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We've Got To Talk About Outcomes

A Question of Purpose:

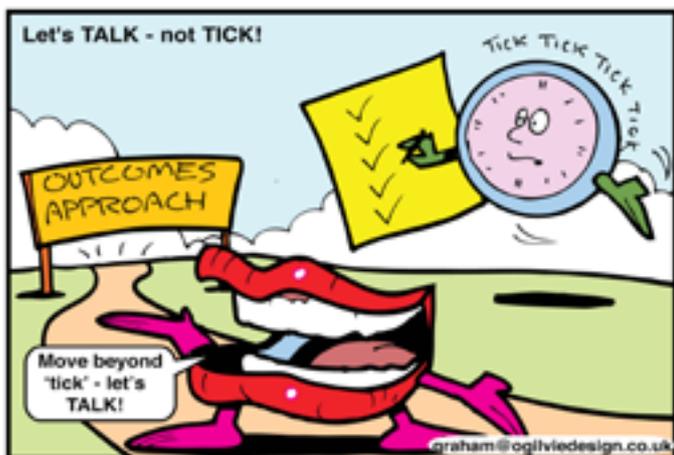
Implementing a Personal Outcomes
Approach in Different
Healthcare Settings

**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

The *Personal Outcomes and Quality Measures* project set out to determine whether and how a Personal Outcomes Approach could be embedded within different healthcare services supporting people living with one or more long term conditions with a view to a) improving and b) reporting their personal outcomes.

However, as highlighted by a recent Health Foundation report³, two important issues are hidden when there is an undertaking to identify and improve outcomes with an individual, but no direct discussion of what counts as the purpose, or what falls within the remit of such collaborative approaches:

- First, there is the issue of what matters most *about* working in this way.
- Second there is the issue of *how far* the focus should be on supporting broader and more personalised quality of life concerns.

This 2nd insight report considers these issues in detail by sharing efforts to introduce a focus on personal outcomes within 3 different healthcare services:

- Intermediate care services provided by teams of allied healthcare professionals
- Generic district nursing services
- Anticipatory care and treatment services for people with complex conditions provided by specialist nursing teams led by advanced nurse practitioners

For each setting in turn, the insight considers the strategic context, plus the characteristics of the care setting and the individual care encounters, together with their potential implications for supporting people to identify and work towards their personal outcomes.

The report examines the importance of ongoing facilitation and support to enable practitioners to translate learning into practice, providing the space for reflection and time to work through any tensions, notably the balancing of risk with professional accountabilities.

The insight draws upon practice examples to illustrate the different ways in which personal outcomes within broader health domains are being supported in the different contexts, the changes in practice that result, and the likelihood of embedding this way of working in future.

Finally, the report identifies a number of common threads that run through the different care scenarios, which together reinforce the message that what is arguably most important about a personal outcomes approach is the development of supportive and enabling relationships.



Key Points

- Introducing a focus on “personal outcomes” (or what matters to the person) into healthcare services presents a number of possibilities and challenges that vary both by context and by individual case
- Focusing on “personal outcomes” can require radically different ways of thinking and practitioners need space and appropriate support to work through the implications
- People accessing healthcare services also have preconceived ideas about the purpose of the care encounter and this needs to be recognised
- Working in an outcomes-focused way entails involving the person in identifying, negotiating, shaping support and establishing their own contribution towards their personal outcomes
- The enabling and therapeutic nature of a personal outcomes approach can represent a clear point of difference from traditional goal setting and is often only understood through direct experiential comparison
- Alongside the identification of personal outcomes, there is a need to consider the different ways in which practitioners might be expected to support their achievement, directly or indirectly
- Project work in several different healthcare settings found that the identification of personal outcomes could serve to:
 - Enhance continuity and consistency by ensuring that everyone is working towards the same set of personal outcomes
 - Ensure that traditional (physical health) inputs are fully aligned with what matters to the person more broadly and are based on an understanding of why it matters
 - Expand the practitioner role to directly support practical or social concerns, notably by fostering connections with the local community
 - Facilitate engagement at a deeper emotional or spiritual level and promote self-reflection
 - Redefine the purpose of the service over time
- Considerations of personal outcomes and risk enablement go hand in hand, and the difficulties that practitioners face in balancing individual aspirations and professional accountabilities need to be addressed directly and worked through
- Focusing on the person’s strengths, taking a step back and adopting a systematic approach to risk enablement can transform care and support, and reduce practitioner stress
- Having a different type of conversation can change the nature of the relationship between practitioners and people accessing care services
- This different type of relationship can contribute to better outcomes for the person and for practitioners, but also has intrinsic value. This intrinsic value should not be overlooked

Introduction

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 towards the **outcome** of this activity for people who use services and unpaid carers. This ensures that services are concerned with the difference they are making to people's lives.

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.
- **Ethics of Engagement** – engaging with people using services and their carers in decisions about their care and support, and their values, 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 approach⁴.

Personal Outcomes and Partnerships Working across Health and Social Care

The Joint Improvement Team's "Talking Points" Programme⁵ has provided a clear focus for activity around outcomes in Scotland. The programme has been firmly grounded in the evidence as to which outcomes matter to people using health and social care services and their carers.

Taking a *Personal Outcomes Approach* requires that you start with the priorities, needs and aspirations of the person and work creatively, drawing on a range of resources towards their "personal outcomes". It is integral to the *personalisation* philosophy promoted in social care.

For people using health and social care services, broader quality of life outcomes are often necessarily attained by working across agency boundaries. Personal outcomes are therefore an important driver for the integration of health and social care. A focus on personal outcomes also requires working in partnership with and drawing upon the resources of the person using the service, their family and local community, consistent with an assets-based and enabling approach.

Taking a *Personal Outcomes Approach* can help to provide a common language and shared sense of purpose across services and disciplines, and also with people using services and their carers. This approach now sits at the heart of the assessment, planning, and review processes employed within health and social care partnerships across Scotland. Personal outcomes data are also being used to bring about important learning at individual, service and organisational levels.

Who Made This Possible?

- Barbara
- Social Work Assistant
- Older People's Team Assistant
- Occupational Therapist
- Physiotherapist
- Speech and Language Therapist
- Community Psychiatric Nurse
- Consultant Psychiatrist
- Mental Health Officer
- Independent Advocate
- Everyone at the Firs Care Home
- Team Manager



Figure 1 - Lavern Valley Older People's Team Case Study, JIT

At the individual level, a focus on personal outcomes ensures that everyone involved in a person's care and support is working with the person towards the same set of outcomes, increasing consistency and continuity, and making best use of the specialist expertise of everyone involved.

For example, the case study developed by the Lavern Valley Older People's Service in East Renfrewshire⁶ demonstrates how various health and social care practitioners worked with Barbara and her friends to think about her capabilities and what she could do, enabling her to get back to living independently in her own home. Despite initially failing a hospital risk assessment that focused on what Barbara couldn't do, and which resulted in the recommendation that Barbara should be considered for long term care, Barbara now enjoys entertaining her friends, cooking, participating in the life of her church, and doing voluntary work. She has no services.

Adopting a Personal Outcomes Approach in NHS Settings

The concept of "personal outcomes" features in a growing number of health and social care policies and in integrated services, such as the Older People's Team above, healthcare professionals are now working alongside social care colleagues in an outcomes-focused way on a daily basis.

However, the concept of "personal outcomes" is virtually unheard of in secondary care settings and to date the adoption of a *Personal Outcomes Approach* in NHS community services has been limited. This was recognised 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, the review

also recognised that a future of health and social integration means that such differences must be overcome.

The first aim of the Personal Outcomes and Quality Measures project was to determine whether and how a *Personal Outcomes Approach* could be embedded within different healthcare services supporting people living with one or more long term conditions with a view to a) improving and b) reporting their personal outcomes. There are however other questions that must also be considered.

Within healthcare services, a focus on "personal outcomes" is consistent with the shift from agendas that are (often assumed to be) narrow and professionally-led towards those that encompass broader concerns that relate to valued living. This shift also requires support to be more *personalised* in the sense that it reflects what matters to a unique and particular person, rather than what might matter on the whole to groups of people with similar conditions³. This presents a number of possibilities and challenges that will vary both by context and by individual case.

A recent report from the Health Foundation³ offers "fresh thinking about collaborative approaches to care for people with long term conditions". This report recognises that making care truly person-centred requires radically different ways of thinking, adding that if we are to see truly



collaborative approaches to healthcare, we will need not only familiar change mechanisms such as leadership and training, but also conversation and space to allow people to reflect upon and reconsider their purpose, attitudes, roles, responsibilities and relationships. This is particularly important when it comes to working with people towards their personal outcomes.

The report³ suggests that two important issues are hidden when there is an undertaking to identify and improve outcomes with an individual, but no direct discussion of what counts as the purpose, or what falls within the remit of such collaborative approaches:

1. First, there is the issue of what matters most about working in this way, and the risk that the intrinsic value of developing supportive and enabling relationships is obscured.
2. Second there is the issue of how far the focus should be on supporting broader and more personalised quality of life concerns. The management of long term conditions can be understood in quite different terms concerning:
 - Biomedical management to monitor and control disease progression and the risk of disability or death
 - The broader management of the unwanted impact of the condition and treatment on the person's life
 - The still broader business of living as well as possible according to one's own values and aspirations while having the condition

These "different kinds of ends", although often interlinked, present different possibilities for collaborative working and pose different challenges for practitioners and for people living with long term conditions.

Enabling People to Live Well (2013) pp19-20
Entwistle V & Cribb A, Health Foundation³

The first issue has been a central concern throughout the lifetime of the "Talking Points" programme. The importance of ensuring that pressures to demonstrate service impact in terms of outcomes for individuals do not undermine engagement and relationship building is a thread that also runs through this series of reports.

It is the second issue that is the main focus of this 2nd insight report. A Personal Outcomes Approach is concerned with "what matters to the person in the context their whole life, not through the filter of services or particular health conditions"². Project work has therefore explored the issues that can arise when healthcare practitioners engage with the "still broader business of living well"³ and considers "what falls within the remit"³ of practitioners when supporting people to achieve their personal outcomes. The insight summarises learning from work within the following care services in turn:

- Intermediate care services provided by teams of allied healthcare professionals
- Generic district nursing services
- Anticipatory care and treatment services for people with complex conditions provided by specialist district nursing teams led by advanced practitioners

Intermediate Care Services

Overview

The following insights were gained through the opportunity to work with what has become known as the “SHINE project” in Fife, as originally funded for one year by a Health Foundation SHINE Programme grant. The “SHINE project” is now in its third year and is part of the Reshaping Care for Older People programme in Fife, positioned within the Community Capacity Building work stream.

Strategic Drivers and SHINE Project Priorities

The overarching driver was identified by local stakeholders as: “reducing preventable admissions to hospital, helping people to get home quicker, and crucially, increasing people’s chances of living independently and maintaining wellbeing at home in the community”.

The approach that the SHINE Project (SHINE) adopted was inspired by visits to and from the Alaskan ‘NUKA’ healthcare system. This model is founded upon the principles of relationship based care and recognises the crucial role played by individuals, families and local communities in maintaining wellbeing. SHINE was also informed by the International Futures Forum’s “3 horizons thinking”, which offers a way of visualising the transition from old to new ways of working. SHINE set out to:

1. Support NHS Fife staff to have conversations with older people during routine care encounters, focusing on the things that are important to them in their day to day lives;
2. Stimulate and support the development of a small support provider (“micro”) sector in Fife with the capacity to work flexibly with older people in ways which are legal, safe and sustainable;
3. Build the infrastructure to sustain this model of provision in Fife

The Care Context

SHINE has been working primarily with the Integrated Community Assessment and Support Service [ICASS] teams, specifically the Community Rehabilitation Teams (CRT) and Day Hospitals. The ICASS practitioners who took part were occupational therapists, physiotherapists and therapy assistants.

Practitioners working in Levenmouth noted that it was a comparatively small and well-defined patch and that they tended to know most of the people using the service. In particular, the Day Hospital was located in a former mining hospital, which had a very important role within the local community. Upon referral to the service, Levenmouth practitioners were often able to think in terms of who was best placed

to see the person, and largely from a continuity perspective. Although always busy, they did not feel the same “pressures from acute” as the teams operating in Dunfermline and West Fife, who had recently relocated and were less likely to know people referred to the service.

The ‘case mix’ for all teams was very diverse in terms of complexity and therefore also the length of engagement with people. Most people referred to the service were over sixty-five. Many had neurological conditions. A significant number of referrals were the result of falls or medical fractures, often notified by the Community Alarm Service. Overall, there was a strong sense that the majority of referrals to the service were for functional problem-based interventions.

Contextual Implications for the Focus on Broader Quality of Life Concerns

The differences identified by teams working across the two localities in terms of their relationships with people accessing the services appeared to present different possibilities for engagement. However, practitioners recognised that this could work both ways and if people were used to a particular style of communication it could be difficult to suddenly change. Most often a person will have been referred to this service to progress a very specific (usually physical) and often tightly time-limited outcome such as ‘improved mobility’ or ‘improved kitchen skills’.

For some practitioners, this initially raised questions about the appropriateness of engaging with broader aspects of wellbeing due to expectations on both sides:

“People are referred to us for a very specific reason; usually there has been an impact on function. We are first and foremost a physical service. That is their expectation too. I don’t think that is always recognised”.

Although the SHINE project was committed to supporting older people by drawing upon whatever resources were most appropriate, the original strap line: *“Micro-enterprise care solutions to reduce acute hospital admissions and facilitate earlier discharge”* had resulted in some confusion amongst practitioners. There were therefore initial concerns about the proposed way of working and the perceived need to try to ‘match’ people to local supports. This presented difficulties when it came to initiating a conversation centred on assumptions about the need for some form support, no matter how individualised that support might be:

“A lot of people I work with are quite happy. Were we trying to create this magic ‘what if’? What if someone could help you with something? Most of the people I see are quite content; were we trying to make them want something else”?

Discovering Personal Outcomes and a Therapeutic Approach to Engagement

Facilitated Learning

At the outset SHINE had assumed that healthcare practitioners would easily be able to engage in a different type of conversation with older people, and that older people in turn would be able to articulate what was important to them readily. However, this proved much harder than anticipated and a framework was needed to support this.

SHINE had, in common with a number of NHS services, initially been introduced to 'Talking Points' as an "evaluation tool" and only became aware of the *Talking Points Personal Outcomes Approach*, which is founded upon outcomes-focused conversations, towards the end of the first year. This was a major turning point. An introduction to Talking Points and ongoing peer learning sessions facilitated by Emma Miller, one of the researchers who developed the approach, addressed several issues that the practitioners had been wrestling with:

a) Whose Outcomes Matter?

Practitioner confusion between "personal outcomes" (what matters to each person) and "project outcomes" (increasing the number of people supported by 'micro-providers') was quickly clarified following initial Talking Points training.

b) Personal Outcomes versus Patient Centred Goals: Therapeutic and Enabling Engagement

Goal setting can be an effective way of working and what constitutes a 'good goal' varies by context. However, there are distinctions between 'patient centred goals' and 'personal outcomes', which the Talking Points training underscored. The main differences are largely a function of the process by which personal outcomes and support actions are identified, and the underpinning principles:

1. A personal outcome gives expression to the things that **matter** in the person's life and is expressed in a way that is meaningful to the person and that also conveys *why* it matters.
2. Thinking about how each outcome might be achieved is conducted jointly through a process of negotiation. This includes considering the role of the person and other people and resources in their lives, consistent with an enabling approach. By supporting the person to reflect upon and recognise their strengths, resilience and the different life skills that they already use or have drawn upon in the past, this broadens possibilities, enhances self-awareness and can in itself have therapeutic value.

Practitioners frequently identified that their traditional assessment approach was goal centred, but also recognised that the

extent to which goals were negotiated and contextualised was variable:

“Normally we do have patient-centred goals, but sometimes they are our goals. Appropriate for the person, but set by us.”

Even where goals were jointly agreed, they were generally not recorded in the language expressed by the person, and clinical outcomes could take priority. The differences often only became apparent after recording personal outcomes and support actions with people and then reflecting back on the content of traditional documentation:

“The penny did drop. We usually write down the problems that someone has, and the goals will have been set with the person, we do start with what they would like to get back to, what’s important to them, but then it is: right, here’s what ‘we’ are going to do. That was quite sobering”

“I think I practice in a very holistic and person-centred way, but when I then looked at our documentation, I couldn’t hear the voice of the person. We have to share notes and I first thought, well that is not what ‘the system’ prioritises. But it was more than that. I had made a lot of assumptions.”

c) Risk and Accountability

On-going peer learning sessions provided not only the structure and evidence base that practitioners had been looking for, but also the “*conversation and space*” for reflection upon roles and responsibilities described in the Health Foundation report³. Much of the discussion focused on system issues that were outwith the practitioners’ control, particularly regarding the rules surrounding moving and handling equipment, which didn’t allow people to have “good days and bad days” or permit families to take carefully calculated risks. However, there were also some tensions between personal outcomes identified and the professional duty of care. Discussions on personal outcomes and risk enablement go hand in hand. Having someone to facilitate the sessions who had extensive experience of outcomes-focused working and who directly addressed the issues faced in their everyday encounters was regarded as essential:

“There are real concerns about risk and we are accountable. You need someone who understands that and can work through it with you. You can’t just dismiss it and say that risk is part of life.”

Identifying and Supporting Personal Outcomes in Practice

Different Ways of Engaging with Outcomes in Broader Health Domains

Over time, practitioners were supported to work with people to identify personal outcomes and potentially more creative ways of achieving them by drawing upon a range of resources. Alongside traditional service inputs, these resources included individual capabilities, plus those of families, neighbours, existing social support networks and organised community-based supports, including the small providers supported by SHINE, as and where appropriate.

The selection of reflections below shares some of the ways that practitioners have been supporting older people to both identify and work towards the things that matter to them.

Aligning Established Practice with What Matters to the Person

The following accounts illustrate the importance of ensuring that inputs to bring about desired improvements in occupational or physical function are fully aligned with what matters to the person, and are based on an understanding of *why* it matters.

The OT's Perspective: The Subtle Art of Prevention

I was working with one lady who had been in hospital and was referred to the service when she first got home. I was there to help her with kitchen tasks to make sure that she was able to make something to eat and drink safely. And through conversation, boiling the kettle, making a cup of tea, she talked about her friends and their support while she'd been in hospital and how lucky she was to have them. Sitting safely in the kitchen drinking a cup of tea from a spill-safe beaker on her own really wasn't what she wanted. She wanted to be able to make a pot of tea and serve it to her friends in her living room. She wanted to reciprocate. It was important for me to support that. We looked at how she would normally do things and together we worked our way through the various obstacles.

Comment: The presence of neighbourliness and a supportive social network makes a huge difference to wellbeing. Disruption to people's lives and withdrawal arises not only because of functional limitations such as restrictions in mobility and fatigue, but also because of embarrassment⁷. Enabling this social rather than physical function took the practitioner a little bit longer. However, the immediate gains in terms of being understood, maintaining identity and enhancing self-esteem are self-evident, while the preventative potential can only be guessed.

The Physiotherapist's Perspective: A Little More Time

I was working with one lady with Parkinson's disease who had been referred to the service by the Parkinson's nurse to work on her outdoor mobility and confidence in walking. She had no family apart from a cousin who was doing her shopping for her. Balance was the main problem, which was affecting her independence and ability to get out and about. After a few visits there had been very little improvement in her balance. We had identified that getting back to the local shops was something to work towards, but as time went by, this seemed more unlikely. I was starting to think about taxi cards, but because of the SHINE project I was able to stick with it a bit longer.

I accompanied her out on an attempted trip to see how far she could go. She didn't get very far at all as lots of people were stopping her in the street and speaking to her. She seemed to know everybody and just lit up. She didn't get as far as the shops, but I realised that wasn't that important to her. It was literally "getting out and about," seeing people, being part of the community again. That was what was really important to her and taking a taxi to the shops wasn't going to help with that.

So we started thinking not so much about getting to the shops, but just getting out and about and what that would mean to her. Then, with a little more time and a bit more input, her confidence came back and she suddenly started to improve. She has a three wheeled walker and is now using that on her own to walk to the doctor's surgery and library, which are quite close by. Her cousin is also sometimes doing the shopping for her and sometimes with her, depending on how she feels, but doing the shopping is not a big issue. She also visits a friend in a nearby care home. She is able to walk there, but not back, so she's made arrangements with the friend's family to let them know when she's going and they'll come and take her back home.

Comment: Practitioners spoke often about time pressures and the need to "move people on". When asked how she felt about giving this lady a little more time, the practitioner acknowledged that she had felt guilty about this, and that it "hadn't seemed right" to be spending time with her when it didn't seem to be helping with her balance. The fact that spending time with the lady was in itself helping to improve her self-esteem and confidence was noted, but it still "hadn't seemed right" with so many other people waiting for physiotherapy. The importance of streamlining work within the team to allow everyone to work in this way was identified by the operational manager who had prioritised attending the peer learning session where this reflection was shared.

Expanding the Practitioner Role: Engaging Directly with the Social Dimension of Health

The selection of examples below illustrate a growing practitioner engagement in identifying and directly supporting what might be classed as 'social' aspects of health. It is perhaps worth stressing that the many of the older people in question would not come to the attention of or be referred to social care services, yet still welcomed some low-level support to live fuller and more positive lives.

Connecting with Community

"I'd been speaking to one lady who was living at home with her husband in a fairly rural setting. It emerged, through the conversation, that she's really missing female company. Normally, I wouldn't have responded to that, well not beyond acknowledging it, not directly. But we had a chat about that and what sorts of things might interest her and the possibilities. I was aware that the befriending service is extending out to the villages in Fife and that was of interest to her".

"I was recently surprised to discover that one lady I was working with was feeling very socially isolated. She had downsized to a nice new flat, but found people in the development kept to themselves and she was lonely. I would not have opened up that sort of conversation before. But after some discussion about what she might like to do, I referred her to MyBus [one of the small providers being supported by SHINE]. It was a little bit of extra work, but with big gains for her".

"Through speaking to one lady about her life and interests, I found out that she was keen to volunteer. She had quite a good family support system, but it was important to her to give something back. I told her about the Local Area Coordinators and she was interested to hear what was available, so I referred her. She is now volunteering at one of the day centres and loving it. That took very little time. We are much more aware of the range of supports and possibilities, even if we don't know all the details, and having the co-ordinators there is great."

Comment: The ways in which practitioners are supporting people to connect with community life can be as simple as giving people information about what's out there to making a referral to a specific support provider. Increasingly practitioners are putting people in touch with the Local Area Coordinators who often have extensive knowledge of what's available within local communities.

This expansion of role has been facilitated in part by an increased appreciation of the growing range and increasing flexibility of supports available in local communities. However, practitioners have also attributed it to their enhanced confidence in opening up these different types of conversations and the enjoyment derived as a result, with much of the value often lying in the conversation itself.

Changes in Practice as a Result of Focusing on Personal Outcomes

The practitioners identified a number of changes to their practice as a result of focusing on personal outcomes. These changes could again be quite subtle and yet profound:

“When working in the hospital, you just don’t think that way at all. You focus on the presenting problem. It made me think outside the box. Before, I think I’ve always thought in terms what people will be able to do, rather than who they’ll be able to be”.

“It [practice] has changed, just by thinking about what people can do and their lives, and then seeing where I fit into that bigger picture”.

The changes were also often firmly set within the realities of system pressures, suggesting that practitioners had reflected upon the purpose of their engagement, their role and responsibilities:

“My role is to support people at home to carry out activities of daily living. What I’d always do is see people, have a chat about what they normally do and what they would like to get back to. We are time limited - we do need to move people on, so people can get out of the acute settings. So I’m focused on the immediate changes, what we can achieve in the short-term. But this has made me think more about their lives after I’ve gone”.

The importance of having these conversations, connecting with people’s lives and relating in

a different way was implicit within a number of accounts, but some practitioners had reflected upon the nature of their relationships more explicitly:

“It changes the relationship. I’m able to put a lot more of me into the conversation now. We were always discouraged from doing that. But it does open up a lot of lines of inquiry into parts of people’s lives that wouldn’t come up otherwise. I don’t think it’s unprofessional. They see the uniform. But I’m a daughter, a wife, a friend and a mother. I just happen to work as an OT. People have expectations too and I need to respect that, but also find ways to break through it where appropriate. People are now thanking me for listening and talking with them at a person level and I’m thanking them in return. It’s a more enjoyable way of working, of relating to each other”.

Embedding a Focus on Personal Outcomes in Practice

Recording and Using Outcomes Information

As a project, SHINE concentrated on establishing proof of concept and, importantly, prioritising and improving engagement. A focus on identifying and supporting people to achieve their personal outcomes had become very much part of practitioners’ conversations with older people accessing the service. With this in place, questions about documentation, recording and the use of information for routine care planning, ongoing learning and demonstrating service impact

could then be addressed and this is being taken forward through the appointment of clinical champions.

Working on a Case By Case Judgement Basis

This is not to say that practitioners are taking this approach with every person referred to the service, nor that they considered this something they would or should aspire to given the diversity of the 'case mix' and individual life circumstances. However, considered thought had been given to the types of encounter most conducive to this way of working.

Length of the engagement was a key criterion, with longer periods of involvement seen as lending themselves to a richer type of

engagement, but this was not set in stone. Some thought had also been given to the type of older person most likely to welcome or benefit from this approach, which again recognised the importance of practitioner discretion and judgement:

"There are no criteria as such, but it has to be someone we feel could benefit from this sort of approach and someone we feel we are engaging with. I don't mean more articulate, to emphasise, engaging is really a two-way thing. With some people it's just a case of, "get me a stick, show me how to use it properly and then let me get on with it". Some older people are quite capable or very well supported anyway".

Generic District Nursing Services

Overview

A further opportunity arose through the SHINE project to connect with generic district nursing services. District nurses had been invited to take part in personal outcomes training and learning sessions to determine if they too might have conversations with older people during routine care encounters to identify ways of supporting them to work towards their personal outcomes.

Care Context

The generic district nursing services are concerned with providing the best care in very diverse situations. The majority of the people supported by the service are older people. Sometimes the nurses will visit people regularly over an extended period, but with each visit typically being of a short duration, such as daily visits to administer injections. In other scenarios the number of visits will be more restricted, down to a short single visit to remove a few sutures.

The district nurses use a range of assessment tools, most often with a very specific clinical focus. In addition, most of the procedures carried out are guided by strict evidence-based protocols. Many of the

'tasks' undertaken are expected to be completed in a specific (and often very short) time period. The ability to set expected times for procedures has resulted in system capabilities to programme the district nurse's day very tightly. Often shorter procedures are grouped together into the early part of the day, which can therefore comprise a large number of visits.

However, alongside this the nurses play an important role in supporting carers and also undertake a growing volume of palliative care giving, which can extend over varying time periods and can require high emotional investment.

Implications of the Care Context for the Focus on Broader Quality of Life Concerns

The clinical nature of main assessment processes and much of the care provided offers reduced scope for 'personalisation' in the sense of being responsive to what matters to the person. There is also often much less dependency on or scope for the person's contribution in achieving clinical outcomes.

While there were situations where the district nurses carried out less clinically oriented assessments, often they only became involved in the event of a crisis:

"Then there are the crises. You can be in the middle of your scheduled visits and you walk in on one. For example, I was treating one man for wound management, but when I arrived he had just fallen. I was there supposedly to carry out a 20 minute procedure. The daughter-in-law was there as his main carer and she was at breaking point. She couldn't cope anymore. I spoke to her about how she was feeling and what we could offer to help and we put in a lot of supports, which she was very grateful for. But that was a crisis situation and I was the fixer, drawing on all our standard services, a bit of emergency respite. Ideally I would go back and see her, but I don't have the space in my schedule to go back and have the longer conversation. Now that wasn't a one-off visit. I'd been in several times before and we'd spoken about how she was getting on, but everything was always okay, the family network was strong. It took a crisis and actually seeing that crisis before she could say how she was really feeling. She thought it was her place to provide the support and she would be judged as uncaring if she said anything".

Comment: The above example illustrates the pressures faced by district nurses and the difficulty in prioritising time for conversations that might result in more preventative forms of support. It also reinforces the importance of establishing trust with carers and building relationships to enable them to open up about feelings such as guilt before any such supports can be considered.

The potential value of applying some of the concepts underpinning a personal outcomes approach in their more everyday conversations with people was recognised by the nurses, but lack of time was again perceived as a major barrier. In most cases, comments were concerned with having insufficient time to open up deeper conversations, but sometimes the issues went further:

"I can see the value of having this type of conversation with people. I really can. I see the crises and it makes sense to try to prevent them. The difficulty I have is that for many of my visits I am there to carry out a very specific clinical task and you need to be in and out like a whirlwind. I can have 17 visits to do in a morning, I need to get blood, make sure injections happen on time. Sometimes I am trying to close that conversation so that I can get that blood dropped off on time. It is not even about not having time to open it up; sometimes I am aware that I am deliberately closing the conversation off because I need to be somewhere else. And ideally you would like to have time to go back and have the conversation later, but that's not the reality".

A further concern raised was whether the nurse was actually best placed to have the conversation and the risk of duplication:

"The community is so big now, there are often so many different teams and so many people involved in a person's care. You have to consider: Are you best placed? Is someone else involved who might be better placed? Are you duplicating? Each case will be different".

Identifying and Supporting Personal Outcomes in Practice

Different Ways of Engaging with Outcomes in Broader Health Domains

Despite the barriers that often prevented the district nurses from engaging with the broader business of valued living, there were always exceptions:

Expanding the Practitioner Role: Supporting Carers Practically and Emotionally

Finding the Time to Avoid the Crisis

I was speaking to one lady who was the wife of a gentleman who was my patient. I had been involved and coming in for a while. We got round to talking about her and how her life was going and that conversation happened gradually, over time. Eventually she asked about an 80+ exercise class, so I tried to get the information for her and spoke to one of the local coordinators about what was available locally. Now she was a very private lady and it took a lot for her to begin to talk about how she was feeling and what was important for her. But she knew what she wanted. She wanted some domestic help to free up some of her time, and with that time she wanted to do something for herself. I got the Fife newsletter and saw that it contained some relevant information and I also got a booklet from the Elderly Forum and gave it to her and she was able to use that.

Comment: The above example again reinforces the importance of building relationships and establishing trust before these sorts of conversations can take place. The extension of the nurse's role can also go beyond helping to find practical or social supports to include the provision of direct emotional support for carers to enable them to open up about their feelings and priorities. This often happened gradually over a series of visits.

Expanding the Practitioner Role: Directly Supporting Emotional and Spiritual Dimensions of Health

Stepping Outside the Comfort Zone: Having the Big Conversations

I have quite a lot of palliative care patients and I can be involved for different lengths of time. Sometimes you're involved for quite a long time. Attitudes and responses to discussions about resuscitation are different in every case and facilitating these types of conversations with the family can be a scary experience. It requires a very frank discussion that is usually passed on to the GP. Usually that's what I'd do. But I had been speaking to one man about what mattered to him and as I listened, really listened, I realised that this gentleman wanted me to do it. He had confidence in me as a nurse and was more comfortable with me. That was what he wanted. He wanted to draw the family together and he wanted me to be there and support him through it.

I did have butterflies and thought what if this doesn't go well? It's such an important conversation to have. But it was his conversation, and he just needed me to be present. I had a mature student nurse with me at the time, and we reflected on how we both felt about our roles and our responsibilities to the man and to each other, and if we were able to support it psychologically. She was able to cope - to combine that maturity and life experience. I pushed myself to my emotional limits and learned a great deal about myself as a person and about just being there with people. I did step out of my comfort zone, but I never felt I put myself in a place where it wouldn't be beneficial to the family. It was a very positive and very powerful experience".

Comment: The above example illustrates the emotional demands placed upon district nurses when asked to engage in life's big conversations, particularly when not accustomed to doing so. It also highlights the importance of dialogue and reflection, self-awareness and awareness of the feelings of colleagues, as well as the feelings of people being supported and their families, consistent with the notions of relationship-centred care.

Changes in Practice as a Result of Focusing on Personal Outcomes

While not applying the concepts routinely, the district nurses were nevertheless able to identify a number of changes to their practice as a result of focusing on personal outcomes:

"I have been thinking about this a lot and while initially I thought no, this doesn't fit with the type of work we do, it has changed my practice. I can think of 5 or 6 cases over the last few weeks where I've had a very different conversation from the ones I'd usually have and a different sort of response. That may not sound many, when you consider how many visits I do in a week, but where the opportunity has arisen, I've been able to think much more about what this is going to mean to the person's life - or end of life".

While time pressures featured prominently, there were also direct benefits from this way of working:

"Just thinking about what people can do means I'm able to leave a lot more with people rather than doing it all myself. You know, they might be perfectly capable and quite happy to phone up community alarms and I can give them the number, or I can give them information about what's on in the community. I don't have to do it all."

Embedding a Focus on Personal Outcomes in Practice

Clinical care protocols, documentation and recording systems used were generally not conducive to personal outcomes focussed working, and opportunities to apply in practice were seriously limited by time constraints. However, there were always opportunities to engage with and to support practical, social, emotional or spiritual issues more directly and deeply.

Anticipatory Care

Overview

The following insights were gained through the opportunity to work with the IMProved Anticipatory Care and Treatment (IMPACT) team in Lothian. The team was established in 2008.

Strategic Drivers and Service Priorities

The IMPACT team is a nurse led service that

was established to improve the quality of life for people living at home with complex and progressive long term conditions and to offer support to their carers. There is also a strong emphasis on preventing avoidable admissions to hospital through support for enhanced self management and anticipatory care. It is quite a resource intensive service and the team's success in keeping people out of hospital is closely scrutinised.

Care Context

The IMPACT team comprises highly experienced district nurses who have received specialist training in supporting people with complex conditions. The team is led by advanced nurse practitioners. Unlike the other services discussed in this insight report, there is little diversity in the 'case mix' or the type of engagement. People supported by the service are primarily living at home with complex and progressive conditions such as Chronic Obstructive Pulmonary Disorder (COPD), and often have multiple conditions. The service has the specific remit of supporting people whose repeated admissions to hospital could potentially have been avoided through better understanding of and confidence in managing their conditions. Although the team does receive some referrals, there is a strong case finding element to the work. This entails using 'SPARRA' scores, which give an indication of people at increased risk of admission based on previous admission patterns. On receipt of SPARRA data, the team then looks at admission histories and individual circumstances in more detail to try to identify people who might benefit most from specialist support from the team. Unusually, contact with the service is therefore largely unsolicited and is often ongoing or for a prolonged duration.

With conditions such as COPD, people usually only see healthcare practitioners when they become very unwell and that often results

in an admission to hospital. The team was set up to support people and their carers to better understand what is happening and not to panic when frightening episodes of illness occur, to anticipate exacerbations and to be proactive in countering them, and also to reduce the likelihood of exacerbations happening by making some lifestyle changes. Again unusually, there is typically no "clinical task" involved in the ongoing care and support provided by the nurses.

In addition, many people supported by the team experience long periods of illness and fatigue, their activities may be curtailed by breathlessness or the need to use oxygen, and often they may have become disengaged with life. A parallel objective is therefore to improve the quality of life for people living with these conditions and to provide support for their carers.

Implications of the Care Context for the Focus on Broader Quality of Life Concerns

Initially, from the practitioner perspective, inputs were concerned with monitoring, reducing the risk of exacerbations, and supporting people to manage the impacts of the condition on their lives. For people where the impact of their health condition on life was the primary concern, input from the nurses was welcome. Many people had had little contact with or were reluctant to 'bother' their GP. Patient experience feedback confirmed that having someone 'reach out' to them was perceived as beneficial in its own right. In such

situations, people would engage readily and take on board the advice that was offered.

However, the team quickly recognised that they were having less success with people where broader life concerns, such as social or material circumstances, took priority over the impact of the condition. In addition, conditions such as COPD can be extremely debilitating and the knowledge that the condition is going to get progressively worse can result in people becoming disinterested in life and disinclined to make the sorts of changes to their lifestyle that the practitioners advocate.

The role of the nurse practitioner therefore needed to become less prescriptive and to find other ways of connecting with people who were “disinclined to engage”. The practitioners themselves recognised that they needed support if they were to adapt to playing this revised role effectively.

Discovering Personal Outcomes and a Therapeutic Approach to Engagement

Facilitated Learning

The team first came across ‘*Talking Points*’ as an “evaluation tool” in 2008. Although later introduced to the *Talking Points Personal Outcomes Approach*, as a new and relatively costly service, an overriding concern with being able to demonstrate impact meant that, in their own words, they “managed to miss the point of personal outcomes completely”. The

team’s introduction to personal outcomes and to the enabling and therapeutic potential of outcomes focused conversations happened in stages, but was largely the result of skilled and sustained input in supporting self-management (as broadly understood) from the Thistle Foundation.

a) Whose Outcomes Matter?

The difference between “personal outcomes” (what matters to each person) and “service outcomes” (reduced number of hospital admissions, understanding your condition and confidence in managing your condition) first became apparent when the team was supported to record digital stories as part of service evaluation. They realised that the storytellers, having been invited to talk about what was important to them in life and how the service was supporting that, did not mention using their inhalers or understanding their condition. Instead people talked about the things (that an enhanced ability to manage their conditions was contributing to) within their day to day lives. Engagement towards self management improved after that to some extent, but the team was largely concerned with identifying personal outcomes as a means to their professional ends. Once personal outcomes were identified, a more clinically focused and often largely predictable action plan would be introduced. This approach again had limited success when used to support people who had other priorities in life or who had disengaged with life completely.

b) The Therapeutic and Enabling Potential of Outcomes Focused Conversations

The team then sought out ways to support its work with people who had very complex situations or were hugely dispirited. Some team members undertook training with the Thistle Foundation, led by Ross Grieves. This very practical training and facilitation incorporated strengths based approaches and techniques from solutions focused brief therapy to broaden people's possibilities and engender hope. The IMPACT team then began to focus on taking a therapeutic approach to engagement, finding out what was important to people as a starting point.

As a result, the team members began to realise that they were getting better at supporting people to identify personal outcomes, although this wasn't why they had gone on the training. The team also felt that their conversational skills improved, they became much better at listening to what people were really saying and started to connect with them in a different way. They also began to realise the enabling potential of outcomes focused working, recognising the important contributions that people made towards their own outcomes that extended far beyond adopting healthier behaviours or understanding and responding promptly to symptom changes.

c) Risk and Accountability

As the team began to support the "broader

business of living as well as possible according to one's own values and aspirations while having the condition"³, questions of risk, professional duty of care and accountability began to arise. The Thistle Foundation employs a very systematic approach to risk enablement, which requires being thorough, professional and person centred in planning risk taking strategies. Specifically, practitioners are encouraged not to take a negative or disapproving view, but to see the person's strengths and capabilities, to learn to step back and then to work with the person to think through the potential issues and to develop any necessary contingencies.

Identifying and Supporting Personal Outcomes in Practice

Different Ways of Engaging with Outcomes in Broader Health Domains

The way in which the IMPACT nurses have been connecting with people to support them to identify and achieve their personal outcomes has become integral to practice. The clinical expertise of the team remains invaluable and is invariably the key to unlocking a more valued way of living, but this expertise is now employed alongside enhanced skills in providing psychological and emotional support. Most significantly, whereas once the team defined its purpose as supporting people to better manage their condition, they now talk in terms of enabling people to live their lives.

Changes in Practice as a Result of Focusing on Personal Outcomes

"Our approach to practice has completely changed. We now start with a conversation and find out about the person and what their hopes are and what is important for them from the first meeting. Sometimes we don't take our nurses bags in with us on the first visit. That would have been unthinkable before".

Perhaps the most significant difference is in the practitioners' attitudes to risk and their

own responsibilities, as a result of the focus on people's capabilities and what they can do:

"We feel the pressure is off, not having to fix everything for everyone all of the time. We have a different perception. Seeing people's strengths has allowed us to step back. Hopefully that will lead to relief from burn out. It's also more enjoyable and rewarding. Some of the nurses have talked about reconnecting with their value base and why they came into the service in the first place".

This ability to 'step back' is illustrated in the following practice example:

Risk Enablement: Learning to Step Back

A gentleman with multiple conditions was referred to the IMPACT service for assessment.

On the first visit, when the nurse asked what was important for him, this took him aback as he was so used to being told how to manage his conditions. However, he said that he wanted to go to Australia to see his family and the nurse asked 'so what's stopping you'? She didn't take a negative view.

He identified that his health wasn't good enough and the nurse asked 'how would you know when you were well enough?' He replied, 'well I would be coughing less, and have less swollen ankles and my blood sugars wouldn't be all over the place'. The nurse took a step back approach and asked 'what is it going to take for you to do this?' and they then worked together to identify what strategies were needed. At the next visit he announced he had booked his flight!! The nurse was slightly alarmed and anxious that perhaps she had encouraged him too much, and began to wonder what would happen if he became unwell and if this was too risky. But again she took a step back approach and together they planned contingency if he became unwell on his trip, including advice, where needed, about rescue mediation and insulin control. He had a great time and sent the team a postcard.

Embedding a Focus on Personal Outcomes in Practice: Beyond Engagement

Having become ingrained within engagement practices, the focus on personal outcomes has now extended to recording practices and use of outcomes information. The team has been supported to redesign the documentation it uses to record and measure progress towards personal outcomes. It captures things in a way that supports people first and foremost, but also makes it easier to understand and improve practice and service provision. The redesign process involved the whole team and was a

process of continual reflection and learning. The team still needs to demonstrate its effectiveness and uses the “Talking Points” outcome categories to do this in summary, alongside harder data. However, the focus now is not simply on ‘measuring outcomes’, but first to identify what matters to each person using the service in the context of their whole lives and to support them to achieve that.

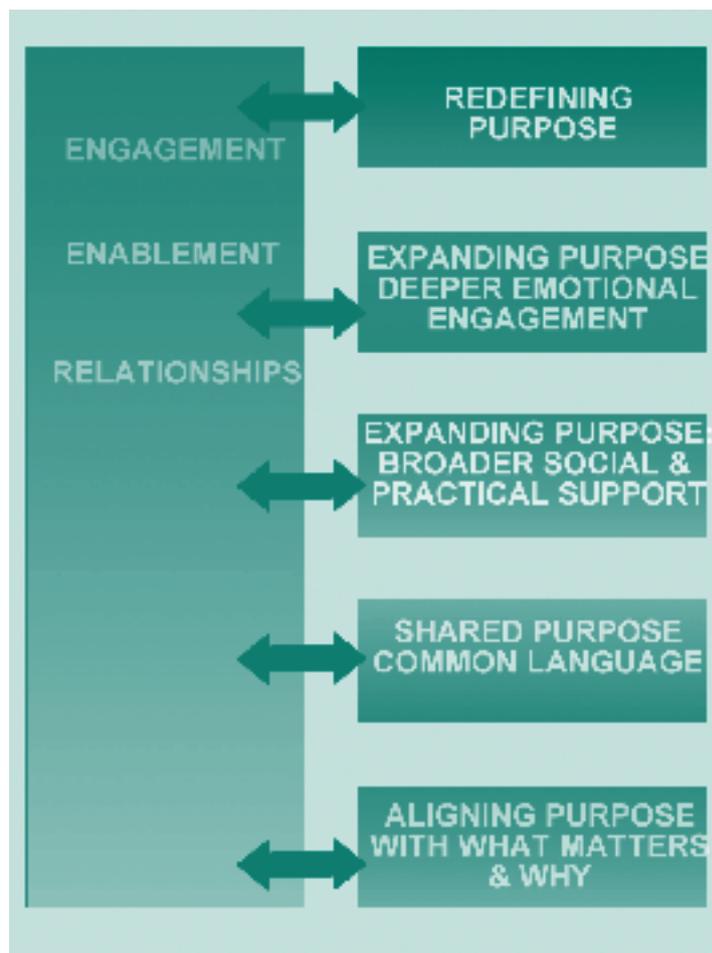
Conclusion

Introducing a focus on “personal outcomes” (or what matters to the person) into healthcare services presents a number of possibilities and challenges that vary both by context and by individual case. This insight report has explored these possibilities and challenges within 3 very different healthcare services.

In particular, it has considered the relatively unexplored issue of the different ways and extent to which practitioners working within the different care contexts might be expected to support the achievement of personal outcomes concerned with the broader business of valued living.

Within the context of partnership working, a focus on personal outcomes can provide a common language, increasing consistency and continuity across a multi-disciplinary team.

Within community rehabilitation and day hospital services, the identification of personal outcomes often resulted in ensuring that ‘traditional’ (function-oriented) inputs were fully aligned with what people valued in the context of their whole lives, and was based on a clear understanding of why things mattered. This resulted in subtle and yet significant changes to established practice. In addition, it sometimes entailed expanding the traditional role a little to engage more directly



with broader (social or everyday practical) concerns, connecting people with community resources to maintain or enhance their wellbeing, often using case by case judgement.

Within one generic district nursing service, a focus on what matters to the person more broadly had resulted in direct provision of practical, social and emotional support to carers over time, again responding on a case by case basis. It had also resulted in deeper emotional or spiritual engagement, encouraging reflection on roles, responsibilities and relationships, including relationship with self and with colleagues. This was deemed invaluable in a context that can require practitioners to switch seamlessly between the frenetic time and task oriented provision of clinical care to being fully present with people and their families at the end of life.

Finally, a focus on personal outcomes redefined the purpose of an anticipatory care and treatment service from one that was concerned with clinical condition and symptom management to a service that helps people to live their lives. This had entailed a significant shift in roles, attitudes and responsibilities, particularly with regard to risk enablement.

Alongside the differences encountered across the settings, which were largely attributable to the primary function, length and intensity of the care encounter, a number of common threads could also be identified:

- The central importance of trusting and supportive relationships
- The preventative potential of outcomes focused working and the subtle forms this can take
- Enhanced practitioner satisfaction as a result of working in this way

The extent to which practitioners engage directly in supporting people not only to identify but also to achieve their personal outcomes will vary by context and by case, but the value of connecting more deeply with people's lives and the development of supportive relationships is universal.

It is important that the value of supportive relationships in their own right is fully understood.



“We need to recognise the substantial intrinsic value of patients feeling valued, respected and supported within collaborative partnerships if we are not to miss a large part of the point of the shift towards a collaborative approach”

Entwistle & Cribb [2013]

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