



## Long Term Conditions Work Stream Executive Summary

Understanding and taking steps to improve ‘patient experience’ is at the heart of high quality healthcare. It makes sense for human, moral, clinical and financial reasons and increases job satisfaction for NHS staff. While there is a growing body of evidence surrounding the measurement and improvement of experience in specific care contexts, most notably the hospital inpatient setting, improvement activity based on the experiences of people living with long term conditions is still at an early stage.

We know that the care experience of people living with long term conditions cannot be reduced to a series of encounters with healthcare services. Despite this, it is possible to distil key learning from experience work conducted by the Better Together Programme in Scotland, and other UK and international studies. The many existing resources use a wide range of experience-based collection methods and improvement techniques. Most focus on episodes of care or relate to specific conditions, but others are more generic in nature.

**Part 1** of this report describes these resources, their purpose and their limitations in the context of supporting people living with long term conditions. We also expand upon each of 3 messages:

Measure what matters to the people who use healthcare services  
Use a range of methods to build a complete picture of experience  
Focus on improvement

When considering ‘what matters’ the distinction is made between ‘transactional’ and ‘relational’ factors influencing the experience of care. These factors require different improvement approaches. The former concern ‘what we do’ and are amenable to established service improvement methodologies. ‘Relational’ aspects of care concern ‘how we do things’ and are influenced more by education, values, leadership, culture and the philosophy of care. ‘*Being responsive to what matters to the individual*’ and ‘*being a partner in care*’ require a shift from ‘doing for’ to ‘doing with’. We expand on the implications of this shift throughout the report.

In **Part 2** ‘*Listening, Learning and Improving Together*’ we focus on understanding and improving the care experience of people living with long term conditions. This work was informed by the “**It’s All About Me**” event, hosted in

partnership with the Scottish Health Council in April 2010. This event gave some clear messages about what contributes most to the experience of care for people living with long term conditions, carers and staff who support them, and also how best to progress the improvement work. Our approach has focused on identifying, sharing and spreading good practice in experience-based improvement activity; supporting staff to conduct experience-based improvements; and supporting people living with long term conditions to be partners in improvement activity.

Guided by the need to use a range of methods to build a complete picture of experience, this work has examined and tested various practical quantitative and qualitative approaches, including retrospective data collection and rapid feedback tools together with collection methods embedded in ongoing care processes. It also highlights the importance of using existing evidence about people's experiences, where available, and cites the example of combining the secondary analysis of qualitative interview studies previously conducted by the Health Experience Research Group at the University of Oxford with a targeted local programme of user and carer engagement.

The work stream spanned a wide range of care and support including supported self management, management of specific conditions, care management, anticipatory and palliative care. Importantly it included experiences of children and young adults, transitions, people living with multiple conditions and the work of Managed Clinical Networks. Despite this diversity, a number of recurrent themes emerge:

'Experience-based' improvement work has expanded from focusing on people's *experience of using healthcare services* to include ways of learning from and making best use of the *lived experience and expertise* of people living with long term conditions and their supporters.

There has been a marked shift from passive consultation to the meaningful engagement of people living with long term conditions in improvement activity, mirroring the shift towards shared decision making and "*being a partner in care*" within individual care encounters.

There is greater recognition that "*being treated with responsiveness to what matters to the individual*" is not confined to "the what" and "the how" of service delivery, but concerns "what matters" in the context of everyday life.

These are encouraging developments but efforts remain largely concerned with what services currently do and how. Yet we know that the experience of care is inextricably linked with the extent to which these services, alongside other supports, enable people to live full and positive lives.

In **Part 3** therefore we look beyond experience to consider care outcomes. By asking why we do things and with what impact, we introduce the possibility of new ways of working. Several examples are provided, beginning with the learning from the Self-Management Fund whereby the lived experience and expertise of people living with long term conditions has been shared, not only to inform service improvements, but also to support others more directly through motivational and educational stories, and in the form of peer support. It is also essential that healthcare professionals are equipped to support people to self manage, guided by the principles of person-centred care planning. Here there is

much that can be learned from fields such as dementia care, mental health, children's services, and in supporting adults with learning difficulties, and the training programme developed by the Thistle Foundation is referenced as an example.

Another example of person-centred planning and assessment is the Talking Points: Personal Outcomes Approach, which is increasingly finding applications in health. The approach offers a them by first drawing on the person's own strengths, capabilities and natural support systems and then on statutory services and wider community supports as appropriate. The outcomes framework used includes a number of 'process outcomes', which share much in them by first drawing on the person's own strengths, capabilities and natural support systems and then on statutory services and wider community supports as appropriate. The outcomes framework used includes a number of 'process outcomes', which share much in common with the factors known to influence experience. By embedding 'process outcomes' within an overarching outcomes framework, it is possible to identify relationships between aspects of services, the way in which support is provided and the attainment of quality of life and change outcomes.

An outcomes-focused approach introduces the possibility of greater choice and, where desired and appropriate, control over how outcomes are achieved. The learning from the Self-Directed Support in Health pilot is shared. Such approaches open the way for rethinking what we mean by 'care' and 'support' and explore the role of communities. Focusing on strengths, potential and assets not only within individuals, but also within communities, can enable individuals, communities and service providers to work together to tackle local issues. This is illustrated through the Healthy Communities Collaborative case study, which presents a refreshingly positive picture of ageing.

An emphasis on strengths, empowerment, enablement and partnership is at the heart of supporting people to live full and positive lives and must be embedded within our approach to measuring, understanding and improving the experience of care. Realising our person-centred Quality Ambition is about shaping the culture, attitudes and human relationships that underpin good quality care and improve experience and outcomes for people.

This report identifies future challenges to be addressed. Not least is the recognition that:

**“People must always come before numbers. Statistics, benchmarks and action plans are tools, not an end in themselves. They should not come before patients and their experiences”.**

**Robert Francis QC**

**The Mid Staffordshire NHS Foundation Trust Inquiry<sup>1</sup>**

The report from Health Service Ombudsman<sup>2</sup> describing the experiences of ten older people across England provides a further shocking warning to healthcare services of the dangers of losing sight of the people they serve. Valuing and investing in patient experience measurement, rapid feedback methods and continuous improvement activity are essential steps towards consistently compassionate practice, enriched care teams and high quality services.