IRISS
Institute for Research and
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Understanding and measuring outcomes:
the role of qualitative data

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Acknowledgements

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About this guide

This guide was developed to support individuals and organisations collecting and using, or planning to collect and use, personal outcomes data. Personal outcomes data refers to information gathered from people supported by health and social services and their unpaid carers about what's important to them in their lives and the ways in which they would like to be supported. An outcomes-focused approach represents a shift in the way services are designed and delivered by putting the person at the centre of the support they receive. The approach calls for a focus on gathering, using and integrating qualitative (eg narrative, personal stories) as well as quantitative (eg numbers, statistics) data which can be challenging.

This guide is organised into three broad sections. Part one discusses the links between an outcomes approach and qualitative data and will explore why qualitative data is important and what it can help achieve. Part two of the guide outlines a practical approach to analysing and using qualitative data about personal outcomes by identifying a number of key steps in the process:

Step 1: Collecting qualitative data
Step 2: Recording qualitative data
Step 3: Analysing qualitative data
Step 4: Helping to ensure credibility
Step 5: Reporting qualitative data findings

The steps contain key messages, reflections from case studies and exercises that can be used with groups to encourage discussion, consideration and debate.

Part three highlights practical approaches to qualitative analysis through case studies developed by individuals who were using qualitative data about outcomes for the first time:

Case study one: *Digging deeper: the value of the conversation*, Julie Gardner, VOCAL

Case study two: *Better outcomes for staff: the home support roadshows,* Jenny Hutton, North Lanarkshire Council

Case study three: *'Getting behind' quantitative data: quality of life for carers,* Erik Sutherland, East Renfrewshire CHCP

Case study four: *Using a different lens: discovering what's missing,* Karen Barrie, Health and Social Care Alliance Scotland

Case study five: *Wearing a different hat,* Lesley Smart, Glasgow City Council

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part 1: introduction

This section outlines the relationship between personal outcomes and qualitative data and explores what qualitative data can help achieve. It also touches on the differences between qualitative and quantitative data.

1.1 outcomes and qualitative data

The recent policy and practice shift towards personal outcomes aims to ensure a focus on what matters to the people who use health and social care services. This is achieved by identifying and working towards the outcomes that matter to individuals, to maximise individual potential and quality of life. This often involves recording information about what the individual describes as being important to them in life, and any barriers they are facing to achieving a good life. It is important to understand the meaning the individual attaches to these factors, to identify their outcomes and to plan how best to achieve those outcomes.

As well as understanding individual outcomes, services can analyse and use collated information about outcomes to inform service improvements. This requires skills in the analysis and use of qualitative data. Some of the concerns raised by practitioners include the time involved in qualitative analysis, particularly for those who haven't done this before. This links to a second and possibly greater concern which is lack of confidence in undertaking qualitative analysis. This guide has been produced to help address these concerns.

1.2 why think about qualitative data? What can it help you do?

While quantitative or numerical data can provide a snapshot of trends in outcomes, examination of the qualitative data, including individuals' stories about their outcomes, can result in improved understanding of what works and why it works (Bryman, 2012). Further, generating and using qualitative data about personal outcomes can have a variety of impacts:

- People who use services and their unpaid carers are listened to
- People who use services are motivated because their contribution to achieving their outcomes is recognised
- Practitioners and services understand how outcomes are achieved
- Practitioners and services understand the barriers to outcomes
- Practitioners feel valued because their contribution is recognised

- Services are improved in ways that lead to better outcomes for people
- Organisations are clearer about their values and purpose
- Recognition of the impact of change and the person's contribution to achieving this
- Support and resources are more likely to be effective if the outcomes that are important to people are known.

1.3 qualitative and quantitative data

There has been a longstanding tradition of debate between proponents of qualitative and quantitative data. The position taken here is that each does different things, rather than it being a question of which is right. Qualitative and quantitative data can complement each other, with qualitative data giving meaning and richness to quantitative data. By combining both, a fuller picture can be produced. Quantitative information tells us about what happened, where, when and who with. Qualitative information helps us identify the factors or reasons affecting behaviour or outcomes – the how and why, supporting depth in understanding.

It is also important to note that there are different types of qualitative data. This guide mainly focuses on the collation and analysis of data collected from many people through routine processes such as support planning and review. Analysing this type of data means that findings are based on what lots of people have said, and the approach to analysis is systematic, which supports the rigour of the findings. However, there is also a place for case studies, which can be useful in providing illustrations or for questioning routine ways of thinking about services. It is important to be clear in reporting on qualitative data which type of evidence is being used.

Qualitative data can also assist with one of the key challenges in analysing and using outcomes information. Establishing cause and effect is a well known challenge with measuring outcomes (Miller, 2012). How can we be sure that any one factor or service is directly responsible for any given effect or outcome? Although qualitative data cannot solve problems of causal connections, it is particularly relevant where there is ambiguity about terms and variables (Silverman, 2010) and can help improve understanding of different contributions towards outcomes, with several advantages. These include that the individual's contribution to their outcomes can be recognised and acknowledged, supporting development of a more encouraging and enabling service culture. The role that practitioners play, including the value of listening and supporting, can be recognised and acknowledged. There is also potential for improving understanding of how different agencies can contribute towards different outcomes, and to the same outcome for an individual, with potential to encourage a more collaborative approach.

Just as there is longstanding debate about the relative merits of qualitative as compared to quantitative data, there are also different views about whether they should be combined. Case study three is an example of where both were used to investigate outcomes for carers in one Community Health and Care Partnership (CHCP), showing how combining both can give a fuller picture of the outcomes of a specific population.
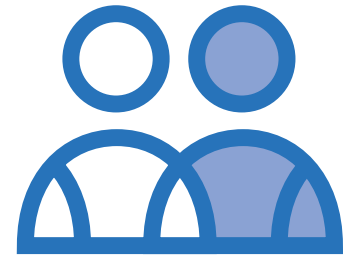
exercise 1:
qualitative data and outcomes

Objectives

This exercise can be used to stimulate discussion about the role of qualitative data in an outcomes-focused approach. It can also encourage reflection about the ways in which outcomes data is being collected and used in teams and organisations. It could be used as part of a workshop, training session or team meeting.

Instructions

You may want to begin this exercise by showing the creative storyboard (an animated, engaging video) *Measuring personal outcomes: challenges and strategies* (Miller, 2012) based on an IRISS Insight (evidence summary) of the same name.

http://www.iriss.org.uk/resources/measuring-personal-outcomes-challenges-and-strategies-video

Depending on the size of your group, split into smaller groups to discuss the following questions:

- What are the differences between quantitative and qualitative outcomes data?
- Why is qualitative data important? What can it help to achieve?
- How does your team / organisation collect it? What is it used for?

After the groups have had some time to talk, ask them to feed back important points from their discussions. Record these on post-it notes or on a flipchart.

part 2: using qualitative outcomes data - key steps

This section outlines five key steps to help support the interpretation, use and reporting of qualitative data. Although the data is usually collected from individuals initially, the focus here is on using information at the collective level. Each step contains points to consider and learning from the case studies (full case studies available in section three).

2.1 step one: collecting qualitative data

Qualitative data can be collected in different ways:

- The most common way of collecting qualitative data in most services is through interviews with individuals, although it is also possible to use group discussions (see case study two)

- It is also possible to collect qualitative data using observational approaches. The use of observation can be particularly important in trying to collect qualitative data from people who have significant communication support needs.
  - Example: staff may observe that an individual resident in a care home, who is no longer able to communicate verbally, enjoys spending time with one of the other residents in particular. This enjoyment of the company of the other resident might be recorded as an outcome for that individual.

- Organisations implementing outcomes-based working have changed their approach to assessment, support planning and review, adopting more qualitative approaches to practice, recording and use of information, as highlighted by Figure 1.

Figure 1: Recording as a critical link in outcomes-based working
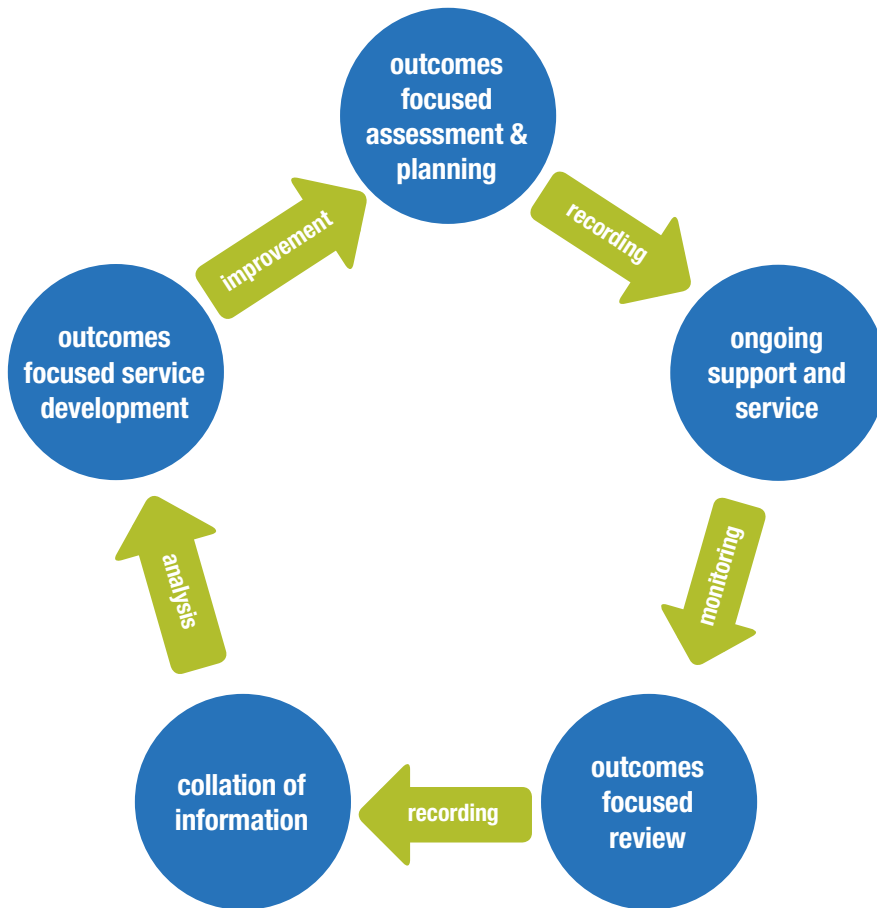
Miller and Cook, 2012

2.1.1 engagement - the outcomes conversation
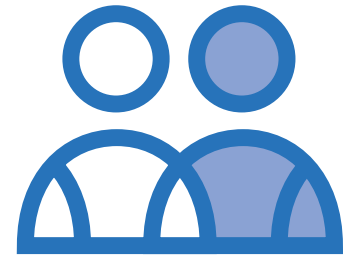
- The outcomes conversation is the primary mechanism for collecting qualitative data about the outcomes important to individuals

- Learning from practice has highlighted the value of the conversation in outcomes-based working. For instance, this approach helps to ensure value is attached to practitioners being able to establish rapport with the individual.

- Evidence shows a range of benefits from a more qualitative approach to information gathering, which allows space for narrative or telling the person's story

- This conversational approach means the person can be actively involved in identifying and working towards their outcomes, and there is more chance of 'getting it right' from the start

- Qualitative outcomes data can provide useful feedback about practice, highlighting the importance of listening to people and relationship building, as evidenced in the case studies
- The outcomes conversation requires a shift from thinking about services, as illustrated in the table below.

	Service led assessment		Outcome focused assessment
endpoint	delivery of service		impact of plan
format	pre-determined question and answer formats		semi structured conversation = open questions
approach	obtaining information required for form filling = 'filtering' information	S H	skilled interaction including active listening and reflecting back
person	client service user or patient who receives services	I F	person in their own right with skills, ability and a role to play in achieving their outcomes
practitioner	expert		enabler and partner
focus	identify problems and deficits and match to a limited list of services	T	build on capacities and strengths towards creative solution
recording	tick box		building a picture towards a clear plan achieving outcomes

Miller, 2011

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exercise 2:
the outcomes conversation

Objectives

This exercise aims to encourage practitioners to reflect on the conversations they have with people who access support and their unpaid carers and to consider if these help identify outcomes.

Instructions

As practitioners, consider the following discussion questions:

- What are your experiences of an 'outcomes conversation'? Is this something you already do?
- How does an outcomes conversation differ from more 'service-led' ways of engaging with people who access support and their carers?
- How do you approach the challenges of identifying outcomes with people with communication impairments or who have English as a second language?

Supporting materials

- IRISS has produced a series of Leading for Outcomes guides. They include exercises and training materials relevant to some of the issues highlighted in this guide. The following signposts to the guides could be used to support this exercise:
    - Leading for outcomes: a guide (http://www.iriss.org.uk/resources/leading-outcomes-guide) The outcomes conversation p24, exercise four (p25)
    - Leading for outcomes: dementia (http://www.iriss.org.uk/resources/leading-outcomes-dementia) The outcomes conversation with people with dementia (p28 & p33)
    - Leading for outcomes: children and young people (http://www.iriss.org.uk/resources/leading-outcomes-children-and-young-people) The outcomes conversation (p22)
- Good conversations: assessment and planning as the building blocks of an outcomes approach http://www.academia.edu/1119820/Good_conversations_Assessment_and_planning_as_the_building_blocks_of_an_outcomes_approach.

2.2 step two: recording qualitative data

- Assessment involves investigation, working with the individual, their family and others to capture their story and the outcomes important to them. Following assessment, the next step is to work with the person to prioritise outcomes and agree a plan.

- Where the same practitioner is involved in review, they discuss whether the relevant outcomes have been achieved

- The review should consider all outcomes, not just those identified in the plan. This allows both for identification of new issues and recognises the impact of any support on multiple outcomes. However, not all outcomes are always relevant to each individual.

- Clear, consistent recording is invaluable at individual and service levels. It supports clarity of purpose for the individual and everyone working with them, at the outset and through monitoring and review. This does not necessarily involve large amounts of information but enough to have a sense of the person involved, rather than simply symptoms/problems. Consistent recording also contributes to good quality data for decision-making at the collated level.

- In the following example, the practitioner has been involved in an assessment, support plan and review with Angus, who is recently widowed and is trying to get back on track after falling at home. Key questions might include:

What are the key outcomes that are important to this person?
(assessment/support plan) *Angus would like to feel less anxious and more confident, so that he can make his daily trip to the Co-op. This would mean he could buy his own food and chat with the other regular customers.*

What are the main issues in relation to the identified outcomes?
(assessment/support plan) *Angus has been feeling very anxious since he fell at home three months ago. He has not been eating as well as he used to before his wife died last summer. He says he has lost his spark since then.*

What actions are required to be taken to achieve the outcomes, and when?
(support plan) *Angus wants to build up his strength and confidence, and to get his spark back.*

What role might the person/their family/natural supports play in this?
(support plan) *Angus is going to try to eat a bit more of the ready meals he gets delivered every Monday. Angus has also been given exercises to do by the physiotherapist, to build up his strength.*

What other support/services might lead to improved outcomes?
(support plan) *Until now Angus hasn't spoken to anyone about how he feels about his wife dying, and wants to speak to a bereavement counsellor, just once or twice.*

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What's already working and what's been changing toward what you want?
(support plan) *Angus said that while working on this plan he has been speaking about losing his wife for the first time since she died five months ago. Although upsetting, that has already made him feel better.*

How will you know that you have achieved those outcomes?
(support plan) *Angus will know he has achieved his outcomes when he gains a bit of weight, feels less anxious and is strong enough to get out again.*

How well are the outcomes being achieved?
(review) *Angus reports that he has reduced his symptoms of anxiety, increased his confidence, and is getting out and about more.*

What role is being played by the person/ natural supports in achieving outcomes?
(review) *Angus stuck to his plan of eating a wee bit more every day and doing his exercises. These were the main reasons for him being able to get out and about again.*

What is being done by services to support the achievement of outcomes?
(review) *Angus said that the exercises suggested by the physio worked well to build up his strength for walking. Angus said that after two sessions with the counsellor, he felt much better because he realised that his anxiety and 'losing his spark' were normal reactions to grief.*

What more/else needs to happen?
(review) *Angus was reluctant to admit that he was struggling with his finances but has no savings at all now and can't make ends meet. A further visit will look at maximising Angus's income.*

What are the outcomes important to this person now?
(review) *Angus is keen to maintain his current level of wellbeing. His only outstanding worry is his income which is now being reviewed.*

Are there other outcomes being achieved than those identified in the support plan?
(review) *Through chatting to customers in the Co-op, Angus was invited to the bowling club which he now attends twice a week. He therefore got involved in new activities and made new friends.*

Are some elements of support no longer required?
(review) *Angus doesn't want any additional support at this stage.*

(case study developed from outline in Miller and Cook, 2012)

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2.2.1 tools for recording - narrative and scale measures

Different organisations are using a variety of tools, and recording different types and amounts of data about outcomes.[1]

- Some tools consist of scale measure data which graphically displays progress on outcomes over time. A scale measure includes a number of tick box options to identify how significant an issue or outcome is. Some tools include numerical scales, so the individual might be asked to grade themselves from one to five or one to ten as to how confident, for example, they feel. Other scale measures use words to categorise an issue or outcome, eg the individual might be asked whether there has been no improvement, some improvement, or a lot of improvement in their confidence.

- Learning from practice has shown that without sufficient training and support for practitioners, tools which primarily focus on measures can close down the conversation, with the focus being on ticking the boxes. The following tools are primarily scale measures, but designed to be interactive and emphasise the importance of the conversation.
  Examples include: I.ROC[2], the wellbeing web[3] or the outcomes star[4].

- Other tools emphasise narrative data, with scale measures as a secondary component.
  Examples include: Talking points[5], Talking points - housing support[6]

- More often, there is a tendency in support plans and reviews to collect both scale measures and narrative information about outcomes. The scale measure data tends to be high level, reporting on categories of outcomes such as 'feeling safe and secure.' The narrative identified the details of the outcome from the individual perspective. Learning from practice suggests that different styles of tool suit different individuals. For example, some individuals with cognitive impairments struggle with numerical scales and prefer words or symbols. Some organisations are therefore developing adapted versions of their core outcomes tool (Miller and Cook, 2012).

- Scale measures therefore can give a numerical rating for outcomes for the individual. By collating scale measure data, it is also possible to track outcomes for a given service or population. The narrative data gives more specific information about outcomes for individuals. By collating and analysing narrative data, through support plans and reviews, it is possible to get a better understanding of what works well and less well in achieving outcomes at a service or local level.

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- Combining scale measure data with qualitative data can help address some of the concerns of people who argue that qualitative data is 'just anecdotal'. The use of scale measure data can help add weight to findings by clarifying whether a large number of people reported improved confidence (or not) and the narrative data can help identify patterns and exceptions in understanding contributory factors to the level of confidence reported.

2.2.2 quality of recording

One of the challenges for organisations beginning to look at qualitative data is that it is likely that recording will be of varying quality. Where there is a plan to use the collated information within the organisation, through feeding the information back to staff, there are opportunities not only to identify what is working with achieving outcomes, but further, to encourage improved consistency of recording through demonstrating to staff how that information can be collated and used. In particular, the collated data can evidence for staff some of the concerns and hunches that they already have about what is working and what is not, and issues around 'unmet need'.

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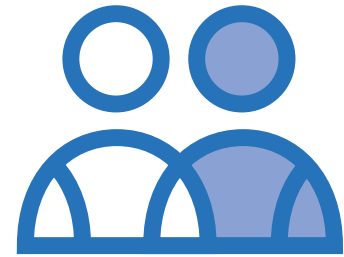
exercise 3:
recording outcomes

Objectives

This exercise can help practitioners to consider how they currently record outcomes and use peer support to consider possibilities for improvement, using a checklist of common errors.

Instructions

Encourage practitioners to work in pairs to think about someone they are working with. Ask each pair to focus on one person, and to talk through and identify the key outcomes for that individual. Once they have had a chance to talk it through, ask them to record the outcomes in a blank care plan. Then hand out the checklist from the recording outcomes guide below (the section titled 'Identified issues with current recording of outcomes, and alternatives'). Ask the pairs to see if there is anything they would change, having read the checklist. Allow time at the end for each pair to feedback reflections on the exercise to the larger group.

Supporting materials

- Recording outcomes in care and support planning and review http://www.academia.edu/1119813/Recording_outcomes_in_care_and_support_planning_and_review

- Leading for outcomes: dementia (http://www.iriss.org.uk/resources/leading-outcomes-dementia) Reflecting on progress p45, exercise 11 p46 and 47

- Leading for outcomes: parental substance misuse (http://www.iriss.org.uk/resources/leading-outcomes-parental-substance-misuse) exercise 10 p41 and 42

- Leading for outcomes: children and young people (http://www.iriss.org.uk/resources/leading-outcomes-children-and-young-people) Recording outcomes p31, exercise 7 p32

2.3 step three: analysing qualitative data

The purpose of collecting and recording qualitative data relating to the outcomes important to individuals is to use this information to tell us something. Different types of outcomes data can tell us different things. Organisations report that tick box data is useful to get an overall impression of which outcomes are being achieved. However, as highlighted in the case studies, it is only through investigating the detail of the personal outcomes that it is possible to achieve an understanding of what is working well and less well in achieving outcomes, which can be valuable information in the planning and shaping of future service provision.

Consideration will be given to different uses of outcomes information in the case studies.

2.3.1 what is analysis? some key points

- Analysis is the process through which you can make sense of the qualitative data. It is important to be systematic and to record the process you go through which can add credibility and transparency to your approach.

- Analysis goes beyond description - it is a process of examination and explanation, making links between themes and interpreting and highlighting messages from the data

- To a large extent, practitioners are already doing analysis at the individual level on a daily basis, identifying what is important and engaging in further investigation

- The focus on outcomes should provide a clear basis for involvement in people's lives, rather than being focused on activity for its own sake. This requires an understanding of the relevant component parts of the individual's life, their aspirations and challenges, as well as risks, and how that all interacts to direct the focus of involvement.

- It is important to emphasise that there is no one way to conduct qualitative analysis. As evidenced in the case studies in section three, the approach taken might be influenced by a range of factors, including the amount of data you have, how it was collected, your previous experience and the time and resources available to you. In two case studies, the people involved explain how they struggled with the textbooks for a while before deciding to just get on with it and work out how to do it in practice.

- Sampling: Qualitative analysis lends itself to having a small sample because of the detailed and intensive work required for the study. So sample sizes are not calculated using mathematical rules. Instead, qualitative researchers should describe their sample in terms of characteristics and relevance to the wider population.

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2.3.2 eight key principles to bear in mind to help with analysis

1. Be open to a range of meanings

Example: In case study two, Jenny describes how through exploration with staff in discussion groups, it was possible to identify what key outcomes meant to staff in practical terms.

2. It is about the person's story

Whether it is an assessment, support plan or review, you might want to consider what the document tells you about the individual described; to consider their story. You might then repeat this with a few additional documents, sifting through the data to get a sense of the themes. In each case you could ask yourself some questions such as:

- What is this person's story?
- What is important to them?
- What does this information tell me about this person's experience?
- What does this tell me about this person's experience in light of their services?
- Are core requirements covered (eg with regard to being safe)?
- What is working well with their services and what is working less well?

3. Look beyond what might usually be expected

- Example: in case study one, Julie describes how the conversations staff were having with carers were having unexpectedly high impact on positive outcomes, resulting in further research within the organisation to find out more.

4. Be aware that you bring your own assumptions

Your own assumptions and priorities can influence your interpretation of service users' comments. How you expect to be treated when you use services may be quite different from the preferences of others, for example. It is also very common for the pressures of service and policy directives to influence approaches to analysis. For example, imperatives to meet delayed discharge targets can create pressures within the system, and a focus on information viewed as directly relevant to getting people out of hospital. Sometimes there is a need to 'turn the telescope round' to look at the circumstances and outcomes for individuals, in order to achieve a better understanding of how things work.

5. Think about the depth of your analysis

Moving beyond individual practice, to consider analysis of collated qualitative data from plans and reviews, it is of course possible to simply give a descriptive account of what was actually said, observed or documented, with nothing read into this and nothing assumed.

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- Example: In case study one, Julie describes how she took a tentative approach, in ensuring that she did not read anything in to the data. She was able to get a clear picture of outcomes for carers this way. However, there are benefits in going beyond description of the data, to develop an understanding of how different components interact, in order to answer 'so what?' questions, and to consider the role of context in influencing a range of outcomes. This higher level of analysis is interpretive, including what is meant by the responses, what was referred or implied, sometimes called deep analysis. This guide includes examples of both.

6. Quality of data collection is important

The quality of data collection will influence what is possible in terms of qualitative analysis of collated data.

- Example: in case study three, Erik describes how the analytical approach adopted by practitioners in their assessments, in turn enabled him to identify factors which impeded carers' outcomes, when he considered the collated data.

7. Resist the temptation to start by quantifying information

Rather than beginning by breaking information up into things that can be grouped together or counted, it can be useful to simply read through the information you've gathered, as suggested under point two.

8. Focus on a particular outcome or service

As this guide is primarily intended to support organisations implementing outcomes, it is worth considering how you might approach your data from an outcomes perspective. You might want to look at one outcome to start with. An example which frequently appears in outcomes tools is 'feeling safe.' So you might consider what are respondents saying about 'feeling safe' for example. There may be examples where the individual has taken action towards achieving their own outcome, which should be acknowledged. You could also look for which services are identified in relation to that outcome. It may be that you are only considering one service, in which case it is still helpful to consider which features of the service are identified in relation to outcomes, or it may be that individuals are using a range of services, and one or more of these could have played a part. Thinking through the questions you want to ask can influence your methods, eg your sampling strategy.

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2.3.3 what is coding?

- Coding is one of the most common ways of handling qualitative data. This involves compiling the data into sections or groups of information known as themes or codes, which are consistent phrases or ideas that come up across different documents.

- This type of approach to qualitative analysis is centred on the concept of constant comparison, which involves continuous consideration of who is saying what, why and in what context (Barbour 2008)

- It relies on identifying both patterns and exceptions in the data

- Once you have read through your first document, you read it again and start writing descriptive codes, next to quotes or sections

- You would then read through the documents again, paying particular attention to the codes you have generated, as you start to create larger themes which connect your codes. Case study five includes examples of codes and themes.

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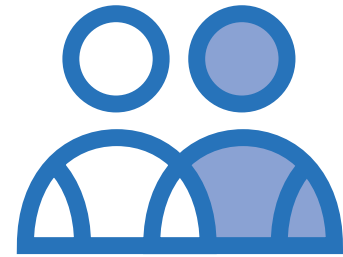
exercise 4:
making sense of qualitative data

Objectives

The objective of this exercise is to give practitioners an opportunity to practice analysis on a piece of sample qualitative data.

Instructions

- A sample of qualitative data can be found in appendix one
- Distribute this data to your group depending on the time available
- Ask them to work together in groups of twos or threes to discuss how they would approach making sense of this data. You could start by handing out the checklist under point two in 'Eight key principles to bear in mind to help with analysis,' included above.
- Once they have read through the data, encourage the group to start identifying themes and / or codes
- Ask the groups to identify any steps they take to make sense of the data. They could then swap with another group to compare and contrast themes, codes or approaches to making sense of the data.
- What are their reflections or reactions to this kind of data? Qualitative data which includes personal stories and narrative can prompt an emotional response which is worth exploring with your group - what influence, if any, might this have on analysis?

Supporting material

This short video presents a simple illustration of the process of constant comparison:
http://www.youtube.com/watch?v=nxIErzX3aQQ

2.4 step four: helping to ensure credibility

2.4.1 discuss with colleagues/compare with similar projects

Once you have started to get a sense of themes in your data, you might want to discuss these with colleagues. This is sometimes called 'triangulation' which involves looking at something from different angles.

Examples:

- In case study three Erik describes a paired reading exercise with a colleague, where both worked together to agree the themes coming out of the data

- In case study two, Jenny refers to groups of staff working together to develop themes from flipchart data recorded at staff roadshows. You could also try to find mention of such themes in reports of services or projects similar to yours.

- In case study five, Lesley undertook a detailed literature review for her research, which helped place her study in context. She also undertook second interviews with each carer participating in her research, where she tested out her findings, to make sure that her analysis was a fair reflection of their views.

- Once you have done this triangulation, you might further refine your themes and re-read the document coding each mention of the themes you have identified.

2.4.2 compare and contrast

- You might want to divide the documents into groups of people that differ on important characteristics to make comparisons which might tell you about how different factors impact on particular groups of individuals, for example

- There are many possibilities to consider, such as how outcomes relate to one another

- Further reading: Ritchie and Lewis (2003) describe how using a matrix can help with relating different outcomes through mapping out sampling criteria such as age, gender, family composition and income. These factors can be mapped horizontally and vertically to help identify patterns, trends and exceptions in the data.

2.4.3 be aware of reflexivity

- Reflexivity means being aware of the influence and perspectives that each individual brings to a process of inquiry. That means awareness of the experiences of those whose data is being considered, of those who collected it, those who are analysing it and all those who are interested in what the data has to say.

- Everyone has their own biases and favourite theories. Reflexivity requires that we acknowledge our own assumptions so that we can approach analysis without unwittingly imposing our perspectives on the accounts and actions of the people whose data we are considering.

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- In considering qualitative data, we should be considering what factors shaped the data collection and what conclusions can reasonably be drawn and which bits of data should be treated with caution, and stating this in our reporting.

  - Example: Case study five is more research oriented than the other case studies. It describes a practitioner researcher in Glasgow, who identified how she had to 'change her hat' altogether to put aside organisational constraints and professional defensiveness, in order to really hear what her research participants were saying (Smart, 2012). Although she describes a piece of research, the basic message about the importance of really 'listening' is potentially useful for anyone involved in gathering and using outcomes information. Information managers may have similar constraints on their practice as practitioners, which may include requirements to focus primarily on organisational objectives and performance indicators. The information manager may also, therefore, need to 'wear a different hat' to fully engage with the stories that individuals are telling about their experiences.

2.4.4 quality and rigour

- Rigour means taking care and being thorough in ensuring that the information is as credible as possible, so that others can have confidence in what you have to say

- Further reading: Some authors have identified aspects of service settings which help to support the credibility of the information gathered. Lincoln and Guba's (1985) influential work on formalising the rigour of qualitative data in real life settings is of relevance. This work supports the credibility of outcomes approaches which are embedded in practice because the content of support plans and reviews should be shared with and signed by the individuals whose data is being considered.

- The credibility of the information is enhanced by practitioners and staff involved in analysis being well acquainted with the settings in which information is gathered. They understand the context.

- To support transferability of information, organisations are encouraged to provide a detailed portrait of the setting in which information is gathered. This enables others to judge the applicability of the findings to other settings. Dependability replaces reliability in this model, encouraging those doing analysis to provide an audit trail (documentation of data, methods and decisions) which can be laid open to scrutiny.

PART 2
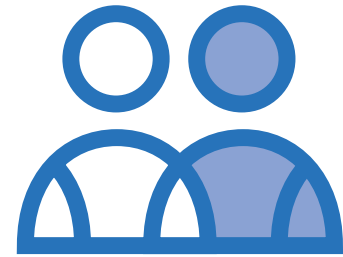
exercise 5:
truth in numbers?

Objectives

This exercise can be used to explore perceptions and confidence around the reliability and credibility of qualitative compared to quantitative data.

Instructions

- Lead a discussion with practitioners around the following questions:
  - Do they feel quantitative data (numbers, statistics) are more reliable than qualitative data? If so, why and in what ways?
  - Do they think there is a 'trust' in numbers more so than data derived from personal stories / narrative?
  - Do they think that qualitative and quantitative data could be combined to strengthen findings?
- Refer to Appendix two which illustrates limitations of the objectivity of quantitative data
- Ask them to identify ways in which they might be able to build in quality checks and rigour to qualitative analysis in their practice.

2.5 step five: reporting qualitative data findings

This step involves communicating what the qualitative data has told you through your analysis. This is a crucial step and will be approached differently depending on who the audience is for your findings and what the purpose is of communicating the findings.

2.5.1 audience

There are many ways in which qualitative outcomes information can be used by organisations, and many potential audiences. Examples can include:

- feedback to staff which is important in acknowledging staff contributions to outcomes, and potentially encouraging improved consistency and quality of recording outcomes data
- reporting to people who use services which is important in helping to illustrate what outcomes are and how things are working
- for identifying gaps in achieving outcomes which can suggest service improvements
- external reporting to scrutiny bodies
- for commissioning purposes.

Reporting outcomes to a range of stakeholders helps to improve understanding of outcomes and clarifies the purpose of your organisations and its activities. Different audiences might include:

- funders
- commissioners
- people who access support
- unpaid carers
- team members
- senior managers / directors
- councillors
- Scottish Government.

2.5.2 purpose

It is worth considering at an early stage what you want to use your outcomes information for.

The IRISS *Insight* evidence summary *Measuring personal outcomes: challenges and strategies* (Miller, 2012) explored the difference between use of information for improvement and for judgement. While in reality, most systems will need to consider measurement both for improvement and judgement, the emphasis given to each can result in very different approaches to the selection of measures, collection of data, interpretation and use, which in turn, will influence the culture of the organisation. Evidence in the *Insight* highlights the adverse effects of prioritising external reporting, particularly in the form of targets. It has been argued that measuring the outcomes of a service should be part of a wider shift of focus onto

the person and their outcomes, and, without the shift of focus, the outcomes tool may become another form which is mechanistically completed by practitioners (McKeith and Graham, 2007). Equally important is the emphasis on involving staff, as evidence from the Audit Commission (2004) has shown that failure to involve staff in defining information priorities and use of information is a key reason for poor data quality.

Examples from the case studies in this guide include using data for quarterly reporting by team managers (case study three) and in-depth reporting by a practitioner researcher (case study five). Regardless of the purpose, a priority in presenting qualitative findings is to provide reassurance that you have been systematic, including an account of the process and approach adopted. It is important to acknowledge exceptions to any patterns identified. Broadly, you want to include a clear account of your data collection, how many individuals were involved and contextual factors which will have impacted on the findings, such as the population involved or the service setting. Where more in-depth analysis has been undertaken, a description of how the themes were derived from the data should also be included. If your data was triangulated, this should be discussed. The findings should be presented in the context of similar studies.

2.5.3 using quotes

The reality of services is that full quotations are rarely available and usually what is available is paraphrased by practitioners. In light of this, examples should be selected because they are poignant and/or representative of the findings.

- Examples: In case study three, Erik uses paraphrasing from assessments and reviews to illustrate themes in his case study. Similarly, in case study four, Karen uses direct quotes from her research with inpatients.

It is helpful to acknowledge the extent to which data is reported directly or whether it is the interpretation of the practitioner. Of course the usual concerns about confidentiality apply to this, and the importance of ensuring that no individual can be identified from quotes used. But it is still possible to include some general information such as gender, age and health status for example, which might still give the sense of the person without specifically identifying them. Within these limitations, the following advantages of quoting still apply:

- Makes reports easier to read – brings them to life = readability
- Evidence that views are being represented = credibility
- Gives the participants a voice = participatory

PART 2

exercise 6:
analysis and audience

Objectives

This exercise aims to support practitioners to explore what influence different audiences might have on analysis of qualitative data and the requirements of different audiences.

Instructions

- Again, using the sample data in appendix 1 (or other qualitative data if you have it), divide practitioners into groups to work together.
- Assign each group a particular audience from the list below (or substitute your own suggestions)
  - Funders
  - Commissioners
  - Senior managers
  - Practitioners
  - People accessing support
  - Unpaid carers
- Ask the groups to consider and record on flipchart paper or post-it notes:
  - What they would highlight from the data for their chosen audience and why
  - What do they think are the priorities and interests of their audience?
  - In what ways could they best communicate the messages from qualitative data to their audience?
- Facilitate a discussion around the key points raised by the group, recording key points.

part 3: case studies

A common theme throughout the case studies below is that people initially feel tentative in approaching qualitative data. However, they also highlight that learning primarily comes from doing, and that confidence grows by making a start.

Case study one explains how analysis of qualitative data about carers' outcomes highlighted the influence of conversations with staff in achieving outcomes for carers, resulting in further research within the organisation to explore how the conversation is best facilitated.

Case study two focuses on an example of improving outcomes for staff. This involved training staff to facilitate events and then working as a group to analyse the data recorded in flipcharts to make an outcomes focused plan for the workforce.

Case study three is based on routinely collected quantitative data about outcomes within a CHCP. The data showed a dip in quality of life outcomes for carers, prompting qualitative analysis to investigate which factors were influencing this change, and resulting in action to resolve the situation.

Case study four explores an NHS improvement initiative. A previous survey had generated extremely positive results. The staff felt the service could be better still, and qualitative interviews about outcomes were used to identify some areas for improvement.

Case study five describes research undertaken by a practitioner researcher to explore outcomes for carers in relation to OT services. This example includes a description of how the researcher developed codes and themes in her analysis.

case study one: digging deeper: the value of the conversation, Julie Gardner, VOCAL

I work for an organisation called Voice of Carers Across Lothian (VOCAL). We moved to an outcomes approach four years ago and have been collecting statistical data on carers' outcomes for over two years. Through this we can identify patterns, including that health and wellbeing is consistently the strongest theme and most important issue for carers in Edinburgh and Midlothian. I had also been thinking about looking at the qualitative data for months, and finally decided to just get on and try to do some analysis. Team leaders provide summaries on a quarterly basis of the comments recorded in their team's baseline and reviews. Our team leaders are not counting the frequency of themes, but they are reporting on what comes up, bearing in mind that the comments recorded are brief.

Based on their returns, I sat and just wrote out which themes were coming up. I was anxious not to put too much of my interpretation on the data and erred on the side of caution. This meant I ended up with long lists of themes, to ensure that I stayed true to what had been reported. I then carefully summarised these down a bit to produce a condensed list. I can confidently assert key themes, and can clearly track these back through the process undertaken. I have to admit I didn't feel comfortable with what felt like taking risks with the data. However, I would like to be able to do something more in depth and there is something about needing licence to do this type of analysis.

Although there were no surprises for VOCAL in the data, it does give us an evidence base and you can see how that could be useful in planning our services and also in the commissioning process. We also did a piece of research based on a finding from our data. It was clear that the conversation between staff and carers is key, and identified as being linked to the following outcomes:

- Carers feel understood
- Carers feel listened to and valued
- Carers feel less anxious and stressed
- Clear boundaries in place
- Carers feels less guilty
- Carers has had a chance to reflect on issues

It seemed important to understand what kind of conversations our staff were having, so we could understand what works for carers, to build this into training and induction, and for our funders. So I invited representatives from two teams to a meeting. Some of the themes that came up included:

- Active listening is crucial
- Using reflection – reflecting the carer's words back to them
- Asking 'what about you?' can be powerful as the carer may not have been asked this before
- We emphasise progress, even if small steps. This helps to build the carer's confidence.
- Acknowledging their expertise – 'If you were advising yourself what would you say?'
- Enabling, breaking it down to manageable steps, giving the carer manageable goals
- Must always remember the carer owns the outcomes – it is about what is important to them
- Acknowledging loss – 'We always planned to travel when we retired.'
- 'Reframing the picture' to help the carer to look at the situation differently.

We are still working on how best to combine and present quantitative and qualitative data. A next step for us will be to take the qualitative analysis a stage further to make sure that we are hearing what carers are telling us.

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case study two: better outcomes for staff: the home support roadshows, Jenny Hutton, North Lanarkshire Council

During 2012 we decided to take a different approach to our annual roadshows for home support staff across North Lanarkshire. We wanted to make the roadshows more interactive, and to give this very large staff group, who often work in quite isolated ways, an opportunity to have their views heard. So we took along life-size cut out figures of celebrities and we asked the staff to use post-its to stick on the cut-outs, to say what they felt about their job, what they thought about their job and what they would like to change. During the events, we were able to use the Word cloud, which is a graphic display tool that gives prominence to the words used most frequently, that then could be displayed on PowerPoint. And there were some big themes that came up time and time again, which included that the staff wanted to be treated with respect and dignity, similar to key outcomes identified through research as important to people who use services.

The second half of the roadshows consisted of discussion groups of six to eight staff each, including staff from admin, home support staff and management. We had trained 14 home support workers as facilitators and they did all the facilitation. They used flipchart paper to record the comments that staff made about what was important to them and how things could improve. Later, we typed it all up and we worked with a group of staff collectively to do some qualitative analysis of the data. We basically cut up the different comments and clustered them into recurring themes. So the series of themes included time, communication, car use and medication. Equal pay was mentioned at every single road show. Dignity, respect and being listened to were hugely important, in terms of how staff are spoken to as home support workers, and how they are treated when they phone in to the office.

So the staff took that data, and developed their own presentation, and their action plan, and they went along to present to the senior management team. They have also gone out to the localities since then to present the same material. So now each locality is developing their own action plan and they have got continuous improvement forums, which I think is an important step forward for this staff group.

There is now a big focus on equal pay, so they are considering how to improve car use and pool cars. There were a few easy things to sort under the theme of dignity and respect. For example, people were talking about having to justify needing new uniforms and sometimes having to produce the worn out items before being issued with replacements. The flipside of that is that staff who work with the council have a duty to look smart and should be able to get the uniform easily without going through a checking process, so we've made sure there are plenty of uniforms for people who need them. So there were quick wins, which addressed the dignity and respect issues raised by staff, and some of the other issues we are working towards in the longer term.
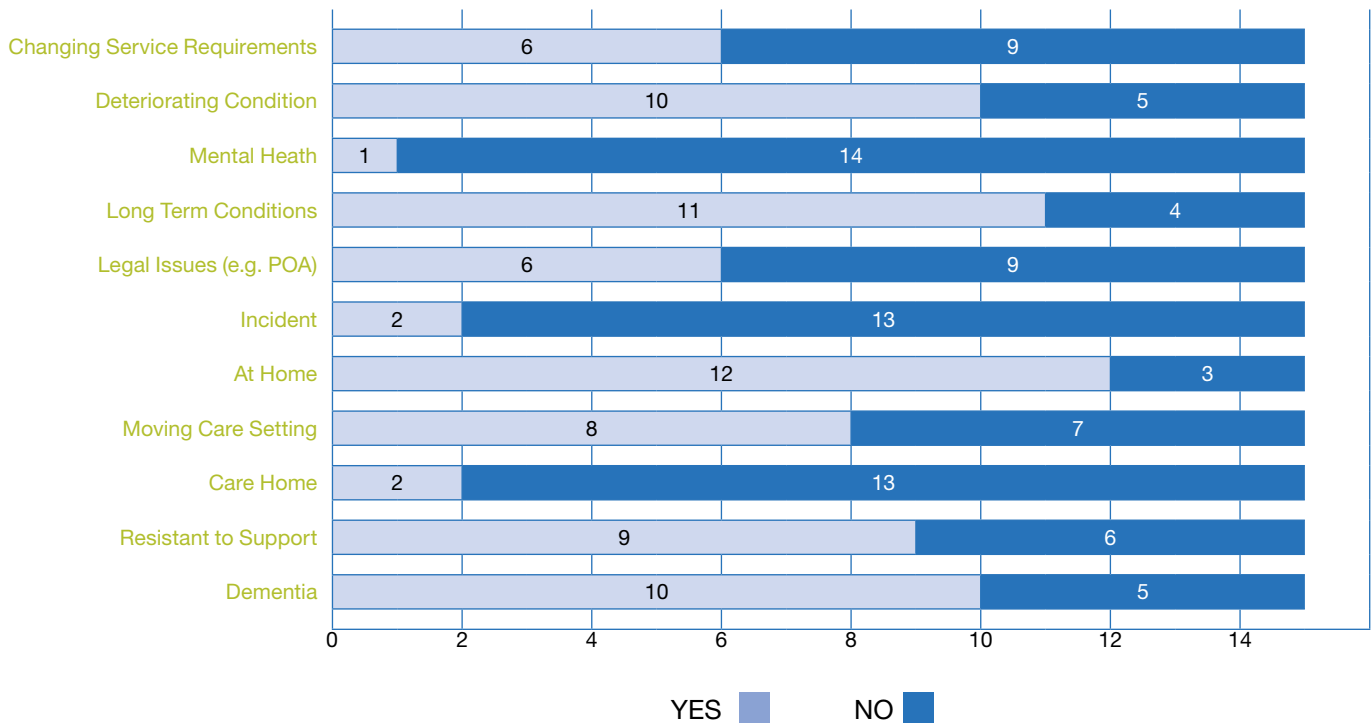
With all the positive focus on outcomes for people who use services, I think it is really important that we consider outcomes for staff too. And home support staff tend to be an undervalued, lower paid and a largely isolated workforce. We are doing a lot of work locally to try to give staff opportunities to be better supported and to feel valued. Using the qualitative data from the roadshows gave us an evidence base to take to senior management and to localities, to make the case for change. Involving the staff directly strengthened the message and hopefully in itself gave them increased dignity and respect. We will be able to check progress until and during our next roadshows.

case study three: 'getting behind' quantitative data: quality of life for carers, Erik Sutherland, East Renfrewshire CHCP

In East Renfrewshire CHCP we have been reporting on Talking Points Personal Outcomes since 2009/10. The outcomes are included both in shared assessment and review documentation in our information system. In the assessment tool, there is space for an outcomes dialogue, which involves practitioners bringing together all the relevant information, including the person's views and outcomes, and drawing conclusions about what needs to happen. In the review, progress in realising outcomes is recorded as 'met', 'partially met' or 'unmet.' Quantitative reports are drawn from the core information system and reported to various strategic and operational groups in the CHCP.

Early in 2012, through quantitative performance reporting, a deterioration in carers' personal outcomes was noted. We wanted to investigate the cause of this and a small-scale audit of unmet personal outcomes was agreed. This audit focused on the 15 carers involved in that quarter where outcomes were recorded as unmet (as compared to 91 met and 38 partially met). Two of us worked together to identify themes within the outcomes dialogue for carers where quality of life outcomes were unmet. We undertook a paired reading exercise and both agreed a number of main themes were arising. A matrix of these themes was then produced to form the basis of analysis:

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Main Themes in Talking Points Personal Outcomes in Unmet Quality of Life for Carers (=15)

Theme	YES	NO
Changing Service Requirements	6	9
Deteriorating Condition	10	5
Mental Heath	1	14
Long Term Conditions	11	4
Legal Issues (e.g. POA)	6	9
Incident	2	13
At Home	12	3
Moving Care Setting	8	7
Care Home	2	13
Resistant to Support	9	6
Dementia	10	5

YES ▮   NO ▮

In cases where carers' quality of life outcomes were unmet, it was found that the cared for person tended to live predominantly at home, with long-term conditions (commonly including dementia) which were often deteriorating. In addition, the audit found that 'resistance to support' was common and transition in care settings figured significantly – though not always from home to care home. Several qualitative comments served to illustrate these themes further. In one instance it was noted that 'personal care is a particular trigger'. In another, it was recorded that the cared-for person was 'reluctant to accept care…does not have insight into difficulties with self-care'. In another case, dementia was recorded as having 'reduced cognitive abilities to self-care' with 'care needs creating a high level of stress' for carers.

Within the qualitative data there was evidence of constructive dialogue between practitioners and carers and the people they cared for. It was evident in these dialogues that there was a focus on reviewing supports, enhancing insight, linking to community assets and promoting resilience in caring relationships to enable carers to be 'less anxious and isolated…[to]…reduce the pressure on the family and thus sustain [the cared for person] for longer at home'. The dialogues include consideration of different forms of short-break, telecare and alternative day opportunities being explored alongside transitions to care home.

We are already starting to use the information on outcomes to influence decision-making within the CHCP. The information about carers' quality of life outcomes has provided an important feedback loop to commissioning processes and the development of more personalised short-breaks. Since the audit, performance on carers' quality of life personal outcomes has started to improve again.

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case study four: using a different lens: discovering what's missing, Karen Barrie, Health and Social Care Alliance Scotland
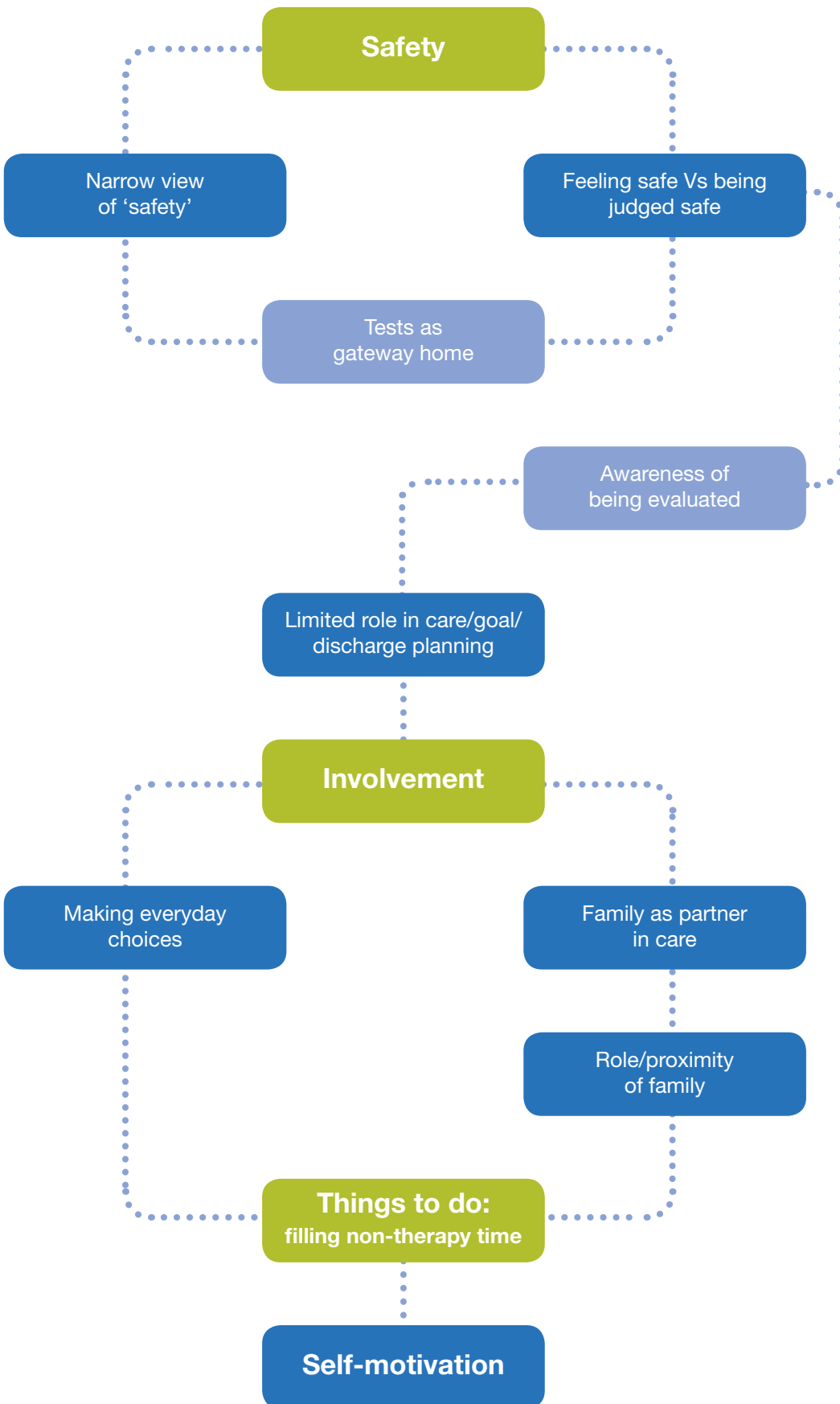
Working with the National Patient Experience Programme, I was often asked to support service improvement projects. One improvement initiative called LEAN took place in an inpatient rehabilitation unit for people with acquired brain injury. An earlier patient experience survey had generated extremely positive results, making it difficult to identify areas for improvement. A subsequent focus group also produced positive findings. While staff were grateful to receive such positive feedback, they felt that there was still room for improvement. So I was asked to do more research in the hope that probing aspects of patient experience in detail might uncover specific improvement actions. Checking through the results of the earlier focus group, it was clear that all environmental and relational aspects of care had already been probed in depth. So we agreed to switch to a different lens, from *what the service did* to *what people were enabled to feel and do*.

I carried out eight interviews with a deliberately diverse mix of people who had recently passed through the service. The interviews were open, but I ensured that the three types of outcomes in the Talking Points framework were covered by asking follow-up questions. The interviews were recorded and then typed up and when I started analysis of the interviews, I read through the data as follows:

- Looking for emphases, elaborations and repetitions within accounts
- Looking for repetitions and similarities across accounts
- Looking for differences between accounts
- Clustering related issues
- Using the Talking Points personal outcomes framework as an organising guide / identifying what was missing from the accounts.

The eight accounts confirmed and expanded on the earlier findings: without exception, staff were regarded as exemplary. There was a committed rehabilitation ethos across staff groups, including domestic staff, with nursing staff keen to support exercise practice back on the ward. Consequent change outcomes centred on improved mobility and function (especially cognitive functioning) and increased confidence. Morale improved as a result of a sense of achievement, the gradual return of hope, and process outcomes, including feeling valued, motivated and encouraged. Anticipated process outcomes such as *feeling listened to* or *having a say* however featured less prominently, because many people identified that they were happy to take a lead from staff in terms of therapy.

From an improvement perspective, three main inter-related themes emerged: *safety, involvement* and *having things to do* during non-therapy time, as illustrated in the diagram on the next page.

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Safety

Narrow view of 'safety'

Feeling safe Vs being judged safe

Tests as gateway home

Awareness of being evaluated

Limited role in care/goal/ discharge planning

Involvement

Making everyday choices

Family as partner in care

Role/proximity of family

Things to do:
filling non-therapy time

Self-motivation

PART 3

When findings were fed back to staff, they recognised that there was a tendency within the service to focus narrowly on physical safety; the priority was ensuring that people were safe to function at home, as often there was a pressure on beds. It was reported in the interviews that people felt pressurised by the test in hospital to check whether they were able to function in the kitchen. Until this point, the therapy staff had not been aware of the emphasis elsewhere in the service on '*passing the kitchen test*' or the fact that it was causing anxiety. They were able to identify the source of this issue and undertook immediate steps to address it.

Another issue that was highlighted several times was the tension between *being judged safe* by staff within the hospital, and the subjective outcome of *feeling safe*. For example "*I was told 'you're safe to go home now'. But I didn't feel safe at all. An elderly neighbour who lived directly below was unwell at the time, and I was really worried what might happen to him if I had a relapse*". This mismatch between perspectives resonated strongly with staff, who reflected on the lack of transparency regarding how patients are assessed for their readiness to return home while in the hospital, and how communications might be improved.

Two of the identified themes also presented an opportunity to inform previously identified LEAN actions. The LEAN work had highlighted '*poor use of non-therapy time*', resulting in a suggested action to involve families in weekend exercise practice and perhaps introduce a programme of activities. The interview analysis however suggested that while the introduction of further planned activities would perhaps relieve boredom and accelerate functional improvements, it would further compound the limited opportunities for people to exercise choice. It was, therefore, agreed that a focus group involving former patients, relatives and staff would explore these themes further.

The focus group confirmed that a planned programme of activities would not be helpful as fatigue levels were problematic and unpredictable. There was also a strong feeling that nursing staff were already very supportive of exercise practice. While some people had used family visits and outings to practice everyday life skills, from ordering and paying for coffees, to treating a trip to the hairdressers as a 'social test', this was not universal. As one relative remarked "*See, we just thought it was good for her to have a change of scene. I mean, we would never have thought of doing anything like that, but I can see how it would have helped*". Because encouragement and support to do this was considered valuable, it was agreed it should be more widespread. While former patients recognised that, due to their brain injuries, they had often lacked sufficient awareness to engage in formal goal setting, several ways of allowing opportunities to make simple choices were jointly identified by staff, former patients and relatives. Interestingly, it was also agreed that staff preparation of individualised colour-coded weekly timetables should be phased out in the run up to discharge. Although former patients had viewed them positively, it was recognised that the change from fully programmed to completely unstructured days was too abrupt, and also did not support making and keeping appointments in the outside world.

This short piece of analysis highlighted the importance of focusing on outcomes, as well as experience of, and attending to, what was not said. The Talking Points Framework was invaluable in supporting this.

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case study five: wearing a different hat, Lesley Smart, Glasgow City Council

I undertook research for my MSc dissertation in 2012. The project was about the outcomes important to unpaid carers in relation to community OT services. I recorded two interviews each with five carers, which were subsequently transcribed. So I had a record of the entire conversations. Being a practitioner does give you some advantages when you are researching within your own organisation, because you know the system. I can see how it does help with some of that, but on the whole I actually think that being inside the system you are researching can make it harder. It is more difficult to be objective when you are part of what you are researching. As a practitioner and a professional, you learn defences that help you to work within the constraints of the system. You also have a tendency to be loyal to your profession, so you want to defend colleagues because you understand how those constraints impact on and limit practice.

When I listened to the recording of my first interview, it struck me that I had approached it as a practitioner. I realised how much I was limiting the conversation because of my OT role. After the pilot interview, I realised the challenge was to set aside my normal role as a practitioner and the approach I would usually take. I had to make a conscious decision to go in with a different hat on - the researcher's hat. It was such a relief. When I completed the first interviews and it came to analysing the data in the transcripts, I read and re-read each individual story. I really wanted to understand what led to people feeling that they had had a good service or not and the elements that contributed to this. I was then looking for similarities and differences between the different interviews.

On the right hand side of the transcripts I would chunk the data up into sections and note words or themes. I had three overarching themes. These were 'it's the person you are dealing with', 'systems failure' and 'where do you go, who do you talk to'. I ended up drawing a Venn diagram so that I could set out different sub-themes within each overarching theme, but also so I could start to map out how themes inter-related. So, for example, when 'budget' came up that would usually be related to the systems theme, but 'provision at the right time' was a theme that overlapped two of the main themes: 'systems failure' and 'it's the person you are dealing with'.

What I learned from carrying out the research was about taking time with people and being aware of my professional role and the departmental agenda, and how that shapes the conversation I have. It has made me reflect much more on my approach and practice and the aspects of the service that are important to people. It became clear in reading the transcripts that honesty was so important to the people I interviewed. People do usually understand that practitioners have limited time and that there are resource constraints and they prefer to know what the limits are. I think what I learned most was that relationship building and honesty are the bits that you can control as a practitioner.

I didn't have training in analysing qualitative data and basically started by reading the books about it. But I could have got stuck on the theory. I had to stop worrying about how I was going to do it and just work it out in practice.

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appendix 1: sample qualitative data

The following three examples are based on data gathered for previous research about breaks from caring. The fictional context is that the carers have been interviewed by staff from the carers' centre as part of a review of a respite service for people with dementia. The existing service is being phased out and decisions have to be made about alternatives. Each carer was asked about their situation, about what was important to them and their experience of respite. In using the material, you might want to start by getting a feel for each individual story and ask questions including those in 2.3.2 under point two. You then might think about key themes that are coming up across the carers and anything which stands out as being different. We have included very preliminary coding to illustrate possibilities. Given the context of the interviews, we have included a focus on comments relevant to transitions between services, as well as comments about accessing information/being informed.

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Mrs J has been caring for her husband who has early onset dementia

Mrs J reported that she really struggled in the early stages to get information about dementia. She said that she only ever managed to find out anything helpful through chance remarks or TV reports. As her husband's dementia has progressed rapidly, she did get information from a specialist nurse.

accessing information about dementia

Mrs J regrets that her husband 'underwent a personality change through dementia', although she says there are still bits of him that are the same as he always was.

A major concern has been managing finances. Not only has Mr J stopped working for two years now, but Mrs J has lost two fifths of her income and has no chance of promotion due to having to take time off.

Mrs J described feeling 'utterly exhausted' and that she had been on medication because she couldn't sleep. She came off one medication because it wasn't helping and the other seems to be helping her to cope. Through word of mouth, Mrs J contacted the carer centre and 'got strength and hope' from there.

Mrs J described respite as a 'very mixed blessing' saying that having to cope continuously meant that she was just getting on with it. Respite had meant that she didn't have to cope for a while and then she felt she had lost her coping mechanisms and she went to pieces both times when her husband came home, taking her a week to readjust.

Mrs J is anxious about getting her support cut. She is open to reviewing respite because the current system is not working for her. Mrs J's priority for her husband is that he is well cared for. For herself, she would like advice and involvement in working out how to make breaks from caring work best to maintain her health.

managing transition carer involvement in decisions

Susan has been caring for her dad who has had Alzheimers for 3 years

Susan said that she and her family struggled with the diagnosis at first, because they thought it would be a quick journey downhill. The reality has been a bit different. Though they didn't know where to turn to get help at the start, the carers' centre and dementia café have been a lifeline. And her dad has more friends through the dementia café than he had before.

accessing information about dementia

accessing information about support

She described how the whole family were unhappy with the idea of respite at first. Her dad didn't want to go because he was anxious that he was 'going into a home' and Susan and her brother felt guilty as a result.

However, from the first visit, the respite worked well and Susan reported that her dad is really well looked after which gave her and her brother the confidence to keep going with it, in the knowledge that he is being well treated. Susan said that she now paces herself; knowing that she is going to get a break every four weeks is making a big difference and she can focus on and work towards the respite date. Without the dates ahead she doesn't think she could cope with rising stress levels.

Susan said her dad described himself as 'one of the boys' in respite, and is animated afterwards because he has lots to talk about. Her main concern is that he should still be able to keep regular contact with friends in the new service.

managing transition maintaining friendships

Jim is caring for his wife and they are both in their late 70s

Jim says that he is coping with caring for his wife and that he will keep on coping because it is his duty and he doesn't want to let her down. However, Jim doesn't think he could cope without breaks and a chance to 'recharge his batteries.' Jim is conscious of the fact that there aren't a lot of resources and doesn't want to take 'more than his fair share'. What he would like to change is to have more of a choice in the dates available for respite. For example, he would like to spend more time with his grandchildren during the school holidays.

Jim found out about respite through his daughter's friend who works in the carers centre. He said that he felt like he was letting his wife down the first time she went to respite but he was reassured when he saw how nice it was. He wouldn't say that she was happy there, but she was settled.

accessing information about support

Jim says he would have appreciated a bit of help, or an intermediary, to persuade his wife that it was a good idea. She was very suspicious at first and it was only when her friend went that she would be persuaded

Jim says he does not want to have to deal with lots of new staff, because his wife does not 'take kindly to strangers', preferring familiar faces.

managing transitions continuity of staff

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appendix 2: what is objective data anyway?

A project was initiated within NHS Borders to develop a strategy for more coordinated and effective use of patient transport. The project focused on bringing together eight different statutory and voluntary organisations.

- The original intention was to use quantitative data around patient journeys from the various agencies providing transport
- Reviewing this data with a small number of key stakeholders revealed that data was captured for different reasons in each organisation, and a variety of assumptions were involved
- As a result, the data sets captured by each organisation varied and were not compatible
- Terminology between organisations differed, and this could cause confusion
- As a result, quantitative data required interpretation that could be subjective
- Qualitative data about the experience of patients and drivers would be more useful
- Qualitative data could be seen as representative of the issues facing each organisation and would, therefore, provide a more objective basis for reviewing services
- Quantitative data could be a useful support to these discussions but would need to be interpreted with care.

Phillip Lunts, Service Improvement Manager, NHS Borders

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