



# Personal outcome measures and postal surveys of social care

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Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

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## Executive summary

### Background

The drive for greater personalisation of social care has led not only to interest in gauging performance by measuring the outcomes of individuals receiving support but also in exploring personalised ways to measure those outcomes. Work has been underway since 2009 among a group of local authorities in England, led by Oxford City Council, to incorporate personal outcome measures (POs) into social care assessments, care package planning and review.

Personal outcomes are the goals people want to achieve through the social care services and support they receive. Personal outcomes are often categorised as ‘soft’ outcomes and placed in contrast to ‘hard’, process-based measures of service performance and throughput. They are also often distinguished from outcomes based on policy or clinical outcomes.

### Aim of this Study

The aim of the study was to assess the feasibility of including a PO measure in a postal survey: the Adult Social Care Survey (ASCS).

### Methods

This report is based on a rapid scoping review of the literature on personal outcomes, drawing on literature available in journals, online and as suggested/provided by LA contacts and researchers at PSSRU.

### How Personal Outcomes have been Conceptualised and Measured

A variety of terms relating to similar concepts to personal outcomes are in use in the literature: self-rated quality of life, user-set goals, individual outcome measures, person-centred outcomes, user-centred outcomes. There are also (at least) two different ways in which ‘personal outcomes’ are conceptualised:

1. As psychological/experiential measures developed from lay, service user views but measured using standardised questionnaires developed from these views
2. As ‘user- defined’ outcomes/responses to open-ended questions around outcomes desired from services which are then reviewed at a later date, and the percentage of ‘met’ outcomes per area, local authority or other grouping reported. As part of this process, the user-defined outcomes may be classified into domains or frameworks (possibly based on ‘domains’ or categories derived from work, as in 1).

We explore both of these in the report but focus mostly on the second approach.

### Approaches to Asking about Personal Outcomes

Wording of PO questions of this type takes various forms, including:

*‘What are the five most important areas of your life at present – the things which make your life a relatively happy or sad one at the moment...the things that you feel determine the quality of your life?’ (SEI-QoL, O’Boyle et al, 1993)*

*The Three Wishes approach, for example – ‘If you could have three wishes that could come true, what would you wish for?’ (Dykens et al, 2007)*

*Sentence completion: ‘I would like...’ (Whereton et al, 2012)*

*‘What are the three most important things you want to happen in your life?’ or ‘What three things matter to you most?’ (Oxfordshire CC)*

## Using Personal Outcomes in a Self-report Survey

The main findings from our review of the literature are as follows. While suitable for use in helping to inform **individual-focused decisions**, in face-to-face situations, and particularly beneficial for care assessment and review, personal outcome measures are less easy to use in informing **comparative decisions** (between service users), especially when relevant information is collected in self-report form, such as a postal survey.

A personal outcomes approach is in keeping with the personalisation of services and can be empowering to service users (Qureshi, 2001) and help improve outcomes (Miller, 2010). These are beneficial features of PO approaches when used in an individualised, face-to-face data collection context.

Ideally these feature would be retained *in moving to a comparative, self-completion basis, collected by postal survey*. However, we identified a number of **challenges** when trying to use personal outcomes questions to in this way. These are outlined as follows along with some measures to reduce these difficulties:

**(a) Finding a way to incorporate the relational, developmental and evolutionary nature of goal determination in PO approaches.** In other words, PO approaches have been able to draw out particular concerns or aspirations through having a ‘conversation’ between respondent and questioner. A particular concern would be the potential for under-reporting of highly personalised, unmet needs in a self-completion context. One approach is to use prompts, hierarchical questions, routing and some open-ended questions, but this remains a key challenge for PO questions in a survey context.

**(b) Overcoming the high cognitive demands of a SC approach,** especially with regard to service user respondent populations and the risk of exclusion of already under-represented groups. Careful cognitive testing of question/instructions that balanced detail against an avoidance of over-complexity would be required.

**(c) Establishing the attribution to the use of care services.** As well as rating overall achievement, some measure would be needed about how much this degree of achievement was due to social care services. An option would be to ask respondents directly. Another possibility would be to use statistical methods looking at the correlation between the type of social care a person receives and the achievement of their objectives. This option would require any comparison problems to be solved, as outlined next.

**(d) Addressing the aggregation and comparison problems.** A key issue is how to ensure that outcomes cited (big and small) are comparable across areas and services. In particular, there would be a need to establish the relative importance of some outcome goals compared to others. In other words, some people

might state aspirations that would be very difficult for social care to achieve compared to others. In assessing the performance of social care, it would be important to account for how inherently hard it would be for these goals to be satisfied.

One option to address this issue is to include additional questions that measure the importance of outcomes and perceived impact of services on these, although this would add to length and complexity.

Another option, one that has been used by LAs to date, would be to use a pre-determined framework to code, weight and map responses. Of course, questions would remain about which framework should be used, who should complete the mapping, and what measures should be taken to ensure bias and 'subversion of service user voice' are avoided.

**(e) Dealing with the dynamic nature of a PO approach i.e. statement of goals and then the follow-up for assessment of the degree of achievement.** Two options are (a) retrospective questioning or (b) longitudinal surveys.

**An open-ended retrospective question** would ask what service users had hoped social care would help them with during the previous six months and a further, closed response question asking the extent to which social care services had helped. This type of question could be added to the ASCS without need to change the basic administration method. Retrospective questioning has been used in Scotland by the Information Services Division (ISD) to obtain a personalised health indicator. This would be cost-effective but may lack rigor due to biases of memory.

**A longitudinal survey** could be developed to measure personal outcomes that service users could complete on more than one occasion. It could assess the extent to which outcomes reported at baseline have been met at a follow-up. This option has the potential to provide more robust data than the first option but raises many practical and resource issues for administration. These issues include: the best timing between 'waves' of the survey, the length of time over which service users would be contacted, how respondents could be 'reminded' of the outcomes given during a previous 'wave' and whether the survey should be staggered (e.g. after a service user's initial assessment) or go out to all respondents at the same time of year. It might also raise issues about confidentiality for respondents.

**(f) The possibility of order effects** – the risk that positioning of PO questions could influence responses to other parts of the ASCS. Again, cognitive testing would be required to gauge the potential for this effect and to configure question ordering appropriately.

### Using Personal Outcome Measures in Practice

A number of local authorities and research studies themselves highlight the beneficial feature but are clear on the challenges of using POs for comparative purposes. Rather than modifying POs for the latter purpose, most local authorities and many researchers instead use a mapping approach. PO gathered information is mapped or coded into various generic frameworks – for example, the Talking Points approach (Cook and Miller, 2012); the Adult Social Care Outcomes Toolkit (ASCOT); domains cited in The White Paper – Our Health, Our Care, Our Say (OHOCOS, Department of Health, 2006); and the Senses Framework (Nolan et al, 2006).

This approach is a way for local authorities to connect with and focus on their core values but this would not be practical within a survey such as the ASCS. It would reduce the value of POs as offering something different – and a ‘service user voice’ – from measures such as ASCOT, which are already included. It would be adding burden to both those responding to the survey and those analysing it without clear ‘added value’.

## Conclusion

In considering the above challenges, a key question is whether there would be added value in adapting a PO approach to work for comparative decision-making on a large scale, rather than use existing measures for this purpose. Indeed, it is not clear that once adaptation are made that a self-completion PO method would look that different from existing, pre-determined, multi-attribute methods such as the Adult Social Care Outcomes Toolkit. These are ultimately empirical questions, although we speculate that the nature of the challenges for using POs in surveys appear significant in theory.

We outline a possible approach to testing PO questions for the ASCS, or as a separate longitudinal survey. This empirical analysis would involve designing, piloting and cognitively testing new PO questions in a survey format, and then using these alongside standard Adult Social Care Outcomes Toolkit (ASCOT) questions in the survey. The relative performance of these sets of measures would then be compared.

## Introduction

Since the 1990s there has been a shift away from needs-led assessment of health and social care to an outcomes focused model. This has led to an emphasis on gauging performance by measuring the outcomes of individuals receiving support. More recently still, there has been consideration of personalised methods to measure those outcomes, particularly the idea of further refining outcomes-led assessment to include or comprise what have been termed 'personal' or 'individual' outcome measures (POs).

Personal Outcomes – the concept of asking what people want to be able to achieve through the social care services and support they receive – were first developed prior to Self Directed Support as a way of looking at both qualitative and quantitative information. It is important to bear in mind this starting point.

A variety of definitions of personal outcomes are available in the literature, most positioning POs in opposition to policy, service-derived or clinical outcomes:

*'These [personal outcomes] are the things that are important to individuals to achieve. Personal goals may be linked to policy goals, but will be different for every person. Both kinds of outcome need to be measured in order to judge the results being achieved by the social care system as a whole'. (Putting People First, 2009 p.2)*

*'For many years there has been an emphasis on measuring the outcomes of human services. It is important to distinguish between personal outcomes, which are defined by the individual, and outcomes, which are pre-determined by the service on behalf of beneficiaries'. (Miller, 2012)*

*'..A Personal Outcomes Approach understands outcomes as what matters to each person and the extent to which these individual priorities are being achieved. It is concerned with engaging with the person to identify their 'personal outcomes' and then determining how best to support the person to achieve them'. (The Health and Social Care Alliance Scotland <http://www.alliance-scotland.org.uk/what-we-do/projects/personal-outcomes-and-quality-measures-project/?rfrm=lucas>)*

*'Personal Outcomes need to be considered alongside clinical outcomes to provide a more rounded picture of quality of healthcare that takes into account individuals' assessments of the impact of treatment'. ISD Scotland (2013)*

*'[personal outcomes are] Defined by the person as what is important to them in life' (Talking points, 2013*

<http://www.ccpscotland.org/assets/files/ccps/policy/New%20Localism%20HT/TALKING%20POINTS%204%20PAGER.pdf>)

Local authorities Kent and Oxford began developing their own PO models and collecting personal outcome data in 2008/09 in response to a perceived gap in personal outcome measures within the National Indicator Set. In 2011, Oxford CC led a programme of work to recommend a model for POs and PO indicator for agreement with the Association of Directors of Adult Social Services (ADASS).

POs are – or have a strong potential to be – salutogenic, that is, they focus on the wellbeing of the service user rather than being based on the common deficit model. Ball et al, (2004) highlight that personalised



outcomes focus on aspirations and not just problems, that they can create greater recognition of the role played by carers; make care plans more 'creative'; and help care providers to 'fine-tune' care packages.

The development of personal outcomes measures as robust indicators of how services support independent living and quality of life has been seen as a key driver to expansion and sustainment of person-centred support (Beresford et al, 2011).

In this report we consider the use of self complete data collection methods such as postal questionnaires as a means to collect national data on personal outcomes. In the first section we explore how personal outcomes have been conceptualised and measured. We then consider the feasibility of collecting personal outcomes information in a self-complete survey. Finally, we outline a method for piloting the inclusion of a question on personal outcomes in the National Adult Social Care Survey.

## **Methods used in this report**

This report is based on a rapid scoping review of the literature on personal outcomes, drawing on literature available in journals, online and as suggested/provided by LA contacts and researchers at PSSRU.

The principle questions addressed were:

How have personal outcomes been defined and measured in social care and other related fields?

How well would an item or items on personal outcomes fit within a postal survey such as the ASCS and what form could it take?

How could personal outcomes items be tested before inclusion in a postal survey?

The report draws principally from work on social care in the UK but, in order to supplement the relatively small amount of available and relevant literature on personal outcomes measurement and methodology, it also includes some work from North America and from the fields of health and wellbeing research.

Online information searches were conducted on both Google and Google Scholar. As a search engine, Google Scholar generated the most results, however not all studies identified were relevant to health and social care. Searches were also performed on specific databases in order to focus the search on peer reviewed articles. The databases used were PsycINFO, PsycARTICLES, PsychSource, PubMed (Medline), BMJ.com and Embase. Initial searches were conducted using the phrases:

- three wishes + social care;
- personalised outcome measures + social care and;
- self-evaluation + social care.

As these terms generated relatively little relevant literature, search terms were expanded to include health care. Furthermore, different combinations of words and formatting (removing the hyphen from 'self-evaluation', using inverted commas, e.g. 'social care' and 'personal outcome' + measure) were used in order to maximise results. Further search terms used were:

- self-evaluation measures + health;
- self-evaluation measures + social care;
- individual outcomes + health;
- individual outcomes + social care;
- personal outcome measures + social care;
- self-evaluation + social care and;
- three wishes as personal outcome measure.

A review of existing literature generated alternative phrases which were used to refer to the outcome measures of interest. These terms were then incorporated into our information and literature searches:

- three magic wishes + social care;
- three wishes projective technique+ social care;
- three wishes task+ social care;
- end of life three wishes + social care and;
- measuring three wishes + social care

This helped to generate examples of the general use of three wishes within research in non-clinical populations and outside health and social care settings.

## **How personal outcomes have been conceptualised and measured**

A variety of terms relating to similar concepts to personal outcomes are in use in the literature: user-set goals, individual outcome measures, person-centred, user-centred outcomes. In this report we use the term 'personal outcomes' (POs). Along with the range different overlapping or synonymous terms in use, the literature also reveals two different ways in which 'personal outcomes' are conceptualised:

1. As psychological/experiential measures developed from lay, service user views but measured using standardised questionnaires developed from these and;
2. As 'user defined' outcomes-responses to open-ended questions around outcomes desired from services which are then reviewed at a later date and the percentage of 'met' outcomes per area, local authority or other grouping reported. As part of this process the user-defined outcomes may be classified into domains or frameworks (sometimes based on 'domains' or categories derived from work as described in 1).

Examples of both of these approaches will be described but we will focus mainly on the second approach as this is where most work has occurred and this is the approach which relates most closely to the type of measures there is interest in developing for inclusion in the Adult Social Care Survey (ASCS).

## 1. Standardised measures developed from service user views

Some ways in which personal outcome measures have been defined and measures developed do not differ significantly from the methods used to develop measures within the ASCS, such as the Adult Social Care Outcomes Toolkit (ASCOT, Netten et al 2011). Here, a personal outcome measure describes measures were developed by, or from consultations with, 'lay' people or service users rather than from the perspective of service providers or as performance measures.

For example, in America, The Council on Quality in Leadership (CQL), a not for profit organisation offering consultancy on personal outcomes measures to health services providers, ([http://www.thecouncil.org/Personal\\_Outcome\\_Measures.aspx](http://www.thecouncil.org/Personal_Outcome_Measures.aspx)) began developing personal outcome measures in the early 1990s. CQL refer to personal outcomes as 'responsiveness to people' and aimed to develop a measure that captured the 'outcomes and support experienced by people with disabilities' (Landsby, 2010). Their PO measure was developed from focus groups where people with disabilities and their families defined the 'outcomes that were most important to them'. These measures were seen as being 'based on the unique characteristics, needs, and desires of each individual.' Importantly, CQL stress that the move to POs also meant that methods of data collection had to change, with personal interviews being 'the foundation of the data gathering processes'. Their tool comprises 21 outcome measures which fall into three factors:

- Myself: who I am as a result of my unique heredity, life experiences and decisions;
- My world: where I work, live, socialise, belong or connect;
- My dreams: How I want my life (self and world) to be.

The outcome measures include safety, support networks, relationships, participation in the community and choices in different areas of life. Annexe 1 gives more details of the outcome measures used in this approach and suggests ways in which these reflect current measures in the ASCS, in particular, ASCOT.

Work in the UK also mirrors similar domains. For example, Waters et al at Lancaster University, cited in *Changing lives together: Using Person-centred Outcomes to Measure Results in Social Care* (Department of Health 2010) developed questions for services users based on rated satisfaction against 'a predefined satisfaction scale' of:

- Dignity in support;
- Choice and control;
- Feeling safe (at home and 'out and about');
- Being a partner in planning support;
- Key relationships.

This approach was cited as being used by six local authorities:

- City of London
- Hertfordshire
- Cambridgeshire
- Worcestershire
- Northamptonshire
- London Borough of Richmond upon Thames.

The approach and choice of domains is seen to be based on service user views in that it:

*has shown that it is possible to work collaboratively to design, construct and employ an approach to measuring outcomes that features the views and experiences of local people and staff who work in social care services features the views and experiences of local people and staff who work in social care services.(p.9)*

## 2. User defined personal outcomes

### Research studies and projects

#### *Standardised measures*

A well-used and reported instrument, which measures personal quality of life (if not personal outcomes), is the Schedule for the Evaluation of Individual Quality of Life (SEI-QoL) (O'Boyle et al 1993). SEI-QoL is a measure of health-related quality of life. With SEI-QoL respondents are asked to identify:

*'the five most important areas of your life at present – the things which make your life a relatively happy or sad one at the moment...the things that you feel determine the quality of your life.'*

After the person administering the measure establishes the core meaning of the areas mentioned by the respondent (e.g. if 'golf' means 'leisure' or 'socialising' or 'mobility'); they are then asked to rate how life is for them in each area from 'worst possible' to 'best possible', by drawing a horizontal line inside a box the bottom of which represents 'worst possible' and the top 'best possible'. Respondents are then asked to rate their present life as a whole in the same way, and finally, a specially designed disk is used to help respondents indicate the relative importance of each of the five areas so that weighting can be applied. While highly personalised and eliciting extremely detailed quantitative information, the SEI-QoL is a highly time-consuming process – a study of its use with hospital patients aged 65 and over (Mountain et al, 2003) found it took a median of 37 minutes to complete (range 15-105 minutes). It is not a method which could be used in a postal survey but could be worth exploring as a method to use in face-to-face data collection.

Along similar lines, the Patient-Generated Index (PGI) (Ruta et al, 1994) asks respondents to first say which areas of their life are most affected by their health and then rate how their current condition matches their expectations on a scale of 0-10. Respondents then have to rank the areas they have specified in terms of importance to them.

Similarly, the Quality of Life Assessment Schedule (QOLAS, Selai et al, 2000) is based on repertory grid technique/construct theory (Kelly, 1955), and asks respondents to say what is important for their quality of life. They then identify ways in which their current health state affects this. 10 "constructs" are elicited, two for each of the following domains of QOL: physical, psychological, social/family, work/economic, and cognitive functioning. Respondents then rate these on a scale of 0-5, where 0 represents 'no problem' and 5 'it could not be worse'. They also rate how much of a problem they would "like" each of these to be, ideally, on the same 0-5 scale. At follow-up interview, respondents are reminded of the constructs they identified and asked to rate them 'now'. While complex and needing face to face administration, QOLAS has been used successfully with patients with mild to moderate dementia and has shown to have acceptable validity and reliability (Selai et al, 2001).

Another generic approach that does not use domains but which, the authors claim, allows patients to define the outcome of any therapeutic service or intervention is PSYCLOPS (<http://www.psychlops.org.uk/about.html>). PSYCLOPS is a one page measure and was developed by primary care professional and therapists at King's College, London. PSYCLOPS comprises questions on Problems, Function and Wellbeing and a scoring system. Respondents describe their main problem or problems and how this/these affects them. PSYCLOPS can be used before, during and after any therapeutic

intervention and measures the processes whether or not it the intervention is completed. It has been validated in a number of languages.

### *Three wishes: Research studies in social care, health and wellbeing*

A small number of studies from various health and wellbeing fields have used the 'three wishes' approach to capture personal outcomes. For example, Dykens et al (2007) individually administered interviews to 128 participants with ID (Intellectual Disabilities) aged 5-50 years (mean = 18.75 years). The study used two 'semi-projective' tasks; sentence completion and three wishes. It also used an IQ test to measure cognitive abilities. The measures used were:

1) Sentence completion task (9 stems)...

I would like to...

I wish that I...

If I only...

I hope...

I am...

I would like the most to...

I am best when...

People think that I...

Sometimes I think about...

2) Magic wishes...*If you could have three wishes that could come true, what would you wish for? What are your three wishes? I'll write them down.*

Responses were coded into content categories but no outcomes were measured and no follow-up occurred. Because of the lack of focus on outcomes and follow-up in this study, it offers limited insights into how well the three wishes approach might be used to measure met or unmet outcomes. It does, however, show encouraging signs that people with learning disabilities are able to respond to such questions in a face-to-face administration.

A study using social care service users – using three wishes, where personal outcomes questions were completed by respondents in their own time – was reported by Whereton et al (2012). Researchers made home visits to 31 participants aged 60-98 regarding assisted living technologies to support independence at home. An initial interview took place, and then the participant was given various items of equipment to use for one week and a 'Home and Life Scrapbook' which included a section on wishes (things they wanted to change or improve). After one week, the researcher returned and reviewed the content of the scrapbook during an interview with the participant. The wish list question was open-ended but, in order to focus priority, was limited to three items. Three sections started with the phrase "I would like...". The three wishes activity aimed to explore what participants wanted as well as needed. The authors provide examples of responses and cite one specific response of "able to breathe better" before providing broader examples such as "visiting places" (remaining active), "be able to stay in my own flat" (ageing in place) and "able to help orphans" (reciprocity). It is reported that responses were identified as providing further insight into factors which impacted on the participant's quality of life and opportunities for support. As such, they were used as a starting point for discussion between the participant and researcher in the final interview of the study. Again, this study did not focus on whether these wishes/outcomes were met.

We only found one example in the research literature of the use of a personal outcomes approach – again, the three wishes approach – in a self-report questionnaire, but this was in a non-clinical, student population. King and Broyles (1997) used a self-report questionnaire which measured three wishes with 405 US college students, and related responses to measures of well-being. The study asked:

*If you could have three wishes, what would you wish for?*

A quarter of a page was allowed for a written response. Of respondents, 96 % listed three wishes and 4 % listed less than three. Two participants listed four wishes, but the study only used the first three. After listing the wishes, the questionnaire included personality and well-being scales. Finally, participants were asked to rate on a scale of 0.0 to 0.1 how probable they thought it was that each wish would come true. Content analysis was used to code responses into content-driven categories and they were rated by researchers on a number of continua such as possibility to attain and breadth. This study focused on the relationship between wishes and gender, personality traits and well-being and so, again, did not explore the stability – or not – of the wishes reported over time or whether respondents consider they had been met at a later date.

### *Three wishes: local authority work*

Older people are certainly able to respond to questions on wishes and dreams and the challenge may be more how this information is used and responded to than eliciting it in the first place. The Oxford Circles and Wishes project, run by the Older People's Programme with Age Concern Oxfordshire, asked people in day care centres, lunch clubs and social clubs what they wished for and what they thought it would take to make it happen. In a series of discussion groups they asked 80 older people, many with disabilities and long term conditions such dementia, depression and Parkinson's disease what their wishes were.

They found that only a very few people had no wish and of these, two said this was because their lives were already very active and full. The majority were able to think of two or three wishes immediately.

The project grouped the wishes cited under 11 general headings (derived from what people had said):

- Trips, visits and holidays
- To do things again (from the past)
- Gain new skills
- Creative arts
- Things to do at the club/centre (e.g have a guest speaker)
- Living arrangements (e.g. to live with family members)
- Religion (e.g. be able to go to church)
- Luxury (e.g. have a massage)
- Fitness and Health

- People (e.g. meet friends or celebrities)
- Life dreams (e.g. run a shop, help disadvantaged people)

### *Other forms of wording*

Oxfordshire County Council were central to the LA development and early stage testing of using personal outcomes as a performance measure for social care in England, working with a group of eight other councils (Putting People First, transforming social care, 2010)

The question developed by these councils is intended to form part of assessment and to enable providers to consider the lives of service users in a more holistic way. People are asked to say 'the three most important things that they want to happen in their lives' or 'What three things matter to you most?'. At review they are asked:

*Thinking back to the three things that matter to you most, how are they going? (Have you been able to do what you wanted? / are you happy with this aspect of your life?) Yes, happy with progress. If not, can you please tell us the reasons why (able to give up to three reasons) Oxfordshire CC workshop Developing practice around capturing personal outcomes (September 2011)*

Oxford CC stress that the choice of three things is not fixed and there should be no compulsion for service users to make three choices. They also emphasize that a PO measure should never be used in isolation and is more powerful if compared with information from other sources.

Importantly, and in contrast to the approaches that are described in the next section below, from the available information it appears that Oxfordshire does not advocate mapping to a designated framework but instead a propose a national measure of the number of people who achieve their three most important outcomes.

Rather more loosely worded and designed as a means of self -directed support and support planning activities, Bowers et al (2007), in *Person Centred Thinking with Older People: Practicalities and Possibilities*, suggest the following questions which could be seen to relate to personal goals:

*What ideas do you have about how you would like your life to be?*

And the use of these prompts:

*Would you like to see and hear what other people have done or other examples of support plans?*

*What matters to you?*

*What is important to you?*

*What do you miss that you do not do anymore?*

And:

*What would it take to get that [your life] back on track?*



*How would you like your week to be?*

*What do you want to change about your life?*

*What would you keep the same?*

*What are your 'must haves' and what are your 'like to*

*haves'?* (Bowers et al, 2007, p89)

What these measures, research studies and local projects suggest is that people can answer open-ended 'what is important to you' and 'three wishes' style questions face to face and, amongst some groups, on their own but they highlight the problem of how to manage the wide variety of resulting responses and the administrative burden that can occur with the more developed and reliable methods such as Sei-QOL, PGI PSYCLOPS and QOLAS.

### **Approaches using framework mapping**

Under the category of user defined outcomes there seem to be a growing number of researchers and local authorities who collect data in the service users' 'own words' and then, rather than content analysing this data, map it upwards on to frameworks derived from other work with service users or derived from policy. We will first describe some of the main frameworks used and the LAs that are using them.

One of the most influential frameworks being used originated at the Social Policy Research Unit (SPRU) at the University of York. SPRU undertook research with social care service users and analysed the outcomes they saw as important. From this work SPRU identified three main categories of outcome:

*Quality of Life* or maintenance outcomes are the aspects of a person's whole life that they are working to achieve or maintain.

*Process* outcomes relate to the experience that individuals have in seeking, obtaining and using services and supports.

*Change* outcomes are improvements in physical, mental or emotional functioning that individuals are seeking from services or support (Qureshi et al 2001).

Building on the work of the Social Policy Research Unit (SPRU), the Talking Points Personal Outcomes Approach (Cook and Miller, 2012) was developed in Scotland by the University of Glasgow for people using health and social care services. The approach groups the outcomes given by service users into SPRU's three broad categories of quality of life, process and change, and has further developed subcategories within each to form a framework. The framework is believed to be at a 'sufficiently high level to be able to capture most issues of importance to most people' (Cook and Miller, 2012, op cit p11). Further developed by the Joint Improvement Team (JIT) within the Scottish Government and community care organisations, the Talking Points Approach is being used by over 40 health and social care provider organisations. Building on SPRU work, Talking Points describes the three overarching outcome types as follows:

- *Quality of Life outcomes* (which are also known as maintenance outcomes) are the holistic goals relating to a person’s whole life. Such goals are likely to require support through a range of services and agencies and engagement with the service users, their family and the wider community.
- *Process outcomes* are experiential in nature and relate to improvements to physical, mental or emotional functioning that a service user obtains or wishes to obtain from services or support.
- *Change outcomes* may enable a service user to move to the goal of maintenance of a certain level or aspect of quality of life. In other cases, a series of much smaller changes, often on a day-to-day basis or short timeframe, may be desired: for example, in managing pain or symptoms of a chronic or terminal illness.

Within each of these higher level categories are a number of sub-categories, derived from previous developmental work with service users.

Table 1 shows the subcategories identified by the Talking Points approach under Quality of Life, Process and Change. Compared to ASCOT domains, there is considerable overlap, with safety, occupation and participation – and, less directly, respect – all seeming to feature.

**Table 1: Talking Points approach categories**

Quality of Life	Process	Change
Feeling safe	Listened to	Improved confidence / morale
Having things to do	Having a say	Improved skills
Seeing people	Treated with respect	Improved mobility
Staying as well as you can	Responded to	Reduced symptoms
Living where you want / as you want	Reliability	
Dealing with stigma / discrimination		

The Talking Points Framework stresses the interdependence of outcomes. Some factors may be both causes and outcomes, and factors are not independent: for example, the quality of life category ‘living where you want’ may be both a goal in itself and a way to reach the change outcome of ‘improved morale’.

Interestingly, the Talking Points approach recognises that a number of services and groups may identify additional outcomes, and again these seem to relate closely to some of those already identified in ASCOT. For example, an additional quality of life measure is ‘personally clean and comfortable’, defined as:

*A person who is unable to carry out their own personal care is personally clean and comfortable, presentable in appearance and has a balanced diet. In a clean and comfortable environment: The immediate environment is clean enough to avoid harm to health and prevent deterioration in morale (Cook and Miller, 2012, p.12)*

Personally clean and comfortable here is clearly closely related to the ASCOT domain ‘personal cleanliness and comfort’. Other additional outcomes suggested by Talking Points include those about cultural and

religious preferences (categorised as 'Process') and improved income (categorised as 'Change'). These do not have current equivalents in ASCOT, or the ASCS as a whole, although they can be regarded as being subsumed to some extent by current ASCOT outcome domains.

The Talking Points approach was also further developed to include outcomes tailored to people living in care homes. Annexe 2 gives more details of the additional outcomes suggested for care home residents.

Elsewhere, there are more examples of approaches to POs where service users' stated outcomes are mapped to different frameworks. Local authorities in England that have mapped PO responses to frameworks include Manchester, who have used POs recorded in service users' own words and then mapped these to the seven Our Health, Our Care, Our Say White (OHOCOS) Paper (Department of Health, 2006) outcomes :

- Improved health and wellbeing
- Improved quality of life
- Making a positive contribution
- Choice and control
- Freedom from discrimination and harassment
- Economic wellbeing and
- Personal dignity.

West Sussex have used individualised support plans as the basis for identifying POs, and these are then categorised in terms of maintenance, change and process from the Talking Points model and the seven domains of OHOCOS.

Cumbria have mapped their outcomes to the Adult Social Care Outcomes Toolkit (ASCOT) and attributed scores to them. They have used ASCOT questions, referred to as the quality of life questionnaire, with service users during assessment and then asked their PO questions relating them to this. Annexe 3 gives more details of this approach and an example of the type of response received.

In Wales, a series of pilot studies of outcomes-focused and relationship-centred work have been received positively (Andrews et al., 2009). They have used the 'Senses Framework', which focuses on the creation of 'enriched environments' of support (Nolan et al., 2006), where outcomes impact on carers and service providers as well as the service user and are related to:

- Security – to feel safe within relationships
- Belonging – to feel 'part of things'
- Continuity – to experience links and consistency
- Purpose – to have a personally valuable goal or goals

- Achievement – to make progress towards a desired goal or goals
- Significance – to feel that ‘you’ matter.

Bowers et al (2007, op cit), in their *Practicalities and Possibilities* project, suggest seven dimensions to which POs might be mapped, derived from consultations with older people as part of The Older People Programme:

- Being active, staying healthy and contributing
- Continuing to learn
- Friends and community-being valued and belonging
- Importance of family and relationships
- Valuing diversity
- Approachable local services
- Having choices, taking risks.

An approach, developed from the work of Oxfordshire CC (above) by Think Local Act Personal

(<http://www.thinklocalactpersonal.org.uk/Browse/SDSandpersonalbudgets>

[/Review/?parent=3249&child=5625&](http://www.thinklocalactpersonal.org.uk/Review/?parent=3249&child=5625&)) asks for user-defined outcomes (in their own words) but asks for these within a number of predefined domains. The template for reviews asks service users to specify their outcomes in each of the following areas:

- Community life: leisure, learning and work
- Managing money
- Families and relationships
- Choices and changes
- Living safely and taking risks
- Health and wellbeing
- Everyday tasks.

and then asks them for information on ‘what is working?’, ‘what is not working?’ and ‘how do you want this to change?’, as well as recording what family and other people who support the service user think is working and not working for them. This approach has been adopted by Lincolnshire Council, who also ask for respondents’ ‘top three’ outcomes that they ‘most wanted to achieve’ in a set period of time which, presumably, may fall within these domains or outside of them.

Putting People First: Transforming Adult Social Care (Bennett, Cattermole and Sanderson, 2009) worked in the opposite direction, using these same domains (i.e. mapping up to these domains from service users' own words). Developed by stakeholders, including disabled people and their carers, the suggested approach is to ask for three personal outcomes and to ask at review:

*Thinking of the three things most important to you in your support plan, has the way you have spent your money helped you to achieve them?*

Respondents can give their answers on using the following categories:

Yes – I have fully achieved this goal

Yes – I am successfully working towards this goal

No.

The Coalition of Care and Support Providers (CCPS) in Scotland lists a number of outcomes resources (<http://www.ccpscotland.org/policy/new-localism/outcomes-resources/Outcomes-Resources-List>), some commercial, some freely available (e.g. ASCOT). One commercial toolkit which appears to explore personal outcomes is the REACH toolkit. This toolkit explores standards in supported living for people with learning disabilities and other users of supported living services. The 'It's my life' toolkit assesses progress towards the outcomes service users want. This is completed by the service user and their 'circle of support'. There is also a Service Review toolkit (which is completed over 12 months) and maps to the National Minimum Standards for Domiciliary Care and Supporting People Quality Assessment Framework. <http://www.paradigm-uk.org/content/Home.aspx>

Another commercial measure/approach is the Carista/Interelate (<http://www.interelate.co.uk>). With costs given as between £25k-100k, it was not possible to obtain further details for the purpose of this report, but this approach appears to use service user interviews and questionnaires which collect both qualitative and quantitative data, and 'personal maps', which can be used to plan individual budgets or self-directed support.

I.ROC (Individual Recovery Outcomes Counter) (<http://www.penumbra.org.uk>) is currently being validated and use incurs a cost. It is based on a questionnaire relating to 12 indicators (unspecified). According to the CCPS website, I.ROC produces:

*'numeric and graphic data ...in order to measure progress against indicators. I.ROC is used in conjunction with HOPE Toolkit which contains personal plans, tools and tips linked to recovery and well-being...Data [are] produced at personal, service and organisational level.'*

The Wellbeing Web has been developed in 2011 by Angus Council <http://www.iriss.org.uk/resources/measuring-outcomes-angus> and is:

*'an interactive tool designed to facilitate an engaging and positive process to measure outcomes with children and adults. The wellbeing web is used to capture specific outcomes, and for those*

*receiving support to recognise where they are, where they would like to be, and what steps they need to take to get there’.*

Outcomes here are described as:

*‘the impact of support on a person’s life and not the outputs of services. Outcomes are the answer to the question: So what difference does it make? Outcomes are the changes or benefits for individuals who access support.’*

This approach uses a visual tool, based on the Outcomes Star developed by Triangle Consulting – a type of spidergram showing the respondent’s position on eight scales (see Annexe 4). The authors claim that the Wellbeing Web can be adapted to a range of settings and service users, and is ‘relevant and compliant with the *Getting it Right for Every Child* national practice model (Scottish Government, 2008)’. *Getting it Right for Every Child* includes eight wellbeing indicators: safe, healthy, active, nurtured, achieving, respected, responsible and included (remembered by the acronym SHANARRI). While focused on children and parents principally, this approach is included here because it shows the use of an approach to personal outcomes that is more quantitative than the majority of others.

The use, by researchers, LAs and other organisations, of mapping up to frameworks is primarily to enable interpretation and comparison of aggregated PO data:

*The [personal outcomes] approach uses frameworks based on evidence of the high level outcomes that matter to people to support the collation, ‘aggregation up’, and interpretation of outcomes data. The collated data can then be used to ensure that decision making at service and organisational level is based upon what works best for different groups of people in achieving their priorities. Importantly, it can also be used to identify priorities that are not being met. (The Health and Social Care Alliance, 2013 <http://www.alliance-scotland.org.uk/what-we-do/projects/personal-outcomes-and-quality-measures-project/> )*

The upward mapping of personal outcomes to evidence-based categories or frameworks allows practical management of diverse responses to POs but begs the question of how much the end data is still personalised and the extent to which ‘service user voice’ – the USP of personal outcome measures – is subverted. Frameworks may be linked to evidence-based categories developed ‘bottom-up’ from work with service users on ‘what matters’ and therefore be based on ‘lay’ rather than expert or professional views, but these are *collective* views rather than personal views when it reaches this stage. The question for national use of such data, then, becomes centred around what ‘added value’ is gained by collecting data in this way rather than using standardised measures based on the same or overlapping categories to these frameworks.

## **Using personal outcomes measures in a survey**

In assessing the relative merits of different approaches to measuring outcomes, including personal outcome tools, it is worth being clear about the different uses of such information. Some important potential uses include:

- Care managers and service users assessing and reviewing the quality, safety and appropriate mix of services and support used by individuals
- Care managers, or equivalents, drawing up care plans with service users
- Personal budget holders deciding how to deploy their budgets
- LA commissioners making decisions about how to deploy LA-level funding and resources, including developing RASs and contracting with providers
- LAs assessing their own strategy performance, and
- Regulators reviewing the quality and compliance of care providers

Broadly speaking, the first three uses are *individual-focused*, whilst the latter three are *comparative* across service users. In other words, with the former, decisions are being made by the individual, or on behalf of the individual, about the person's own experiences. In the latter, decisions are being made that affect more than one service user and are *aggregated* in nature.

There are also options for how relevant outcomes information is collected. This might be by:

- face-to-face interviews (F2F), or by
- self-completion (e.g. postal or internet questionnaire) (SC)

In theory, either collection method can be used to gather data that inform both individual-focused and comparative decisions. However, in practice, because of the costs of F2F methods, SC methods have been used to collect outcomes information with relevance to comparative decision-making across an appropriate number of service users. The National Adult Social Care Survey (ASCS) is an example.

There is strong support for POs amongst many service users and providers. A number of benefits are cited and otherwise apparent when used within assessment and review processes. However, our focus is mainly on the use of these instruments in self-report form for the purpose of comparative assessment. In this respect, while a SC approach provides an efficient and cost-effective means to gather data on outcomes in general, it may not be ideally suited to the collection of *personal* outcomes data, for reasons which we outline below. Where possible, we suggest ways that the identified limitations might be addressed, and risks minimised.

There are a number of beneficial features of PO approaches (when used in an individualised, face-to-face data collection context), that we would hope to retain in moving to a comparative, self-completion basis. There would also be additional requirements, particularly in making the results suitably comparative. The main challenges would therefore be:

- Finding a way to incorporate the relational, developmental and evolutionary nature of goal determination in PO approaches;

- Overcoming the high cognitive demands of a SC approach, especially with regard to service user respondent populations;
- Dealing with the dynamic nature of a PO approach, i.e. goal statement and the follow-up assessment of the degree of achievement;
- Establishing attribution to the use of care services. As well as rating overall achievement, respondents would need to be asked about how much this degree of achievement was due to social care services;
- Addressing the aggregation and comparison problems. Some POs will mean more to some people than others. To develop balanced comparisons between all service users involved in the outcomes assessment process, we need to find a way to reflect the importance and significance of outcomes, and, building on the previous point, how difficult these outcomes were to achieve for social care services.

### The relational and development nature of POs

Because most work using personal outcomes has formed part of assessment and reviews, it occurs in the context of (mostly) one-to-one meetings between the service user and provider, and this may form an important part of what makes it attractive and also effective. These interactions provide opportunities for relationship building, with evidence that involving the person in identifying their priorities and required support can itself improve outcomes (Miller, 2010) and be empowering (Qureshi, 2001).

A personal outcomes focus gives social care professionals a 'clarity of purpose' (Thomson, 2008) and, at an organisational level, it can help refocus and clarify what is the 'value base' of service providers and the difference they can make to people's quality of life (Miller 2011).

Personal outcomes measures have been seen as a way to 'open up communication between service users, carers and professionals' (Miller, 2010, op.cit p117), and the importance of the process of engagement in person centred care has been stressed

*[Service providers have said] that they are 'already doing person centred care'. By this they often seem to mean that they are asking older people what they want, or anticipating what they might want, but often without really involving and engaging them as equal and valued citizens (as opposed to service users). (Bowers et al (2007) p9)*

However, how well PO measures fit in the context of the least interactive of data collection methods – the self-report questionnaire – remains to be seen. In our search of the literature and consultation with professionals, we found no examples of research where personal outcomes were being used in self-report questionnaires with social care service users. This may reflect either the difficulty of doing this or the relative newness of personal outcomes measures, or both.

The majority of work and studies undertaken were administered face to face. In most cases, POs formed part of the assessment and service planning and/or review process. The Talking Points Approach described above, for example, is clear that 'a good conversation' forms the basis of developing a personal outcomes



measure. The collection of POs here is seen as central to relationship-building between service providers and service users. Further, the importance of the innate or learnt skill of the person collecting POs (ordinarily, the person undertaking an assessment or review) is implied: to ensure that the service user 'engages' with the outcomes.

Oxfordshire CC, who have led in the development of personal outcomes in social care in England, also stress the conversational nature of collecting information on POs. Questions 'should flow from natural conversations with people' and be 'interactive', and not 'rely on one specific form of question' (PO workshop, materials, 2012) These approaches are entirely appropriate in an assessment or review but present challenges to the robustness of POs gathered in this way. Moreover, it highlights the difficulties of using POs outside face-to-face methods of data collection; and indeed Oxfordshire make it explicit in their workshop materials that POs '[do not] work well through survey'. Other local authorities that have piloted POs have commented that even in a face-to-face situation, such as during an assessment or review, service users may struggle to deal with a 'blank page' approach and need some guidance in identifying POs (Contracting for Personalised Outcomes: Learning from Emerging Practice, 2009 p.5)

A facet of this issue is that people might be encouraged to express concerns and unmet needs. When undertaken as part of assessment and review, the fact that POs can be used to identify unmet needs is a further benefit. For example, Oxfordshire CC has used POs to follow up on service users who reported unmet needs. This is a way in which POs can be at their most effective for use in service improvement and delivery. However, in an anonymous postal survey this would not be possible and could be problematic. The effect of being asked directly by a careworker or service provider to suggest personal outcomes might be empowering to the service user as they have a chance to impact on their services, to explain their needs and circumstances, and get immediate feedback. However, in a postal survey the same questions could seem more intrusive and the impact of reporting very specific and personal unmet needs in this way would need to be considered.

This relational, developmental characteristic of existing PO approaches is a serious challenge for any attempt to embody this approach within a comparative, SC methodology. Hierarchical questioning, prompts and routing could be used, but anticipating the full range of responses would be difficult. Instead, we might use a SEI-QoL or PGI type approach, with respondents choosing from a menu of potentially relevant outcomes. However, as noted above, these approaches are costly and time-consuming.

### **Cognitive demands**

Personal outcomes questions aim to capture individual goals and aspirations. They are predominantly either deliberately broad – for example, asking someone what is most important in their life – or ask about a specific area – for example, leisure – but still require respondents to say what they want to achieve in that area in their own words. They do not fit with a 'tick-box' approach, and require the respondent to consider the things that affect their life most profoundly.

The cognitive demands of answering a question on personal goals in a self-report questionnaire, where no support or help can be assumed, is a challenge. There is already concern that survey methods exclude significant groups of service users with cognitive and communication impairments. The response format of PO questions would need to be open-ended to allow any type of outcome to be cited by respondents.

Open-ended questions tend to have lower response rates than closed questions (Reja et al, 2003), suggesting higher cognitive burden. Development work has already suggested that the wording of PO questions may need to be adapted for different groups within face-to-face administration: this would need to be considered.

The cognitive burden of PO questions in a SC questionnaire could be tested using the methods described in the final section of this report and this would need to happen before their inclusion could be recommended.

### **The dynamic nature of the PO approach**

To assess how far social care services meet the needs or goals set as personalised outcome measures, data ideally need to be collected at two timepoints (or more) during which services or support have been delivered and an impact on POs might be expected. This poses problems for collection of PO data in random, cross-sectional surveys such as the ASCS. The ASCS does not go back to the same people each year and therefore it cannot ask people to reflect on POs they have previously cited. As POs are collected during assessment and review in many LAs, with others working towards this, an alternative would be to ask people to refer to other documentation where these were recorded, such as a review plan. However, this again places burden on the respondent and would be likely to reduce response rates significantly.

If POs are to be administered using SC methods there are essentially two options: **the use of a retrospective question in a cross-sectional survey**, such as the ASCS currently is, or **the development of a new, longitudinal survey to measure POs** (with or without other types of outcome measures and data). Each of these options has trade-offs and limitations, and each will be discussed, but by far the best approach, methodologically, would be a longitudinal survey.

### **A retrospective question on a cross-sectional survey**

If a cross-sectional survey – as the ASCS is at present – were the only possible vehicle for data collection, a retrospective question would probably be the only manageable option. A retrospective approach to asking questionnaire-based questions on POs has been taken by the Information Service Division (ISD) in Scotland. From the patient survey of GP and community health services, a ‘Personal Outcomes quality outcome indicator’ is derived by asking respondents to consider if they have had any health treatment to address pain, depression and anxiety or their ability to do their usual activities in the last six months, and if so how much this has created improvements for them in these three domains. It asks them to say, with regard to each of these three domains, what the effect of their treatment was for each domain: better than before; same as before; worse than before; too soon to say. This is not ‘personalised’ to the same degree as other PO approaches described above, and we would recommend that, if a retrospective approach was taken, the question allowed respondents to define their own outcomes more freely than this example, but it does indicate that people are able to answer questions about the outcomes of services retrospectively.

Such an approach would be much cheaper and simpler than developing a completely new survey and would overcome some of the practical difficulties, such as linking data on personal outcomes at the baseline time point to questions posed at ‘follow-up’. However, the trade-off here is that retrospective questions can be subject to biases and are reliant on memory. They provide a much less powerful and robust measure of the impact of services on personal outcomes than would a longitudinal approach.

If a retrospective approach were taken we would suggest asking an open question, anchored to a set time period and made specific to social care services. Possible wording, based around aspects of personal outcome development work already undertaken by LAs, might be:

*In the last six months, what have you most wanted (hoped?) social care services to help you do/help you with? This could be anything large or small and could be about something staying the same, changing or improving, for example, maintaining your level of mobility, feeling less lonely or isolated, keeping in touch with friends or family.*

This question would be open-ended with space left for a free text answer.

It would be followed by a closed response question:

*How much have social care services helped you do this/helped you with this?*

answered on a scale, for example: Completely; A lot; Partly; A little; Not at all; Too soon to say. Then additional space could be left for any further comments.

Or alternatively a single question could be used:

*What, if any, difference have social care services made to you in the last six months?*

But the trade-off here would be that this would yield only qualitative data which would then need to be analysed. Answer categories could be added, but this would then run the risk of duplicating the 'satisfaction with services' question.

Such questions would need comprehensive testing to ensure that respondents could answer them and to understand more about the quality of data collected.

### **Order effects**

An additional aspect of adding a retrospective (or any new) question to the current ASCS or other established postal survey is that its placement in relation to other items needs to be considered carefully. The addition of any type of question could influence responses to the other questions, especially those adjacent to it. Open-ended, holistic questions – such as a question on POs would be likely to be – are generally placed at or towards the end of a survey, but the exact placement would need to be considered carefully and probably tested. Because at least part of a question on POs would be open-ended, there could be a tendency for respondents to interpret the answer required in the light of other nearby questions. For example, if a PO question followed activities of daily living questions, there could be a tendency to report similar types of outcomes.

### **A longitudinal survey**

Repeat sampling of the same individual clearly supports the dynamic nature of the PO approach. To be undertaken using a SC methods at present would require the development of a new survey to collect data. This would have the potential to provide better quality data than a retrospective question added to the ASCS or other existing survey, but would have major cost and resource implications.

Personal outcomes can, by definition, only be judged to have been met when they are reviewed at a later date (by which time services have either been obtained or changed, and it is expected that the service user would be able to discern a difference or maintenance of a goal, outcome or some aspect of their life). Testing and extensive piloting would be necessary to determine the optimal timing of each 'wave' of the survey; how long respondents would remain in the survey; if, how and when the sample size would be boosted, and whether the survey would be staggered in some way (e.g. one month after initial assessment for 'baseline' and every six months thereafter) or if everyone would receive it at the same time. The timing of the initial and subsequent waves is likely to be crucial to the quality of the data collected. Work at Oxford CC on collection of POs through assessment and review suggested that initial assessment may be too soon for some people to be able to formulate personal outcomes.

As well as cost and resource issues at a national and local Government level for the development of a SC survey, there would be practical and ethical issues to overcome. In order to answer questions about whether previous outcomes had been met, questionnaires would need to include personalised information on what the respondent said previously. This would add a very heavy administrative burden to the survey. It would also mean that, even if previous responses were generated by computer using a code, it would not be an anonymous questionnaire. Including a respondent's personal outcomes on a postal questionnaire could also breach confidentiality, given that there is no certainty that only intended respondents would open or have sight of the questionnaire, and stated outcomes might concern family members and friends.

### **Establishing importance and attribution**

To be useful, it is not enough to ask respondents about their personal outcomes at time 1 (baseline) and the extent to which they have been met at time 2 (follow-up). Outcomes and their importance to a service user can change over time and will influence their impact on wellbeing and through this satisfaction with services. One way to account for this issue is to include qualifying questions on the rated importance of stated outcomes. Without this information, it is not possible to distinguish between four possible results for any selected outcome:

1. The outcome is important at t1 and t2 and is met > **outcomes met**
2. The outcome is important at t1 and t2 but is unmet > **outcomes unmet**
3. The outcome is no longer important at t2 but is met > **outcomes met**
4. The outcome is no longer important at t2 and is unmet > **outcomes unmet**

In any aggregation of the percentage of outcomes met in an area, service or CASSR, the first and third situations listed above would be counted as outcomes met successfully, and the second and fourth situations would be counted as outcomes not met. It is clear, however, that from the perspective of the service user, situations 1 and 3 and situations 2 and 4 are very different; what matters is the importance of the outcome and this is what is likely to influence wellbeing and satisfaction with services.

Questions around rated importance could be included and used to adjust the statistics reported by CASSRs but would add to the length and therefore burden of completion, analysis and reporting.

Ensuring that fair comparisons of aggregated data can be made will be challenging. Other qualifying questions may be necessary, such as items that measure how much a service user thinks social care support and services could (or have) helped them achieve the selected outcomes. Again, there is a trade-off in doing this. It risks greatly increasing the length and complexity of the data collected, and the burden, both to the respondent and to analysis of the data. Another possibility would be to use statistical methods looking at the correlation between the type of social care a person receives and the achievement of their objectives. This option would require any comparison problems to be solved.

Where a service user has support from a range of health, social care and other agencies, attributing change to social care support is additionally challenging, although it is fair to say that this applies to all kinds of outcome measures and not just personal outcomes. Where qualitative, face-to-face information can be collected, it has been suggested that this attribution problem can, in part, be addressed by gaining the views of services, carers, and others on the 'causal chain' leading to outcomes (Culpitt and Ellis, 2003). However, this is unlikely to prove practical on the scale required to make comparisons at a higher LA or regional level and is itself at risk of subjective biases.

### **Ensuring equally achievable outcomes – relative importance**

The essential characteristic of personalised outcomes is that they come 'bottom up' from the service user and are specific to them, and are not restricted to or by pre-set categories. Development work within LAs has stressed that those collecting personal outcomes should encourage service users to identify any outcomes 'big or small'. Some outcomes relate to maintenance of a state, behaviour or circumstance; some to change; and some to achievement. What this means is that some outcomes will be manifestly easier to meet than others. This is not of concern in itself, but an understanding of the 'distribution' of outcomes in any area would be necessary to make fair comparisons.

What is needed, ideally, is that any PO questions produce responses from service users at time 1 that reflect the true range of outcomes they would like – which will vary in how achievable they are through social services – and that this distribution will be (largely) similar across all areas where comparisons are to be made. Then, the extent to which these outcomes have been met at time 2 should be a measure of how well services have helped to meet these outcomes. However, if the majority of respondents set very easily achieved outcomes, the PO measure will not provide good discriminatory power (similar to an aptitude question that almost everyone gets right). Equally, if there are large differences in the 'achievability' of goals set by service users in different areas and there is not a data collection method to capture and adjust for this, PO measures would not provide a fair starting point for monitoring and evaluation.

In a face-to-face situation, as part of assessment and review, respondents can be guided to a selection of outcomes that are – or could be – achievable through social care support and services. In a self-report questionnaire, however, this is more difficult. Respondents need to be given freedom to select outcomes that are personal to them, but there could be a danger that without further guidance these could be outside the scope of social care, or too easily achieved.

Early evidence from review-based work suggests that the latter may be more likely. It is reported that there may be a tendency for people to say their outcomes had been met, and 'further work is needed to encourage goals to be set that may not be so easily met' or reduce the likelihood of '[giving] the answer

they think a social worker want to hear' (Putting People First, Bennett, Cattermole and Sanderson, 2009 ). It remains to be seen whether this 'floor effect' would also feature in data collected in a survey.

### **Categorising and comparing the outcomes**

One way of increasing the comparability of measures derived from PO data would be to have some means to categorise the POs reported. As can be seen in the section above on how POs have been measured, the use of categorising frameworks that place POs into different domains or areas is a common feature of the work currently being undertaken by both practitioners and researchers. Many of these frameworks are derived from policy documents, and/or reflect outcomes that have previously been identified by service users of different kinds. Such frameworks are personal in as much as they are 'bottom up' and 'data driven', rather than emerging top down from the interests of providers; and mapping to them can be valuable in evidencing how well outcomes match the values of a provider and policies under which they are required to work.

However, if outcomes are to be categorised into 'types' or mapped to frameworks after (or before) use in a SC survey the questions become:

- by whom should this be done?
- when and to what agreed classification system/framework should this be done?
- how can we judge 'achievability' – i.e. if all outcomes are equally easy or hard to achieve?
- how can we ensure that all of the above processes are done systematically with minimum bias?

There is the potential for 'lost' outcomes which do not appear to fit any of the categories. Further, there is a potential for differences in counting of met outcomes when one outcome maps to more than one category. Importantly, classification would add burden and cost to administration of the survey.

Moreover, if we are ultimately reducing personal outcomes down to a set of 'domains' or 'types' or categories of a framework in order to have comparability, we have to question what added value there is to including them. They will not be fully personalised, and the types of categories, factors or domains used so far in development work show a good deal of overlap with those included in standardised measures such as ASCOT. We would need, therefore, to be sure that the data collected were not simply duplicating what we already collect in a more standardised way.

### **Study design for a comparison of a personal outcomes measures with ASCOF measures**

From the discussion above, it is clear that there are many challenges to using POs in a postal survey, such as the ASCS, and it is questionable how much benefit would be gained in terms of 'added value' above and beyond measures already included, such as ASCOT, and satisfaction with services.

Many of these are empirical issues. Further analysis might involve the following stages:

1. Develop PO questions. This task would include developing the wording, configuration and routing of items. It would be undertaken by an advisory group consisting of the research team, representatives from the Department and SSUSG, local authorities, representatives from QORU's public involvement group and other service user and carer representatives.
2. Testing of the new questions through cognitive interviewing with a sample of service users and through consultation with service user groups and organisations, and familial and professional carers – to refine the wording of questions, visual formatting of questions (e.g. amount of space for answers) and best position for placement of questions within the survey. In particular, this stage should purposively seek the views of often excluded groups and those who may require easy-read questions, such as people with learning disabilities and autism.
3. If PO questions were added to the ASCS, they could be trialled in a random sample of recipients (in addition to those selected in each LA to receive the standard version). Power calculations would be required to select an appropriate sample size to enable detection of differences between the PO version and standard version with regard to:
  - Response rates across the items of the survey
  - Distributions of responses to PO questions
  - Added value of POs above ASCOF measures

Or, if a longitudinal survey was to be used, it would be necessary to calculate the panel size and composition necessary to counterbalance attrition rates and allow sufficient numbers for sub-group analyses. The survey would then be trialled in a smaller group – perhaps two or three local authorities – at 2 or 3 different times to help determine wording, timing and general feasibility.

From both approaches, quantitative analyses would explore the extent to which met outcomes covaried with satisfaction with services and social-care related quality of life and added value to the measures already on the ASCS; and qualitative analyses (with co-rater agreement) would explore the range of responses and how well responses mapped to any chosen framework.

## Concluding points and some next steps

The argument for the use of personal outcomes is that they offer something above and beyond the areas and concepts captured by other standardised measures, and fit with the increasing move towards person-centred care.

By way of context, we identify two broad categories of decision-making that would be informed by outcomes information. The first is *individual-focused* decision-making, the key example of which is care managers and service users assessing and reviewing the quality, safety and appropriate mix of services and support used by individuals. The second set of decisions are those which are explicitly *comparative* across service users, such as when LA commissioners make decisions about how to deploy LA level funding and

resources, including developing RASs and contracting with providers. In the latter, decisions are being made that affect more than one service user and are *aggregated* in nature.

There are also options for how relevant outcomes information is collected, with a distinction between face-to-face interviews and self-completion (e.g. postal or internet questionnaire).

In the first instance, 'personal outcomes' measures collect qualitative data, often focused on the individual. In other fields outside social care, the term 'personal projective measures' is sometimes used instead, reflecting the highly qualitative nature of these data. It is not easy to fit these kinds of data into a quantitative form such as a self-complete questionnaire.

Personal outcomes work well for *individual-focused* decision-making, such as in social care assessments with an individual, but there are difficulties 'scaling this up' for use in service improvement, monitoring and evaluation: that is, for *aggregated, comparative* decision-making. Miller (2010) summarises the tension between differing uses of personal outcomes:

*A further continuing challenge is the competing requirements made of assessment, including person-centred aspects which require flexibility and qualitative elements, as compared to information requirements for service improvements and more managerialist concerns such as centrally directed performance management systems, which tend towards standardised and quantitative approaches. One study in the review of shared assessment concluded that it is questionable whether any instrument can be developed to meet all the ideal requirements (Richardson et al., 2005). It is a question therefore, of balancing and prioritising these demands.(p.10)*

What we have found is that many different LAs, groups and organisations use pre-defined quantitative frameworks (either top down to frame PO questions or bottom up to map responses) to help make sense of, and utilise information from, personal outcomes, as well as to support respondents in the task of identifying POs. Many of these frameworks show strong similarities to measures already in use in the ASCS, such as ASCOT. What this similarity seems to suggest is that outcomes in health and social care – whether measured as personal outcomes or through 'predefined' categories or domains – can be categorised into a relatively small number of reasonably universal or 'archetypal' goals upon which there is a good deal of agreement from service users, as well as practitioners and service providers. If this summarisation into pre-determined categories is giving enough information for comparative purposes (collected in surveys), then it may be that the additional information potentially provided by POs is not required. Testing/piloting work may be needed to fully answer this question.

In any case, there would be significant challenges to the inclusion of PO questions in the ASCS at present, and finding a design that was sufficiently robust, practical and true to the spirit of POs.

Nonetheless, some aspects of a PO approach could be retained in a self-completion format. Essentially, this would require:

- Finding a way to incorporate the relational, developmental and evolutionary nature of goal determination in PO approaches. One approach is to use prompts, hierarchical questions, routing and some open-ended questions.



- Overcoming the high cognitive demands of a SC approach, especially with regard to service user respondent populations
- Dealing with the dynamic nature of a PO approach: i.e. statement of goals and then the follow-up for assessment of the degree of achievement. Two options are (a) retrospective questioning or (b) longitudinal surveys
- Establishing the attribution to the use of care services. As well as rating overall achievement, respondents would need to be asked about how much this degree of achievement was due to social care services.
- Addressing the aggregation and comparison problems. The options include having the individual self-rate both the degree of achievement of their PO and also the weight they attach to each outcome.

Some of these challenges are easier to address. The others are much harder to overcome. These challenges and the 'costs' and 'benefits' of adapting a PO approach should be considered in relation to existing outcome measures that were purposively designed for informing comparative outcomes decision making using self-completion methods.

We have discussed the benefits and limitations of adapting a PO approach to use with self-completion methods. Assessing whether there are positive net benefits is ultimately an empirical question, although we speculate that the nature of the challenges for using POs in surveys appear significant in theory. One important task would be to work up what a real-world example of a self-completion PO questionnaire might look like.

The next step might be to develop a pilot self-report PO measure and cognitively test its use and validity for informing comparative decisions. We have outlined a study design for this purpose in the paper that would involve: initial development of PO questions; cognitive testing; and then a comparative study using PO and alternative measures in the adult social care survey.

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## Annexe 1: Council on Quality in Leadership's Personal Outcomes Measure

The Council on Quality in Leadership, a not-for-profit organisation offering consultancy on personal outcomes measures to health services providers (CQL) ([http://www.thecouncil.org/Personal\\_Outcome\\_Measures.aspx](http://www.thecouncil.org/Personal_Outcome_Measures.aspx)) began developing personal outcome measures in the early 1990s. Their PO measure was developed from focus groups of people with disabilities and their families, where people defined the 'outcomes that were most important to them'. Their tool comprises 21 outcome measures which fall into three factors:

- Myself: who I am as a result of my unique heredity, life experiences and decisions
- My world: where I work, live, socialise, belong or connect
- My dreams: How I want my life (self and world) to be

Table 1.1 shows the 21 personal outcome measures included in the CQL model and possible ASCOT and ASCOF equivalents:

**Table 1.1: CQL outcome measures and possible ASCOT equivalents**

<b>CQL personal outcome measure</b>	<b>Possible ASCOT equivalent</b>
People are connected to natural support networks	Social participation and involvement
People have intimate relationships	No equivalent
People are safe	Safety
People have the best possible health	No equivalent
People exercise rights	Control over daily life
People are treated fairly	Dignity?
People are free from abuse and neglect	Safety, food and nutrition?, personal cleanliness and comfort?
People experience continuity and security	Safety, dignity? Social participation and involvement?
People decide when to share personal information	Control over daily life? Dignity?
People choose where and with whom they live	Accommodation cleanliness and comfort? Control over daily life?
People choose where they work	No equivalent
People use their environments	No equivalent/unclear
People live in integrated environments	No equivalent/unclear
People interact with other members of the community	Social participation and involvement
People perform different social roles	No equivalent/unclear
People choose services	No equivalent
People choose personal goals	No equivalent
People realize personal goals	No equivalent
People participate in the life of the community	Social participation and involvement
People have friends	Social participation and involvement
People are respected	Dignity? Control over daily life?

## Annexe 2: The Talking Points Approach: Additional Outcomes for Care Home Residents

The Talking Points approach (Cook and Miller, 2012) developed additional outcomes tailored to people living in care homes. Table 2.1 shows the outcomes suggested for this group

**Table 2.1: Talking points outcomes for care home residents (Cook and Miller, 2012)**

Outcomes Important to People Living in Care Homes
Quality of Life Process Change
I feel safe and secure
I see people
I have things to do
I live in a nice place
I live life as I want and where I want
I stay as well as I can
I belong to a community
I am treated as an individual
I am valued and respected
I am listened to
I have a say in decisions about my care and support
I am supported to live well and plan for a good end of life
My family and friends are involved if I want
I can trust staff and rely on them to respond
My privacy is respected
My skills are improved
My confidence and morale are improved
My mobility is improved
My health has improved or my symptoms are reduced
I have settled in to where I am living



## **Annexe 3: Mapping Personal Outcomes to ASCOT (Cumbria County Council)**

Cumbria County Council have mapped their outcomes to the Adult Social Care Outcomes Toolkit (ASCOT) and attributed scores to them. They have used ASCOT questions, referred to as the quality of life questionnaire, with service users during assessment and then asked their PO questions relating them to this.

The text below gives an example of the questions used and an example of a set of responses to these.

**Thinking about the above quality of life outcomes [ASCOT domains] consider:-**

**What is important to you?**

To have a good quality of life and remain in my own home

**What is good in your life that you do not want to change?**

I have returned home from hospital with live-in care and support – I am very happy with this arrangement and feel safe and secure in my home. I have considered residential care but am keen to remain at home in an environment I know very well and being supported by people I know and trust implicitly. I do not wish to consider residential care unless a catastrophic event happened as I think this would remove the last level of independence and control I have over my life.

**Is there anything you do want to change?**

I am very happy with the arrangements that have been made for me – L has arranged for live-in care and this is working very well for me and I feel safe, secure and happy in my home. I have discussed having a hospital bed before and I would now like to get this arranged. I am finding that my chair is uncomfortable and difficult to get out of so I would like to look at new seating arrangements.

**Bearing in mind what is important to you and what works well and what you want to change, tell us what outcomes you would like to achieve through this support plan. This can be as few as one, and should be in your own words. Score each outcome by thinking about where you are now in relation to achieving it. 5 represents the best possible outcome for you, and 1 the worst.**

The respondent then gives a score which is recorded and the same process occurs at review. Outcomes are then designated as 'being met' or 'in progress' depending on how they are scored.

## Annexe 4: The Wellbeing Web

The Wellbeing Web has been developed in 2011 by Angus Council  
<http://www.iriss.org.uk/resources/measuring-outcomes-angus> and is:

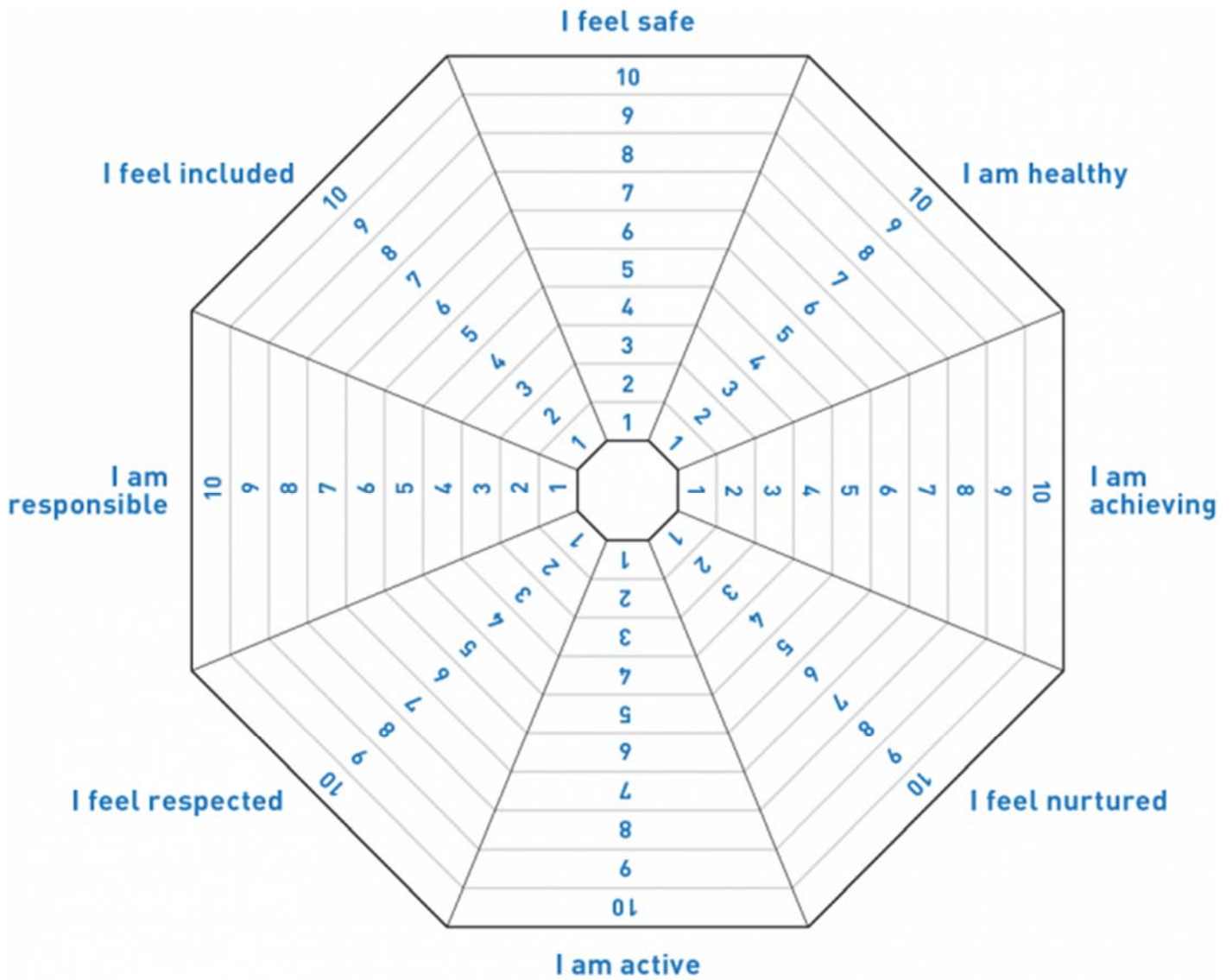
*‘an interactive tool designed to facilitate an engaging and positive process to measure outcomes with children and adults. The wellbeing web is used to capture specific outcomes, and for those receiving support to recognise where they are, where they would like to be, and what steps they need to take to get there’.*

Outcomes here are described as:

*‘Outcomes refer to the impact of support on a person’s life and not the outputs of services. Outcomes are the answer to the question: So what difference does it make? Outcomes are the changes or benefits for individuals who access support.’*

This approach uses a visual tool, based on the Outcomes Star developed by Triangle Consulting. The authors claim that the Wellbeing Web can be adapted to a range of settings and service users and is ‘relevant and compliant with the *Getting it Right for Every Child* national practice model (Scottish Government, 2008)’. *Getting it Right for Every Child* includes eight wellbeing indicators: safe, healthy, active, nurtured, achieving, respected, responsible and included (remembered by the acronym SHANARRI).

The wellbeing web is based on The Outcomes Star (copyright Triangle Consulting [www.outcomesstar.org.uk/terms-conditions](http://www.outcomesstar.org.uk/terms-conditions)). The Outcomes Star has been used to measure support and progress for people experiencing issues as diverse as homelessness, mental health problems and substance misuse. The concepts used to make the radial lines of a star can be tailored to the focus of services (and therefore could, in theory, be tailored to personal, user-defined outcomes). Outcome stars are designed to be completed by service users and professionals together. Individuals say where they feel they are on each scale and then this is repeated at a later time to measure progress. The example below is the Outcome star used as part of the Wellbeing Web to map to the eight *Getting it Right for Every Child* Indicators



Scaling key:

1 = Not at all true of me

10 = Very true of me

**Figure 1: The Wellbeing Web, based on the Outcomes Star (©Triangle Consulting)**

The wellbeing web is used with prompt cards, developed through work with children, parents and professionals, to help to relate the eight indicators to understandable and relevant concepts for children and parents.