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We've Got To Talk About Outcomes

Reconciling Patient Reported Outcome Measures and Personal Outcomes

The Personal Outcomes & Quality Measures Project

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About This Series

"We've Got to Talk about Outcomes" is a series of insights developed by the Personal Outcomes and Quality Measures project, hosted by the Health and Social Care Alliance Scotland. Focusing on the outcomes important to people who use care services offers real potential to realise person-centred and enabling objectives, but at the same time challenges several tenets of healthcare quality measurement. This short project set out to determine whether and how a personal outcomes approach could be embedded within several diverse healthcare services supporting people living with one or more long term conditions. This series of insights summarises the key project learning.

The series takes its title from the *Review of the Talking Points Personal Outcomes Approach*[1] that was carried out in 2012 by Professor Alison Petch, Institute of Research and Innovation in Social Services (IRISS).

The title is a bit of a play on words, referring primarily to the central role of conversation within a Personal Outcomes Approach.

There has been an excessive emphasis on questionnaires, checklists and tick boxes in recent years[2]. In contrast, supporting people to achieve personal outcomes requires genuine dialogue between those accessing and providing services and reasserts the importance of supportive relationships.

However, there are other reasons why **we've got to talk about outcomes**. Several issues need to be discussed and resolved if future decisions about the design and delivery of care and support for people living with long term conditions are to be not only driven by evidence of 'what works', but are also responsive to what matters to individuals who use health and social care services and respect the principles of 'co-production'.

This series of insights hopes to contribute to that discussion and will inform the focus on personal outcomes within the *People Powered Health and Wellbeing* programme that is being led by the ALLIANCE.

The **"We've Got to Talk about Outcomes"** series:

1. **Reconciling PROMS and Personal Outcomes**
2. A Question of Purpose: Implementing a Personal Outcomes Approach in Different Healthcare Settings
3. Talking the Same Language: Translating a Personal Outcomes Approach into Support for Self Management
4. Rethinking Enablement: The Enabling Potential of Outcomes Focused Working
5. Using the Talking Points Outcomes Frameworks for Evaluation: Limitations, Principles and Practicalities

Key Points

- The importance of improving outcomes for people using services is now recognised across health and social care

- Two approaches with somewhat different intents have emerged in parallel

- Health and social care organisations are seeking to engage with people using services about outcomes to meet improvement and performance priorities

- There is mutual learning to be gained from practical application of PROMs and Personal Outcomes Approaches in different settings

- Context, purpose and principles are key considerations

- In practice settings, quality of engagement can be compromised by evaluative undercurrents

- Using outcome 'measures' at decision making levels other than those for which they were intended is problematic and requires some compromises to be made

- A comprehensive set of healthcare outcome measures should reflect the person centred quality ambition and support the integration of health and social care

- Giving people the opportunity to comment on the impact of interventions on their quality of life in pre-defined terms is welcome but insufficient

- There is a need to be responsive to what matters to people (collectively and individually) and increasingly, to accommodate broader quality of life concerns

- There is an also a need to support and recognise the contribution of the individual and their own resources in achieving outcomes, consistent with principles of co-production

- A Personal Outcomes Approach has the potential to support the person centred quality ambition, together with preventive, enabling and integrative policy objectives

- This presents a number of possibilities and challenges that will vary by context

- There is a need to understand what these different possibilities and issues are in different healthcare settings and to translate the Approach accordingly.

'There will be challenges in marrying a personal outcomes approach with the somewhat different interpretation of outcomes prevalent in health…. However, a future of health and social integration requires such disparities to be overcome.'

Review of the Talking Points Personal Outcomes Approach[1]

A Petch (2012)

Context

In recent years there has been a significant shift within policy and practice across the UK away from the inputs, processes and outputs of health and social care systems and towards the **outcome** of this activity for service users and carers.

There are two main overarching drivers for the focus on outcomes:

- **Effectiveness** – as financial pressures on the health and social care system increase it is more important than ever to ensure that all resources are used effectively and have the desired outcome for people accessing care services and supports.

- **Ethic of Engagement** – engaging with people using services and their carers in decisions about their care and support, and their values individually and collectively, as well as involving them as partners in care or self care is recognised by research and policy as key to maximising health and wellbeing. It is also essential if care and support is to be legitimate and properly respectful of the people using services, consistent with a human rights based approach[3].

At the centre of developments has been a concern with how the difference services make to individuals can be measured. In a climate of financial decline, there is less money available for independent, arms-length evaluation, resulting in a shift towards self-assessment that is carried out by people in the organisations themselves and is

more embedded in service delivery[4]. This trend is likely to continue into the foreseeable future.

About this Insight

The concern to measure outcomes for individuals has long been shared by researchers and clinicians and two different approaches have emerged.

This first insight considers these different approaches with specific reference to the role of **Patient Reported Outcome Measures** and **Personal Outcomes**, which receive different emphases in health and social care policy. Consideration is given to some of the fundamental questions regarding the identification and measurement of outcomes that are important to and reported by people accessing care services, and the various uses of outcomes data at different levels of decision making.

The insight first considers **Patient Reported Outcome Measures (PROMs),** which are a central feature of the *Healthcare Quality Strategy for NHS Scotland.* PROMs are most commonly

understood as structured questionnaires that capture people's perspectives on the impact of an intervention or condition on pre-defined aspects of their health-related quality of life. However, this insight shows that PROMs come in different shapes and sizes and are finding many applications in routine healthcare practice and service delivery. The extent to

which the 'patient voice' has been incorporated and retained during the design, development and validation of widely used PROMs is then examined, together with the implications for their use as a measure of 'person-centredness'. In particular, the use of PROMs as a means of prompting person-centred care planning is considered in detail, with close attention paid to the barriers to their successful application in this context.

The discussion then turns to **Personal Outcomes,** which feature in a growing number of health and social care strategies, are an important driver for the Integration of Adult Health and Social Care in Scotland, and integral to the 'personalisation' philosophy promoted in social care. Research, policy and practice have highlighted the value of frontline practitioners engaging with individuals to identify the outcomes important to them in life, and recording and using outcomes information not only for individual care and support planning, but also for service improvement, planning and performance purposes[5].

Drawing upon the learning gained from the Talking Points Personal Outcomes Approach[5] over the past six years, this insight highlights the value of an outcomes focused approach to engagement. It then considers the dilemma encountered in deciding how best to record personal outcomes, notably the tension between qualitative conversational recording and the use of proxy quantitative measures, however summary, in a way that readily supports the aggregation needed for wider use, without compromising the quality of engagement.

The insight draws together the key issues surrounding the different uses of PROMs and Personal Outcomes data at different levels of decision making. It highlights limitations in the use of PROMs in support of the person centred quality ambition, offering criteria to assess their fitness for purpose in collective applications, before making the case for the adoption of a personal outcomes approach, consistent with the principles of "co-production".

Essentially co-production is:

- An assets approach which builds on the skills, knowledge, experience, networks & resources that individuals and communities bring

- Built on equal relationships where individuals, families, communities & service providers have a reciprocal and equal relationship

- An approach where services 'do with, not to' the people who use them and who act as their own catalysts for change

Co-Production of Health and Wellbeing in Scotland (2013)[6]

Patient Reported Outcome Measures (PROMs)

### What are Patient Reported Outcome Measures (PROMs)?

Patient Reported Outcome Measures (PROMs) typically take the form of standardised questionnaires that ask people about their health status (or condition) and its impact on their health-related quality of life. They do not ask about the experience of care or satisfaction with treatment. They are based on the assumption that health-related quality of life can be objectively measured and quantified, but beyond this PROMs come in different shapes and sizes, designed for use at various levels of healthcare decision making.

Generic Measures: Generic utility and generic profile measures were designed for use at strategic decision-making or population level, informing healthcare planning, priority setting and policy. Many of the popular generic measures date back to the 1970s, funded largely by American statutory bodies to monitor the health-related quality of life of the population, to rationalise service development and to predict future service demands. Generic measures are popular because of their ability to support comparison across a range of conditions and, in the case of the EQ5D, to support (international) economic evaluations in conjunction with the Quality Adjusted Life Year (QALY). Generic measures tend to include a number of dimensions that are likely to be irrelevant to some people and exclude aspects that are important to others. This can result in a lack of sensitivity and responsiveness to change[7].
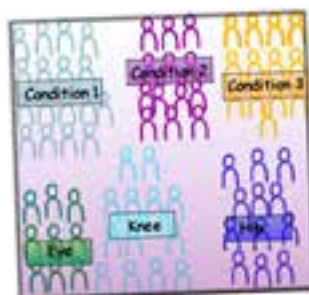
Specific Measures: Specific to a given function, health dimension, body part or, more frequently, health condition, there has been a huge growth in the development of these measures since the 1980s, coinciding within advances in psychometric testing. They are typically used to measure the influence or impact of an intervention by capturing before and after scores. Most were developed for use within clinical trials. They tend to be more responsive to small changes following an intervention, but may focus too narrowly on specific symptoms to capture broader aspects of quality of life such as social or emotional wellbeing, and do not allow comparison across different health conditions[7].

On account of their different properties, generic and condition-specific measures are often used together. Both assume that the factors relevant to the population under investigation can be pre-determined, together with their relative importance, the prompt questions to be asked and the set of possible response options.

'Idiographic' Measures: These individualised measures began to emerge in the late 1980s as a direct challenge to the reliance on externally pre-determined categories and values in the assessment of quality of life, health-related or more broadly. They allow respondents to nominate the areas of life which are most important to them, rate their level of functioning or satisfaction with each, and indicate their relative importance to their overall quality of life at a given time.[7] Measures such as SEI-QoL, PGI and MYMOP2 have been used successfully in clinical settings, particularly in primary care, but are criticised for failing to provide the form of standardisation required for comparison of results. However, the elimination of irrelevant items removes much of the 'noise' typically associated with standardised questionnaires and facilitates greater responsiveness to change.[8]

Health Related Quality of Life: How is it Defined and Who by?

The way in which 'health' and 'health related quality of life' are conceptualised within PROMs also varies widely, from a narrow biomedical focus to a very broad understanding of health, or by considering only those aspects of quality of life most likely to be directly impacted by a given condition to the broader aspects of valued everyday living. The extent to which the 'patient voice' is incorporated during PROM development also varies considerably. For example, in the case of multiple sclerosis (MS), the MS-QOL is a 54-item measure comprising the g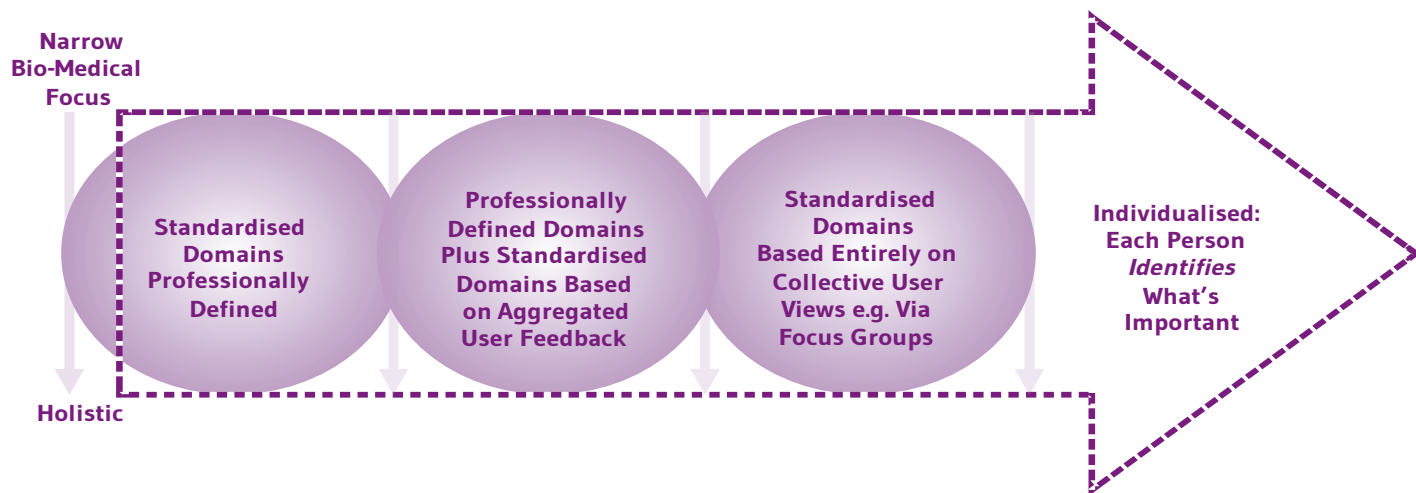eneric SF-36 measure plus 18 items identified as important by two clinicians. In contrast, the Leeds MS-QOL contains items identified via a series of focus groups, and subsequently validated and refined by people with diverse life circumstances living with MS. The latter prioritised factors such as fatigue, social life and work, all of which are absent from the more bio-medically focused, professionally derived instrument.[7]

Psychometric Priorities: Retaining the Patient Voice during Validation

There is currently an expectation that if data are to have maximum impact on healthcare decision making, then they need to be robust. Robustness, conveyed through psychometric properties, is the central concern in the development and validation of PROMs.

This point can be illustrated by considering the DemQoL PROM[9], which is an interviewer administered questionnaire for people living with dementia. This PROM was developed using Gold Standard techniques, beginning with the construction of a conceptual framework informed by literature review, extensive qualitative interviews and subsequent refinement with people with dementia. The developers of DemQoL set out with the explicit aim of keeping the perspective of the person with dementia at the centre throughout. The conceptual framework was consistent with this aim, comprising 5 domains. However, this broad conceptual foundation gave rise to a rather unmanageable 73 individual items. During the subsequent item reduction, the key priority was maximising the psychometric scores, with the result that the final 28-item questionnaire no longer matches

Narrow Bio-Medical Focus

| Standardised Domains Professionally Defined | Professionally Defined Domains Plus Standardised Domains Based on Aggregated User Feedback | Standardised Domains Based Entirely on Collective User Views e.g. Via Focus Groups | Individualised: Each Person *Identifies* What's Important |

Holistic

the conceptual framework, with the "*self-concept*" domain disappearing entirely. The absence of "self-concept" is entirely attributable to the difficulty in capturing its essence in a highly structured recording instrument, rather than a reflection of its importance to people with dementia. It is therefore important to understand not only what PROMs do measure, but also what they do not.

The Routine Use of PROMS in Health Service Delivery: Issues and Challenges

PROMs are not only gaining an unprecedented prominence in many aspects of health services policy and research, but are also increasingly finding more routine applications within health service delivery and performance management.

Since 2009, the routine use of PROMs has been mandatory in England for certain elective surgery procedures. The National PROMs programme is presented as having an important role to play,

not only in monitoring performance and effectiveness, but also, by publishing results, informing 'consumer choice' of provider. As the potential scope of this programme could extend far beyond elective procedures, with pilots currently considering the use of PROMs in support of the management of six long term conditions, PROMs data are expected to provide "**a powerful new means of managing the performance of the NHS**"

While the recent revelation that doctors may opt out of the 'surgery league tables' casts some doubts over this assertion, the potential cannot be ignored. The Kings Fund Report '*Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision making*'[10] considers some

of the uses of PROMs made possible through the programme. These include the potential to link provider payments to their performance in improving patient health, and to support the direct comparison of the efficacy and economic value of interventions, in turn informing commissioning and disinvestment decisions. Other more controversial uses include selective referral processes based on predicted patient health gains.

Although issues such as 'provider choice' and 'payment by result' remain less relevant in the NHS in Scotland, PROMs are a central feature of the *Healthcare Quality Strategy*[11]. Indeed, embedding the use of PROMs in routine practice and service delivery across all NHS services is identified as the first priority action area in support of the Strategy's *person centred quality ambition.*

The *Strategy* positions PROMs as a vehicle enabling people who use healthcare services to comment systematically on the effectiveness or impact of their treatment, with a further undertaking to use such data to drive service improvements.

A small-scale survey carried out in 2012 by Healthcare Improvement Scotland[12] confirmed that PROMs are already finding diverse applications in routine practice and service delivery across Scotland, including uses not set out in the *Strategy.*

The different applications of PROMs are illustrated in Figure 1. This growing diversity of PROMs applications at various levels of healthcare decision making merits considered attention.

One Size Fits All?

Different applications in different populations or settings often require different concepts, measures and approaches. However, one problem is that a 'one size fits all' approach to outcome measurement is often assumed. Generic PROMs are increasingly finding uses at different levels of decision making as they allow diverse comparisons to be readily made. The growing use of the EQ5D also supports economic evaluations, although some economists question the use of PROM score 'values' calculated for the general population rather than specific patient sub-populations in drawing conclusions[13]. In addition, the generic concepts within these measures may not be meaningful to respondents, particularly people with cognitive impairments. They also may not be important. So while presented as 'giving people more of a say' in key aspects of the NHS, a concern is that the growing use of these externally devised instruments actually preserves the supremacy of professional judgements to the detriment of individuals' autonomy in expressing their own priorities.[14]

The Issue of Attribution

When used routinely in service delivery rather than within the controlled environment of the clinical trial, there are also concerns that there is not a clear enough link between PROMs data and quality of care to support provider comparisons.[13] The experimental design of

Level of Aggregation:		
	Group or Population Data	**Individual Data**
Used at the Professional: Service User Interface? — **NO**	Population monitoring and screening	
	Quality assessment (services and interventions)	Informing multi-disciplinary team communication
Used at the Professional: Service User Interface? — **YES**	Decision aid	Screening Monitoring 'treatment' **Promoting person centred care (care / support planning)**

Figure 1 -Taxonomy of PROMs Applications [Adapted] [20]

the clinical trials supports a proper analysis of impact by affording comparison of outcomes achieved 'with versus without' an intervention. 'Before versus after' measures in contrast fail to account for other factors. Publishing PROMs data to inform 'consumer choice' could be misleading or misunderstood. Commissioners have also expressed concerns as to whether variations in outcomes can be attributed to differences in the quality of care, even when used for seemingly very specific interventions such as hip operations (e.g. failure to recognise the significant contribution of the individual or carer in regaining mobility after returning home).[13]

Attributing broader quality of life outcomes to specific interventions is widely recognised as problematic.[5] A preoccupation with proving or isolating intervention impact can result in effort being expended trying to control or remove other influences rather than understanding and promoting their contribution.

Potential Sources of 'Error'

Various potential sources of 'error' can be identified regarding the more routine use of PROMs data in making decisions. These include respondent 'comprehension' errors and 'accuracy' of response, in the sense that they do not align with the developer's meaning or the respondent employs an estimation of change based on current or recent status as opposed to that recorded in the baseline.[15]. Such 'errors' tend to get lost in more routine data processing. Response shifts[16] are also prevalent, particularly for people living with one or more long term conditions, whereby changes reported may be attributable to a natural process of adaptation and adjustment, or the lack of change the result of unrelated deteriorations. A further challenge is that quality of life is a highly dynamic concept, subject to recalibration of individual rating scales, the relative importance of different domains or even what constitutes quality of life.

This lack of stability calls into question a number of established psychometric indices.[16] Startling inconsistencies can also be identified between verbal accounts of quality of life and PROM responses. Standardisation of questions does not ensure equivalence of meaning across different groups. Cognitive interviewing techniques have uncovered the diverse hidden and unanticipated processes that people use to interpret and respond to PROMs, threatening several psychometric notions of validity.[15]

The Use of PROMs to evaluate Person Centred Care

As discussed, generic PROMs were developed to address issues of supply and demand and their economic implications at population level, while condition-specific PROMs were developed to evaluate and compare the effectiveness or impact of different interventions. Most of the frequently used PROMs were developed in the 1970s or early 1980s and therefore pre-date the current emphasis on person centred care.

In NHS Scotland, PROMs are positioned as supporting the person centred quality ambition[11]. Different understandings of term 'person centred' exist, and this undertaking is consistent with more service-oriented interpretations that put the interests of 'the patient' (as a collective entity) at the centre of service design and delivery (versus individual or relational understandings). The move from a reliance on professional judgements in determining the success of interventions to including feedback from the people experiencing them is welcome, but even at this collective level, is still some distance from the commitments to shared decision making and co-production set out in the person centred quality ambition.

Metrics and Meaningfulness

The extent to which the 'patient voice' (collective or individual) is included in the development of PROMs varies enormously, as does the emphasis on biomedical or more holistic concerns. When used as a measure of person-centred care, it can be argued that failure to incorporate the perspectives of people using services within a PROM is insupportable. Further, a narrow biomedical focus is inconsistent with contemporary healthcare priorities that are increasingly concerned with the ongoing support of people living with long term conditions in pursuit of valued living. Incorporation of the 'voice of the person' within PROMs affords significant opportunities for a more person-centred evaluation of services, and also for the design of more responsive interventional strategies[7]

If the concepts contained within standardised measures have little or no bearing on the respondent's perception of quality of life, what then are PROMs measuring? The meaningfulness of a measure, best encapsulated through the properties of face and content validity, should be of central importance in such collective applications.

By thinking about outcomes in pre-defined terms, it is assumed that a group of people (with a given health condition), each receiving the same form of support, delivered consistently, should achieve the same outcomes. While this may hold true for tightly-defined clinical interventions and their impact on biomedical aspects of health, it sits at odds with current understandings of people's diverse capabilities and complex

social realities, and the growing application of such understandings in long term conditions management[17].

Conversational Elicitation of Outcomes

The use of standardised questionnaires minimises interaction between respondent and interviewer, suppressing the crucial elements of ordinary conversation through which the intended meaning of items might be clarified and responded to. While face to face interviews are reported to elicit more social desirability bias, whereby respondents feel obliged to give the 'desired' answers, the development of a trusting relationship can help[18]. Interviewer bias has also been found to be much less problematic than comprehension errors.[15] As a result, more collaborative approaches are advocated where respondents and interviewers work together towards a mutual understanding of questionnaire items, in which interviewers exercise discretion in response to individual contexts.[15]

Deficits versus Assets Based Approaches

An analysis of PROMs through an 'assets' lens reveals that the majority are inherently deficit based, as by definition they are concerned with the aspects of life that are adversely affected by a health condition, the relative burden of disease or caregiver burden. While more recent instruments may incorporate different conceptualisations of health, most traditional measures reflect concerns such as morbidity and impairment. Equally, while some health definitions include positive factors such as health potential and psychological reserves, these aspects are harder to measure reliably and seldom feature in rigorously validated PROMs.[9]

This deficits orientation sits at odds with the emphasis on enablement and self-management that characterises much of the support for people living with long term conditions, whereby energies are challenged into the enjoyment of full and positive lives. On occasions where PROM cognitive testing has considered the impact of negative word stems and associations on respondents, such concerns have been overridden if conducive to securing better psychometric scores.[9] This has potentially profound implications when considering use with people whose emotional wellbeing may also be affected by the progressive or degenerative nature of their health condition.

A further development is the growing use of counterfactual questions that directly ask people how things would have been without a given service or support, such as employed by the Better Futures outcome measure, or the IIASC project which has sought to measure the 'added value' of social care services.[19] Although helpful to decision makers concerned with attributing impact to specific services for rationalisation and commissioning purposes, the consequences of being asked questions that emphasise service dependency remain relatively unexplored.

PROMs: Fitness for Purpose in the Context of Person Centred Care

Together the above findings point to several considerations to ascertain the 'fitness for purpose' of PROMs when conducting service or intervention level evaluations under the umbrella 'person centred care':

PROMs Assessment Considerations in Support of Person Centred Care

- The purpose for which the PROM was developed and alignment with planned usage
- Transparency of purpose and whose interests are being served
- The way in which 'health related quality of life' has been conceptualised
- The extent to which the 'patient voice' has been incorporated and retained during the design, development and validation of the instrument
- The emphasis on deficits and the possible implications for respondents
- The emphasis placed on numeric scores versus relative improvement
- The method of administering the questionnaire
- Ultimately, the relevance and importance of the content to any given respondent

The discussion until now has considered the use of aggregated PROMs data to inform decision making at strategic or service level. Policy makers, commissioners and service managers typically cannot enter the life worlds of individuals, but have to exercise impartiality and represent the interests of groups. Such applications are largely concerned with effectiveness, with the opportunities for engagement reduced to the completion of questionnaires. Consideration now turns to the use of PROMs in routine practice, starting with traditional clinical practice in terms of treatment decisions and condition monitoring before considering the ongoing care and support for people living with long term conditions.

Using PROMs in Everyday Practice

Informing Treatment Decisions

In practice settings, aggregated PROMs data gathered from clinical trials have also been used as decision aids. These PROMs inform people about the impact of different interventions on aspects of quality of life, as expressed by people who have actually experienced the intervention, rather than relying solely on professional opinion. This application, informing individual choice as to whether to pursue a particular treatment or procedure, or choose one intervention over another, is highly valued by many.[20]

Screening and Monitoring

Individual level PROMs data have also found successful applications as screening tools, especially for depression or anxiety, which although common in certain care settings such as primary care, can often go undetected. PROMs have also been used to monitor individual changes, prompting discussion as to whether a given treatment is having the desired impact not only on symptoms, but also on broader quality of life concerns[20]. 'Measures' used in everyday clinical practice have quite different time constraints than those used in research or economic evaluation, and shorter forms of many PROMs have been developed to support this, often serving as a cue to discussion rather than a substitute.

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Supporting Person Centred Care Planning

The application of PROMs in promoting person-centred care planning serves first to facilitate communication and to identify individual priorities regarding quality of life. By eliciting such information, at a minimum the healthcare practitioner is better placed to formulate and monitor therapeutic plans. Such use may also serve to heighten the person's self awareness and is particularly important when discussions move from the clinical realm of controlling disease progression or managing the unwelcome impact of symptoms to consider the broader business of living as well as possible. This use of PROMs has also been found to improve communication, leading to a greater sense of being listened to and respected by the person and an enhanced care experience for the person and the practitioner.[20]

Enablers

Literature regarding the use of PROMs in this context identifies several enablers including:[20]

• Choice of instrument (favouring individualised measures)

• Conversational elicitation of information (as opposed to box ticking)

• Information being recorded in a format that fits with existing practices

• Ability to readily feed back to all parties throughout the decision making process

• An implementation approach that fosters local ownership

Barriers

While this use of PROMs has been shown to influence the extent to which wider quality of life outcomes are discussed and understood, success in changing clinical decision making processes and ongoing care management, or in improving outcomes, remains limited. The literature again offers important insights as to why retaining a focus on what matters to the person in the wider context of his or her life may prove more challenging in certain NHS settings. Recurring issues include:[20]

• Patient expectations: a reluctance to discuss or focus on broader quality of life issues with clinicians generally or with specific professions

• Conflicts with practitioner accountabilities and beliefs regarding 'the duty of care'

• The importance of evidence-based interventions and clinical governance

• A protracted decision making process (involving other clinicians)

Uses of Information

The primary use of information elicited this way is developing shared understandings and shaping care, with the ability to quantify quality of life changes generated as a by-product. However, the favouring of individualised instruments means that understanding the dimensions of quality of life identified by

any given patient population requires deeper thematic analysis. While this has been conducted within practice-based research[21] it proves less feasible in routine clinical practice or service delivery.

PROMs and Personal Outcomes

Applications of PROMs to promote person-centred care planning, whilst continuing to quantify 'quality of life', serve to identify what matters individuals in their own terms at the outset of engagement and to use this information not simply as a baseline against which to measure change, but as a foundation for negotiating appropriate care in support of the individual priorities and aspirations - personal outcomes.

The discussion has considered diverse applications of PROMs in healthcare including:

1. Strategic and policy decision making via the monitoring of population health

2. Evaluating the effectiveness of interventions in health service research

3. Routine applications in NHS service evaluation and performance management

4. Clinical decision making through the screening and monitoring of individuals

5. Shared decision making and support planning, starting with a focus on what matters to the person in the wider context of his or her life (personal outcomes)
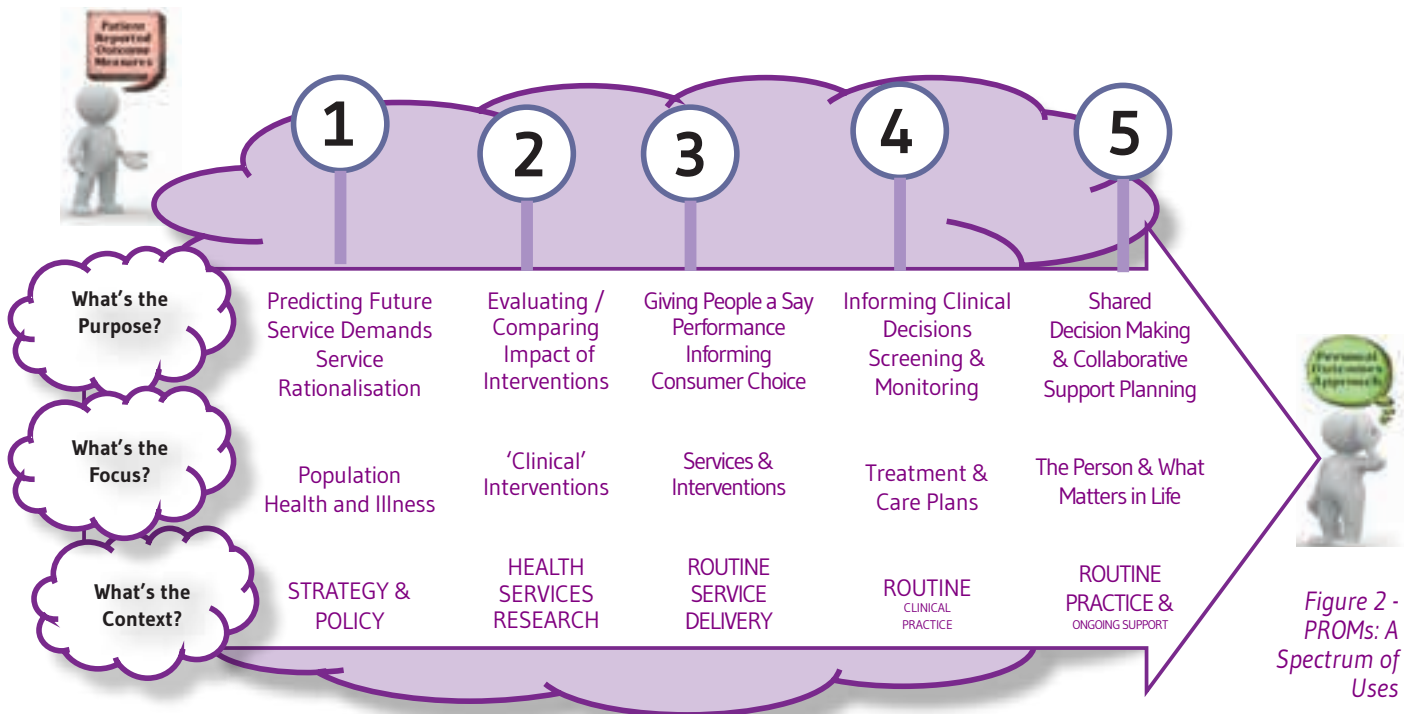

	1	2	3	4	5
What's the Purpose?	Predicting Future Service Demands Service Rationalisation	Evaluating / Comparing Impact of Interventions	Giving People a Say Performance Informing Consumer Choice	Informing Clinical Decisions Screening & Monitoring	Shared Decision Making & Collaborative Support Planning
What's the Focus?	Population Health and Illness	'Clinical' Interventions	Services & Interventions	Treatment & Care Plans	The Person & What Matters in Life
What's the Context?	STRATEGY & POLICY	HEALTH SERVICES RESEARCH	ROUTINE SERVICE DELIVERY	ROUTINE CLINICAL PRACTICE	ROUTINE PRACTICE & ONGOING SUPPORT

Figure 2 - PROMs: A Spectrum of Uses

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The next section considers the concept of 'personal outcomes' in more detail and their potential to support person-centred, enabling, preventive and integrative policy objectives.

It also considers recording, and the use of personal outcomes information at various levels of decision making, consistent with a personal outcomes approach.

Personal Outcomes

Figure 3 - The Personal Outcomes "Policy Daisy"[1]

The concept of personal outcomes is integral to the personalisation philosophy promoted in social care and now sits at the heart of the assessment, support planning and review processes employed within heath and social care partnerships across Scotland. A focus on personal outcomes helps to provide a common language and shared sense of purpose across services and disciplines, and also with people using services. Personal outcomes are therefore an important driver for the integration of health and social care and feature in a growing number of health and social care policies and strategies.

Research, policy and practice have all highlighted the value of practitioners engaging with individuals to identify the outcomes important to them in life, and recording and using this information not only for individual care and support planning, but also for the purposes of practice development, service delivery, improvement and evaluation, and service planning and commissioning[5].

Engagement, recording and **using information** are the 3 core elements of practice underpinning a personal outcomes approach. All 3 elements need to be brought together in a circuit if a personal outcomes approach is to succeed.[5]
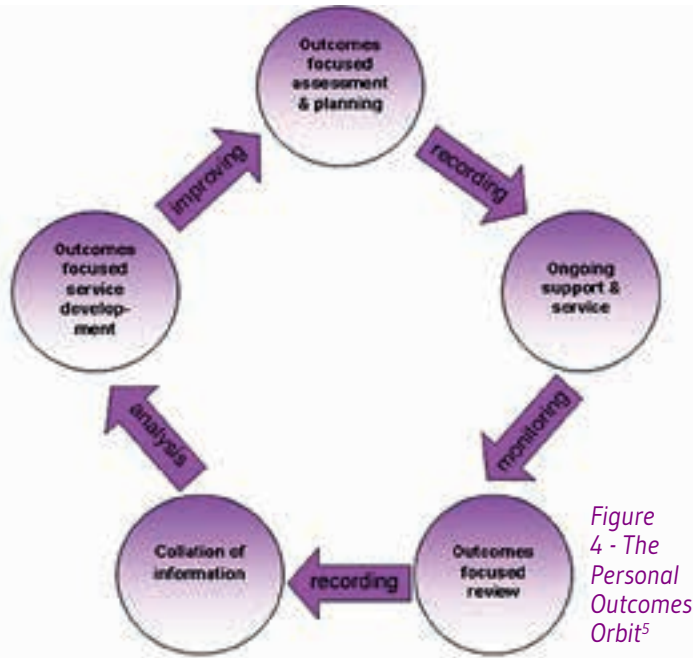
Figure 4 - The Personal Outcomes Orbit[5]

The Talking Points Personal Outcomes Approach

The personal outcomes approach that first inspired and has informed the Personal Outcomes and Quality Measures project is *Talking Points*, developed in Scotland by the Joint Improvement Team.

A full account of the *Talking Points Personal Outcomes Approach* is provided in the Practical Guide developed by Ailsa Cook and Emma Miller.[5]
Although developed in support of partnership working between health and social care in the community, many of the principles and practice issues addressed in the guide are relevant to outcomes based working across various service sectors.

The Talking Points Outcomes Framework

Central to the Talking Points Personal Outcomes Approach is an evidence-based framework that summarises the outcomes important to adults living in the community who use health and social care services. [*Outcomes Frameworks have also been developed for unpaid carers and for people living in care homes*]

The outcomes framework is founded on a strong evidence base, secured through focus groups and interviews, and comprising the views of people using health and social care services about the outcomes important to them in life and the impact that services had on outcomes. The framework sets out in very broad terms the categories of outcomes to emerge from this research, which fall into 3 main types[5]:

Process Outcomes are the outcomes that individuals experience through seeking, obtaining and using services and supports

Change Outcomes relate to the improvements in functioning and wellbeing that individuals are seeking from any particular service or support

Quality of Life Outcomes are the aspects of a person's whole life that they are working to achieve or maintain in partnership with services and other forms of support

Table 1- Outcomes Talking Points Outcomes Important to Adults Using Services[5]

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

The outcomes framework has been used in practice and research settings with thousands of people across a wide range of services. This experience has shown that the 15 outcome types it comprises are sufficiently high level to be able to capture most issues of importance to most people. However, specific additional outcomes may be relevant for inclusion by particular services and in particular care settings.[5]

Engagement: Good Outcomes Focused Conversations

An outcomes focused conversation can be a very important intervention in its own right. It provides an opportunity for meaningful engagement with a view to establishing the priorities of the individual and thoughtful consideration as to how they might be achieved. It is important to establish that having an outcomes focused conversation is not the same as goal setting. If conducted by a skilled practitioner, it can in itself have therapeutic benefits for the individual, drawing from assets-based and solutions-focused

approaches to achieve person-centred, enabling and preventive objectives. Given this potential, it is crucial that the quality of engagement is not compromised by service evaluation, organisational performance or various policy data collection demands. This risk is compounded by the different understandings of outcome at play.

Figure 5 - Talking Points Good Conversations[5]

Identifying Personal Outcomes

The starting point is clarifying outcomes. This may involve a process of negotiation around what's important to and also for the person. Solutions-focused approaches may be helpful in situations where people find it difficult to identify what's important to them, in some cases by first re-establishing a sense of hope and possibility. Importantly, the Taking Points outcomes framework can be helpful in focusing on both quality of life and change outcomes.

Change outcomes are usually time limited and commonly associated with recovery and rehabilitation, but can also be important in the supported self management of progressive or degenerative conditions, including the

development of increased confidence, morale and skills such as adaptive strategies and coping mechanisms.

Quality of life outcomes, although often neglected by traditional rehabilitative frameworks, are equally important. For older people or people living with progressive conditions, maintaining the things that give their life meaning and purpose is vital and can help to delay deterioration and dependency, and result in profound preventive effects.

'*Personal' outcomes* take the form of unique expressions that are meaningful to the individual and convey not only what is important to the person, but also why. For instance, the outcome type 'improved mobility' could find the following expressions in the lives of three people using different services:

Box 2: Personal Outcomes Process	
Mo, an older lady recovering from stroke	Being able to regain enough movement in my right hand and arm to hold and cuddle Chloe, my new grandchild
Alan, a dad of two who has Motor Neurone Disease	Finding support equipment that will allow me to fulfil my promise to Debbie to walk her down the aisle in June
Sheila, a young woman with a history of self-isolating behaviour	Being able to leave the house and use public transport to start getting out and about again - it would mean a lot if I could visit my friend Sharon, as she's not very well

Thinking about How Personal Outcomes Might be Achieved

Once outcomes are identified, the next stage is thinking how they might be achieved. This is conducted jointly, bringing together all perspectives. Crucially, this includes considering the role of the person and other people and resources in their lives, consistent with an enabling approach.[5] Solutions-focused approaches may also be helpful in supporting the person to recognise their own strengths, resilience and the different life skills that they already use or have drawn upon in the past, broadening possibilities and enhancing self-awareness.

Many quality of life outcomes often can only be achieved through partnership working between the individual, family, existing support networks, health, social care or other support services, affording significant integrating potential.[5] This is very different from service-led approaches or assessments solely concerned with determining practitioner inputs.

Focusing on Outcomes at Review

Revisiting outcomes during review first and foremost serves to ensure their continued relevance. It also enables progress made towards desired outcomes to be determined. Recognising that what matters to the person does not remain static, the outcomes framework can be used to identify any new outcomes, or to recognise any unexpected outcomes. The framework also

calls attention to process outcomes. While some in part are the result of the way that care is organised, most are relational in nature, thereby affirming the importance of supportive relationships in the provision of care and support.

Paying close attention to outcomes during assessment and review ensures that care and support are appropriate and effective. This is critical in avoiding patterns of service use that do not make the required difference to the person's wellbeing and life.[5]

Recording, Measuring and Using Outcomes Information: Possibilities and Practicalities

The primary purpose of recording is to ensure that the outcomes focussed conversation is reflected accurately and contains enough detail to be meaningful to all relevant parties without proving cumbersome for the practitioner to complete. However, the Talking Points outcomes framework can be used to support an element of outcome 'scoring' during (assessment and) review, enabling progress in achieving individual outcomes to be measured using numeric scales or Likert-style importance and / or improvement scales.

Scoring, if applied consistently, supports 'counting' of outcome types at team, service, organisation or partnership level, establishing which types of outcome are and are not being met for people.

Aggregating individual outcomes

Service level improvement & performance monitoring

Service planning & commissioning at organisational level

National thinking

Importantly, supporting text descriptions can be used to increase understanding of factors contributing to or impeding outcome attainment of outcomes, the key relationships between different outcome types, and learning from positive and negative exceptions. The approach can therefore inform service redesign and improvement, contribute to outcomes focussed planning and commissioning, and has the potential to inform national thinking.

While the Talking Points outcomes framework

offers strong *potential* to enable personal outcomes data to be collated and used at various levels of decision making, realising this potential is less straightforward. The most significant issue is deciding how to record personal outcomes data, notably the emphasis placed on capturing qualitative data or relying upon quantitative scoring mechanisms in a way that readily supports aggregation for reporting purposes.[5] Objections to the latter centre on a reluctance to interrupt the flow of the conversation, coupled with concerns that summary scores are overly reductive and cannot adequately capture crucial aspects of the person's life. The extent to which services are prepared to commit to qualitative data analysis is another factor influencing approaches to recording and, by implication, assessment and review processes.

The approaches used in practice can be located along a continuum[1]:

Recording, Measuring and Using Outcomes Information: The Appeal of Outcomes Tools

There is now a proliferation of outcomes recording and measurement tools across service sectors, with varying formats and content. Outcomes tools are sometimes designed with a very specific user group in mind, whilst others can be used more generally.[22]

While the outcome types or domains that the tools comprise vary, as most are based on evidence of what's important to people in their care encounters and in life, there is generally a good read across between tools. However, the Talking Points outcomes framework is somewhat unique in incorporating process outcomes, and also making the distinction between change and quality of life outcomes. As discussed, the latter is an important distinction in view of the growing policy emphasis on prevention and partnership working, while process outcomes reassert the
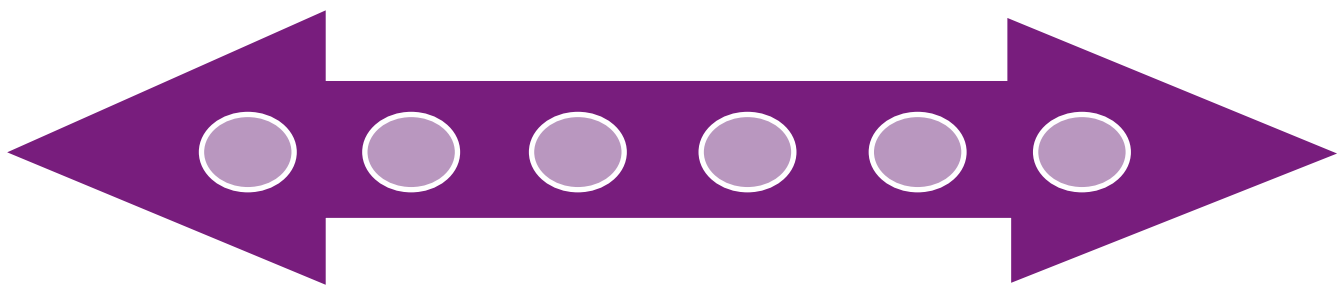
Form or Tool Lead   **Conversation Lead**

intrinsic value of collaborative ways of working and supportive relationships. This is crucial at a time when the emphasis placed on choice and shared decision making has sometimes resulted in care encounters being reduced to task oriented information exchanges, potentially undermining healthcare professionalism and eroding the qualities needed to deliver person centred care.[23]

Some organisations have reported benefits from designing their own outcomes tools, including creating an outcomes orientation during development and promoting ownership by staff. However, as any tool should serve simply to enable rather than replace or indeed undermine professional judgement, the effort expended developing a tool should be proportionate and should not detract from efforts to enhance the quality of engagement.[22]

Depending on the context, outcomes tools can be used to track and share outcomes visually with individuals. Using graphics such as stars, wheels and spiders webs may have intuitive appeal and be highly valued by some user groups, but where reliant on the use of concrete questions and tightly specified scales, can present challenges to people with cognitive or communication support needs. Choice of tool should be tailored to the context and reflect the priorities and expectations of the people who use the particular services and supports.[22]

The proliferation of tools is encouraging,

illustrating the attention afforded personal outcomes in various services and settings. However, particularly given the various demands for outcomes data, this can result in a tendency to try to short-circuit, or to use the tools with a primarily evaluative intent.

No matter how visually appealing and deceptively simple any given tool appears to be, unless the underlying philosophy and principles of a personal outcomes approach are firmly understood across the organisation, and the engagement is effective, there is significant risk of completely missing the point of outcomes focused working.

Reconciling PROMs and Personal Outcomes

This insight set out to consider two very different approaches to improving and measuring outcomes for people using health and social care services:

- The implementation of PROMs in routine service delivery to evaluate the impact of healthcare interventions and use this data to drive improvement, as set out in the Healthcare

Quality Strategy for NHS Scotland[11]

- The adoption of a Personal Outcomes Approach to enable people using services and supports to achieve the things that matter them, and to learn from these endeavours at service and organisational level, as practiced by health and social care partnerships across Scotland and numerous third sector providers

The differences between the two approaches are summarised in the table below:

	Impact Evaluation Approach	Personal Outcomes Approach
Driver	Accountability to health service users collectively	Responsiveness to people using services as individuals and collectively
Purpose	Evaluation – Quantifying the impact of a care intervention or service on health-related quality of life to support comparison and manage performance	Engagement and Evaluation – Informing person centred support planning and later reviewing relevance and assessing the impact of support for individuals and collectively
Central Concern	The care intervention or service - does it make a difference? Is it worthwhile?	People using services - are we enabling them to achieve their priorities in life? How?
Understanding of Outcomes	The end results or impacts of services or activities for (and as reported by) the people who use them on perceived health-related quality of life (as defined by 'us')	'What matters' to people using services – what they hope to achieve (as defined by them) - and the impact of services and activities on people's lives (as reported by them)
Outcome Types of Interest	Emphasis on time-limited Change outcomes - the difference made to aspects of quality of life related to a given health condition; Excludes Process outcomes purposefully	Change, Maintenance / Quality of life and Process outcomes all valued - consistent with a preventive focus and recognising the intrinsic value of relationships in care encounters

	Impact Evaluation Approach	Personal Outcomes Approach
Approach to Gathering Outcomes Data	Providing opportunities for people to comment systematically on the impact of a care intervention, by capturing 'before and after scores' for pre-determined factors	Conversational and relationship-based elicitation of individual priorities, which are recorded in support plans and subsequently reviewed to ensure relevance and 'assess' progress
Approach to Outcomes Measurement	Measured in quantifiable terms using numeric scales, using standardised generic and / or condition-specific questionnaires	Measured in quantifiable terms using context-appropriate 'scales' and in qualitative terms to reflect context and support interpretation
Measurement Properties of Interest	Psychometric properties are key Validity: Reliability and Responsiveness	Emphasis on Content and Face Validity: meaningfulness – does it pass the 'mirror test'
User Perspective Reflected in Measures	A spectrum of measures exists but to support comparison, favours measures comprising externally defined generic domains plus condition-specific measures which *should* comprise evidence-based domains reflecting collective user priorities (but not always the case)	What matters to the person is the starting point; Only relevant and specific outcome instances (personal outcomes) are recorded for each individual Underpinning outcomes frameworks comprise evidence-based domains important to people using services;
Underpinning Assumptions: Impact Attribution	Impact can be attributed to a given service or intervention - if appropriate controls are adopted to exclude other actors [Response shifts and adaptation discounted]	Many outcomes can only be achieved by different agencies working together with the person and family – concept of contribution more useful, offering integrative potential
Enablement / Assets Focus	The contribution of the person in achieving outcomes is viewed as a 'confounding variable' to be controlled	The contribution of the person in achieving outcomes is encouraged and recognised - effective power is as important as 'choice'
Person Centredness	Giving people the opportunity to complete questionnaires ensures that the collective 'user voice' is incorporated in service level and strategic decision making	Instruments must accurately reflect the collective 'user voice' during their development and validation AND care approaches must access and prioritise the views of the individual

As with all summary characterisations of different practices, the above table has a number of limitations and does not reflect the different nuances encountered in the real world. The two columns do not represent mutually exclusive categories with no middle ground.[17]As the previous discussions have highlighted, in reality the distinctions are less clear cut, with compromises required in order to transcend different levels and forms of decision making.

On the one hand, PROMs have found applications in person centred care planning. Attempts to take PROMs developed for applications at intervention or population level and use them in individual care planning encounters have proved problematic. This has given rise to a new breed of 'individualised PROM,' the adoption of more conversational methods of outcome elicitation, and close attention to recording practices.

On the other hand, the appeal of using personal outcomes information to inform higher levels of decision making has, in some cases, resulted in heavily forms-led or tools-driven approaches to assessment, support planning and review being imposed, compromising the quality of engagement and introducing evaluative undercurrents or overtones.

The ultimate conclusion, that it is principles, intent and practice rather than the choice of measurement instrument that matters, is not new. However, this insight illustrates that there is important mutual learning to be gained from the practical application of PROMs and Personal Outcomes Approaches in different settings, reaffirming the importance of context.

Reconciling PROMs and Personal Outcomes - The "i-ROC" Example

One practical example of the mutual learning to be gained from the application of PROMs and Personal Outcomes Approaches is illustrated by the approach taken by Penumbra, a Scottish mental health charity. The approach combines the use of a PROM in informing and shaping care planning with the core elements of a Personal Outcomes Approach.
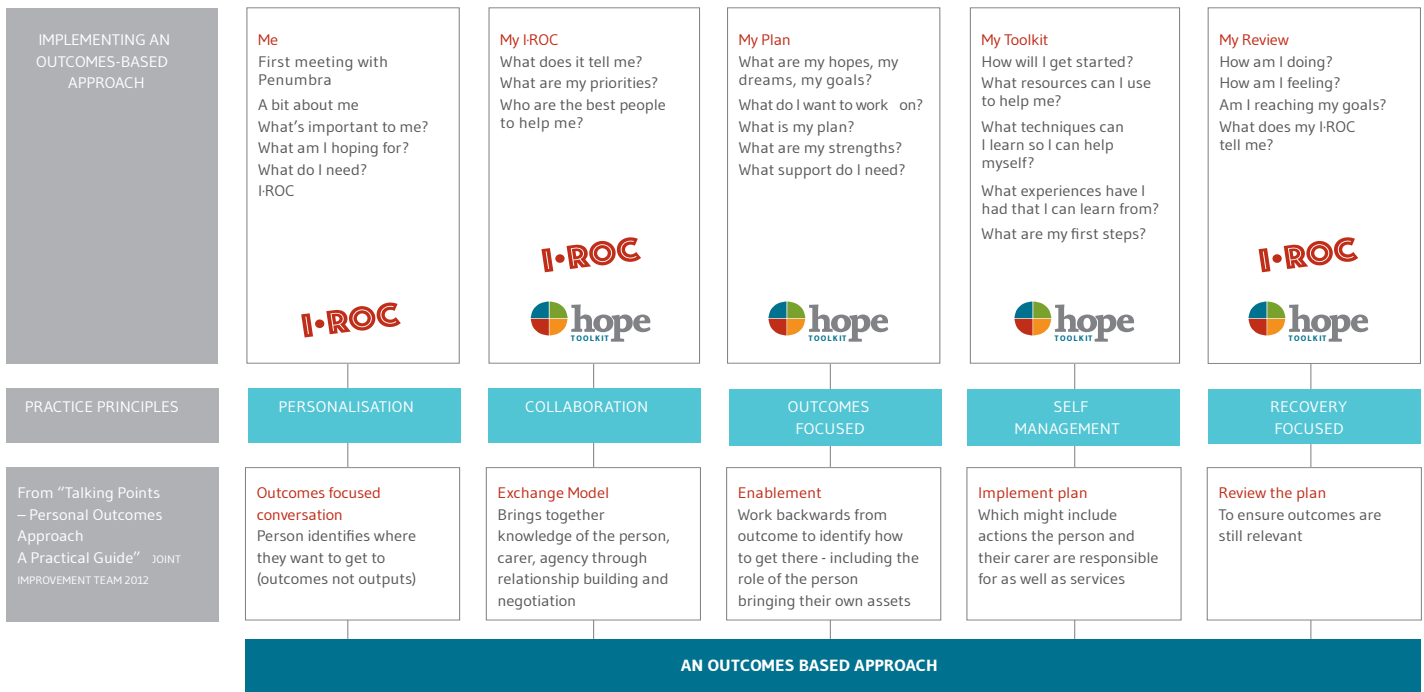
The PROM is embedded in an online graphical tool call "i-ROC" - the individual recovery outcomes counter, which has been developed by Penumbra over a number of years. "i-ROC" is part of Penumbra's HOPE toolkit (Home, Opportunity, People and Empowerment). This was developed to enhance staff-user relationships and to improve the effectiveness and meaningfulness of support according to 5 practice principles: Personalisation, Collaboration, Outcomes Focused, Self Management and Recovery Focused.[24]

As discussed previously, a growing number of outcome measurement tools now exist, which are available under different conditions of use and licensing arrangements. The purpose here is not to promote the "i-ROC" tool over and above other measures, but rather to illustrate how it is used within an overall personal outcomes approach that is consistent with the 5 step approach to Good Conversations set out in the *Talking Points Personal Outcomes Approach Practical Guide.*

It should also be emphasised that person centred and outcomes focused principles and practices were already firmly established within the organisation and the tool has emerged from practice, rather than shaping it. "i-ROC" is not a substitute for skilled engagement or a more creative and enabling approach to support planning, but simply a precursor.

Typically in personal outcomes applications, summary outcomes scoring would happen after or in some cases during the outcomes focused assessment and review conversations. However, in Penumbra the "i-ROC" questionnaire is administered through a facilitated self-assessment at the very start of the engagement.

IMPLEMENTING AN OUTCOMES-BASED APPROACH	Me	My I·ROC	My Plan	My Toolkit	My Review
	First meeting with Penumbra	What does it tell me?	What are my hopes, my dreams, my goals?	How will I get started?	How am I doing?
	A bit about me	What are my priorities?	What do I want to work on?	What resources can I use to help me?	How am I feeling?
	What's important to me?	Who are the best people to help me?	What is my plan?	What techniques can I learn so I can help myself?	Am I reaching my goals?
	What am I hoping for?		What are my strengths?		What does my I·ROC tell me?
	What do I need?		What support do I need?	What experiences have I had that I can learn from?	
	I·ROC			What are my first steps?	
	I·ROC	I·ROC hope TOOLKIT	hope TOOLKIT	hope TOOLKIT	I·ROC hope TOOLKIT
PRACTICE PRINCIPLES	**PERSONALISATION**	**COLLABORATION**	**OUTCOMES FOCUSED**	**SELF MANAGEMENT**	**RECOVERY FOCUSED**
From "Talking Points – Personal Outcomes Approach A Practical Guide" JOINT IMPROVEMENT TEAM 2012	Outcomes focused conversation Person identifies where they want to get to (outcomes not outputs)	Exchange Model Brings together knowledge of the person, carer, agency through relationship building and negotiation	Enablement Work backwards from outcome to identify how to get there - including the role of the person bringing their own assets	Implement plan Which might include actions the person and their carer are responsible for as well as services	Review the plan To ensure outcomes are still relevant

AN OUTCOMES BASED APPROACH

The "i-ROC" uses a numeric 1-6 Likert scale for each indicator question spanning 12 outcome domains or life areas. While the use of numeric scales can disrupt a conversational flow, it does permit a score to be calculated for each indicator and presented as a spidergram.[24]

This provides the individual with a visual representation of the areas of comparative strength within their life and areas where support is needed.

The spidergram then enables a more focussed conversation to take place separately to articulate the things the person would like to change and maintain (their personal outcomes) within their self-prioritised life areas. It can also be used to track individual progress over time.

This visual representation is valued by service users and is repeated on a quarterly basis as part of ongoing support.

While the example spidergram opposite depicts improvements in all life domains, for individuals whose mental health is likely to fluctuate quite significantly, it can also serve as an important record of previous wellness, providing vital hope for the future at times when the person feels most lost to their illness.

One of the main challenges encountered when recording personal outcomes data is ensuring that the use of summary scoring or tick boxes does not undermine the conversation about what's important to the person. Here the issue is addressed by having two separate meetings.

This separation of concerns, while not unusual in mental health services[23] would not be practicable in every care context, nor would the very explicit approach to outcomes measurement. One potential disadvantage is that the person has narrowed down the life areas to be discussed in the second meeting, without having had the opportunity for a fuller discussion around all life domains, including their strengths and capabilities. However, for some people, focusing on one or two things at a time may be more manageable. It also affords the advantage of total transparency and individual ownership of the scoring process, which is critical in the context of mental health.

The indicator scoring approach also supports 'counting' at service and organisational level. Importantly measuring relative improvement rather than attaching artificial significance to the numerical scores themselves. This, coupled with the use of supporting text comments, informs service planning and development and provides evidence of service impact to commissioners and funders.

It therefore represents a very practical illustration of one way in which PROMs and Personal Outcomes can be blended.

Example Spidergram

Once completed, service users' I-ROC scores are displayed on a spidergram. This can be used to track changes over time.

Towards a Comprehensive Set of Outcome Measures in the NHS

Healthcare quality outcome measurement frameworks favour quantitative measurement practices. PROMs are consistent with this ethos and are an important means of assessing the effectiveness of different tightly defined interventions and determining which have the greatest impact on particular pre-defined aspects of people's health-related quality of life.

However, a comprehensive set of outcome measures for people using services should ensure that care is not only safe and effective, but also person centred, supporting shared decision making and respecting what matters to each person in the context of his or her life, rather than through the filter of services or conditions.[2] Notwithstanding the different understandings of 'person centred care' that exist, including those that reflect a service orientation that responds to collective feedback from people who use services, the use of measures that are deficit based and that fail to reflect the priorities of people who access care is increasingly less tenable. Criteria have been offered to assess the fitness for purpose of PROMs in support of such collective endeavours, and approaches to retrospective and more arms-length service evaluations that remain consistent with the ethos of outcomes focused working are considered in the 5th Insight in this series.

Beyond such service oriented applications, there are other understandings of person centred care that are more consistent with the philosophies of personalisation and individual level co-production. This calls into further question the comprehensiveness of the set of outcome measures within current healthcare frameworks for the following reasons:

- Quality of life is a highly individualised and dynamic concept, making standardisation problematic.

- Communication between individuals and the service should prioritise the things that matter to the person[5]

- Being involved in defining and agreeing the outcomes they want to achieve, rather than simply rating the current level of attainment for pre-determined outcomes, is empowering for people, enhances the relevance of care and support, reconnects staff with core values, and can also result in improved outcomes[5]

- Where the focus is too firmly on evaluating the impact of a particular intervention, there is a risk of focusing exclusively on 'changes', overlooking the importance of 'quality of life' or 'maintenance' outcomes. The latter have been found to be crucial in the context of preventive

work, delaying deterioration, offsetting dependency and enhancing recovery through continuity.

- Where the focus is too firmly on evaluating the impact of a particular intervention or service, there is also a risk of underplaying the role of the individual and existing natural support systems in 'co-producing' the desired outcomes.[5]

- As healthcare is increasingly concerned with supporting people with long term conditions to lead full and active lives, and much of this care is provided by people themselves and their existing supports, ideally outcome measures should reflect this.

- A comprehensive set of outcome measures should also underpin the outcomes for the Integration of Adult Health and Social Care and a personal outcomes approach has strong integrative potential.

> The adoption of a personal outcomes approach has the potential to address these shortcomings.

Translating a Personal Outcomes Approach in Diverse NHS Settings

A Personal Outcomes Approach is now widely used by health and social care partnerships across Scotland, but to date adoption in health-led services in community settings has been more limited.[1] The continued promotion of Talking Points as an 'evaluation tool' (a throw back to its original incarnation as the UDSET: User Defined Service Evaluation Toolkit) has meant that a focus on 'outcomes' has often been introduced with a purely evaluative intent. In other cases, rapid implementation has amounted to little more than established ways of working being rephrased in the language of outcomes. The concept of 'personal outcomes' is virtually unheard of in more mainstream and bio-medically oriented NHS services, where clinical outcomes measures and PROMs are more familiar.

The limited uptake in healthcare settings was recognised in the 2012 Review of the Talking Points Personal Outcomes Approach.[1] It was attributed, in part, to the somewhat different interpretation of outcomes that is prevalent in health. However, the review also recognised that a future of health and social integration means that such disparities must be reconciled.

There are some indications that this reconciliation is happening. The *National Delivery Plan for Allied Healthcare Professions in Scotland (2012-2015)*[25] suggests that the integration of health and social care will drive increasing cross-fertilisation of ideas and approaches, making explicit reference to the 'personalisation' philosophy promoted in social care, the focus on personal outcomes, and its alignment with the ethos of Allied Health Professions.

Facilitating personal outcomes requires more than a different understanding however. A Personal Outcomes Approach demands a significant shift in the way that data are managed, analysed and understood. It also necessitates a departure from consistency, standardisation and compliance to embrace flexibility and responsiveness using case by

case judgement and authentic motivation. That will be challenging within NHS settings where managerialist approaches to service delivery, clinical governance and evidence-based practice are the cornerstones of quality, and it may be premature or even inappropriate in some settings.

A focus on personal outcomes is consistent with the shift from narrow professionally-led agendas towards shared agendas that accommodate individual values and aspirations. The possibility that healthcare professionals might be required to support the achievement of outcomes in other domains presents a number of new challenges, not least the issue of *how far* the focus should be on supporting broader and more personalised quality of life concerns.[17]

The *Talking Points Practical Guide* is purposefully generic and non-prescriptive to facilitate

widespread applications. It's recognised that what counts as the purpose a *Personal Outcomes Approach* will vary by context, presenting different possibilities and issues for each of the core elements: **engaging, recording** and **using information**. How the different elements should be interpreted and applied will depend very much on the peculiarities of the care setting.

> There is a need to understand what the different possibilities and issues are and to translate the approach accordingly. The Personal Outcomes and Quality Measures project has begun this process of translation in a small number of healthcare settings. The results are described in 2nd and 3rd Insights in this **"we've got to talk about outcomes"** series.

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