# Resource sheet: measuring outcomes and Experience Led Commissioning

## Context

The Experience Led Commissioning process is designed to provide a strategic framework to mobilise values-based, person-centred care healthcare at scale. It provides a systematic way of commissioning that is aligned to achieve better outcomes because it helps system leaders to deeply understand and respond to what matters to people.

## Where does measurement of health outcomes fit with ELC?

A decade of research into organisations that have achieved better outcomes while often lowering costs demonstrates that they consistently work within a strategic framework that has three pillars.

1. **Understanding what matters:** values-based healthcare begins with identifying and deeply understanding patients so that you can describe a consistent set of needs determined by their health and related life circumstances. This equates to the ELC Discover stage
2. **Collaborative delivery:** interdisciplinary teams of caregivers work together to design and deliver comprehensive solutions for patients that meet those holistic needs. This equates to ELC Dream and Design stages; although ELC takes this stage to a higher level of participation as people and families who use services codesign with providers
3. **Measuring what matters:** system leaders need to align health care organisations around a common purpose. Health outcomes are the focus in a values-based healthcare system. Meaningful measurement of outcomes is thus fundamental to values-based healthcare. It is also essential to understand and capture the cost of its care for each patient. The outcome measures need to support providers to address what matters most to people and help them to understand what is enhancing their health and what is getting in the way of their recovery or self-management of long-term health issues. This requires a holistic approach with non-clinical, psycho-social interventions may be as important as medical care. Information drives improvement, the insights developed through the ELC process can provide the foundation for bespoke person-centred outcome measures that support this pillar

Working in a values-based way is, by default, outcomes focused and experience-led.

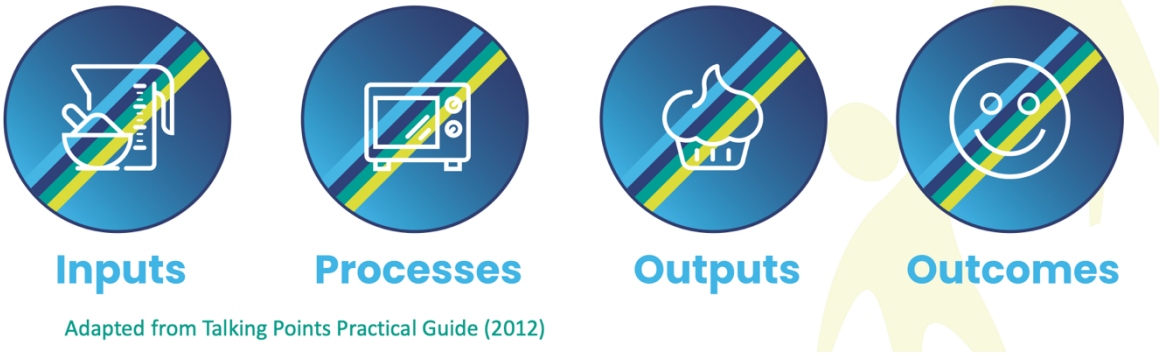
Bering focused on outcomes that matter to people demands that everyone thinks differently about their role within the health and care system and about the design of services provided for people and families.

ELC is aligned with this strategic framework and supports health and care systems to realise this shift in culture and practice by providing a systematic approach that delivers all the essential elements of system planning in one, tried and tested, evidence-based process.

## Measuring the outcomes that matter to people

As we have seen, being able to measure outcomes is essential to a values-based health system. Most systems will need to innovate in relation to outcomes measurement as part of this transition.

## What is an outcome?




Adapted from Talking Points Practical Guide (2012)

To better understand what outcomes are, it is helpful to illustrate using a metaphor. The metaphor is baking a cake.

**Inputs:** when we bake a cake, we use a recipe that specified ingredients (inputs) in very specific quantities. These are easy to measure and quantify. In a health and care system we can also easily measure inputs e.g. number of staff employed, cost of running the estate. Because inputs are objective, visible and easy to measure, they often dominate management thinking – the “cost” based model.

**Processes:** when we bake a cake, the recipe also defines the processes we use e.g. beat eggs and sugar together, bake for 30 minutes at a set temperature. Again, processes are easy to define and measure. In health and care systems, processes can also be defined e.g. a quality standard for a care pathway. Compliance with the pathway process or quality standard is visible and relatively easy to measure if we have good data collection systems. Because processes are objective and relatively easy to measure, they are often used as metrics within health and care systems.

**Outputs:** when we bake a cake, the output is the cake we produce because of the inputs and process. We can describe the cake – we can describe its colour; whether it has a filling, whether it has a topping. We can describe how it tastes

e.g. vanilla or chocolate. **Outputs are subjective**. What one person thinks about the cake and whether they like the taste may be different to how another person perceives it. In a health and care system, outputs are also measured, often self-reported by patients and thus more subjective. For instance, patient satisfaction with the service received, measures of pain, mobility, depression are outputs. Patient Reported Experience Measures (PREMs) are also output measures.

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**Outcomes:** the outcomes we create when we bake a cake describe how sharing the cake or giving the cake to a person who is celebrating a birthday makes them feel and impacts on their life. For instance, the birthday person may feel celebrated and loved. The cake will create positive memories and be the focus of the birthday event organised for the person. **Outcomes are unique to the person and thus highly subjective**. The same is true in health and care systems. For instance, for one person, the outcome they seek from a hip replacement may be playing with their grandchildren; another may want to be able to walk their dog; another may want to run a marathon; another to go back to cycling. For most, no longer being in pain will also be key. This output is the precursor to the personalised outcomes that follow. This illustrates the complexity of the measurement challenge that health and care systems have when they seek to be person centred, outcomes and values based.

## What tools are available to measure outcomes?

Most often, health and care systems measure outputs and processes rather than outcomes.

With the emergence of outcomes- and values-based care, that is changing, and people are exploring different ways of measuring what matters to people. In fact, the success of values-based health systems is predicated on the availability of tools that measure health outcomes in a holistic way.

Patient Reported Outcome Measures (PROMs) move us closer to measuring outcomes; although most PROMs create a numerical measure, which is counter intuitive to defining what matters to an individual person.

Rather than focusing on numbers, it may be more useful to think of outcome measures as a framework of domains.

These are sometimes presented as a series of “I statements” or “We statements” – and to work with the person to explore what good likes for them in relation to each domain.

Teisberg et al (2020)[1] describe health outcomes in terms of three domains: capability, comfort, and calm.

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[1] Teisberg E, Scott Wallace JD, O’Hara S. Defining and implementing value-based health care: a strategic framework. *Acad Med*. 2020; 95: 682–685

- **Capability** is the person's ability to do the things that define them as an individual and enable them to be themselves. A surrogate measure of this would be functional measures that indicate physical capability
- **Comfort** is having relief from physical and emotional suffering. In addition to reducing pain, improving patients' comfort requires addressing the distress and anxiety that frequently accompany or exacerbate illness
- **Calm** is the ability to live normally while getting care. It encompasses freedom from the chaos that patients often experience in the health care delivery system, and it is especially important for people with chronic and long-term conditions.

The authors suggest that care that improves outcomes across all 3 domains creates a better experience for patients and that capability, comfort, and calm describe outcomes that stem from the efficacy and empathy of health care delivery, rather than hygiene factors like hospitality.

Routine clinical practice cannot support the voluminous health outcome measure sets used in clinical research. There is clearly a need for innovation and new thinking around defining outcomes from a person's perspective – because generally outcomes are very person-specific. In the pursuit of this, health and care systems have explored the potential of person-centred outcomes.

## What are person centred outcomes?

The ability to measure whether services improve outcomes and address what matters to people is fundamental to a values-based health and care system and remains a challenge for most health and care systems.

Person centred outcomes (PCOMs) offer a solution. They measure the outcomes that matter to people on an individual level. These outcomes are usually unique to the person and expressed in their words.

Talking Points Scotland pioneered this approach and have described how to develop and embed PCOMs[2]. Their report, Talking Points: A Practical Guide, is provided in the toolkit folder Theoretical Foundations of ELC and provides a solid foundation for developing PCOM culture and practice.

Examples of quality of life outcomes frameworks developed by Talking Points for two communities of interest are provided in Table one below.

The insights generated through ELC Discovery process describe the consistencies and differences around what matters within a community of interest. This helps us to define clusters of outcomes by community of interest. For instance, the outcomes

[2] https://lx.iriss.org.uk/content/talking-points-personal-outcomes-approach-practical-guide.html

that matter most to people living with congestive heart failure are strikingly consistent and markedly different from the outcomes that matter most to women who are pregnant.

**Table one: example quality of life outcome frameworks Talking Points**

| Community of interest | Person centred outcome domains |
|---|---|
| Quality of life outcomes for older adults living in the community | • **Social contact:** The person feels that they have enough contact with significant other people and that they have opportunities for social participation (to avoid isolation). This can include family, friends, other service users and staff<br>• **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 can include hobbies, voluntary work, education, and employment<br>• **Safety:** The person feels safe and secure at home and in their community. The person feels safe and secure when using services. The person also feels emotionally safe and can rely on access to support when they feel less safe. Where significant concerns about risk arise consideration should be given to a risk assessment being undertaken<br>• **Staying as well as you can:** The person feels that they are as physically and mentally well as they can be, given any illness or condition they have<br>• **Living as you want and where you want:** The person can plan and have control over their daily life and is able to live where they want. |

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| Quality of life outcomes for unpaid carers | • **Health and wellbeing:** Negative impacts of caring on health and wellbeing are minimised. The person has sufficient sleep, exercise, and some fulfilment in their life<br>• **Having a life of their own:** The carer can engage in activities which are meaningful to them, including employment where relevant, and to maintain social links, or meet other obligations<br>• **Supporting or improving the relationship with the cared for person:** The carer feels sufficiently supported to maintain, or where relevant improve their relationship with the person they care for, including access to mediation where views conflict<br>• **Accessing financial advice:** The carer has access to information about benefits entitlements and other financial advice for both the cared for person and him/herself. |

The Talking Points programme team develop outcomes frameworks by undertaking qualitative research that mirrors the ELC Discovery stage with the focus community of interest. From the insights generated, they define outcome domains and their descriptors.

They have tested how to build these outcome domains into baseline assessments and on-going reviews undertaken by clinicians or formal carers with people as part of regular care and support so that caregivers track outcomes and measure progress towards personal goals within each domain as part of routine care and support.

The data generated by these “talking point” conversations can be aggregated to provide a population level picture of what matters to people and whether the care they are getting is helping them achieve their personal outcomes and thus adding value.

Because ELC Discovery enables collection of the same insights, ELC Discovery data can be repurposed to create person centred outcome frameworks that can be used by clinical teams within values-based contracts.

The ELC team has developed a robust process to translate ELC Discovery insights into PCOM frameworks to create Life Improver Scores™. Life Improver Scores can then be incorporated into assessments and reviews and provide a way of measuring

outcomes at all levels of the health and care system so that health outcome data is generated automatically when the right information management systems are in place.

By embedding PCOMs, measuring health outcomes is no longer seen as a complex and onerous task for clinical teams.

Instead, at the individual patient and family level, providers benefit from incorporating discussions about what defines improved health, what matters to the person and the outcomes they want to focus on improving into planned clinical conversations – and what matters most informs treatment choices and clinical management decisions.

ELC had already developed Life Improver Scores™ for several communities of interest. More information about the ELC Life Improver Score™ programme is available from: georgina@elcworks.co.uk