Evidence Search and Synthesis NHS Education for Scotland

How can local health and social care partnerships generate and interpret system-level evidence about how their services improve personal outcomes?

This document summarises current evidence on how integrated health and social care partnerships can generate and interpret evidence on how their services improve personal outcomes.

As the use of the personal outcomes approach is generally in its early stages in the UK, the bulk of the evidence consists of opinion and case reports on implementation. It is expected that as the approach matures, more evidence should become available on the interpretation and use of the information generated.

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1 Key messages

- Personal outcomes measurement is difficult.

- Personal outcomes information is best generated through conversations with users, during routine processes like assessments, planning and reviews.

- Various tools or frameworks can be used to structure and record personal outcomes information. No one method is recommended above others; however, the Talking Points approach is frequently cited.

- The recording of personal outcomes information needs to be accurate, complete, detailed and shared, in order to be useful for service improvement. Current IT systems are generally not geared towards recording personal outcomes.

- Using personal outcomes information for service improvement is an under-reported area; however, the evidence highlights challenges in aggregating and interpreting the data in a meaningful way.

- Training and support for staff, and buy-in at all levels of the organisation, are vital if personal outcomes measurement is to succeed. At the higher level, outcomes-focussed practice is likely to require a change in organisational behaviour and culture.

2 Research gaps

- Little if any of the evidence found came from fully integrated services.

- Little evidence of how outcomes data was used to improve services was found. This suggests that few services are sufficiently advanced in their personal outcomes measurement practice to report on this area.

- Independent and high-quality evaluations of what works in personal outcomes measurement are lacking; a large percentage of the material found consisted of descriptive reports from organisations on their own work.

3 Background

This research was commissioned by Chris Bruce, Joint Improvement Team (Scottish Government).

Under the terms of the Public Bodies (Joint Working) (Scotland) Bill 2014 (National Health & Wellbeing Outcomes) [1], Integrated Health and Social Care Partnerships in Scotland, are expected to demonstrate that they deliver Person Centred Outcomes.

Services need to change from counting what they do to measuring Person Centred Outcomes. There is currently very little guidance available to service leaders on how to achieve this.

The purpose of this document is to summarise the current material available on the collection and use of person-centred outcomes data, and to highlight good practice.

4 Questions

Local health and social care partnerships need to generate meaningful and measurable evidence about how they improve personal outcomes, and to use that evidence to inform service improvements.

- Who is showing/has shown good practice in this area?
- What have they done?
- How have they done it?
- What are the lessons learned that can help other services implement and use personal outcomes information?

The bottom line was to find evidence of services demonstrating that they have gathered/used person centred outcomes evidence in a *meaningful and measurable* way.

5 Search process

A search for relevant evidence was carried out between January and February 2015 within the following electronic databases: ASSIA; Cochrane Database of Systematic Reviews; Epistemonikos; Health Management Information Consortium; Health Systems Evidence; IRISS; The Kings Fund; and Social Care Institute of Excellence (SCIE).

Search strategies for each database were constructed around three broad concepts which were combined to produce the final set of results (see appendix 1 for a sample search strategy):

1. Integrated care
2. Person centred outcomes
3. Measurement

Searches were limited to English language material.

A number of additional websites were searched to identify relevant research projects, policy document and reports. A list of these can be found in appendix 2.

Limitations of the search and the evidence base

We did not limit to a specific level of evidence or study design. While every effort was taken to identify relevant systematic reviews and other synthesised material, it was anticipated that very little of this type of material would be found.

A 2012 SCIE research briefing [2] on integrated working between health and social care services, found that the evidence base largely consisted of "small-scale evaluations of local initiatives which are often of poor quality and poorly reported" [p.1] [2]. It also noted that patient/carer centred outcomes were rarely included in evaluations of joint working. [p.14] [2]. Evidence of personal outcomes measurement in so-called "patient-centred" services is also lacking: a recent rapid review by the Health Foundation [3] noted that although patients were at the heart of person-centred health care, "few approaches to measuring person-centred care have been driven by patients or built on aspects identified by patients as being most crucial." [p.23] [3].

Finally, the 2014 EPPI-Centre systematic review of systematic reviews to support the use and development of the adult social care outcomes framework [4] noted that health-related quality of life measures were still the dominant outcome measure in the systematic review literature, and that there was a "need for the further use and development of social care relevant outcomes such as social care related quality of life measures in research" [p.112] [4].

After discussion with the client, it was agreed that case studies, policy documents and project reports were all likely to be sources of information of relevance to the topic.

It is likely that there have been further studies and evaluations of practice which we were unable to obtain due to the difficulties of tracing unpublished internal documents. While the client was extremely helpful in providing lists of contact names and details of ongoing work that he was aware of, it is impossible to assess how much relevant work is currently being undertaken but has not got to the stage of publishing results. Due to time restrictions, we had limited capacity for tracing unpublished grey literature. The resulting summary is therefore necessarily a partial snapshot of work being undertaken in this area.

6 Results

The search process retrieved 56 relevant documents. The following questions were asked of each reference to justify inclusion:

1. **Personal outcomes** – did the reference focus on outcomes identified as important by the individual, or outcomes otherwise based on individual priorities?

2. **Measurement and usage** – did the reference discuss personal outcomes measurement and/or use of data for service improvement?

3. **Good practice** – did the reference include either case study examples or recommendations for good practice?

The 56 included documents were analysed by close reading of the full text and extraction of themes relevant to the question. These themes were recorded using the Literature Analysis Tool developed by NHS Greater Glasgow & Clyde Library Network and owned by NHS Education for Scotland (http://www.lat.scot.nhs.uk).

7 Summary of themes identified within the literature

The core of this narrative is formed from themes and details contained in the six final project partner reports that were released in February 2015, as part of the Meaningful and Measurable project [5-10]. This was felt to be valid because of the reports' currency, case studies and relevance to Scotland. The issues highlighted by the reports were then supplemented by the remaining evidence, a significant amount of which was generated by the development of the Talking Points approach over the past 15 years. We would like to thank the Meaningful and Measurable project leads for alerting us to the imminent availability of material that was of such relevance to the question.

To give some idea of the currency (and perhaps the maturity) of the topic, almost eighty percent of the references were published within the last five years, with only one of the remainder published before 2000. Almost three quarters of the evidence studied examples from the UK; within that number, approximately half contained reports about Scottish experiences. Only six pieces of evidence reported on projects outside the UK. Although there are well-known examples of integrated services in North America, Scandinavia, Italy and elsewhere, no published material concerning personal outcomes measurement was located for these projects.

In terms of the user groups studied, the most frequently-featured were older people; carers; users with mental health issues; and any adult users of social care services. Their prominence in the evidence is perhaps not surprising, given the strong likelihood of these users interacting with partnership services. There were fewer references for users with a learning disability; users with communication issues; users of rehabilitation and reablement services; and children.

Of those evidence sources that indicated the type of service in which measurement was taking place, half related to services that were either integrated, or were at least patient-centred and hence likely to involve various agencies working in partnership; the other half were in non-integrated services or acute care. Of this latter group, most were in social care services in the community. It was noted that while a personal outcomes approach has been adopted within social care and other integrated services, uptake within health-led and more mainstream NHS services has been more limited. [11,12]. Possible explanations included the focus on meeting time targets in acute care settings, which did not enable personal outcome discussions [11], or that information collecting information about patients' preferred outcomes was not a traditional function in the health care setting [13]. However, imminent integration of services means that these differences will have to be addressed.

The following narrative explores the question of generating and using personal outcomes information by looking at the basic elements of what, when, where, who and how. Note however that the question did not ask *why* personal outcomes were to be measured, so the theoretical aspect is not explored here. Similarly, there is no discussion of how personal outcomes were to be achieved; the spotlight is firmly on measurement.

What is meant by personal outcomes?

The most widely-used definition found in the literature described personal outcomes as those outcomes, aspirations or priorities which an individual identified as being important to him or her. This contrasts with previous practice, where outcomes were defined by the priorities of the service or by the practitioner.

Defining terms from the start is important, because, as will be seen below, a *clear and shared* understanding of personal outcomes by all staff within an organisation is deemed crucial for meaningful measurement and use of information, and indeed for the overall success of a personal outcomes approach [14]. In addition, if outcomes are by definition individualised [15], then using outcomes-generated data for service improvement beyond the level of the individual could prove challenging.

Generating information: the conversation rather than the tool

The evidence describes two main methods of gathering information about personal outcomes, one quantitative and one qualitative:

1. Self-completed standard questionnaires which aim to capture measures of service users' Quality of Life, experiences, satisfaction or similar pre-determined outcomes. These included Patient Reported Outcome Measures (PROMs); Patient Reported Experience Measures (PREMs); or other surveys based more closely on outcomes derived from service users' input.

2. Conversations to identify outcomes specific to an individual service user

The main benefits of using a quantitative method includes quicker, more efficient completion, which can be done by the user alone; and standardised information which is easier to aggregate. Some questionnaires are aligned more closely to a personal outcomes approach, insofar as they were developed according to outcomes previously identified by service users as being important, or they allow people to skip questions which do not relate to their own priorities.

However, a greater number of references support a conversation-based, qualitative approach, and the first of the "We've got to talk about outcomes" reports argues persuasively that the quantitative method is not suited to personal outcomes-focussed practice. Questionnaires lack interaction between the practitioner and the user; misunderstanding of questions cannot be addressed; there is a reliance on measuring pre-determined elements, rather than those identified by the individual; and there are no opportunities for clarification and elaboration that conversation could enable. By comparison, using conversations to gather information permits "genuine dialogue between those accessing and providing services and reasserts the importance of supportive relationships." [p.2][16]. The evidence therefore suggests that generating outcomes information through direct engagement with users is preferred: "the conversation with the service user is at the heart of the personal outcomes approach, and hence of personal outcomes measurement" [23].

The Talking Points is one such approach and has been used by a large number of services [7, 10, 12, 21, 22, 24-33], but it was also recognised that any tool that supports and enables good practice, in terms of listening to what individuals want to achieve and taking an overall person-centred approach, would be acceptable [5, 9, 7, 10, 12, 18, 21, 23, 26, 29, 31-37].

In summary, the conversation should be the tool of personal outcomes information, not questionnaires or paperwork [38]. However, although the qualitative approach can generate more *meaningful* information about an individual's personal outcomes, capturing and analysing this information for further use – translating it into something *measurable* – is arguably more difficult. The Meaningful and Measurable project (meaningfulandmeasurable.wordpress.com) aims to develop an effective personal outcomes approach that incorporates both elements, while recognising that there is a tension between them. Finding ways to generate and use information that is both meaningful and measurable is a recurring theme in this narrative.

8 Talking Points and the circuit of practice

The following discussion is structured around the core elements of the Talking Points approach to personal outcomes-focussed practice: namely, engagement, recording and using information [14]. All three elements are part of a circuit of practice which underpins a successful outcomes approach, with meaningful and measurable information an essential component at each stage.

It was evident from the literature that many organisations had employed a personal outcomes approach with regard to at least one of these elements, but there were few examples demonstrating that the complete circuit had been successfully established. Measuring and using personal outcomes data is described in several sources as being at a relatively early stage [25, 39, 27, 36] and the experiences reported in the literature confirm this.

8.1 Engagement

In order to generate information about personal outcomes, they first have to be identified through some form of engagement with the individual service user. As already highlighted, the key method of engagement is the conversation, but how does this work in practice?

Choice of tool

Using a formal tool for outcomes measurement can help to structure the conversation around personal outcomes, so that the practitioner and the service user have something to focus on. A simple example is the Three Wishes method, which asks service users to identify the three things they would most like to see happen or achieve [21, 40, 41]. Alternatively, the conversation can be based around a tool which represents personal outcomes visually: examples include Better Futures; the Angus Wellbeing Web; I.ROC; and the Outcomes Star [5, 10, 23, 36, 42, 43]. Being able to see a chart, spiderweb or other graphic representation which plots progress is valued by both staff and service users [23]. In addition, the attractiveness and simplicity of these tools can be particularly appropriate for some user groups: for example, the Angus Wellbeing Web has been used with children of various ages, who find the visual element easy to understand [5].

Many individual outcomes recording tools are cited in the evidence, ranging from those created in-house by a specific service, to those which have been commercially developed for widespread use. This report's purpose is not to provide a descriptive list, but rather to highlight those features of tools which illustrate particular challenges of personal outcomes measurement. Leaving aside the Talking Points approach, which is not a tool in itself, no single tool has been recommended above others. Any reliable and valid approach usable in routine practice would be acceptable [8, 13, 34, 40, 42, 44], and is likely to have its own individual strengths and weaknesses [7].

Developing a bespoke tool within a service can instil outcomes-focussed practice and encourage staff ownership [16]; nevertheless, the tool itself should not be seen as the ultimate goal, but should be the "accompaniment and enabler" [30] to good outcomes-focussed practice. An outcomes approach should be embedded first in an organisation, and any tools developed should emerge from practice, rather than shape it [16]. Lastly, the chosen tool should align with existing relevant frameworks, such as Getting It Right for Every Child (GIRFEC) in the case of the outcomes model for disabled children and young people in Scotland [27].

Does one size fit all?

It is recommended that instead of using the same tool for measuring the personal outcomes of all users [25, 41, 45], specific tools should be for particular user groups [2, 3, 21, 27, 29, 30, 33, 35, 36, 39, 44, 41]. Although concerned with quantitative measures such as PROMs, Lawrence and Kinn's systematic review [35] concluded that a truly person-centred approach should focus on the specific circumstances of the user, rather than employ generic measures. User-specific examples include the Better Futures tool [23] which measures outcomes relating to housing support; I.ROC [10], which supports recovery for users of mental health services; VOCAL's (Voice of Carers Across Lothian) system to record carers' outcomes [9]; and the various tailored versions of the Outcomes Star [36]. A specific point was made regarding any outcomes framework used with disabled children: it should be based on the same outcomes identified for non-disabled children, but must take into account additional functional needs and the child's individual circumstances [27].

Including a quantitative aspect

There is some support for using a balance of qualitative and quantitative measures during engagement [3, 5, 10, 11, 21, 25, 33, 36, 46]. For example, using a scale measure, such as a Likert scale, can provide some structure to a conversation while introducing an element of quantitative measurement [5, 10, 21, 23, 36]. However, the evidence presents inconclusive opinions. Scales may provide a clearer picture of impact over time [8], but might also adversely affect the all-important conversation by interrupting the flow [16]. Options include using a numeric scale, or a "traffic light" system for outcome achievement, such as "met/partially met/unmet". However, there is disagreement about the latter's effectiveness: some authors state that 'big difference/no difference/worse' is an easy system for people to understand [14, 32], while others feel that such measures are too "black and white" and insufficiently sensitive to capture complex details or the "grey areas" [7, 16]. The Outcomes Star tool attaches specific definitions to its scale numbers [36] which would seem to provide a way to address this issue, but we could not find an evaluation this particular feature.

Categorising information using scales involves judgement, and is best done through a process of negotiation between the practitioner and individual [14]. Finally, regularly sharing practice, for example discussing case studies, may help staff to reach agreement about the meanings of scale measures [33].

Communication issues

The challenges of identifying outcomes through conversation with users who have cognitive impairments or communication difficulties are highlighted in numerous sources [18, 21, 22, 27, 32-35, 41, 47] and Talking Mats has been used by some services as a solution (www.talkingmats.com).

More generally, many people may find it hard to communicate and/or envisage their personal outcomes, simply because they have never previously been asked to think in this way [11, 12, 21, 23, 27, 39, 47]. A specific issue concerning accurate perception of outcomes was noted: Angus Council reported that children were found to exaggerate their scores when asked to use scale measures to describe their situations, so the numbers assigned had to be interpreted within the context of the whole conversation [5].

Integrating measurement into practice

"[t]he most sustainable way to gather information about outcomes from people using services is via routine processes." [33] [p.6]

The introduction of personal outcomes measurement is less likely to be seen as onerous, or as an add-on to existing work, if it is integrated into routine processes [8, 11, 24, 33, 34, 45, 47-49]. In other words, *when and where* measurement takes place should be considered if it is to be effective. Standard local processes such as assessments, care planning and reviews provide ideal information-gathering opportunities [8, 18, 19, 25, 28, 33, 45, 47, 50].

It is important to collect data at more than one point in the person's service "journey", so that any changes are discovered. A lesson learned from the UDSET research was that a review based on personal outcomes was difficult to carry out effectively when the initial assessment had been focused on outputs [14]. Moreover, what is important to the individual can change, so the review is a suitable point at which to capture any new outcomes or highlight any unexpected ones [32]. Meanwhile, process outcomes, such as being listened to, or being treated with respect, are only experienced as the service is delivered, so should to be assessed over a period of time [16].

There can also be issues regarding the time and context of the outcomes conversation. Bridgend County Council reported that the initial assessment visit could take place at a time of crisis where the focus was on fixing immediate issues, not identifying future aspirations; a series of case notes gathered over time were a more effective source of information [6]. An evaluation of fifteen-minute home visits in Moray found that it was not always clear if personal outcomes could be achieved within the parameters of this particular service [50]

Whose outcomes are measured?

There is often more than one stakeholder in the personal outcomes conversation, for example service user and professional; service user and their carer; child and parent; and each person's own outcomes may overlap or be distinct and even in conflict. Reflection and negotiation may be required regarding the influence of input from the professional in recording the user's personal viewpoints and ensuring that both points of view are recorded may be considered good practice [10].

Carers' personal outcomes also need to be identified, and it should be recognised that, if possible, this should be a separate conversation to that of the needs of the service user. While the care needs of their loved one will be of importance, they may have other personal outcomes relating to their own wellbeing [2, 9, 19, 27, 34, 35, 38, 40, 41, 47-50].

Conversations about personal outcomes may become even more complex in the case of children with a disability, where parents, carers and professionals will all have inputs and needs, and there may be tensions between identified outcomes and the needs of the family. [27]. Some disabled service users may have fundamental outcomes that may need to take priority over their stated personal outcomes.

Lastly, there could be tension between a user's personal outcomes and the practitioner's professional duty of care. In these scenarios, discussions on personal outcomes and risk enablement

go hand in hand [12, 15]. By developing relationships with service users over time, trust can be built up and conversations can be more open [5-6, 9, 12, 17-19, 20-23).

Recommendations for engagement

The organisational support needed for successful outcomes measurement is discussed in detail in the facilitation section below. However, some of the specific support needs for successful engagement are worth emphasising at this stage.

- Since conversation and listening skills are key in building relationships with users during the engagement process [5, 9, 12, 17, 18, 20-22, 26-28, 31, 32, 38] both staff and services will need to adapt in order to successfully implement new recording practices.

- While service users can find it difficult to identify their personal outcomes, the literature also shows that staff can struggle in this area [8, 9, 12, 14, 20, 21, 28, 33, 37, 48]. Both clients and professionals will need help to master this ability.

- In relation to work processes, gathering personal outcomes information takes more time than other forms of measurement [11, 12, 22, 25, 27, 28, 32, 34, 39, 47, 51, 52]. There are two elements to this: the extra time required to meaningfully engage with the user [11, 12, 14]; and the time required for reflection and recording conversations afterwards [9, 11, 25, 15, 22, 26, 31, 48].

- In order to engage with users at the depth required to identify outcomes, conversations may happen over several meetings, and should be unencumbered by the pressure of targets or deadlines. This is likely to be a particular challenge in those services which focus on meeting time-related targets.

In summary, the engagement process is important for personal outcomes measurement, because if outcomes are not meaningfully generated in the first place, this will have an impact on subsequent service delivery [7] – and by extension, on subsequent outcomes information analysis and service improvement.

8.2 Recording

Recording personal outcomes information, such as transcribing an interview or inputting data into a system, appears to be a relatively-neglected aspect of the overall outcomes measurement cycle [14]. The process may be seen as a burden, removing staff from their "real work" [13]. This is reflected in our search findings, which located few detailed accounts of how personal outcomes information was being recorded in practice. Nevertheless, recording data should be elevated above the concept of a bureaucratic task [9]. In order to achieve this, staff need to understand the importance of what they record and its impact on service improvement.

Quality of data

Data of any sort need to be of robust quality if they are to be aggregated or analysed for service improvement or a similar organisational purpose [10, 25, 27, 34, 47, 49], however, good reporting does not necessarily follow on from good outcomes conversations [9]. Services report that even if outcomes-focused conversations are taking place, what is being recorded may not accurately reflect

practice. Poor quality information is a major issue, and a variety of explanations have been suggested, several of which were are similar to those encountered in the engagement process. These reasons are summarised in Miller and Cook's report on recording [32], and include the following:

- **Lack of understanding about outcomes.** Practitioners can struggle to identify outcomes, and to distinguish them from needs and services or from the service's priorities. At the recording stage, there is a tendency to record activities and outputs; to connect the individual's circumstances to established service solutions; or to concentrate on the steps needed to achieve an outcome, i.e. goals.
- **Lack of clarity about what to record.** Staff may enter quantitative data into systems without sufficient contextual detail from notes and other qualitative sources to make the quantitative data more meaningful [5]. Outcomes are stated very generally, such as the individual wanting to feel safer or to feel healthier, as opposed to capturing the more specific outcome: e.g. being able to get out and about without fear of falling, or being able to be more active with grandchildren.
- **Lack of consistency or completeness**. There can be problems with missing documentation, e.g. action plans and care plans containing important outcomes information might not be saved in online systems. In cases where information is being generated by many different agencies, often in the case of children and families, the difficulties of recording and/or accessing data from all of them means that the overall picture is incomplete.

Equally, good reporting does not necessarily mean good practice is taking place. Bridgend County Council [6] noted that staff could simply record "the right things", which didn't actually reflect what was happening during engagement. Whichever tool or framework is used has to accurately capture client/staff encounters. Miller and Cook suggest that staff who expected that their work might be challenged at a later date might practice "defensive recording" [32].

One way to begin addressing these issues is to carry out an audit of records, which may highlight existing practice and systemic problems [6-8, 10] and provide a baseline for improvement [6].   Once again, providing adequate staff training is identified as an important response [9, 33].

Recording processes and systems

It is important that the process of recording information should be made as manageable as possible [5, 8-10, 14] and, as with engagement, practitioners must have sufficient time to carry it out effectively. This should include time to reflect on the conversation and to let meaning emerge without feeling pressure to immediately capture outcomes on paper [9]. Efficient systems are invaluable to support this process.

Most services currently use paper documents, some of which were developed for use with particular measurement tools, and it is suggested that the recording process could be made easier if data could be entered directly into electronic systems, saving time by reducing duplication of effort [8, 10]. This approach is seen in practice in the Better Futures housing support tool, where outcomes information is recorded live onto the system. However, its implementation required significant IT investment in systems development and support. The Aspire housing service reported a 40% reduction in

paperwork as a result of using the system, and this could be improved further if it were to be made available as an app [23].

Inadequacy of current IT systems is one of the most frequently-identified barriers to improved recording practice [6, 8, 11, 13, 20, 23, 32, 34, 37, 43, 53]. Recording systems are often still primarily focused on producing management information and performance indicators, rather than being outcomes-focused [32]. Some individual organisations have created their own bespoke IT systems for recording outcomes, such as VOCAL's Carer Impact Shared System [9]. However, the challenge remains to develop IT systems able to record data from several different services and agencies.

Recommendations for recording

- Staff supervision can be used to clarify the purpose of recording and to reflect on the quality of current practice

- Feedback for practitioners about how the information recorded is being used for service improvement will improve practice, by showing the importance of quality data to the organisation [14].

- Staff should share their understanding and use of recording processes and systems with colleagues [9].

- At a higher level, joint working between different parts of the organisation, including IT, should be used to develop effective recording processes [14].

8.3 Usage

As well as looking at the generation of personal outcomes data, we also wanted to see how services were using system-level data generated from outcomes measurement for service improvement; however less than half of the material found provided any kind of information on how outcomes data was being used to improve services.

There is some evidence of local partnerships aggregating data from care and support plan reviews to provide useful information [25, 33, 37, 47] and some anecdotal reports of practice improvement resulting from an outcomes approach [7, 9, 10, 13, 15, 33, 47], but generally speaking, this is the most under-reported section of the circuit of outcomes practice. This may be because services are currently less likely to have reached this stage in their development of an outcomes approach.

How personal outcomes data can be used for service improvement

Cook and Miller [33] outline the ways in which personal outcomes data can inform service improvement:

- Which aspects of the service are having a positive impact on outcomes and for whom?

- Which aspects of service are hindering the achievement of outcomes and for whom?

- Where can improvements be made in relation to process outcomes?

- To what extent are outcomes improved by the services in place?

Elsewhere, personal outcomes data is described as "a 'tin opener' for internal use, designed to prompt further investigation and action where needed" [30] [p.3]. A straightforward example of this was reported by a service using the Better Futures tool. For managers, the tool illustrated patterns taking place within services, which could highlight service delivery changes that were needed, as well as any external influences that could be having an effect [23].

It should be borne in mind that the primary aim of gathering outcomes information is to improve the outcomes for the *individual* and to assess his or her progress [25]. By using that information, the service ensures that any improvements are driven by the priorities of its users [14]. One of the beneficial elements of outcomes measurement for service improvement is that the approach can identify unmet needs at the review stage. For example, Oxford County Council follows up on service users who identify outcomes that have not been met [54].

Beyond the individual level – aggregation issues

How can outcomes information be used to inform broader patterns of improvement which require system-level data, beyond that of the individual? A key challenge is the need to aggregate data without compromising quality [16], which reflects the tension identified earlier between generating and using information that is meaningful, and information that is measurable.

Some quantitative scoring of outcomes using scale measures, as described above, can enable counting and aggregation at service or organisational level, and can show the extent to which progress is, or is not, being made on particular outcome types. However, some potential difficulties with this approach have been identified: "isolated use of individual and aggregated numeric scores is problematic and, in the absence of adequate supporting contextual information, could be misleading" [5] [p.4]. In other words, statistics cannot stand on alone without reference to their accompanying narrative [11]; as one practitioner put it, "one person's 3 is another person's 4" [10] [p.10]. Perhaps this latter problem could be overcome by the Outcomes Star, where specific meanings are attached to the numbers of its scales. This allows aggregated data to be interpreted in terms of the typical behaviour and attitudes that it describes [36]. However, none of the evidence that we found evaluated this feature in practice.

Meanwhile, analysis and use of "small" quantities of aggregated information is problematic, because the variations between individual users are too great [10, 30]. Penumbra staff felt that aggregation of data for smaller group sizes (less than 50 individuals) made interpretation meaningless. As a result, staff found it necessary to include qualitative information, such as "quotes, comments and recovery stories" to create a more meaningful analysis. [10] [p.5].

Aside from scores or scale measures, more qualitative data could be aggregated by mapping service users' "own words" upwards onto the general categories provided by existing outcomes frameworks (e.g. Talking Points, ASCOT) to enable interpretation and comparison [54]. However, Apps queried how far this could be considered analysis of truly personal outcomes [54]. Although these frameworks may be based on categories developed from work with service users about what they identify as being important, such aggregation ultimately represents *collective* views rather than *personal* ones, and seems somewhat at odds with the focus on the individual that a personal outcomes approach promotes.

In summary, the evidence showed that personal outcomes information can be used successfully for individual-focused improvements, but there are difficulties in scaling information upwards for system-level service improvement [54]. An ongoing challenge remains to make aggregated data meaningful for this purpose.

Ways to use qualitative data

Various sources warn that services should resist the temptation to concentrate on quantitative data and look instead at what is really making a difference [8, 11, 15, 18, 24, 27, 30, 47]: in other words the qualitative information. There are various recommendations as to how qualitative data could be analysed for service improvement. For example, textual analysis of a sample of documents including assessments, case records and reviews may reveal information about the issues users face and how they relate to outcomes, or what aspects of the service and the person's own life contributed to achieving outcomes [14, 29]. The quality of analysis is more important than the quantity: for example no new themes might emerge after examining eight sets of case notes, so there would be no need to look at another ten sets [9]. Staff group discussions of individual cases could highlight relevant themes for service improvement [14]; services agreed that discussing outcomes could prompt creative responses and stimulate different service responses [12, 15, 19, 23, 48, 55]. Overall, there is great value in the individual comments and details recorded and more work needs to be done to develop practical ways of making use of this type of information [31].

Did the service make the difference?

Difficulty in attribution has been highlighted [7, 10, 27, 30]: how can it be stated with confidence that the service(s) have made the difference in achieving the outcome, and to what extent? Cook and Miller suggest that the individual service user is usually best placed to identify the services and other factors that have had an impact [14]. The relevant qualitative information should be captured during the recording process, and should also include the contribution made by others, such as family and friends [7].

Recommendations for usage

- As qualitative analysis becomes more important, practitioners will need training in analytical skills [9, 14].

- The extent to which services commit to qualitative data analysis is an important factor influencing approaches to recording and data usage [16].

Examples of data usage in practice

In Orkney, analysis of review evidence revealed a considerable number of cases where it looked like the user would benefit from intervention under the Adults with Incapacity (Scotland) Act 2000 to help with and protect their finances. This evidence was used to make the case for a dedicated Adults With Incapacity support post, which was duly funded [33]. Also in Orkney, review evidence from service users who were placed out of Orkney contributed to the formal Best Value review of the Council's use of Out of Orkney Placements. This allowed the service to show that almost all people in out of area placements were happy and settled and did not wish to return to Orkney. This evidence

helped to convince local elected members that the use of such placements was appropriate and that returning individuals to Orkney should not be a priority for Council spending [33].

Finally, the following questions raised by practitioners in July 2014 encapsulate the ongoing difficulties faced when using outcomes information at a systems level [37]:

- Measurement requires common, unambiguous understanding – are these factors present in personal outcomes?
- Can you attribute services to the achievement of personal outcomes?
- Can achievement be aggregated?
- Is experience measurable?

8.4 Facilitation

Although not part of the original question, it became increasingly clear from the evidence that good practice in measuring and using outcomes information cannot happen in isolation, and requires support at all levels. This section recommends what needs to happen in organisations as a whole to facilitate a personal outcomes-focused approach.

A prominent message throughout the literature is that personal outcomes measurement is difficult [2, 8, 9, 11, 12, 18-23, 25, 27, 28, 30-33, 36, 37, 43, 41, 51] and that "simplistic approaches do not work" [6] [p.6]. General problems associated with outcomes measurement are summarised by Greenhalgh and Meadows in the earliest piece of evidence in our findings (1999): "the practical barriers include the general lack of time, money and human resources needed to collect, analyse and then make use of the data … Lack of IT support for storing and retrieving data coupled with health professionals' lack of knowledge in this area are also problematic" [13].

More recently, five critical success factors for an outcomes-focussed approach are identified by Cook and Miller [14]: staff engagement; high-level buy-in; leadership for outcomes; peer learning and support; and shared definition of outcomes. Most of these came to light in the evidence, as follows:

Change fatigue

Change fatigue is likely to have an impact on staff acceptance of any new ways of working [6], so staff will need support to undertake outcomes-focussed practice [5, 6, 8-12, 15, 18-21, 23, 25-28, 31-34, 37, 39, 43, 47, 48, 51, 52, 55] and they will need relevant training [5, 8-12, 15, 18, 20, 21, 23, 26-28, 31-33, 37, 39, 48, 52, 55]. Specific training needs have been discussed already, but the evidence provided several examples of the general training and support that would help to embed personal outcomes-focussed practice :

- Outcomes-focussed supervision, including coaching and mentoring, can promote an outcomes approach [6]

- Peer support activities, such as focus groups facilitated by outcomes experts, help to validate experiences and practice [6]

- Making and hearing personal stories with users facilitates a shift towards outcomes-focused practice for staff, and is very empowering for users [6]

- Sharing good practice to avoid duplication of efforts is important [5, 9, 23, 27], but reports should develop a greater emphasis on evaluation, rather than simple description [27].

Training case studies

Prior to the introduction of an outcomes-based assessment tool in Midlothian, workshops on "Embedding Personal Outcomes" were attended by almost 400 staff across the council, health, voluntary and independent sectors, including managers, senior staff and frontline staff, beginning in January 2013 [26]. The main objective was to provide staff with the opportunity to reflect on how really listening to service users, instead of looking at how to "fix" things, was key to identifying their personal outcomes. The hope was that this training would help to develop an outcomes approach throughout all the services. In East Renfrewshire staff development included emotional intelligence training, which built confidence and skills in engagement and understanding of others' perspectives [14]. In Midlothian, practitioners were given vignettes and a blank outcomes-focused support plan. Working in pairs, they role-played service users and care managers. This exercise helped to promote understanding of different user perspectives [14].

Systems and practice

"[T]here is a need to unpick existing practice and redefine it" [33] [p.1]

- IT systems are often not fit for the purposes of personal outcomes data recording and aggregation; this is a particular problem for services tied to a contract that they cannot withdraw from easily [6].

- It will become increasingly important to be able to share data across different agencies: for example, Argyll and Bute Council's Pyramid system collects data from health, independent and third sector partners [53].

- Small IT changes can have an impact: Stirling and Clackmannanshire Council noted that introducing a weekly reablement review document into the IT system enabled production of reports which could track goals and outcomes at the weekly review meetings [8].

- Aligning practice towards personal outcomes measurement will require new or revised documentation; reviews of administrative and IT systems; and reviews of procedures, or development of new ones, such as how and when assessments, plans and reviews were undertaken, and how to engage with and record outcomes [14, 15]. However, such developments should not happen before organisational changes are in place to support new practices [33].

- More time must be factored in to allow staff to carry out engagement, recording and analysis activities [5, 8, 10, 14]. Although this will require significant time investment in the short term, in the longer term savings will be achieved because services will be more effectively deployed [14].

- Fragmentation of processes across different services and agencies continue to pose challenges to personal outcomes measurement [6, 11, 27, 28]. Some doubt was expressed

that a single coherent outcomes model can be successfully employed in these circumstances [27].

Shift in organisational culture and attitudes

Two further related themes identified in the literature are that the implementation of personal outcomes measurement requires considerable behavioural and organisational change [6, 8, 11-13, 18-20, 23, 27, 30-34, 37, 43, 51] and that existing staff culture and attitudes can act as barriers [6, 11, 13, 20, 25-28, 33-35, 48, 52, 56].

- Outcomes measurement is at odds with existing systems and practices which historically favour performance indicators [3, 9, 11, 20, 30, 32, 37, 56]. Instead of the top-down approach associated with performance management, the focus is likely to shift to frontline members of staff, as they engage with qualitative personal outcomes data [7].

- In practice, most organisations will need to measure both for improvement and performance purposes [30], and senior management will need to give careful consideration to the competing purposes of information gathering within the organisation [30-32].

- Strategic leaders must establish the clear message that personal outcomes are a priority [11, 33] and need to prioritise investment for outcomes measurement [11].

- Implementation of an outcomes approach cannot happen at the frontline alone [14]; it requires buy-in and commitment from all levels of staff, organisations and service users in order to work [23, 33], along with local ownership of the outcome tools, processes and overall agenda [3, 6, 19, 25, 34].

- By involving staff throughout a service, ownership of the outcomes agenda can be strengthened [8]; change advocates and champions throughout the organisation can become coaches and mentors [15].

- Tools for organisational development and project management can be used to embed an outcomes approach, such as logic modelling [14, 30].

- Collaboration with all stakeholders is needed [6, 12, 27, 28, 43, 48], including stronger partnerships with the third sector and primary care [11].

Finally, adopting a personal outcomes approach can make a significant difference to staff:

"We also feel the pressure is off, not having to fix everything for everyone all of the time. We have a different perception. Seeing people's strengths has allowed us to 'step back'. Hopefully that will lead to relief from burn out. It's also more enjoyable and rewarding" [31] [p.18].

The focus on achieving personal outcomes for users should be mirrored in the way staff are treated and valued [6].

9 Conclusion

This report has attempted to outline the challenges of generating and interpreting personal outcomes information, based on the experiences of services who are currently working at the "sharp end" of developing new outcomes-focussed practice.

It will not be an easy transition to make. The difficulties of generating and using meaningful and measurable information at each stage of the personal outcomes process, and the considerable change required within organisations in order to embed an outcomes approach, will challenge senior management for some time to come. The imminent integration of health and social care is bringing these issues to the fore, as personal outcomes measurement becomes mandatory.

However, if case studies and evaluations of good practice continue to be shared and published, progress can be made in this important area of health and social care practice.

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Appendix 1. Example search strategy

Database searched: Health Management Information Consortium (HMIC) (Similar strategies were adapted for the other search sources)

1	outcome measurement/ or outcome measures/ or health outcomes/ or patient outcome/
2	((user* or person* or client* or carer* or patient* or individual* or people) adj2 (outcome* or need* or satisf* or experience* or feedback*)).ti,ab.
3	(measur* or record*).ti,ab.
4	2 and 3
5	1 and 4
6	integrated care/ or collaborative care/ or health & social services interaction/ or integrated child development services/ or exp integration/ or collaboration/ or coordination/ or joint working/ or interagency collaboration/
7	5 and 6
8	(integrat* or merg* or collaborat* or multiagency or multi-agency or joint* or partner*).ti,ab.
9	5 and 8
10	7 or 9
11	patient centred care/
12	((patient* or person*) adj2 (centre* or center*)).tw.
13	11 or 12
14	4 and 13
15	1 and 13
16	14 or 15
17	review.ti,ab.
18	16 and 17

19	((outcome* adj1 star*) or daisy wheel* or carmen or procare or vittorio or rovereto).tw.
20	(udset or cdset or caring behaviours assurance or talking points or better futures or east renfrewshire or midlothian or monmouth* or torbay).tw.
21	(intermountain* or southcentral* or alaska* or jonkoping or esther or ska?vinge or lincolnshire*).tw.
22	(prisma or sipa or onlok or pace).tw.
23	(healthy communities or care trust plus or wellbeing board*).tw.
24	(denmark or danish or finland or finnish or new zealand or japan* or (northern ireland or northern irish) or quebec or british columbia or alberta or canad*).tw.
25	19 or 20 or 21 or 22 or 23
26	2 and 25
27	2 and 24
28	limit 27 to english
29	26 or 28
30	17 and 29
31	13 and 25
32	13 and 24
33	limit 32 to english
34	5 or 10 or 16
35	29 or 31 or 32

Appendix 2: Additional sources

Convention of Scottish Local Authorities (COSLA)

http://www.cosla.gov.uk/

Health & Social Care Alliance Scotland

http://www.alliance-scotland.org.uk/

Health Foundation: Person Centred Care Resource Centre

http://personcentredcare.health.org.uk/

Joint Improvement Team

http://www.jitscotland.org.uk

Joseph Rowntree Foundation

www.jrf.org.uk

Meaningful & Measureable Project Blog

http://meaningfulandmeasurable.wordpress.com/

Nuffield Trust

http://www.nuffieldtrust.org.uk/

Personal Outcomes Collaboration

http://personaloutcomescollaboration.org/

Quality & Outcomes of Person Centred Care Policy Research Unit (QORU)

http://www.qoru.ac.uk/

Scottish Government

www.scotland.gov.uk

Social Policy Research Unit (SPRU)

http://www.york.ac.uk/inst/spru/pubs/occp.html