, the authors recommended a set of specific measures or resources for each domain.

In the **fourth step**, the panel was approached again with a short document describing the revised set of core domains and the recommended measures to assess each of the domains. For the latter, a summary of available evidence was provided, together with copies of actual instruments. The same platform and reminder as in the first survey were used for this second survey.

The data from the second survey were analysed in a similar way to the first survey. Based on these results, a final set of domains and measures was recommended for research in adult social care.

Results

Domains

Seven domains (well-being, health-related quality of life, psychological well-being, functional ability, experience with services, service use and costs and carers' perspectives) were agreed as core domains for research in social care to be put forward to the panel.

Well-being is enshrined as a core principle in the 2014 Care Act (Care Act, 2014) in England and therefore was chosen as one of the core domains. In the scoping review that was sent to the panel, we referred to the Care Act's

multi-dimensional view of well-being to include elements such as personal dignity, protection from abuse and neglect, control by the individual over their day-to-day life, and cited more academic multi-dimensional views of well-being as including autonomy; environmental mastery; positive relationships with others; purpose in life; realisation of potential and self-acceptance.

Health-related quality of life, a distinct sub-set of the domain of quality of life that addresses the broader impact of illness upon individuals' lives, was kept as a separate core domain. Similarly, psychological well-being that covers the mental, social and emotional aspects of life was proposed as a distinct core domain. Functional ability defined as the actual or potential capacity of an individual to perform the activities and tasks that can be normally expected (Kirch, 2008), was chosen to reflect the functional aspect of life. Service user experience (alongside safety and clinical effectiveness) is considered a key component of quality of care (NHS England, 2013) and so was included as one of the domains. This domain covers both 'satisfaction' (i.e. asking the service user to say how they feel about a service or a health/social care experience) and 'experience' (i.e. focussing on what did or did not happen). To ensure high-quality adult social care service provision and delivery, there is a need for good data and understanding on how money flows through organisations and on how it feeds into services. Therefore, service use and costs was selected as one of the core domains. Finally, it is essential to cover carers' perspectives as the caring role has been shown to impact carers' quality of life and can lead to both positive (such as a sense of achievement or fulfilment) and negative outcomes (such as feeling burdened by the role) (NHS Digital, 2019; Goranitis *et al.*, 2014). Carers should be supported by health and care services in order to maintain their own quality of life and to stay able to keep supporting the person accessing services. Hence the measurement of carer outcomes was included as a core domain.

First Survey

A total of 30 individuals were asked to participate. Twenty-five responded, comprising eleven researchers, eight members of the public, four social care professionals and two social care managers and commissioners. In terms of the overall principle of developing a core outcome set for adult social care research, the majority (20/25) were supportive. When the remaining five respondents who were negative elaborated on their view in an open text box, none expressed outright negativity, but felt that they had mixed views; and that trials were uncommon in the field or that the idea needed further testing. Respondents were further asked whether the overall approach being pursued by the current research was too problematic to be further pursued. Only four respondents held that view: mainly because the approach appeared too inflexible or prescriptive given the inherent variability of social care interventions. One respondent felt strongly that more fundamental consultation with stakeholders about what matters to them was preferable to assessing the value of existing measures of outcome.

The majority of respondents considered all proposed domains to be essential in a core outcome set, although relatively less support was given to 'psychological well-being' and 'service use and costs' (Table 1). Additionally, several respondents considered that there was overlap and duplication between psychological well-being and other domains such as well-being.

Only a few new domains were suggested by respondents with any significant level of support. Although expressed in various ways, four domains were suggested: social ties and community connectivity (five respondents) independence and control (three respondents), engagement and relations between clients and service providers (two respondents) and improvement in financial status (one respondent).

Revision of domains

The authors reviewed the feedback from survey one and drafted revised recommendations of domains, using the 70% support criterion for all but two domains. It was decided that 'psychological well-being' should not be recommended as a separate domain. It was one of two domains less strongly supported and, a number of respondents (13/25) felt strongly that there was significant overlap and duplication, especially with the domain of well-being. 'Psychological well-being' is therefore seen as a component of the domain of 'well-being.' The authors proposed that 'service use and costs' be retained as a proposed domain, despite having the lowest level of support in the survey. The domain would be put one more time in the second survey, partly because some opposition to the inclusion of this domain seemed to be based on a conceptual uncertainty about whether use of services and their costs could in principle be considered an outcome.

The authors considered in turn the invaluable suggestions made in the survey for additional domains. Social ties and connectivity are important issues, but for this exercise were considered as a component of the already identified domain of well-being. Reviews of well-being usually included social well-being as a core element; measures of well-being such as Adult Social Care Outcomes Toolkit (ASCOT) specifically assess social participation and involvement as a domain (Bowling, 2014; Care Act, 2014).

It was felt that in an exercise trying to reduce duplication in any final core outcome set it would be unwelcome to advocate 'well-being' and 'social well-being' as distinct domains.

The same logic was applied to the suggestions that 'independence and control' be defined as a new domain for a core outcome set. As leading measures of well-being, Investigating Choice Experiments of CAPability (ICECAP) and ASCOT both contain 'control' as a key element of measurement. To include this construct as a distinct domain risked overlap and duplication with 'well-being.' In other words, key constructs had been suggested but they were at least partly addressed in existing measures.

Two respondents felt that engagement and relations of clients with service providers should also be a separate domain. This construct seemed to relate very directly to the existing domain of 'experience with services' and was certainly insufficiently distinct to warrant two core domains with overlapping content. Finally, one respondent expressed support for a new domain of outcome of 'improvement in financial status' of client. It was felt that with only one advocate this was not a strong basis for recommending a new distinct core domain. Moreover, it is commonly discussed as a component of well-being, for example 'economic well-being,' so not lost from sight.

Selection of measures

A review of literature was undertaken to identify suitable measures for each of the finalised domains. The document sent to the panel describing this review had to be selective. For example, the document drew the attention of the panel to a review that identified over 90 different measures of adult well-being (Linton *et al.*, 2016); time, resources and the attention of the panel did not permit re-viewing all measures. Similarly selective reporting was necessary for other domains such as health-related quality of life and functional ability where very large numbers of measures were found. Where available, the document referred the reader to structured reviews or comparative studies of measurement properties of instruments.

Sufficient evidence was available to recommend specific measures for some domains. For well-being, two measures,

Table 1: Response to inclusion of proposed domains in the two survey rounds.

| Domain | Support for the inclusion of each domain in the first survey (n = 25) | Support for the inclusion of each domain in the second survey (n = 19) |
|--------------------------------|---|--|
| Well-being | 23 (92%) | 18 (95%) |
| Health-related quality of life | 19 (76%) | 17 (90%) |
| Psychological well-being | 18 (72%) | — [†] |
| Functional ability | 20 (80%) | 16 (84%) |
| Experience with services | 20 (80%) | 18 (95%) |
| Service use and costs | 17 (68%) | 16 (84%) |
| Carers' perspectives | 21 (84%) | 17 (90%) |

[†] Based on the feedback in the first survey, the psychological well-being domain was merged with the well-being domain in the second survey.

ICECAP (Al-Janabi *et al.*, 2012; Grewal *et al.*, 2006) and ASCOT (Netten *et al.*, 2012) had been well-validated and sufficiently used in the social care research context to warrant recommendation as alternatives. For health-related quality of life, although the report recognised that a wide range of general purpose measures existed, only one measure, EuroQol- 5 Dimension (EQ-5D) (EuroQol Group, 1990), had sufficient evidence of validation and use in social care to be recommended. For functional ability, it was felt necessary to separately consider measures of basic function, such as washing and dressing and more complex functions such as shopping and managing household budgets. Two measures, Katz Index of Independence in activities of daily living (Katz ADL) (Katz *et al.*, 1963) and Barthel Index (Mahoney and Barthel, 1965) were recommended as alternative measures of basic functional ability and one measure, Lawton and Brody instrumental activities of daily living (Lawton IADL) scale (Lawton and Brody, 1969), recommended to assess more complex functional ability. For the carer’s perspective, a range of measures was considered in the report and one measure, ASCOT-Carer (Rand *et al.*, 2012), was recommended. A number of comparative studies identified it as having superior measurement properties compared with alternatives (for example, (McCaffrey *et al.*, 2020).

For two domains, no measure with any significant supporting evidence could be found from our searches and therefore, no specific measures could be recommended for these domains. However, for experience with services, the report did draw attention to items from the regularly used Adult Social Care Survey (ASCS) (NHS Digital, 2020). Similarly, the report highlighted the widely used and respected Unit Costs of Health and Social Care resource (UCH&SC) (Curtis and Burns, 2019) for the domain of service use and costs.

Second survey

Of the 30 members of the panel asked to contribute to the second survey, nineteen responded (ten researchers, one social care professional, and eight members of public).

A clear majority (i.e. over 70%) responded positively to all of the six domains recommended (lowest level of support, 16, for both functional ability and service use and costs) (Table 1). No compositional effect could be identified for changes of response in the panel between surveys, so changes are likely to reflect real changes of view about domains.

With regard to specific measures, 17 agreed with the recommendation that ICECAP and ASCOT were equally appropriate. One participant preferred the ICECAP. All 17 who gave a view supported EQ-5D as a recommended measure of health-related quality of life. Similarly, all 17 who gave a view supported ASCOT-Carer as recommend measure for the carer’s perspective. For basic functional ability, 10 out of 16 giving a view agreed with the recommendation of Barthel Index and Katz ADL as being equally appropriate while three preferred the Barthel Index. For more complex function measurement, 13 out of 16 agreed with the recommendation of the Lawton IADL as the appropriate measure. Regarding experience of services, 16 of 17 who gave views agreed that no measure could be recommended. One respondent argued that despite the absence of a single recommended measure, items of the Adult Social Care Survey (ASCS) were sufficiently widely used and valued that it was far preferable that they were resorted to, rather than efforts made to develop and validate new measures. They also suggested that predecessors of the ASCS, namely DH-supported user experience surveys (Malley and Fernández, 2010) could be considered for relevant (service or cohort specific) items. Surveys of experience are so service-specific that generic items were unlikely to emerge. Similarly, 14 of 16 giving views supported our recommendation to highlight, but not recommend the UCH&SC report. One respondent felt that work on the Standardised Resource-Use Measure (ISRUM) be highlighted (Thorn *et al.*, 2018).

Having in mind the review of evidence and the views of the panel expressed in two rounds of survey, we concluded that the core outcome set of domains and specific measures in Table 2 be recommended. Although total

Table 2: Recommended domains and measures.

| Domain | Measures |
|--------------------------------|---|
| Well-being | ICECAP [†] and ASCOT recommended as alternative options |
| Health-related quality of life | EQ-5D |
| Functional ability | <u>Basic ADLS</u> Barthel Index (for older adults only) <u>More complex, instrumental ADLS</u> Lawton IADL |
| Experience with services | No measure recommended |
| Service use and costs | No measure recommended, UCH&SC report highlighted |
| Carers’ perspectives | ASCOT-carer |

[†] It should be noted that there are two versions, ICECAP-O (for older people) and ICECAP-A for adults.

Key: ADL: Activities of daily living; ASCOT: Adult Social Care Outcomes Toolkit; EQ-5D: EuroQol- 5 Dimension; IADL: Instrumental activities of daily living; ICECAP: Investigating Choice Experiments of CAPability; UCH&SC: Unit Costs of Health and Social Care resource.

numbers of participants in the panel was small, each item in **Table 2** was supported by at least 70% of participants.

This paper also highlights other potential measures or resources that should be drawn to the attention of researchers but which do not have either the support of our panel or a substantial evidence-base. With regard to experience with services, the ASCS provides items that have been widely applied and results of which are greatly respected. Such resources need to be considered by researchers before contemplating the development of new measures. Regarding service use and costs, a group has recently developed a core outcome set of standardised measures of resource use (Thorn *et al.*, 2018). It very largely focuses on healthcare-related resources and has yet to be tested in trials or evaluative studies.

Discussion

This paper indicates that, despite the modest tradition of trials in social care research, it is possible to progress the idea of a core outcome set that might inform and guide future research. We found significant support for the idea as well as considerable agreement in a diverse panel about core domains and some recommended measures. The results are consistent with some of the recommendations of more traditional reviews of measures in social care research (Makai *et al.*, 2014; Bulamu *et al.*, 2015; Bulamu *et al.*, 2018). A similar initiative used published evidence and consensus opinion to reach recommendations of outcome measures for the long-term care sector; with some specific instruments such as ICECAP, ASCOT and EQ-5D being endorsed there as in this study (Edvardsson *et al.*, 2019). Core outcome sets usually inform the content of RCTs but there is no reason why they may not be applied to other evaluative study designs more commonly used in social care research. Although quantitative evaluation of social care is particularly challenging, our results provide encouraging evidence for some core principles of measurement in the field.

There are limitations in the study. The very limited evidence base of trials meant that we drew on a broader range of types of evidence about outcomes (for example reviews of instruments' measurement properties) than would be relied upon in developing a core outcome set for a health-related topic. Reviews sent to the panel were selective, rather than comprehensive, structured systematic reviews, for pragmatic reasons. In defence of this approach, panel members were encouraged to identify omitted domains or instruments. Because we were exploring the applicability of a quite unfamiliar approach to social care research, we were unsure about likely tolerance for the more frequent rounds of testing consensus often employed in standard core outcome sets and confined the task to participation in two rounds.

The size of the panel was modest and unfortunately, despite reminders, there was attrition in participation in the second survey. The study was conducted in a year (2020) in which all involved in social care were concerned with dealing with the impact of the Covid-19 pandemic and we were positive about the engagement that was achieved.

It is important to recognise that there are a range of approaches to cause-and-effect modelling and attribution that may work in social policy research in addition to evidence from trials and evaluative studies (Bovaird, 2014). Theory-based evaluative methods such as contribution analysis offer alternatives to the use of outcomes presupposed in the current paper (Wimburg *et al.*, 2012). More generally qualitative methods have played a distinctive role in informing the evidence-base of social care (Moriarty, 2011). The quantitative measures of outcome explored in the current paper complement such approaches.

The applicability of the proposed core outcome set will be tested over time by whether researchers adopt the set, and if research funders and policy makers encourage use of the approach. Social care comprises an extremely heterogeneous range of services and interventions. More specialised core outcome sets may be required for particular services, as has already occurred with the core outcome set for social care aspects of dementia (Reilly *et al.*, 2020). Similarly, there are important ongoing debates about the key goals of social care and particular constructs such as empowerment, and assets- and strengths-based models of care may need greater emphasis in the measurement of outcomes.

Note

- ¹ Policy Research Units (PRUs), funded by the NIHR, undertake research to inform the UK government and arms-length bodies making policy decisions about health and social care. The units create a critical mass of experts for research in priority areas for health and social care policy (<https://www.nihr.ac.uk/explore-nihr/funding-programmes/policy-research.htm#two>).

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Competing Interests

The authors have no competing interests to declare.

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