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We've Got To Talk About Outcomes

Talking the Same Language:

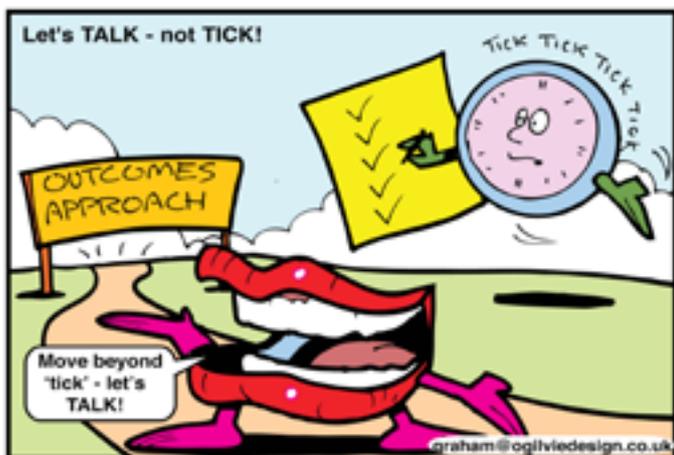
Translating a Personal Outcomes
Approach into Support for Self
Management

**The Personal Outcomes
& Quality Measures Project**

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 years². 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

About this Insight

This insight considers the reporting and use of personal outcomes information in the context of *Support for Self Management*.

Despite key similarities between the principles that underpin engagement practices in *Support for Self Management* and those advocated within a *Personal Outcomes Approach*, the two often differ in the use made of individual care plan data. The report therefore looks at the various possibilities, and considers the care contexts and levels of decision making where the different applications may be more or less relevant.

The report then turns to the *Talking Points Outcomes Framework*, which comprises the high level categories of outcome that have been found to be important to people living in the community who use care services. It is this evidence-based framework that supports the organisation, management and various

uses of outcomes data. The report describes Project work to investigate the applicability of the *framework* for people living with long term conditions who are being supported to self manage. It examines the specific forms the outcomes take within one service supporting people who have complex and progressive conditions to self manage, describing the development and application of a set of service-specific outcomes 'prompts' in the language used in the local practice setting.



“You know, the terminology can be so confusing for staff and it keeps changing. We are jargoned out - self management, outcomes focused, solutions focused, assets based - when really it is all very simple and they all fit together with the person in the centre”.

Advanced Nurse Practitioner

Key Points

- A number of similarities were found between the engagement practices used within a selection of Support for Self Management scenarios and those advocated within a Personal Outcomes Approach.
- Certain measures used within the Support for Self Management scenarios may have transferable appeal within outcomes focused working more broadly, notably the complementary use of the CARE Measure.
- In contexts where a broader and more integrated approach to improving wellbeing is supported:
 - Continued use of measures that are based on narrow understandings of health related quality of life and that neglect the circumstances of people's lives is questionable
 - The inclusion of information derived from outcomes focused support planning in service improvement and strategic decision making holds significant potential
- The applicability of the Talking Points Outcomes Framework for people who use services has been confirmed in the context of Support for Self Management:
 - A clear rationale for addressing outcomes important to people who use services and outcomes important to people being supported to self manage within a common framework has emerged
 - Very few additional high level outcomes types were required but the unpacking of the outcomes types into more context specific expressions or 'prompts' proved helpful
 - The 'prompts' may find wider applications, either directly in similar settings or by prompting reflection about the applicability of the high level outcome types across diverse care contexts
 - The use of locally meaningful language is particularly important at a time when many practitioners report being overwhelmed by the terminology at the heart of current policy directives

Introduction

The concept of 'personal outcomes' or 'what matters to the person' features in a growing number of health and social care policies. It is integral to the 'personalisation' philosophy at the heart of social care and a key driver for the integration of health and social care.

The Joint Improvement Team's 'Talking Points' Programme³ has provided a clear focus for activity around outcomes in Scotland and is grounded in the evidence as to which outcomes matter to people using health and social care services and their carers. Over the past six years it has developed what has come to be known as the *Talking Points Personal Outcomes Approach*

A Personal Outcomes Approach is now used within health and social care partnerships across Scotland, but to date its adoption remains limited within health-led or NHS settings. This was



identified in the 2012 Review of the Talking Points Personal Outcomes Approach¹ and attributed in part to the different interpretation of 'outcomes' that is prevalent in health.

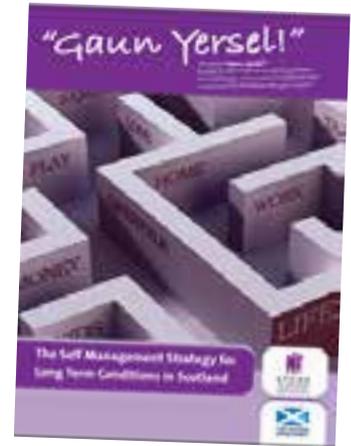
However, while the term 'personal outcomes' is not widely used within health, there are many scenarios where healthcare practitioners are working collaboratively with people living with long term conditions to support them to live full and positive lives according to their own values and aspirations. This is particularly the case where people are being supported to self manage.

There has been increasing emphasis on supporting people living with long term conditions to self manage in recent years.⁴⁻⁵ The Health and Social Care Alliance Scotland (formerly LTCAS) has played a leading role both in developing the *Self Management Strategy for Long Term Conditions in Scotland*⁴ and supporting its implementation.

This has ensured that efforts remain grounded in what matters to people with long term conditions in the context of their everyday lives, with broader understandings of 'Support for Self Management' and a greater diversity of approaches emerging as a result.

'Support for Self Management' and a 'Personal Outcomes Approach' are both responses to the realisation that health and social care as currently provided are not sustainable. They reflect a desire to work with and empower

people to live well and as fully as they can in relationship with each other in community settings, not simply for reasons of effectiveness, but because this is essential if care and support is to be legitimate and properly respectful of people, consistent with the principles of a human rights based approach.⁶



The *Talking Points Personal Outcomes Approach: Practical Guide*³ is purposefully generic to facilitate widespread applications. Precisely what it means to implement a Personal Outcomes Approach will vary by context, with different implications for each of the core practice elements: **engaging**, **recording** and **using outcomes information**. Some translation will be needed.

This 3rd insight begins this process of translation into *Support for Self Management*, establishing similarities and departures in terminology, assumptions and approach.

As a more integrated and multi-dimensional approach to wellbeing than we have had in the past is emerging, it is important that such commonalities and differences are understood and opportunities for mutual learning identified.

Personal Outcomes and a Personal Outcomes Approach

The Talking Points Personal Outcomes Approach

A full account of the *Talking Points Personal Outcomes Approach* is provided in the Practical Guide developed by Ailsa Cook and Emma Miller.³ What follows is a brief summary of the core components.

Central to the Approach is an evidence-based framework that summarises the types of 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 framework is founded on a strong evidence base, secured through extensive focus groups and interviews, and comprising the views of people about the outcomes important to them in life and the impact of health and social care services on outcomes.³

The 3 core practice elements underpinning a Personal Outcomes Approach are **engagement**, **recording** and **using outcomes information**. All 3 elements need to be brought together if a Personal Outcomes Approach is to succeed.³

Engagement: 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 in the context of his or her whole life, and thoughtful consideration and negotiation as to how they might be achieved.³

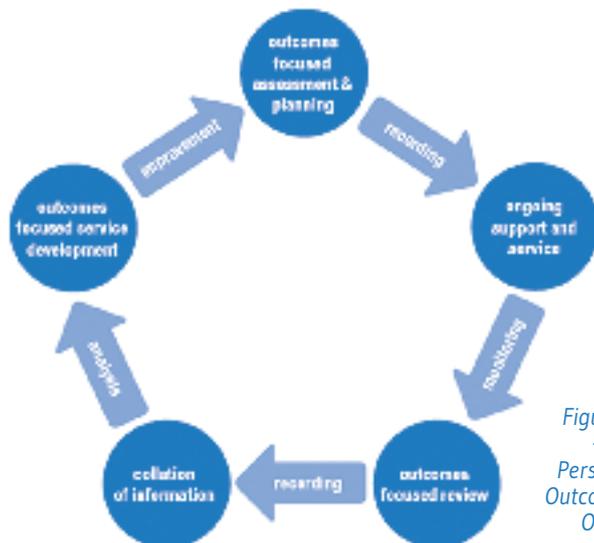


Figure 1 - The Personal Outcomes Orbit³

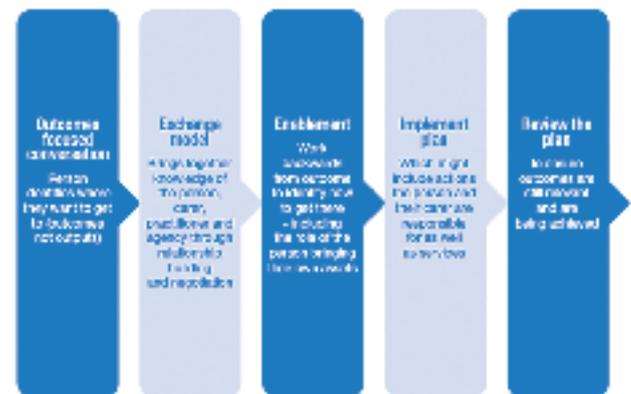


Figure 2 - Talking Points: Good Conversations³

The engagement model is consistent with a broader understanding of shared decision making, based upon making connections, building relationships and trust. If conducted by a skilled practitioner, it can in itself have therapeutic benefits for the individual,

drawing upon and developing the person's own hopes, capabilities and strengths to achieve person-centred, enabling and preventative objectives. Done well, this approach not only means that support is more relevant, but also paves the way for more innovative solutions, involving the person and their existing social support networks in achieving personal outcomes, alongside services and supports as appropriate.³

The subsequent review is an opportunity to reflect on progress towards outcomes, what has worked well and less well, and why, to confirm the continued relevance of support or to identify any required changes. Continuity of care in both informational and relational terms is critical.

Recording

The outcomes focussed conversation is recorded as a text account in a language that is meaningful to the person. It should reflect the conversation accurately and contain just enough detail to be useful to all relevant parties without proving cumbersome for the practitioner to complete. In addition, the Talking Points Outcomes Framework can also support an element of 'scoring' using either numeric scales or importance / improvement ratings for each of the high level outcome categories.

Using Outcomes Information

The primary use of the outcomes information is to facilitate implementation, monitoring and review of the individual support plan and to assess progress made towards achieving personal outcomes. However scoring, if applied consistently, also supports outcomes counting at service or organisational level, establishing the extent to which the different outcome types are being progressed, and which are proving most and least problematic.

Importantly, the text descriptions can be used to determine whether or not people are being supported to achieve the outcomes that they want from the service or intervention (as opposed to outcomes set out in standardised measures). Text analysis can also increase understanding of different factors contributing to or impeding the attainment of outcomes, including aspects of the service or intervention, individual and local factors. They can also help to identify relationships between different outcome types, and facilitate learning from positive and negative exceptions.



Figure 3
- Using
Outcomes
Information

Collectively, outcomes information can build a picture of the issues people face, the types of services and supports people want to access, and the sorts of outcomes that are proving least and most challenging to progress for different people.

The Approach can therefore inform service redesign and improvement, contribute to outcomes focussed planning and commissioning, and provide explanatory insights into the outcomes scores collected for evaluation and performance monitoring purposes. It also has the potential to inform national thinking by

revealing the characteristics that high performing organisations share.³

A Personal Outcomes Approach and Support for Self Management

The Personal Outcomes and Quality Measures project set out to determine whether and how a Personal Outcomes Approach can be embedded within different healthcare services supporting people living with one or more long term conditions.

The 2nd insight in this series reported efforts to introduce a Personal Outcomes Approach into different healthcare settings, highlighting the

possibilities and challenges.

However, it was also recognised that collaborative work is already taking place in a number of healthcare settings to support people to live well with long term conditions according to their own values and aspirations, but without using the language of 'personal outcomes'. A parallel strand of Project work therefore investigated existing approaches to engagement, recording, and use of information for a number of scenarios, each with a focus on Support for Self Management. This 3rd insight report first summarises key developments in Support for Self Management in recent years, before describing the Project findings for each scenario in turn.

Developments in Support for Self Management

Self Management and the Need for Support

'Self management' is not a new concept. People with long term conditions have always taken steps to manage the impacts on their lives and to live well using whatever capabilities and resources they have. However, living with a condition can have a devastating effect on an individual, impacting upon social, economic, psychological, physical, cognitive and cultural aspects of life.⁴ People cannot be expected to manage without some level of support. **The key**

issue is how well people manage and how well services support them in this.⁷

Approaches to Supporting Self Management

The support that people living with long term conditions require varies enormously and can be located on a continuum from very little to 24 hours each day. The levels of support needed may also change significantly over time.

Support for self management depends upon care professionals embracing a person centred and empowering approach in which the individual is the leading partner in managing his or her own life and condition(s). The role of health and social care professionals and services is to support the person's journey towards living well in the presence or absence of symptoms.⁴

The support for self management provided within the NHS has traditionally taken the form of group or sometimes individual programs centred on education, goal setting and coaching. However, while hugely beneficial for some people, stand alone programs don't suit everyone. There are a number of factors influencing uptake, including practical concerns about travelling, sitting for prolonged periods of time, or difficulties attending at a preset time due to fluctuations in health or work commitments. There are also limited entry points into these programs.⁸ A further limitation is that people at greatest risk of serious decline in health are often unlikely to take part and there is therefore a concern that they may actually exacerbate health inequalities.⁸

Support for self management cannot be one dimensional: It is important that support for self management is not targeted toward those with high capacity to meet an ideal of self management that focuses on self initiation of healthcare, or a set of health behaviour targets.⁸ Support for self management can include recovery of self respect, emotional wellbeing,

spirit or independence.⁴ Moreover, a range of inequality issues play a part in influencing people's abilities to cope with the impacts of illness. It is critical that the self management agenda takes account of structural issues which can exclude people and makes provision for the support needed to overcome these barriers.⁴

The vital roles played by the third sector, community groups and peer support networks in supporting self management have increasingly been recognised. Often deeply embedded in local communities, these forms of support may be able to provide more tailor-made solutions and to reach out to people from deprived or other marginalised groups.⁹

There is no one way of providing support for self management: it has evolved to include a range of approaches provided by health, social care and third sector services, and there are increasing calls for its integration into routine service provision across the whole system.⁵

"Self management is the successful outcome of the person and all appropriate individuals and services working together to support him or her to deal with the very real implications of living the rest of life with one or more long term conditions".

'Gauk Yersel':

The Long Term Conditions Self Management Strategy for Scotland⁴

Developments in Support for Self Management: Selected Scenarios

Support for Self Management Using Psychological Approaches

Overview

Preparation for life and for self-management of a long term condition often requires inputs to support people to live with the knowledge that the condition will not get better. Many approaches to supporting self management therefore incorporate psychological models and techniques to varying degrees. The scenario described below however considers the application of a psychological approach in isolation to more fully understand its contribution.

A range of psychological approaches exist, each with different emphases and purposes, based on assumptions about the relationship between complaints and psychological wellbeing.¹⁰ There is a growing consensus that certain types of complaint have to be lived with, and treating them as either a problem to be solved, or an experience purely to be avoided, may constitute a problem in itself.¹⁰ A recent advancement in psychological therapies is the promotion of approaches that are flexible and focused on the present moment.¹¹ One example of this is mindfulness-based stress reduction. Another is acceptance and commitment therapy (ACT).

Acceptance and Commitment Therapy (ACT): Purpose and Principles

ACT is an evidence-oriented development of the cognitive behavioural tradition. Although ACT has been most extensively developed for adult mental health problems, it is highly applicable in management of long term physical conditions, particularly those that are chronic, hard to diagnose or treat medically, and where the impacts of the condition are distressing and disabling in that they can stop people from feeling and doing the things that they value.¹²

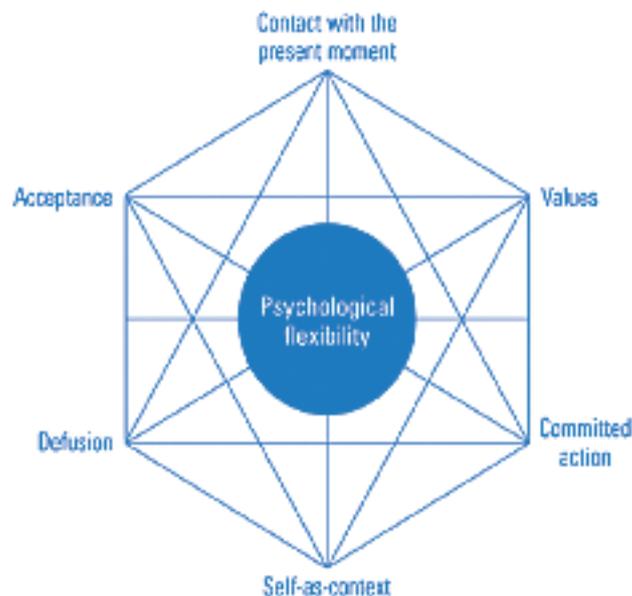


Figure 4- The ACT Hexaflex¹⁰

The role of ACT is to help individuals to identify what they value in their lives and to help them pursue this effectively.¹³ The process starts with the identification or clarification of values, which can draw upon a range of tools such as the *Valued Living Questionnaire* or *Life Purpose Statement Builder*.¹⁴ ACT recognises both values and goals as important, but serving different purposes. Values are likened to a compass bearing. The advantage of clarifying values is that whereas goals can be far off in the future, and at times a source of preoccupation or frustration, acting on values, including small actions, gives life meaning and purpose in the present. Goals in turn are values-based, and very carefully specified, seeing symptomatic control, such as an improvement in mood, very much as a secondary concern.¹⁴

Identifying and Recording 'Outcomes': Setting Values-Based Goals

The identification and recording of values-based goals follows a 3 step process:

1. Identify the domain of life to work on
2. Identify the values underlying goals in this domain of life
3. Set values-based goals for the immediate, short term, medium term and longer term

The generic life domains are: work, education, leisure / recreation, health / physical self-care, friends / social life, parenting, intimate partner, family, community life / environment and spirituality / personal growth.

Goals are set using SMART principles, but

interestingly according to a variant of the acronym [Specific, *Meaningful*, *Adaptive*, Realistic and Time-framed].¹⁴ The use of 'meaningful' rather than the customary 'measurable' and 'adaptive' rather than 'achievable' is particularly noteworthy, underscoring the significance the approach attaches to the alignment of goals with what matters to the person in life, rather focusing heavily on their attainment.

Use of Information

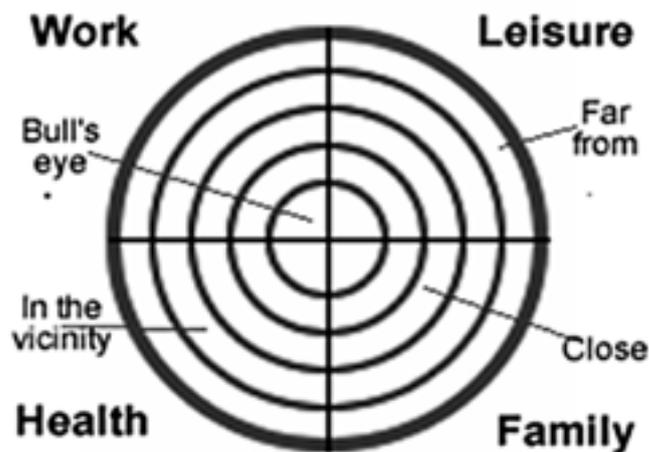


Figure 5 - The ACT Bull's Eye¹⁴

At an individual level, 'success' is assessed in terms of the realisation of values-based goals, and progress made towards valued living more generally. Sometimes progress is charted visually using simple scoring mechanisms such as the 'bull's eye'. However this is not intended to be a measure that the person judges himself against, but rather helps to move on in a valued direction.

At intervention level, the level of attainment of individual goals can be aggregated, but such measures are usually augmented by validated outcome measures of wellbeing to demonstrate effectiveness, together with feedback reports on the experience of the consultation itself. Qualitative accounts may also be gathered.

ACT and a Personal Outcomes Approach: Similarities and Differences

Engagement: The identification of life domains, values and values-based goals within ACT is similar in many respects to the identification of personal outcomes within a personal outcomes approach. Both take a person-centred, holistic and values-based approach, starting with understanding what matters to the person in a whole life context, and why it matters, and then thinking of ways of working towards this. However, when thinking of actions to be taken, the sorts of barriers that ACT is intended to overcome are primarily cognitive and within the control of the individual. The approach is explicit about differentiating between the types of issues that cannot be 'fixed' and where it would be beneficial for the person to accept and commit to living with them, and issues where a very different approach is necessary. In addition, while it is increasingly recognised that a focus on personal outcomes can have therapeutic value, in ACT the therapeutic benefit is very much expected.

Recording: The concept of the 'outcomes focused assessment and support planning' emerged from contexts where different services and supports have traditionally been required to facilitate the achievement of outcomes, and where the support plan set out the contribution of all parties. However, in ACT the consultation IS the intervention. The resultant 'willingness and action plan' is very much the responsibility of the individual and the recorded values, priorities and goals are for the individual's own use.

Use of Information: While ACT is concerned with establishing whether or not values-based goals are realised, the actual content of the goals or the life domains they relate to are not especially relevant. As above, the individual assumes sole responsibility for progressing outcomes. Service improvement and planning questions such as which types or aspects of services contribute to which types of outcomes, or which types of outcomes are proving problematic to achieve due to lack of appropriate forms of support therefore do not arise. Questions of effectiveness are confined to the 'performance' of the individual and the therapist. The use of standardised outcome measures (improvements in wellbeing) is complemented by evidence that people are setting and making progress towards realising their values-based goals. Qualitative accounts can also provide deeper explanatory insights.

Embedding Support for Self Management in Primary Care Planning

Overview

There have been calls for support for self management to be embedded in routine care, particularly within primary care.⁵ This is again an area where a number of important developments are taking place, including an increased emphasis on emotional and psychological support, and an increase in 'social prescribing' to connect people with community resources to progress outcomes associated with valued living more broadly. A major challenge is the limited time available for routine primary care consultations, and quite diverse approaches are being trialled to counter this.

The Personal Outcomes and Quality Measures Project had the opportunity to connect with and learn from two very different approaches that have been developed and tested in primary care:

The first takes the form of a clinical trial currently underway to establish the efficacy of the 'Care Plus' intervention for people with multiple health conditions living in areas of high deprivation in Scotland. This scenario integrates techniques drawn from mindfulness-based stress reduction, which is from the same stable as ACT described above, into primary care consultations. The consultations adopt a 'bio-psycho-social approach' which, critically in areas of deprivation, afford due attention to social and material circumstances, as well as biomedical and psychological factors. The intervention also makes some provision for connecting people with existing community services and resources.

The second is an approach to care planning

in primary care developed by the Year of Care Programme in support of people with diabetes, and that is now being taken forward by the Year of Care Partnerships, hosted by Northumbria Foundation Healthcare. This approach is also grounded in tackling health inequalities, but with a much firmer emphasis on the role of community based services in supporting marginalised groups. This focus is addressed through a whole systems approach centred on connecting individual support needs with macro level commissioning. Despite the differences in commissioning arrangements in England and Scotland, this model provides some useful insights into the potential uses of personal outcomes and other types of data.

The 'Care Plus' Intervention: Purpose and Principles

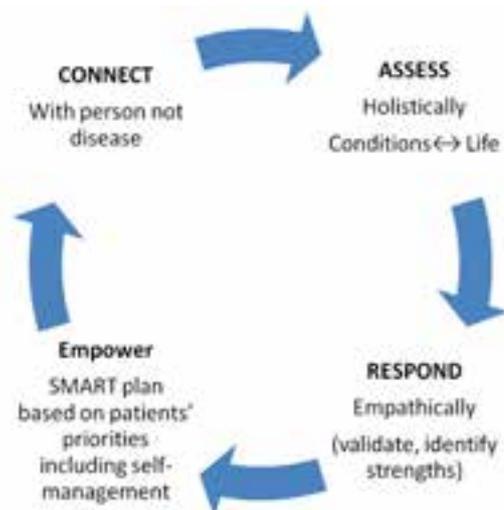


Figure 6 - The CARE Approach¹⁵

The 'Care Plus' research study takes the form of a

clinical trial, comprising an intervention and a control group. It hypothesises that an intervention that combines: a) longer consultations and continuity of care, b) training and support for primary care practitioners, and c) additional self-management support will lead to improvements in health-related quality of life and well-being¹⁵

The 'Care Plus' consultation is the core of the intervention. The 'ingredients' are an empathic person-centred approach, a holistic assessment, and a specific and agreed plan of action. It is based on a simple model, called the CARE Approach¹⁶ [Connect, Assess, Respond, Empower] as shown in figure 6.

People taking part in the intervention also receive a self-management pack, centred on mindfulness-based stress reduction techniques. As much as possible, the practitioner is encouraged to link people with relevant local resources and community services, including third sector supports.¹⁵

Identifying and Recording Outcomes: Agreeing Priorities and Objectives

The 'Care Plus' consultation begins by establishing how the person's medical condition(s) is affecting life, and also how life is affecting the person's condition and wellbeing, including consideration of personal factors, relationships and social circumstances.

The consultation is not designed as a 'tick box' exercise, but documentation of what is discussed, prioritised and planned is required. An essential component is the formation of a short agreed list of priorities based on the person's needs and views, together with a documented plan of action. This may include things that the practitioner will do in addition to the actions to be taken by the individual.¹⁵ SMART objectives are set, using the more common understanding of the acronym (Specific, Measurable,

Achievable, Realistic, Time-bound).

The documentation also records whether or not the mindfulness support pack was issued, and if not, whether the clinician decided against this or the person declined. It also records whether or not the person was encouraged to take up local community supports, and if not, whether the practitioner decided against this, the person declined, or the clinician was unsure about what was available.¹⁷

An essential component of the intervention is the follow-up, to review progress against the plan, plus any other progress or setbacks, to help problem solve, and to repeat the process, moving prioritised items up the agenda to be tackled in the revised plan of action. Continuity is a critical component and the number and frequency of consultations required is jointly agreed.¹⁵ In addition to recording progress against actions undertaken by the person and the clinician, a reflective record of the consultation is documented in the 'Care Plus jotter'.¹⁷

Use of Information

As the intervention is being tested within a clinical trial, the study serves to test the research hypothesis. The central concern is the 'Care Plus' intervention - does it result in the expected improvements? There is therefore a requirement to measure improvements using validated measures of health-related quality of life (EQ5D-5L) and Well-Being (W-BQ12) at pre-determined intervals. Secondary outcomes measures are depression, self-efficacy and self-esteem, again using validated and easily administered instruments. The 'CQI-2', which combines the CARE Measure (Compassion And Relational Empathy) and Patient Enablement Instrument,¹⁸ is also used at the first consultation in both groups, and then retrospectively at 6 and 12 months with people participating in the

intervention. This serves to better understand the experience and consequences of the consultation itself. All measures are completed outside of the consultation. An economic analysis will also be carried out, based on the EQ5D scores and health service utilisation in the control and intervention groups.

'Care Plus' and a Personal Outcomes Approach: Similarities and Differences

Engagement: There are strong similarities between the purpose, principles and processes employed within the 'Care Plus' consultation and outcomes focussed conversations. The identification of life priorities / objectives and the identification of personal outcomes both employ a conversational, strengths-based approach that is concerned with enabling the person to live well according to his or her own values and aspirations in a 'whole life' context. While there is a clear emphasis on action by the individual, it's anticipated that additional support will be required and that this may be clinical, psychological and /or social. While the emphasis on building a therapeutic relationship and establishing empathy is a more explicit concern within the 'Care Plus' intervention, both approaches recognise the 'conversation' as an important intervention in its own right, and that having this type of conversation requires a bit more time .

Recording: There are also some similarities in the two approaches to recording. Neither advocates a tick box approach to recording the consultation or outcomes focused conversation itself. Actions towards the agreed priorities / SMART objectives or personal outcomes are recorded in a support plan and include those to be taken by the person and also by the practitioner (which may include referral to other services). However, there is no attempt to categorise

the priorities or associated objectives within the 'Care Plus' intervention. Instead various pre-determined health and wellbeing outcomes are recorded outside of the consultation using a range of standardised and validated outcome measures. In addition, the importance of the way that all forms of support are provided is reflected in 'process outcomes' recorded at review stage within a Personal Outcomes Approach. In contrast, the experience and perceived enabling capacity of the consultation is explicitly measured for the 'Care Plus' intervention, including immediately after the initial consultation, but the impacts of the way in which any other services and supports are provided is not recorded.

Use of Information: The information recorded within both approaches serves broadly similar purposes at the individual level, namely informing ongoing support and reviewing progress. However, aggregated information addresses very different concerns.

A Personal Outcomes Approach promotes the use of aggregated outcomes information at service and organisational level. It can be used for service improvement, redesign and local planning purposes, planning and commissioning at organisational level, and can also contribute to the monitoring of the effectiveness as a by-product.

The 'Care Plus' intervention is currently being tested as part of a clinical trial and is therefore concerned with 'proving' that the intervention is effective in making a measurable difference to people's health and wellbeing in pre-defined terms. As such, no categorisation or aggregated use of individual priorities or accompanying SMART objectives is indicated and the specific details of community services and supports accessed are not a primary concern. While a range of validated

outcome measures are used, 'social' outcomes or the extent to which 'personal' outcomes are progressed do not feature explicitly. The 'Care Plus' consultation is the intervention core and this is measured using the 'CQI-2'. This measure can be helpful in supporting the ongoing development of practitioners' consultation skills, but within the context of the clinical trial serves primarily to allow these consultation skills to be analysed as important variables.

The "Year of Care" Approach: Purpose and Principles



Figure 7 - Year of Care House Model⁹

The 'Year of Care'⁹ approach is presented as a model of how to deliver personalised care during routine clinical consultations for people with long term conditions, using diabetes as an exemplar. It aims to put self management support into practice in a systematic way, with a view to achieving better 'clinical and social' outcomes.

The model places a firm emphasis upon the role of community services and supports (what it calls 'non-traditional providers') alongside the primary

care consultation itself. It requires a whole system approach.

The "house model" emphasises the importance of each component, with the care planning consultation at its centre and commissioning providing the foundations.

The approach first aims to make sure that routine consultations are truly collaborative. This has required the development of comprehensive training for clinicians, encompassing the philosophy of care planning and self management, consultation and engagement skills, joint decision making and action planning. This again incorporates psychological techniques, particularly to support collaborative working with people who are disengaged. It also provides a clear rationale for the extra recording required and raises awareness of the value of 'non-traditional providers'.⁹

The approach secondly aims to make sure that the range of local services and supports that people need and want to improve their health and wellbeing is available through commissioning. It recognises the need to rethink the balance of support for self management provided within NHS services and within communities. This opens up a much wider range of solutions during service redesign and gives legitimacy to other important community based supports during service planning and commissioning discussions.⁹

Identifying and Recording Outcomes

The Year of Care approach starts before the consultation. One of the pillars of the house model is 'an informed and engaged patient', and ensuring that the person received adequate information and structured education is a key ingredient. This includes sending out clinical test results, with supporting explanations, ahead of the consultation.

The consultation then combines clinical assessment with a more holistic approach. Much like the 'Care Plus' consultation, it addresses both how the condition is affecting life, and also how life is affecting wellbeing. Through a process of identifying issues and priorities, information giving, discussion, shared decision making and action planning, the aim is to jointly agree a 'year of care' plan that meets all of the person's needs and aspirations for improved health and wellbeing.

The concept of outcomes is used explicitly, and the 'Outcomes Star' is endorsed as the preferred engagement and recording tool, helping to identify priority life areas over 8 broad domains [Lifestyle, Looking after myself, Managing symptoms, Feeling positive, Work and activities, Where I live, Money, and Family & friends). This tool, which is available for use under licence, serves to record a baseline score for each life domain.

The person is presented with a 'menu' of local activities and supports consistent with their prioritised life areas and aspirations. The person may be referred to these local supports, access them directly, or may identify other ways of working towards their outcomes. Where relevant services or supports cannot be found locally, this is recorded as 'unmet need' and fed back into the commissioning process.

The person takes ownership of the individual outcomes plan, but the plan also stipulates actions for the practitioner plus any referrals to other services and supports, including 'non-traditional' providers. Progress against the action plan is subsequently reviewed, including assessing the extent to which the desired outcomes have been achieved and how useful the educational, care planning and different support service components are perceived to have been. This is again recorded using the Outcomes Star

tool, which allows individual progress to be displayed visually. 'Health related quality of life' is additionally measured in standardised terms using the EQ5D. The importance of the care planning consultation itself is again recognised as of critical importance and the 'CQI-2' measure is routinely completed to capture each person's perspective on its empathic and enabling value.

Use of Information

At an individual level, the information recorded is used to shape ongoing support and to monitor progress. The CQI-2 measure is used primarily for practitioner feedback, reflection and consultation skills development purposes.

At an aggregated level, a central concern is ensuring the availability of local services that people need to support the actions they want to take to improve their health and wellbeing. While there is an emphasis on community based supports, the need to look across the whole care and support system is recognised. Outcomes information is used to build a picture of the types of issues people face, their priorities and the types of services and supports they want to access, the types of services and supports that are available and most effective in supporting different types of outcomes, and the sorts of outcomes that are proving least and most challenging to progress for different people.

The EQ5D scores are also aggregated to measure improvements in the health related quality of life of the entire 'patient population' and, together with health service utilisation data, to support economic evaluation.

Year of Care and a Personal Outcomes Approach: Similarities and Differences

The Year of Care approach, while having a much stronger clinical and educational focus, is broadly

consistent with the ethos of a Personal Outcomes Approach in many respects across the practice components of **engaging, recording** and **use of outcomes information**:

- The primary focus is improving personal outcomes rather than achieving goals or proving that pre-defined outcomes are being achieved
- The approach is relationship-based and requires establishing a different type of relationship between people who use and provide services
- The importance of achieving a shift in practitioner mindset is recognised: person centred care planning first requires person centred *thinking*
- A very different type of conversation is required
- It's recognised that personal outcomes that relate to valued living more broadly can often only be achieved by a range of different agencies and supports working in partnership with the individual

- Individual outcomes are categorised, aggregated and used to inform decision making at service and strategic levels
- The types of services and supports wanted and accessed by people, and their contribution to achieving outcomes are key concerns
- Complexity is highlighted, including changes in service infrastructure and data management (with links with the commissioning cycle explicit and integral)

Key differences include the additional use of health-related quality of life measures to determine improvements at population level and to inform economic evaluations. Consultations are again assessed using the 'CQI-2' measure, but primarily to support ongoing development of practitioners' consultation skills. 'Process outcomes' for services and supports are not recorded.

Personal Outcomes and Support for Self Management: Shared Learning

The developments in the Support for Self Management scenarios described are each centred upon a therapeutic relationship, serving to establish the person's values and aspirations and to agree ways of working towards them. Consistent with a Personal Outcomes Approach, the application of psychological concepts has been instrumental in achieving many advances in the conversations and consultations conducted

in routine practice, notably the emphasis on values and strengths.

Beyond this core, the contribution made by individuals and their social support networks, clinicians, other statutory services and community based services and supports will vary on an individual basis and by setting, but all dimensions require attention at system level and in the context of a person's life.



Figure 9 - Dimensions of Support for Self Management

The small selection of scenarios discussed also highlighted similarities and some significant differences between the recording and use of information in Support for Self Management and a Personal Outcomes Approach, suggesting opportunities for mutual learning, as set out below:

Assessing Empathy and Enablement

Assessing the empathy and enablement of outcomes focused conversations, although reflected in part within 'process outcomes', is not an explicit feature of the Talking Points Personal Outcomes Approach. There is however a growing awareness of the important 'therapeutic' dimension of outcomes focused conversations among practitioners and service managers,

together with variations in practitioner confidence in conducting these conversations. The CARE measure was developed for General Practitioners, but healthcare practitioners from a variety of professions have been using the measure to inform and develop individual practice. Throughout the course of the Project, discussions with practitioners working in an outcomes focused way have generally found the CARE measure to be a 'good fit with Talking Points'. The option to input results into a national database, which supports 'private' comparison with a national score profile by profession, is welcomed by many.

The CARE measure is also often used in conjunction with the Patient Enablement Index. This measure is centred on the concept of 'self-efficacy'. Although helpful in gauging perceived improvements in people's confidence in their ability to cope with the impacts of a condition, there are some concerns that measures rooted in self-efficacy make individualistic assumptions that ignore familial, social, economic and cultural constraints on people's lives.⁷ Given that both 'Care Plus' and the 'Year of Care' approach are committed to tackling health inequalities, such constraints must be recognised and the mechanisms by which they can be overcome more fully understood. However the concept of looking a bit more closely at the enabling value of outcomes focused conversations more broadly is an interesting addition. This is discussed in more detail in the 4th insight in this report series.

Assessing the Impact of the Way that Services and Supports are Provided

The increased attention paid to the contribution

of the consultation or outcomes focused assessment as an important intervention in its own right, such as captured through the CARE measure, is important. However, the impacts of the way in which all forms of support are provided are also important and should not be overlooked. The inclusion of 'process outcomes' within the Talking Points Personal Outcomes Approach counters the risk of such oversights.

Quantifying Health Related Quality of Life and Economic Considerations

One notable difference between use of information in a Personal Outcomes Approach and Support for Self Management is the emphasis the latter places on the quantification of health related quality of life. The 'EQ5D' emerged as the health related quality of life measure of choice in each of the Support for Self Management scenarios discussed, consistent with the increasingly widespread endorsement and use of this measure within health. Its popularity is attributable in part to its simplicity and ease of application. The 1st insight in this report series discussed the development and use of various Patient Reported Outcome Measures (PROMs) in detail, but in short the EQ5D was developed for use at population level. It is a generic utility measure, designed to yield a single summary score and is intended to evaluate and quantify any given health state, previous, current or hypothetical future¹⁹. This single 'utility' score can then be matched to the 'value' that the general (UK) population attaches to it, usually expressed in Quality Adjusted Life Years (QALYs), for the purpose of economic evaluation. One key concern with this matching process is that people often think quite differently about the things they value

in the face of illness than society in general.²⁰

This measure is reliable according to psychometric properties, but may not be at all relevant to an individual's present life situation. It comprises 5 domains: mobility, self care, usual activities, pain/discomfort and anxiety/depression, and therefore may fail to incorporate the things that are most important to a person, notably within the social and spiritual dimensions of health. Alongside this, EQ5D has been criticised for its lack of sensitivity to the effects of interventions, or to changes in the progression of a condition²¹. It is therefore not particularly meaningful or insightful when used at the individual level, and indeed is not intended to be.

Although widely endorsed for use at population level, it's important that the limitations of this measure are not overlooked. The making of strategic decisions based upon calculations derived from an instrument that incorporates a narrow definition of health related quality of life is problematic, particularly in light of emergent multi-dimensional approaches to wellbeing.

Using Personal Outcomes Information at Different Levels of Decision Making

The Talking Points Personal Outcomes Approach first prioritises engagement, yet also makes the link between what's important at the individual level and what's important across the whole care and support system. Many current measurement approaches make assumptions about people's behaviours, values and aspirations and ignore their life circumstances. Given these limitations, the inclusion of information derived from outcomes focused assessments and reviews into

service planning and commissioning decisions is a very important development in an increasingly integrated landscape. Notwithstanding the different commissioning arrangements in Scotland and England, the Year of Care approach confirms the place for such thinking in primary care.

The use of outcomes information at different levels of decision making is complex. The Personal

Outcomes and Quality Measures project included the objective to test the applicability of the Talking Points Outcomes Framework for different care scenarios supporting people living with long term conditions and to refine as necessary. This insight now shares the findings of project work to test the framework applicability in a service which embeds support for self management within anticipatory care and treatment for people with complex and progressive health conditions.

The Talking Points Outcomes Framework

An evidence-based framework summarising the outcomes important to adults living in the community who use health and social care services is at the heart of the *Talking Points Personal Outcomes Approach*. The framework sets out the high level categories of outcomes to emerge from extensive research. These categories are organised into 3 main types:³

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

Quality of Life	Process	Change
<ul style="list-style-type: none"> • Feeling safe • Having things to do • Seeing people • Staying as well as you can • Living as / where you want • Dealing with stigma and discrimination 	<ul style="list-style-type: none"> • Listened to • Having a say • Treated with respect • Responded to • Reliability 	<ul style="list-style-type: none"> • Improved confidence / morale • Improved skills • Improved mobility • Reduced Symptoms

Table 1- Framework: Talking Points Outcomes Important to Adults Using Services³

The outcomes framework has been used in practice and research settings with thousands of people across a wide range of services. It comprises 15 high-level outcome types that the original research found to be important across diverse 'groups', notably older people, adults with learning disabilities and adults with mental

health conditions. The framework has since been widely tested in research and practice settings and the outcome types within the framework have been found to be sufficiently high level to capture what's important to most people in most settings.

However, it's also recognised that additional outcome types may be important to some individuals or groups, while other outcomes types may need to be 'unpacked' or to find different expressions in order to be meaningful in specific care contexts.

Applicability of the Talking Points Outcomes Framework for People Living with Long term Conditions Being Supported to Self Manage

The applicability of the framework for people living with one or more long term conditions of varying complexity and severity had not previously been tested explicitly and the Personal Outcomes and Quality Measures Project undertook to do so.

The Talking Points framework details *outcomes important to adults living in the community using health and social care services*. The Project initially considered if it would perhaps be necessary or appropriate to develop a separate framework of *outcomes important to adults living in the community being supported to self manage*. This involved a series of meetings and discussions, including with the researchers who developed the Talking Points Personal Outcomes Approach, strategic stakeholders and policy leads directly engaged with the self management agenda, self management facilitators and practitioners, coupled with a review of existing outcome

measures for supported self management and related concepts. Ultimately it was concluded that a separate framework was not appropriate for the following reasons:

- The ethos of support for self management, understood in a broad sense, shares much in common with the ethos of a personal outcomes approach
- The Talking Points outcomes framework was developed by asking people about what's important to them in context of their whole lives
- Testing and use of the Talking Points framework in a vast array of research and practice contexts has found that while the ways in which outcomes are achieved, and the relative contributions that the individual and various services and supports make in progressing specific outcomes may vary, the high level generic outcome categories remain the same
- Analysis of a selection of widely used measures of self management and related concepts found that the outcome domains within these instruments could readily be mapped to the high level Talking Points outcomes categories
- Self management doesn't mean going it alone; while the level of support needed varies enormously and over time, people who are supported to self manage and people who use health and social care services are not distinct groups
- It is important that support for self management is not seen as something separate, but rather is increasingly embedded within services and routine practice, and in a way that is consistent with the emerging multi-dimensional and integrated approach to improving wellbeing

It was concluded that rather than developing a separate outcomes framework for people who are supported to self manage, it would be more pertinent to develop a process for thinking about the different forms that the high level Talking Points outcome categories take within various services committed to supporting self management. This process was conducted for one community nursing service as described below.

The Care Setting

The IMPACT (IMProved Anticipatory Care and Treatment) team is a nurse led service that was established in 2008 to improve the quality of life for people with complex and progressive long term conditions through support for self management and to offer support to their carers. The people supported have usually been identified as at risk of repeated admission to hospital due to sudden exacerbations in their conditions. The team was first introduced to “Talking Points” in 2008, initially as a service evaluation tool. However, the team has more recently received training and facilitation from the Thistle Foundation to enhance its capacity to support self management in the broadest sense, drawing upon strengths based and psychological techniques. This training has included a strong focus on engaging with people about their personal outcomes.

The Personal Outcomes and Quality Measures project had an opportunity to connect with the team in partnership with the Thistle Foundation. This input served to support the team to refine recording practices and to think about using outcomes information. As part of this work,

there was an opportunity to access and analyse outcomes focused review data that the team had collected over a number of months. The review documentation was structured around the high level Talking Points outcomes categories. Although the text descriptions were limited and there was some variation in the quality of recording, it was possible to build picture of the various expressions these high level outcome categories found in the lives of people supported by the team.

Unpacking the Talking Points Outcomes Categories

This work was largely informed through the analysis of the personal outcomes review data. This ensured that the outcomes prompts developed were expressed in a language that was meaningful in the care setting. This was particularly important as staff had reported feeling a bit ‘jargoned out.’ This work was complemented by the findings from an analysis of widely used questionnaires pertaining to self management and related concepts. In particular, given the complex and at times distressing nature of the conditions people supported by this service were living with, it was important that the emotional, psychological and spiritual consequences of changes in life circumstances were explicitly recognised. The questionnaire analysis was therefore extended to include mental health recovery measures, particularly those with an integral self management component, and also a report describing the recent development of a Spiritual Care Patient Reported Outcome Measure, which included a helpful conceptual model and literature review.²²

This work found that very few *additional* high level outcomes types were required (and those identified were already recognised as important context-specific additions within the Talking Points Practical Guide). However, it was necessary to 'unpack' many of the outcome types in order to express the very different forms they can take and to explicitly 'name' some of the more existential instances 'hidden' within

the generic outcome types.

Some of these more specific expressions were found to align directly with 'enablement indicators'. Given the growing importance of enablement in policy and practice, their discovery and potential applications are described in detail in the 4th insight in this series.

The main output of the planned work, namely the set of outcome 'prompts' is provided below.

The Outcome 'Prompts'

Prompts Related to the Care, Support and Embedded Support for Self Management

For people with complex and progressive chronic conditions

Talking Points: Quality of Life/ Maintenance Outcomes

Safety: "The person feels safe and secure at home (and in the local community if appropriate)

The person is physically safe from harm (*but consistent with a risk enablement philosophy*)

The person feels emotionally secure and can rely on access to support when they feel less safe

The person feels safe and secure when using services" ³

In this care context "feeling safe" has often been found to take the following forms:

"Not being scared of my illness" "Feeling supported and not alone in this" and "Facing the future without fear"

Specific concerns may include:

- Managing fears about the physical impacts of the conditions: e.g. addressing concerns about being unable to access oxygen when out of the house in the event of breathlessness; addressing the fear of collapse or of any sudden exacerbations, particularly in a public place
- Feeling safe within the home environment: e.g. addressing the risk of falling or concerns about being able to get out quickly in an emergency / proximity of help if suddenly taken unwell
- Feeling safe from physical harm or neglect: addressing concerns about 'vulnerability' or physical frailty and a growing dependency on others, or fears about coming to harm from others including relatives, neighbours or unsolicited /bogus /nuisance callers
- Feeling emotionally secure and content: maintaining or regaining hopefulness, a sense of worth and significance, particularly being able to seek emotional support and comfort from others when feeling down, including interpersonal relationships / the community / one's faith or spiritual beliefs / care practitioners and other support services
- Being able to face the future without fear when living with a condition that "will only get worse", including fear of (carers) being unable to cope, talking openly about disability, dying or death

This outcome type often links closely with the change outcomes: improved confidence / morale and reduced symptoms and the process outcomes: being listened to, treated with respect, reliability and being responded to

Having things to do: “The person has opportunities to undertake activities which interest them, both at home and outside the home (if they wish). This includes hobbies, voluntary work, work, education and employment”³

In this care context “*having things to do*” was often found to be closely linked with a continued ability to “*get out and about*”. For many people this can be restricted by the extent of the impacts and complexity of the conditions the person is living with. This can sometimes be improved through better condition management, physically and psychologically. In other cases an inability to get out and about and do things may be attributable in part to a lack of appropriate support.

However, for some people where the condition has progressed significantly, getting out and about may no longer be possible. In such situations, this outcome type is concerned with supporting people to finding meaning and purpose in the things they are able to do and that they *value* doing. This can take the following forms:

- Things that I enjoy doing
- Things that provide me with a sense of direction, purpose or achievement
- Making a contribution (to the lives of others, in life, to ‘the world’)

This outcome type can relate to aspects of emotional security [sense of significance] and the change outcome improved morale / self-esteem

Seeing people / social contact: “The person feels they have enough contact with significant other people and that they have opportunities for social participation. This can include family and friends and staff”.³

In this care context “*seeing people*” was again often found to be closely linked with a continued ability to “*get out and about*”. Where this was no longer possible, improvements in seeing people were often attributed to “*increased contact with care staff*” and the quality and supportive nature of these relationships was very important. It may therefore be helpful to think about both the person’s support network and also the social network.

This outcome type is about the *quality* of social contacts rather than the *quantity*. It is possible for someone to ‘see’ lots of people and still feel lonely. It can take the following forms:

- Not feeling lonely or isolated - having visitors or getting out to see people
- Seeing the people whose company I enjoy (choose to keep)
- Maintaining contact / sustaining positive relationships with people who matter to me / my existing support networks
- Developing new social relationships and networks
- Developing new personal support networks

It can again relate to aspects of emotional security [sense of ‘connectedness’ / significance to others] and the process outcomes: being listened to and treated with respect.

Staying as well as you can: “The person feels they are physically and mentally as well as they can be, given any illness or condition they have. This includes having access to support and treatment when they become ill”.³

In this care context “*staying as well as you can*” often concerns the “*ability to manage the impacts of the condition(s) upon every day life*”

As there can be a tendency to focus on the physical aspects of the condition, it may be helpful to think of physical health and mental health separately. It can also be helpful to think both in terms of the ‘impact of the condition on life’ and the ‘impacts of life upon wellbeing’.

This outcome includes being able to navigate or ‘find my way round / access the care system’ and *being able to access appropriate supports as and when needed*, including equipment or medications.

For people where the condition is more advanced, this outcome type can also include *being well nourished* and *being supported to stay clean and comfortable*³

This outcome type can link closely with the change outcomes: reduced (or contained) symptoms and increased (self management) skills. It can also relate to dealing with stigma and discrimination - where this has acted as a barrier to the person accessing the care system in the past.

Living as / where you want: "The person is able to plan and have control over their daily life and is able to live where they want" ³

For people in this care setting *living as you want* on a day to day basis is again often concerned with the ability to *manage the impacts of the condition*. This includes both the development of coping and pacing strategies to facilitate planned activities and the ability to respond quickly to flare ups.

It can also include being able to plan and have control over the longer term future, including '*getting affairs in order*' including do not attempt resuscitation orders, advanced directives and living wills.

Living where you want is often concerned with being able to stay at home, including adaptations to make this possible. It may relate to not having to go into hospital if it can possibly be avoided or getting out of hospital as soon as well enough. It can also include moving to more suitable accommodation as a condition progresses.

Dealing with stigma and discrimination: "The person is able to deal with the inappropriate behaviour and attitudes of others". ³

In this care context, this outcome type was found to be important to roughly 1 in 10 people, but where identified it often had a significant influence on their quality of life.

A particular issue was the attitude of and treatment by other care and support services, including the relationship with the GP and hospital staff, particularly for people with a history of alcoholism. This sometimes necessitated liaison or advocacy by the practitioner, as well as developing coping and response strategies for the future.

However, the discrimination could also include more subtle forms, including by family members who often unintentionally '*negated*' people, which again could require intervention by the practitioner to facilitate conversations to address this.

This outcome type links closely with aspects of emotional security and improved confidence and morale. It can also relate to staying as well as you can by affecting the ability or desire to access the care system.

Economic Wellbeing / Accessing Financial Advice

Although not a 'core' Talking Points outcome, financial matters may often be a key concern for people who have been living with a progressive condition for some time. This outcome type is concerned with ensuring that the person has access to information about benefits and entitlements and other financial advice, including for dependents in the event of the person's death. ³

Prompts Related to the Care, Support and Embedded Support for Self Management

For people with complex and progressive chronic conditions

Talking Points: Change Outcomes

Improved confidence /morale: “The person is working towards dealing positively with changed life and health circumstances, and / or personal or societal attitudes towards ill health and disability”³

In this care context, this outcome type very much captures the essence of support for self management and therefore requires careful and extensive ‘unpacking’. Morale and confidence are closely interconnected and together concern a positive engagement with life.

Morale relates to a sense of hopefulness and a positive relationship with self and with life.

Confidence encompasses general confidence, as well as confidence in own abilities and capabilities, including the ability to self manage.

This outcome type includes:

- Adapting or adjusting effectively to living life with one or more conditions
- Coping with, accepting and dealing with changed life circumstances / resilience
- ‘Self efficacy’ - confidence in own ability to deal with symptoms and challenges
- Taking control of the impacts of the condition - “this condition does not control me”
- Confidence in managing daily life - “feeling able to get on with it”
- Belief in / hope for the future, as well as self-belief - seeing new possibilities
- Making sense of things / gaining a new sense of perspective
- Valuing myself / increased self esteem / self-respect
- Identity - “back to who I am again”, “finding a new sense of self”
- Recovery of spirit / enthusiasm for life

Improved (knowledge and) skills: “Relevant where staff are supporting the person to regain or develop skills and capacities”³

In this care context, this outcome type is integral to support for self management and primarily concerns improved understanding of the condition (and knowing how to use this understanding in pursuit of valued living) and improved self management skills and strategies. This includes:

Technical (condition specific) skills *e.g. symptom monitoring, inhaler techniques, using rescue medication, breath control, positions of relaxed breathing*

Increased ability to apply self management strategies:

- Improved problem solving, experimenting, anticipating changes (such as warning signs of setbacks, relapse)
- Condition-related decision making
- Being reflective (learning from set backs)
- Developing contingency plans, relapse management (I know what to do when ...)

Generic (life or emotional /psycho-social) skills including:

- Managing sleep, stress, fluctuating pain, energy, mood levels (pacing)
- Planning, goal setting (managing motivation),
- Mindfulness (self awareness, knowing what I can and can’t do, awareness of strengths)
- Communication - self talk, assertiveness
- Staying hopeful and future planning

'Improved' mobility: "The person is working towards improved ability to get around within the home and / or outside (includes equipment, adaptations, therapy and transport)"³

In this care context sustained improvements in physical / functional mobility are unlikely due to the progressive nature of the conditions people are living with, although small improvements may be possible and hugely significant. There may be a stronger focus on preventing or slowing deterioration in mobility, which is crucial given the importance attached to the ability to 'get out and about' within a number of quality of life outcomes. This can include successful application of graded exercise/ activity programmes. However, this outcome type assumes a broader understanding of 'mobility' than often found within health contexts. This encompasses support from others to continue to access the outside world, the use of equipment within the home and outside, such as walkers, including local barriers to use, and access to transport

Reduced symptoms: "Experiencing fewer symptoms, feeling less depressed or anxious, improved sleep, improved relationships"³

In this care context sustained reductions in primary symptoms are again unlikely due to the progressive nature of the conditions people are living with, although as with mobility, small improvements may be possible and hugely significant. There may be a stronger focus on managing these 'symptoms' and working towards the management and reduction of the impacts of the conditions, as understood more broadly. This includes:

- Management of primary symptoms (breathlessness, chest pains etc.)
- Reduced secondary impacts such as inactivity, restlessness, poor sleep
- Improved management of persistent and disabling impacts such as chronic pain, fatigue
- Fewer negative emotions, notably stress, anxiety, sorrow
- [Increased calmness, comfort, peace of mind]

Prompts Related to the Care, Support and Embedded Support for Self Management

For people with complex and progressive chronic conditions

Talking Points: Process Outcomes

To feel listened to: "The person feels that their views about their own situation are listened to by staff"³

A prerequisite to feeling listened to is that the person feels able to talk about what's on their mind

This includes:¹⁸

- Feeling at ease with the listener
- Being able to tell my story / talk about my concerns, hopes and fears
- Being *really* listened to / having the person's whole attention
- Feeling significant / worth the person's time - taking a genuine interest in me
- Having concerns acknowledged and understood

Choice / to have a say: "The person's views are taken into consideration, including regarding the nature and timing of support"³

This includes:

- What matters to the person is understood and recognised as important
- Recognising and valuing capabilities
- Feeling supported to take control over decisions
- Honesty - being told about any support limitations
- Being supported to develop a plan of action, including setting out own role (if appropriate)

To feel respected: “The person feels that they are treated as someone who has a right to services and as a fellow human being with individual needs”³

This includes:¹⁸

- Feeling the practitioner was interested in me as a person
- Having my concerns acknowledged or validated
- Feeling my strengths, capabilities, knowledge and life experiences were recognised
- Being honest with me
- Feeling supported and positively encouraged

Reliability: “The person feels they can rely on staff to turn up or do what they say they will”³

This can refer to staff taking action, referring on to other services, providing advocacy, being in regular contact, being contactable, checking in on the person

Being responded to: “The person feels that services respond to their changing needs and that they can rely on services to respond if particular difficulties arise”³

In this care context, knowing that services will respond in the event of an exacerbation or uncertainty is particularly important - people often simply want reassurance

For people with complex and multiple conditions, aspects of service delivery that contribute to their feelings of being responded to (and respected) include relational continuity and a ‘treatment burden’ that is acceptable to the person.

Applications of the Outcomes Prompts

The set of prompts were developed primarily for use by new or seconded staff and placement students joining the team. However, practitioners within the team have also found them helpful, providing another piece of the jigsaw. In particular, the prompts have highlighted that there are different ‘depths’ or layers to many of the outcome types, and a sense of progression, notably with regard to improved confidence and morale, which is critical to work of this team. As there is little scope for sustained physical improvements for many of the people supported, unpacking improvements in the way people that are feeling about themselves and life also has important implications for practitioners’ own sense of achievement.

Although developed specifically for future use within the service setting in question, the ‘prompts’ may also be applicable in other care settings supporting people with complex and progressive conditions, or provide food for thought about the applicability of the high level outcome types across diverse care contexts.

Conclusion

It’s recognised that what it means to implement a Personal Outcomes Approach will vary by context, with different implications for each of the core practice elements: **engaging, recording** and **using outcomes information**. The Personal Outcomes and Quality Measures project

has investigated the implications for these components for a number of scenarios, each with a focus on Support for Self Management.

This work found similarities in approaches to engagement and to some extent in recording practices.

Some of the additional measures used within the various self management scenarios may have transferable appeal within outcomes focused working more broadly, particularly the complementary use of the CARE measure.

However, the Project found significant differences in data use, with efforts to make the links between individual assessment and care plan data and service level and strategic decision making remaining very much in their infancy in health. The project also identified a growing recognition of the importance of addressing the emotional, psychological, social and cultural implications of living with a long term condition, and a firm emphasis on addressing health inequalities. As such, the continued use of measures that are based on narrow understandings of health related quality of life and that neglect the social and material circumstances of people's lives is increasingly questionable. The inclusion of information

derived from outcomes focused support planning in service planning and commissioning decisions holds significant potential, and may be essential in more integrated delivery contexts.

The Project also undertook to test the applicability of the *Talking Points Outcomes Framework For People Who Use Services* in different care scenarios supporting people living with long term conditions, and to refine as necessary. This work found that very few additional high level outcomes types were required (and these were already recognised as important context-specific additions within the Talking Points Practical Guide). However, it was necessary to 'unpack' many of the outcome types into the more specific expressions they found within the care setting.

While the resultant set of outcomes 'prompts' were developed primarily for use with new and seconded staff within the care setting, existing practitioners have also found them helpful, particularly in highlighting the different layers and depths within many of the outcomes categories. It is hoped that the 'prompts' may find wider applications, either directly or by prompting reflection about the applicability of the high level outcome categories across diverse care contexts.

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