Sharing the Learning

Report from the Better Together Long Term Conditions Work Stream

March 2011

LTCAS
LONG-TERM CONDITIONS ALLIANCE SCOTLAND
people not patients

Long Term Conditions Collaborative

Better Together
Scotland's Patient Experience Programme

Contents
Foreword

Foreword 1

Executive Summary 2

Part One: Patient Experience 6

Why is Patient Experience Important? 7

'Measuring' Experience 8

Useful Resources 14

Part Two: Listening, Learning & Improving Together 22

Experience and Long Term Conditions 23

A Snapshot of Current Activity 26

Supporting Local Care Teams to Engage in Experience-Based Measurement and Improvement Activity 41

Supporting People Living with Long Term Conditions to be Partners in Improvement Activity 47

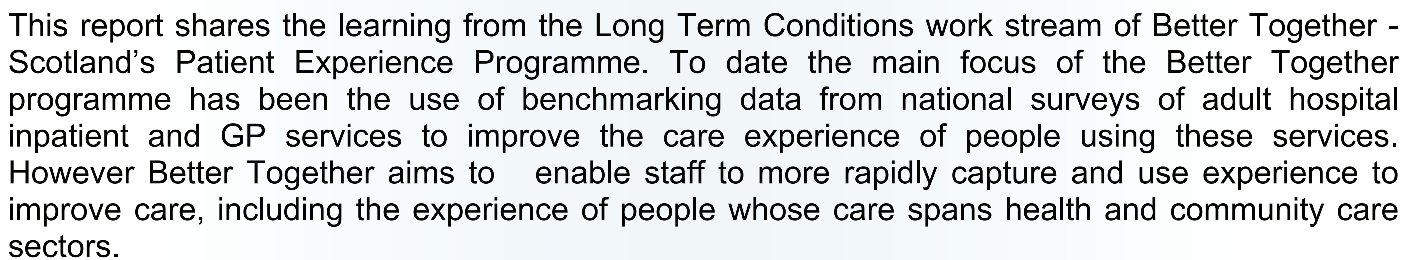
Part Three: People Not Patients 54

Moving Beyond Experience to Outcomes 55

Future Directions 63

Definitions 64

References 66



This report shares the learning from the Long Term Conditions work stream of Better Together - Scotland's Patient Experience Programme. To date the main focus of the Better Together programme has been the use of benchmarking data from national surveys of adult hospital inpatient and GP services to improve the care experience of people using these services. However Better Together aims to enable staff to more rapidly capture and use experience to improve care, including the experience of people whose care spans health and community care sectors.

To support this aim the Better Together - Long Term Conditions work stream has explored practical ways to encourage and use regular and timely feedback to improve the experience of care for people living with one or more long term conditions. These individuals and their carers often have multiple contacts with different professionals and services and greater need for coordination and continuity of care and support. As most people with a long term condition lead full and active lives and provide much of their care themselves, it is also important that we understand and improve the experience of self management support to enable this.

The aim of our Person Centred Quality Ambition and social care policy on personalised outcomes as well as self directed support is to empower and enable people to have greater choice and control and to participate in shared decision making. We know this requires a change in the way we design and deliver our services together. We have taken this work stream forward in a spirit of co-production and in partnership with the Long Term Conditions Alliance Scotland (LTCAS). In addition, the work plan and philosophy were informed by the **"It's all About Me"** event, hosted by Better Together and the Scottish Health Council in April 2010 and in collaboration with LTCAS and the Long Term Conditions and Mental Health Collaboratives.

Between August 2010 and March 2011 we have learned from people of all ages who use our services. We have tested ideas with professionals and support staff from acute and primary care, social care and community and voluntary sectors – all committed to improving the way we deliver care and support together.

In the context of this work we have recognised that the use of the word patient sits at odds with supporting people with long term conditions. We know that we need to understand the impact on people living with long term conditions beyond when they engage with healthcare services, and also how those services enable them to live full and active lives wherever possible. We also recognise that understanding and improving the care experience requires insights from families, carers and other supporters in local communities.

We encourage you to share and spread this report widely and to use the practical tools and resources it highlights as you strive to continually improve the experience and outcomes of care. We also encourage you to mirror the spirit of partnership and collaboration with the third sector to fully support those living with long term conditions.

Foreword

Anne Hendry National Clinical Lead for Quality - Work Stream Chair

Carol Sinclair Better Together Programme Director

Audrey Birt Chair Long Term Conditions Alliance Scotland

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. 'B*eing 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

Executive Summary

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.

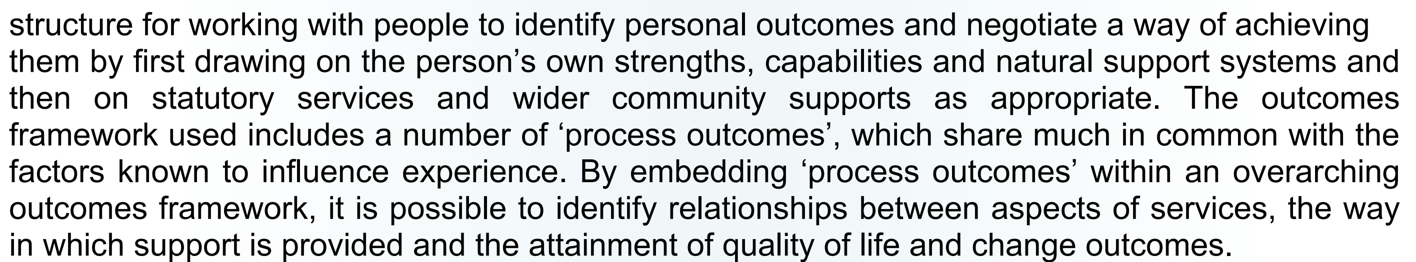
The work stream spanned a wide range of care and support including supported self management, management of specific conditions, care management, anticipatory and palliative care. Importantly it included experiences of children and young adults, transitions, people living with multiple conditions and 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



structure for working with people to identify personal outcomes and negotiate a way of achieving 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[1]**

The report from Health Service Ombudsman[2] 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.

Part One

Patient Experience

Part One:
Patient Experience

Why is Patient Experience Important?

> **"If quality is to be at the heart of everything we do, it must be understood from the perspective of patients"**
>
> **Lord Darzi, NHS Next Stage Review[3]**

The self-reported experience of the people who use any service is an important indicator of the quality of service delivery and can pinpoint the issues that people accessing the service think are important. Until recently, the means of providing feedback about healthcare services have been limited, often confined to satisfaction surveys or complaints.

While measures of satisfaction can be useful in benchmarking services or monitoring trends over time, they fail to provide a clear indication of what needs to be done to improve care. No organisation would wish to rely on complaints as ta means of identifying areas for improvement.

> **"I didn't want to complain. I'm not one for making a fuss. I just wanted to make sure that the same thing didn't happen to anyone else. But I was told that if I wasn't happy then I should follow the complaints procedure. There didn't seem to be any other way to make my point"**
>
> **Digital Storytelling in Health and Social Care Project (2009)**

Recent high profile service failures have highlighted a lack of attention to what people were saying about their experiences of care, with reports describing the experiences of ten older people, no matter how unrepresentative, spelling out the truly harrowing consequences that can result:

> **"The difficulties encountered …were not solely the result of illness, but arose from the dismissive attitude of staff, a disregard for process and procedure and the apparent indifference of NHS staff to deplorable standards of care".**
>
> **Health Service Ombudsman Report (2011)[2]**

Experience is however a product of the whole system of care. Measuring experience aims to capture people's perspectives on the quality of care in a way that makes the link with improvement transparent and direct.

Understanding and taking steps to improve 'patient experience' is at the heart of high quality healthcare. There is increasing evidence of an association between experience and clinical outcomes[5] and improving experience is also justified in terms of value for money. Staff too want to work in an environment that provides a positive care experience and the quality of caring relationships influences job satisfaction.[4] Ultimately, ensuring a patient positive experience is vital for moral and human reasons. Improving patient experience makes sense.

Part One:
Patient Experience

Measuring Experience

> **"Our NHS will listen to peoples' views, gather information about their perceptions and personal experience of care and use that information to further improve care".**
>
> **The Healthcare Quality Strategy for NHS Scotland (2010)[6]**

In order to improve 'patient experience', we need evidence to better understand the current quality of experience, to identify the aspects of experience where improvement is needed and to measure improvements over time. Direct feedback from people who use care services and from their families and other supporters is the core method of gaining this understanding.

The focus on measuring 'patient experience' is a recent development, with much of the initial activity focused on acute or discrete episodes of care.

For people living with long term conditions, we know that the experience of care cannot be reduced to what happens during a series of encounters with healthcare services, and is inextricably linked with the extent to which these services, alongside other supports, enable them to live full and positive lives.

While work to measure and improve the experience of care for people living with long term conditions is in its infancy within the NHS, it is however possible to distil important learning messages about measuring and improving 'patient experience' that are relevant irrespective of the care context and therefore provide a useful foundation to build upon.

Below we identify 3 key messages that appear consistently in the outputs from national and international commentators in the field, reiterated by our own NHS Scotland Boards:

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

Measure What Matters

Measurement of 'patient experience' should focus on what matters most to the people who use care services. Experience is by definition highly subjective and measurement therefore tends to focus on the factors which make the most difference to the experience of care. Here a number of evidence-based frameworks have been developed. While differing in purpose and coverage, they nevertheless all point to a core set of very similar themes[7]:

Transactional Aspects of Care – The 'What':

- Maintaining physical comfort
- Getting the right information at the right time
- Participation in decisions, feeling confident and in control
- Experiencing coordinated, joined up care (either across parts of the health service or with other services such as social work and the voluntary sector)
- Receiving prompt care and treatment (generally, not just in an emergency)
- Being provided with clear explanations

Relational Aspects of Care – The 'How':

- Being treated with respect by all staff, and preserving dignity and privacy
- Being treated with care, compassion and empathy and as whole person
- Being treated with honesty, listened to and involved
- Being treated with responsiveness to what matters to each individual
- Being a partner in care

The distinction between 'transactional' and 'relational' aspects of care, as featured in *Patient Experience: The Intelligent Board Report* (2010)[5] is useful as the two domains require quite different improvement approaches. While the former are amenable to service improvement methodologies, 'relational' aspects of care pertain primarily to practice and are influenced by education, values, leadership, environment and culture, and by the philosophy of care.

In addition to the above generic influences, other factors or more specific derivatives may also emerge as important within particular care settings, or for particular types of service. For instance, in the case of general inpatient experience, environmental factors such as noise and cleanliness are known to be important, together with food and drink, while for mental health inpatients, factors such as feeling safe on the ward, access to talking therapies, meaningful activities and fresh air are important, together with respect of rights.

National Patient Experience surveys can be a useful starting point for identifying pertinent aspects of experience for a specific care setting or service, as they are invariably informed by comprehensive importance work, including qualitative research, literature review, focus group verification and prioritisation of identified themes and issues. For instance, the content of the Better Together national patient experience surveys has been informed by UK and International experience work focused on completed episodes of hospital care or access to general practice. The questionnaires are available at: www.bettertogetherscotland.com.

We consider the factors that make the most difference to the care experience of people living with long term conditions in Parts 2 and 3 of this report.

Part One:
Patient Experience

Use a Range of Measurement Approaches

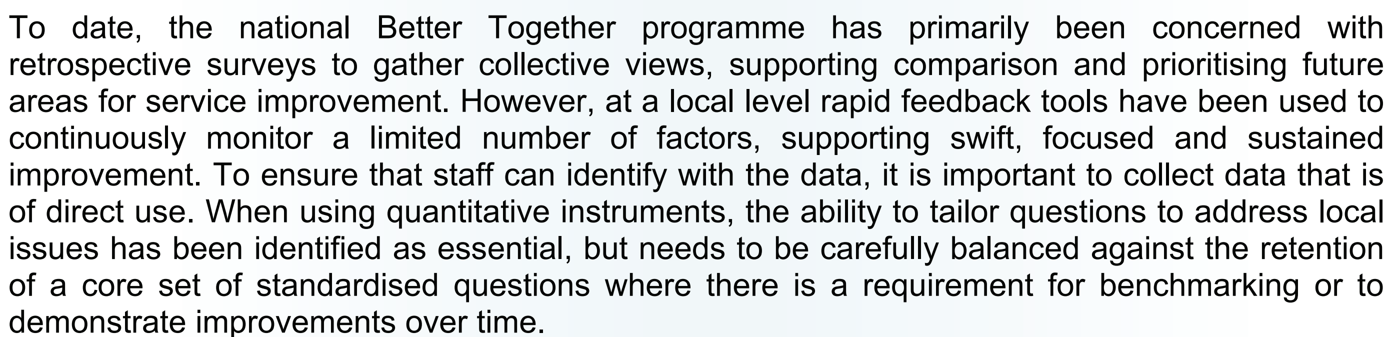
> **"It is important to guard against the rise of a measurement industry that detaches frontline staff and caregivers from patients and their experiences by focusing too narrowly on statistical indicators and measures. Instead, a range of approaches is needed".**
>
> **The King's Fund: Point of Care Programme (2009)[4]**

There is no perfect 'patient experience' measurement tool and no one method should be over-relied upon. Rapid quantitative snapshots are useful in monitoring quality continuously but are not statistically representative, while robust retrospective data may not be timely enough for improvement needs. Equally, experience surveys can identify broad issues where improvement is needed (the 'why') but rarely pinpoint the specific problems, including those not previously recognised, or provide answers as to how these might be resolved that may not occur to those immersed in delivery (the 'what' and the 'how'). Here accounts gathered through qualitative approaches can be a rich source of information, either directly or through thematic analysis, while individual accounts can also help care professionals to reflect on their own and their team's practice, or to provide human insights at Board level.

Appropriate methods will vary according to purpose, as detailed in Table 1 below.

Purpose	Method
Human insights	Reflective practice using complaints, personal stories and feedback from observed practice, plus significant event analyses
Rapid identification of emerging issues	Customised Rapid Patient Feedback Surveys Comment cards and issues raised verbally or through observation
Individual experience and outcomes improvement	Listening to stories, emotional touch points Goal setting, care planning and review
Testing services	Mystery Shopper
Deep dives	Local surveys Interviews, focus groups and formal observation Rich patient narratives
Ongoing engagement	Patient panels
Tracking in-year progress and local benchmarking	Local 'fixed content' surveys and routine data
Monitoring national trends, board-level benchmarking & identifying priorities for NHS Boards, larger hospitals and GP services	National Better Together surveys and routine data

Table 1 - Aligning Method and Purpose



To date, the national Better Together programme has primarily been concerned with retrospective surveys to gather collective views, supporting comparison and prioritising future areas for service improvement. However, at a local level rapid feedback tools have been used to continuously monitor a limited number of factors, supporting swift, focused and sustained improvement. To ensure that staff can identify with the data, it is important to collect data that is of direct use. When using quantitative instruments, the ability to tailor questions to address local issues has been identified as essential, but needs to be carefully balanced against the retention of a core set of standardised questions where there is a requirement for benchmarking or to demonstrate improvements over time.

In some longer stay inpatient facilities, methods that collect information as part of the care process to improve the ongoing care experience for the individual have also uncovered the need for local changes and wider service improvements. These methods may be more applicable for people with long term conditions and the development of information systems that collect data as part of ongoing care and support subsequent extraction and analysis will further heighten the utility of prospective patient level measures of experience.

Reaching the full range of people using a particular care service, including marginalised groups, will require the use of a number of different data collection techniques. Particular consideration needs to be given to issues associated with children, people with sensory, learning or mental health conditions, or people with different literacy levels or communication needs. An Equality Impact Assessment can help to pinpoint particular population groups that risk being under-represented or excluded.

Consideration should also be given to using experience data for multiple purposes. For instance, the Edinburgh Napier University and NHS Lothian Leadership in Compassionate Care Programme has made use of personal stories gathered through an approach called ‘emotional touchpoints’ to improve ‘transactional’ and ‘relational’ aspects of care in the following ways:

- Improving individual care experiences - responding to real-time issues
- Student education - thoughtful use of story within the curriculum
- Staff training and practice developments – via reflection and discussion
- Local service improvements - thematic analysis of stories
- Board level improvements - upward reporting of emergent issues
- Wider service improvements – journal publication and conferences

Finally, it is also important that people accessing care services have opportunities to provide feedback about their experience without having to be directly invited to do so, either anonymously through simple mechanisms such as comment cards, or by ensuring that issues identified during everyday encounters are acted upon.

Part One:
Patient Experience

Focus on Improvement

> **"Measurement for improvement is different from measurement for research or for making judgements about performance. It is based on sequential testing with 'just enough' data, working with data that is 'good enough' rather than perfect".**
>
> **The How-to Guide for Measurement for Improvement [8]**

It's now agreed that collection and improvement activity should be grounded with local care teams, as this is where people's experience is influenced[9]. While team members should be supported to develop the skills and knowledge needed to understand experience data and translate this into improvement activity, it is essential that this enhances rather than detracts from caring. Equally, there may be valuable opportunities to embed the capture of experience data within care processes, but the process of 'measurement' should never interfere with meaningful engagement.[10]

Service improvement activities should be grounded in the Model for Improvement[11] and its core small tests of change cycles. Here it can be more effective to focus on one or two key improvements at a time, rather than trying to tackle every issue at once.

People providing feedback must be able to see that it has been acted upon.

> **"We've been told for years that the NHS is listening to patients, but where is the proof"?**
>
> **Listen to Patients, Speak Up for Change, The Patients Association, 2011**

Simple mechanisms such as displaying "You Said, We Did" boards can be highly effective, providing the responses convey a genuine desire to make things better, rather than simply serving to justify why something happened. More and more, people with experience of accessing care services, unpaid carers and lay volunteers are becoming actively involved in experience-based data collection and improvement activity, and opportunities to use participatory methods should always be explored.

The distinction was made previously between 'transactional' and 'relational' aspects of care known to influence patient experience, each of which requires a different improvement approach. Staff need to understand what part they play in improving experience and how measuring experience might require changes to current care practices. Effective engagement with all staff is essential. In particular, negative feedback, while useful to the service, can be difficult for staff and for managers to hear. In time, this can be overcome by making routine use of 'experience data'. However, when first working to make improvements, particularly around some of the softer, relational aspects of experience, care must be taken not to disengage or demoralise staff.

Adequate preparation and careful facilitation are vital.

The analytical framework developed by the King's Fund, which depicts the various levels of influence on 'patient experience', can be useful in situating the impact of individual interactions in a wider context and making it plain that 'patient experience is everybody's business'.[12] Much can be gained from detailed consideration of positive experiences and the factors contributing to them and approaches such as Appreciative Inquiry[13] may also find successful applications.

Staff will also benefit from attending learning events to:

- Provide hands on practice in using experience tools
- Highlight the value and learning to be gained from positive feedback
- Explore the challenges of giving and responding to feedback
- Provide opportunities to share ideas, good practice and lessons learned

The correlation between patient experience and staff experience is now well documented:

> **"Organisations and local services looking to improve patient experience must create and nurture an environment in which their most important asset, their workforce, is valued and treated with the same level of dignity that the organisation expects its employees to provide patients and families".**
>
> **Shaller 2007[14]**

Here the framework, measurement approach and improvement process being developed by the Leadership in Compassionate Care Programme is of particular interest. The framework comprises a set of caring practices, grouped under six key themes:

Caring conversations
Flexible person centred risk taking
Feedback
Knowing you knowing me
Involving valuing and transparency
A compassionate environment

The caring practices are illustrated through examples drawn from practice, with measurement asking staff and patients to what extent things like this happen in the care area. While the specific examples are drawn from the inpatient setting, the framework and approach, informed by the principles of relationship based care, may find wider applications in advancing improvement work regarding relational aspects of care.

Part One:
Patient Experience

Useful Resources

While there is a growing body of evidence surrounding the improvement of experience in specific care settings, most notably the hospital inpatient setting, understanding of experience-based improvement activity for people living with long term conditions is still at an early stage in the NHS, and we are not yet in a position to provide a definitive guide.

Many toolkits and resources are available however, describing a wide range of experience-based collection methods and improvement techniques. While most focus on specific service lines or care settings, and a few relate to particular conditions, others are more generic in nature. We reference these resources below and set out their purpose and limits of use in the context of understanding and improving the experience of people living with long term conditions.

Patient Experience Toolkits and Guidance

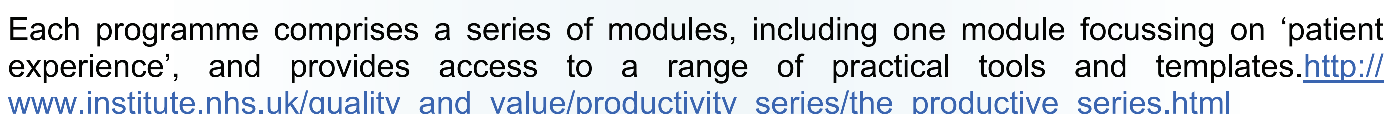
Picker Toolkit – Using Patient Feedback
This generic guide explains the principles of gathering feedback from people who use healthcare services and then outlines what to do with the feedback in order to bring about improvements. The toolkit pays careful attention to 'patient experience' feedback and offers a simple but complete guide to the entire improvement cycle.

In the context of long term conditions, it is however confined to encounters with healthcare services and has little to say about improving relational aspects of care.
http://www.pickereurope.org/usingpatientfeedback

NHS Institute for Innovation and Improvement: Patient Experience Network
The aim of the network is "to share ideas and practice to drive improvement in patient experience". The network provides access to a range of practical resources and enables people working to improve patient experience to connect and exchange experience and knowledge.

A series of "High Impact Actions for Improving Patient Experience" are being determined alongside research into what matters. While much of the activity shared pertains to the inpatient setting, contributions from other care settings are increasing with time.
http://www.institute.nhs.uk/share_and_network/pen/welcome.html

Releasing Time to Care: Productive Series
The Releasing Time to Care Productive Series developed by the National Health Service Institute for Innovation and Improvement supports NHS teams to re-design and streamline the way they manage and work. It comprises several programmes, each applicable to a different care setting including the Productive Ward, Productive Mental Health Ward and the Productive Community Hospital.



Each programme comprises a series of modules, including one module focussing on 'patient experience', and provides access to a range of practical tools and templates.http://www.institute.nhs.uk/quality_and_value/productivity_series/the_productive_series.html

A recent addition, Productive Community Services, is of particular relevance in the context of long term conditions and is described in Part 2.

NHS Education Scotland - Little Things Make a Big Difference
"Little Things Make a Big Difference: Valuing and Enhancing Patient Experience" is an online resource for frontline NHS staff. Designed "to act as a gateway for NHS Scotland staff to support the enhancement of patient experience", the website supports rapid access to key documents and deeper exploration of resources and current literature. In particular, the Making a Difference section provides access to materials on:

- Developing patient-centred approaches
- Strengthening leadership at all levels
- Applying values in practice
- Developing reflective practice
- Passion and power

This resource is particularly useful in addressing the relational aspects of experience and the content is largely generic in nature.http://www.knowledge.scot.nhs.uk/making-a-difference.aspx

Patient Experience Surveys

Survey results are a useful means of finding out what people collectively are saying about their experience of care and identifying the positive and less positive aspects of that experience. Survey questionnaires are a useful means out finding out the sort of questions being asked about the experience of people in different care contexts or of people living with specific conditions.

Scottish Government: National Patient Experience Survey of GP Services (2010)
The GP Patient Experience Survey is a postal survey which was sent to a random sample of patients who were registered with a GP in Scotland in October 2009. The survey asked patients about their experience of accessing their GP Practice, making an appointment, visiting reception, seeing either a nurse and/or doctor at the surgery, receiving prescribed medicine and care provided overall. The national results are available at:
http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey

Results at GP practice level are available at:
http://www.bettertogetherscotland.com/bettertogetherscotland/922.28.501.html

Part One:
Patient Experience

The questionnaire used in this survey is also available at:
http://www.bettertogetherscotland.com/bettertogetherscotland/661.322.342.html

National Patient Experience of Inpatient Services (2010 and 2011)
The Inpatients Patient Experience survey (2010) asked a range of questions about people's experiences of staying overnight in a Scottish hospital during 2008/09. Patient feedback was gathered through a primarily postal survey, which was developed on the basis of international literature and research on public priorities in Scotland regarding inpatient services. In total, 62,308 survey packs were sent to patients and 30,880 were returned, giving an overall response rate of 50%. The national results are available at:
http://www.scotland.gov.uk/Publications/2010/09/28112720/2

Results at NHS Board level and for larger hospitals are available at:
http://www.bettertogetherscotland.com/bettertogetherscotland/923.28.502.html

The survey is being repeated in 2011. This survey covers the period October 2009 to September 2010. Results will be available on 30 August 2011.

The questionnaire for the 2011 inpatient survey is available at:
http://www.bettertogetherscotland.com/bettertogetherscotland/901.322.461.html

NHS Quality Improvement Scotland: Patient Experience Survey of Renal Services (2009)
NHS QIS, in collaboration with the Scottish Renal Registry, carried out a renal patient experience survey of all adults receiving renal replacement therapy in Scotland. Over 2,500 respondents took part in the survey which was undertaken between November 2008 and January 2009.

The findings of the survey are presented in two reports: one relates to dialysis and the other to kidney transplant.

England

National Patient Survey Results: Setting / Service Specific:
National survey results covering patient experiences of a range of specific care settings / services in England are available from the Care Quality Commission:

Emergency Departments (2008)
The survey asked about the experiences of people who have visited an emergency department (also known as Accident & Emergency or Casualty).

Inpatients (2009)
The survey asked about the experiences of people who had been admitted to hospital and had at least one overnight stay. Questions cover the issues patients consider important in their care.

Outpatients (2009)
The survey asked people about their most recent visit to an Outpatient department. The survey includes questions on waiting for the appointment, hospital facilities, seeing a doctor, any tests and treatment undertaken during the appointment, as well as any medications prescribed.

Mental Health Acute Inpatients (2009)
The 2009 survey of people who had recently had an inpatient stay for acute mental health problems was the first of its kind. The survey asked people about their experiences of acute inpatient mental health services along the pathway from admission to leaving hospital, including the care and treatment they received, day-to-day activities, and relationships with staff.

Maternity (2010)
This survey looked at women's experiences of maternity care in England. All women aged 16 or over who received care from NHS Trusts in England, and who had either given birth in a hospital, birth centre, maternity unit or at home were eligible to take part.

Community Mental Health (2010)
Survey about the experiences of people receiving community mental health services.

National Survey Results: Condition Specific

Cancer (Department of Health): National Report (2010)
The report provides insights into the care experienced by cancer patients across England who were treated as day cases or inpatients during the first three months of 2010. The 2010 survey is the first to involve patients with all types of cancer.

Coronary Heart Disease (Healthcare Commission): Key Findings Report (2004)
The survey of Coronary Heart Disease (CHD) patients aimed to assess the quality of NHS patient care, as seen by hospital patients who had been treated for CHD. Inpatients and day patients were included. The postal questionnaire was sent to discharged patients at home. It covered a range of issues relevant to all types of patients including emergency and planned admissions, care and assistance from doctors, nurses and other hospital staff, treatment, tests and surgical operations, pain management, the hospital environment and leaving hospital.

The core questionnaire used in the survey developed by Picker Institute Europe is available at: http://www.nhssurveys.org/survey/605

Part One:
Patient Experience

Diabetes (Care Quality Commission): Primary Care Trusts: National Findings Report (2006)
The survey asked whether people with diabetes get the care, treatment and information they need to manage their diabetes well and to reduce the risk of complications. Local primary care trusts sent the questionnaire to almost 125,000 adults (aged 16 and over) with diabetes, asking about their experiences of services provided by the NHS.

Stroke (Healthcare Commission): Key Findings Report: Stroke Patient Survey (2004)
The aim of this survey was to evaluate patients' experiences of stroke care in England. The survey was developed and carried out by the Picker Institute Europe on behalf of the Healthcare Commission.

The questionnaire used in the survey, developed by Picker Institute Europe, is available at: http://www.nhssurveys.org/survey/711

Local Survey Tools

The NHS Surveys website contains questionnaire compilation tools and guidance materials to support NHS organisations in England to carry out local patient surveys using the same questions and approach as employed in the NHS patient survey programme. The following surveys are currently available:

- A&E Department Local Survey
- Community Mental Health Local Survey
- Day Case Surgery Local Survey
- Inpatients Local Survey
- Maternity Local Survey
- Mental Health Acute Inpatient Local Survey
- Outpatients Department Local Survey
-

Generic Rapid Patient Feedback Survey

'Rapid Patient Feedback' is a mechanism to support continuous improvement at operational and strategic levels. It is not intended to be used as a performance management tool, but is an early warning system. It may not tell you precisely what the problem is, but it tells you where to look sooner than any other indicator.

NHS Lothian has developed a core set of questions for gathering rapid feedback about the things that are consistently found to matter to people within all care settings across the organisation. Provision is also made for the capture of qualitative comments.

While applicable in any given care setting, as not devised specifically in the context of long term conditions, questions relating to factors such as coordination of care across settings and with social care are not included. 5x5x5 Rapid Feedback Report

Story Work and Qualitative Approaches

Gathering Stories and Qualitative Accounts - Method Considerations

As the unique role of 'story' in understanding the care experience has been recognised, the term has come to be used as a catch-all term for almost every form of feedback that is not gathered through survey or structured questionnaire, from short comments to rich narratives. Each 'story' type has a role to play in understanding experience and helping to inform improvements, but method choice is very much a Question of Purpose.

This resource considers the strengths and weaknesses of different collection approaches in different use contexts and provides links to guidance on popular methods such as Facilitated Storytelling, Discovery Interviews, Patient Journeys, RCN's Patient Stories Methodology, Emotional Touchpoints, Digital Storytelling and Story Cards.

While not focussed specifically on eliciting the experiences of people with long term conditions, the principles are generic. A Question of Purpose

Understanding Experience – Analytical Use of Qualitative Accounts

Busy care practitioners tasked with making sense of qualitative data and presenting the findings in a concise yet meaningful way may feel overwhelmed by the potential scale of the task. This resource offers practical advice, moving beyond using people's accounts of their experiences to highlight 'things to fix', instead considering the identification of key themes and patterns, but without expecting practitioners to become fully-fledged qualitative researchers. Illustrative examples are provided throughout.

As above, while not focussed specifically on analysing the care experiences of people with long term conditions, the principles described are generic. Analytical Use of Stories: From Finding Things to Fix to Picking out Patterns

Reflecting On Experience –: Using Stories as an Educational Resource

A Different Way of Knowing developed by Better Together in association with NHS Education for Scotland, provides a flavour of just some of the ways that people's accounts of their care experiences can be used to stimulate individual reflection or seed group discussion to inform care practice.

Finding Stories - Story Libraries

Personal stories can be extremely powerful communication tools and have found increasing use in education, values-based training and individual reflective practice. The following libraries provide access to quite different types of story, including stories about the experience of care, care outcomes, self management and living with a long term condition.

Part One:
Patient Experience

Healthtalkonline
Healthtalkonline lets you share in more than 2,000 people's experiences of health and illness elicited through qualitative research led by experts at the University of Oxford. The stories are catalogued by condition and focus on the lived experience of health and illness.
http://www.healthtalkonline.org/

Patient Voices
While many stories focus on specific encounters with healthcare services rather than the ongoing experience of living with a long term condition, the search facility combines free text searches with the use of keywords and the stories offer poignant insights into the care experience. www.patientvoices.co.uk

Care Story Library
The library contains over 100 digital stories told by people living with long term conditions, unpaid carers and staff. The stories depict the impact that health, social care and housing services can have on the lives of people across Scotland and are catalogued in a number of ways to support ease of discovery. Resources are also available to support the making and use of digital stories. www.carestories.co.uk

LTCAS Personal Stories Project
LTCAS believes in the power of personal stories from people living with long term conditions. This project will bring LTCAS' messages to life, give human faces and voices to our work, create a tool that can be used by members in their own work and enable people with long term conditions to hear each other's experiences. http://www.ltcas.org.uk/personal_stories.html

My Condition My Terms My Life
LTCAS launched the *My Condition, My Terms, My Life* campaign to help improve public understanding of what self management means for people living with long term conditions, and to encourage people living with long term conditions, and the people who support them to adopt a self management approach. The campaign features real people living with long term conditions, telling their stories to encourage other people to get started with self management.
www.myconditionmylife.org

Scottish Recovery Network Stories
The Network provides access to a number of stories submitted via the website, as well as stories that have been shared as part of the Network's Narrative Research Project. These stories can inform and inspire people with experience of mental health issues, carers and service providers alike. They offer hints and techniques on recovery and recognise that people in recovery are 'experts in their own experience'. They also help us learn more about the factors which help and hinder the recovery process and to better understand what recovery means.
http://www.scottishrecovery.net/Submit-Your-Story/submit-your-story.html

Learning from Positive Experiences - Appreciative Inquiry

"Change begins with the questions you ask".
Peterson (2000)[15]

Instead of focusing on the negatives in an organisation and trying to change them *Appreciative Inquiry* looks at what works well and uses that as a foundation for future development. It is essentially life-affirming rather than deficit-based and this has the effect of increasing the amount of energy and enthusiasm in the organisation.

Positive aspects of developing quality care are rarely mentioned alongside the negative in justifying the need for change. Furthermore approaches to research in caring and change initiatives have tended to focus on the barriers to caring and what needs to be fixed to make it better.[16]

Appreciative Inquiry has been adapted by Edinburgh Napier University and NHS Lothian Leadership in Compassionate Care programme for practical use with local care teams working in busy inpatient wards.

Far from encouraging complacency by ignoring the negative aspects of care, it has created an increased appetite for questioning the way things are done and making ongoing improvements.

More information is available at:
http://www.napier.ac.uk/fhlss/NMSC/compassionatecare/practicemethods/Pages/AppreciativeInquiry.aspx

While the above adaptation was applied in the inpatient care setting, *Appreciative Inquiry* has much wider applications:

Appreciative Inquiry Commons: This is the worldwide portal for all Appreciative Inquiry resources http://appreciativeinquiry.cwru.edu

The AI Practitioner: Journal containing a number of articles about Appreciative Inquiry practice in different fields www.aipractitioner.com

Part Two

Listening, Learning & Improving Together

Part Two:
Listening, Learning & Improving Together

The Care Experience and Long Term Conditions

The work plan and philosophy of this long term conditions work stream were informed by the "**It's all About Me**" event, hosted by Better Together and the Scottish Health Council in April 2010 in collaboration with LTCAS and the Long Term Conditions and Mental Health Collaboratives. This gave us 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, together with suggestions as to how best to take forward improvement activity.

DELEGATE VIEWS: WHAT NEEDS TO BE DONE AND WHY?

Recognise the importance of joint working and of capturing views of patients, carers & staff because shared understanding can be reached and the ideas generated are grounded in reality.
Health/social care worker

Show the public it's not just a tick-box exercise, that views and experience are being used productively. This will encourage trust & more dialogue.
Voluntary sector worker

Ensure that the survey results are transferred into local areas so that there is local ownership of this agenda.
Health/social care worker

Focus on improving transitions for LTC patients because it's the hardest part.
Person living with LTC/Government/local authority employee

Better engagement with individuals, active listening, abandon acronyms in order to treat individuals with respect and for better feedback and understanding.
Health/social care worker

Continue to promote patients' views because it makes a difference.
Government/local authority employee

Listen to patients about their experiences and take action to improve because health professionals do not always meet patients needs. They can be too focused on clinical targets.
Person living with LTC/Government/local authority employee

Lobby to change care structure making it more care-influenced than funding-restricted because care provision should be person-centred not resource-centred.
Health/social care worker

Influence needs to be on local decision making to ensure people matter and are at the centre of care because the NHS seems to have moved away from being the 'caring profession' to being a 'target-driven' business.
Health/social care worker

Listen to feedback and work with other health teams because it'll provide a better, broader range of services
Person living with LTC/Government/local authority employee

Facilitate nurses to have less paper-work and more patient contact so we know what their agendas/goals are.
Health/social care worker

Continue to strengthen patient self-management and integration of service providers because respect between service providers improves patients outcomes.
Health/social care worker

Listen and act on patient comments because people complain and nothing changes.
Person living with LTC

Part Two:
Listening, Learning & Improving Together

GP and Inpatient 'Topic Reports' will be published in May 2011 as part of the suite of publications sharing the findings of the first-ever national Patient Experience Surveys in Scotland. The reports will provide differential accounts of experience by a number of characteristics, including people who identified themselves as having a long term condition, whether or not they have a physical impairment or disability, and the extent to which day-to-day activities are limited.

Although there will be important transferable learning from these reports, as the following quotes illustrate, we cannot reduce experience for people living with long term conditions to a series of episodic encounters with NHS services.

"It will while I was in hospital that I met Pam. Her condition was a lot worse than mine, but she was a very spirited lady and I learned a lot about how to manage things from her - not just physically but mentally as well".

"Being told that you have something that's incurable and that's going to get worse – that's pretty hard to cope with. It can be hard to stay upbeat, especially at night when you are on your own".

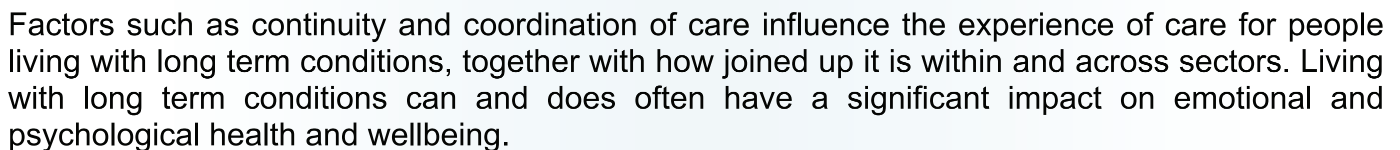
"Since I've been care managed I find it's not just the practical things she does - that's the least of it. It's having that one person that you can talk to, and share all your worries with, and your hopes with, no matter how silly, and have a laugh, and build a relationship with".

"For the past 5 years Dot has benefited physically and mentally from periodic physio and relaxation, while I received respite. But when she reached her 65th birthday, this service was no longer available to her – the only 'alternative' being a stay in a care home".

"I've has psoriasis since I was 3, I was classed as chronic at 7. By the time I met my husband and got married, my skin had really started to deteriorate. Talk about the Blushing Bride"!

"I miss not being able to work, it's not just the work itself, or even the money, but because a lot of my friends were through work and I miss going in and having a laugh with them".

"I have now put aside thoughts about diabetes being smelly and isolating, but only because I have been able to speak to a good person-centred counsellor".



Factors such as continuity and coordination of care influence the experience of care for people living with long term conditions, together with how joined up it is within and across sectors. Living with long term conditions can and does often have a significant impact on emotional and psychological health and wellbeing.

The term 'patient experience' has also been used a convenient form of short-hand, with the need to understand the experience of relatives and unpaid carers implicit in its meaning. People living with long term conditions have told us that this is simply "not good enough". Carers have their own experiences to share and the impact of caring for someone living with a long term condition over a prolonged period of time can be profound. Carer experiences and outcomes need to be explicit and need to be distinct.

We therefore need an approach that addresses the emotional and psychological dimension of experience and with a clear focus on:

- Experience considered around key 'touch points' in the care journey, as identified by the person living with the long term condition
- Experience of transitions
- Experience of unpaid carers and relatives
- Experience of community health, social care and voluntary services
- Experience of supported self management
- Experience of all age groups including children and young people, and much older people
- Experience of people with multiple conditions

The focus of this work stream has been:

- Identifying, sharing and spreading good practice;
- Supporting local care teams to gather and use people's experience to make improvements;
- Supporting people living with long term conditions to be partners in improvement activity.

Successful current methods have been identified and documented. A range of approaches has been tested in different contexts and with different care groups, training delivered and case studies captured to support staff to use specific approaches.

This work is shared in the following sections.

Part Two:
Listening, Learning & Improving Together

A Snapshot of Current Activity

What follows is by no means an exhaustive account of experience-based improvement work around long term conditions. Instead it offers a flavour of some of the quite different types of activity taking place, from generic surveys, through experience-based improvement activity in specific care settings and condition-specific services, to ongoing efforts to understand and improve the experience of specific groups of people, notably children and young people, and people living with multiple conditions.

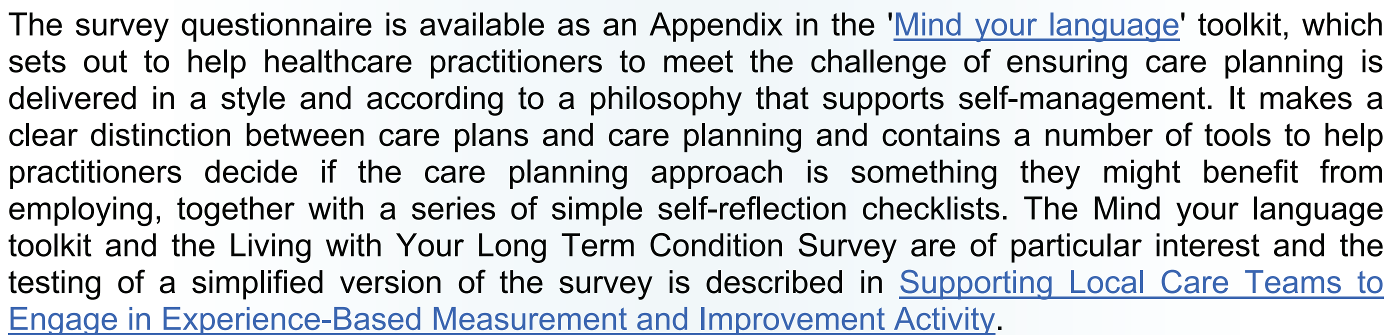
The Living with Your Long Term Conditions Survey

The Living with Your Long Term Condition Survey was developed by the Year of Care for Diabetes Programme in England. The Year of Care sets out to put people with long term conditions firmly in the driving seat of their care and support them to self manage. It aims to do this firstly by making routine consultations truly collaborative through person centred care planning, and then ensuring the local services people need to support this are commissioned.

The survey was developed to measure the effectiveness of this programme in supporting people to self manage and with a view to being completed following a consultation serving to develop or review a personal care plan. It was created in response to the absence of any alternative surveys in routine practice in the UK or internationally to help drive quality improvements in services for people with long term conditions. Specifically, the evidence base in long term conditions demonstrates that high quality services should support people to develop confidence and competence in managing the challenges of living with their condition(s) in order to have a better quality of life, better outcomes and make more appropriate use of resources. The questions within the survey derive from, and relate to, this evidence base. In addition to a small number of questions about the respondent, the questions take the form of established measures of:

- enablement
- the quality of the consultation itself
- the continuity of care
- key aspects of the support and care over the past 12 months
- quality of life outcomes

The inclusion key aspects of care and support over the past 12 months, notably a question about how joined up the care has been, represents an important departure from surveys that are confined to a single consultation, episode of care, or specific service. Although its developers are keen to position the survey as a measure of 'clinical effectiveness' and not 'patient experience', many of the questions asked relate to factors that people with long term conditions identify as important influences on their care experience.



The survey questionnaire is available as an Appendix in the 'Mind your language' toolkit, which sets out to help healthcare practitioners to meet the challenge of ensuring care planning is delivered in a style and according to a philosophy that supports self-management. It makes a clear distinction between care plans and care planning and contains a number of tools to help practitioners decide if the care planning approach is something they might benefit from employing, together with a series of simple self-reflection checklists. The Mind your language toolkit and the Living with Your Long Term Condition Survey are of particular interest and the testing of a simplified version of the survey is described in Supporting Local Care Teams to Engage in Experience-Based Measurement and Improvement Activity.

Releasing Time to Care: Productive Community Services

Community care services provide essential advice, care and support for many people living with long term conditions, enabling individuals with more complex care needs to enjoy a quality of life free from crises. In view of the commitment to 'shift the balance of care', it is vital that the quality of care in community settings is understood and improved where necessary.

What is the productive community service programme?
Productive Community Services is a recent and important addition to the Releasing Time to Care Productive Series which supports local NHS teams to streamline the way they manage and work.

If it's about productivity, how does it help improve 'patient experience'?
Patient experience is central to all Productive programmes, but Productive Community Services takes a different approach than its predecessors by positioning it firmly within the context of engagement. Specifically, the programme contains a suite of tools under the banner '*Patient Perspective'*, which underpins and informs all other improvement modules in the programme. A distinction is made between 'experience', 'opinion' and 'ideas for improvement'. Each is recognised as an important type of feedback, but captured by different practical tools. This seemingly subtle change in terminology represents a significant move away from the somewhat passive role of people as 'experience donors', recognising their potential as vital sources of knowledge, views, skills and capabilities that can be used to help shape services.

What tools and methods does it use?
The practical tools for gathering and improving experience also differ from those featured in previous Productive programmes, notably an experience questionnaire focussed firmly on the emotional impact of care. This supports the identification of the 'touch points' in the overall care experience that present emotional issues for people. It also makes use of images to address literacy issues. A template for creating personal diaries is also included, recognising the ongoing nature of care for many people in community settings. Diaries can support the capture of peaks and troughs, together with issues of continuity, coordination and transition, and are of equal utility for carers, although analysis can be time-consuming.

Part Two:
Listening, Learning & Improving Together

'*Patient Perspective'* also sets out the growing role of armchair involvement, which is an important means of consulting and ultimately engaging with people from the comfort of their own homes. Equally, Experience Based Design (described below) is highlighted as a potentially resource-intensive, but highly insightful approach to service redesign.

How useful is it in the context of long term conditions?
While the Productive Community Services programme has been developed to improve the quality of care for the full range of people accessing community care, not exclusively people living with long term conditions, the tools are highly conducive to application in this latter respect. In support of this programme, the Long Term Conditions Collaborative has developed a CD of resource of materials, adapted to the Scottish context and making links with the survey work of Better Together. The CD, which is available to staff completing the Productive Community Services programme, also supports local customisation, such that emergent approaches can be included following validation. For more information contact: Sam.Atkinson@scotland.gsi.gov.uk

Experience Based Design

The Experience Based Design (EBD) approach has been used in global industry for many years, but its application in healthcare is more recent, informed by the work of Bate & Robert (2007)[17]. The approach involves working closely with people with personal experience of accessing care services, unpaid carers and care staff to better understand the experience of care, applying a range of techniques, but making extensive use of story. The approach shares much in common with Discovery Interviews and the Patient Journey Approach, and like these approaches is typically applied in the context of condition-specific services. However, unlike the other approaches, in its purest form, the three groups of people who share their experiences are then brought together to identify the key 'touch points' within stories that have shaped the overall experience in both positive and negative ways. Thereafter a series of co-design workshops are held to jointly prioritise the areas for improvement and to develop improvement actions.

The methodology, although highly successful, can be very resource intensive. This has called its utility into question in the current financial climate. However, the following examples illustrate quite different potential workarounds.

Experience Based Design Case Study: Cancer Pilots
To assess the utility of the EBD approach in the Scottish context, NHS Lothian, NHS Greater Glasgow & Clyde and NHS Grampian were awarded national funding to pilot experience-based improvement within cancer services. The core aim of the pilots is to enhance healthcare experience for people living with cancer and their carers, including marginalised communities. The pilots are also expected to identify transferable learning regarding the application of the EBD methodology.

What methods have been used?

In view of the altered financial climate, each site has adapted the EBD approach by using ‘low resource’ tools and methods that can be applied in real time. These include experience / rapid feedback questionnaires, clinic observations, stories, shadowing, patient interviews, ten minute interviews, staff discovery interviews, staff logs, focus groups, emotional touchpoints mapping and ideas walls at coffee mornings. No compromises have been made however in terms of ensuring that a range of views are heard. Increasingly the pilots are training and supporting staff to undertake their own experience work to promote ownership, while ensuring capability and sustainability within cancer services, and in other services.

What have we learned about the care experiences of people living with cancer?

The care experiences of people living with cancer and their carers have been largely positive, with many of the factors influencing experience adversely easily remedied, providing a huge source of encouragement for service providers, notably frontline staff.

What improvements have been made or identified to date?

- Re-designing patient information including: better information for non-English speaking patients; service leaflet to prepare people for attending outpatient oncology clinic; newly diagnosed information guide; standardising information; ‘top tips’ created for and by people attending clinics; sources of support from other organisations.
- Structural changes, from large scale such as ward layout redesign, through re-converting an office into a quiet room for patients, to improving waiting areas.
- Workforce development e.g. expanding role of health care workers to support chemotherapy nurses; developing volunteer role in ‘meeting and greeting’.
- Better protocols and pathways such as a pathway for follow-up by appropriate personnel; move to a one-stop clinic; new young person transition clinic; better prescription processing .
- Introduction of relaxation techniques for people undergoing radiotherapy.
- Introduction of a distress monitor for sharing people’s concerns.
- Reducing waiting times.
- Providing additional support between receiving test results to appointments.
- Small changes at ward level e.g. more clocks.

Subtle changes in the human side of caring have also been observed and although harder to evidence, it is important that these are not lost when demonstrating impact.

What are the challenges and how are they being addressed?

The methodology is not without its challenges, not least the perception that it’s resource intensive and that the ends may not always justify the means. This concern is being countered by pilot efforts to adapt approaches to reflect constraints and by evidencing the impact on services. As the pilots continue, ensuring sustainability beyond pilot funding is at the forefront of thinking. Here enthusiastic uptake by staff within cancer services and beyond, coupled with work to support people living with cancer and their carers to become full partners in improvement activity are of particular significance to the future of experience-based design.

Part Two:
Listening, Learning & Improving Together

Rapid Experience Based Design

Experience Based Design in its purest form has been centred on the collection and thematic analysis of in-depth qualitative accounts of experience. This is a labour intensive and highly skilled task. While the use of ‘low resource’ methods represents one possible solution, alternative means are also being sought that can expedite the process, but without impacting on the richness of accounts or the thoroughness of thematic analyses. Here Rapid Experience Based Design is a promising development.

Rapid EBD has been taken forward by the University of Oxford’s Health Experiences Research Group (HERG), which collaborates with the DIPEx charity to publish selected extracts from an archive of over 2,000 interviews covering 55 health conditions through Healthtalkonline.

What’s the theory behind Rapid EBD?

Where a wealth of research evidence exists, it makes good sense to use it rather than embark on local resource-intensive collection exercises, or make changes based on the views of a small number of people, which may not reflect the concerns of the vast majority of people using the service. The archive contains rigorous research data involving a broad sample of users and a full range of different perspectives. The HERG believes that the themes identified through their national studies cover very similar ground to what local people would say mattered to them.

Is there any evidence to support this theory?

To test this, a scoping study was carried out comparing a ‘best in class’ investigation into the experience of end of life care in one Primary Care Trust with a secondary analysis of an existing HERG dataset.[18] Matches were found for the vast majority of locally identified themes, with those not matching concerned with local access and opening hours; issues already known to the Trust. The national study also identified several themes in addition to local study themes that would likely have been of concern to local people, including advance aspects of anticipatory care planning.

How would local experience issues be verified?

It’s believed that targeted secondary analysis of archive data will provide datasets identifying the important aspects of experience or ‘touch points’, without requiring local capture. The established Experience-Based Design process would then allow identified touch points to be sense-checked locally through a co-design workshop involving people accessing care services, carers and staff, to establish both the completeness and quality of these aspects of experience locally.

What next?

The concept of national qualitative datasets is an important development in healthcare. While this remains a future possibility for Experience Based Design, work has already been carried out to develop ways of transferring this knowledge to the NHS within the context of Experience Led Commissioning for GP services, notably development of a standard secondary analysis process.

The Patient Journey Approach

A variation on Experience Based Design is the 'Patient Journey Approach' which, as the name suggests, looks at the entire patient journey. This approach aims to make improvements to all dimensions of quality, including but not specifically focusing on 'experience'. It was developed by the City Hospitals Sunderland NHS Foundation Trust.

What is it?

The Patient Journey Approach is a six-step multi-professional, collaborative approach to person-centred service improvement/practice development. A team is set up with as many representatives as possible from a selected healthcare journey, (including support staff, nurses, doctors, consultants OT, physio, pharmacy, diagnostics, trust managers, primary/secondary care, for example) so that they might jointly discuss and review their current service, make plans and set goals for future improvement.

What about the experience of people using the service?

Central to this process are the views and experiences of people using the service which, when combined with the views and suggestions of those delivering the service, provides an effective and powerful catalyst for change and person-centred improvement. The approach is facilitated by an outsider to the service to avoid bias and typically takes six months to complete.

What has been the impact on quality of care?

Learning about people's experiences has highlighted where quality might be improved and for example led to securing funding for basic equipment; revised information leaflets; a change in the short notice admission procedure; pre-set theatre lists; the installation of a direct line for people to contact the Nurse Practitioner (amongst others)

What has been the direct impact on experience for those taking part?

The people who participated really appreciated the opportunity to have their views heard.

Has there been an impact on costs?

The approach highlighted where duplication in services existed; where services might be more effectively and efficiently delivered (cost savings), encouraged greater inter-professional teamwork, ownership and learning from each other.

Has the approach been verified elsewhere/

The model has been used extensively by the Trust with repeated success and independently validated through an action research study[19], during which a newly qualified nurse with personal experiences as a patient implemented a new patient journey in an unrelated hospital trust.

Part Two:
Listening, Learning & Improving Together

The Experience of People Living with Multiple Conditions

The previous examples all hail from experience-based work in condition-specific services. The structure, philosophy and funding of health services and research is largely condition-specific. Indeed many medical research trials exclude people with more than one condition and the complex needs of people with multiple conditions is poorly understood. Many voluntary organisations are also concerned with supporting people living with a particular condition. Yet 29% of people with long term conditions live with more than one condition and this proportion will rise in future.

The impact of multiple conditions can be profound and can influence all areas of a person's life. People may have markedly poorer quality of life, poorer outcomes and longer hospital stays.

But what we do we know about their experience of care?

While there is a small but growing body of evidence about the experience of care management for people with highly complex needs, less is understood about the experience of people who have multiple conditions, but who do not require high intensity professional support. What little evidence there is suggests poorer experience of care and treatment, with problems appearing to be system wide, rather than confined to specific services. In taking forward work to understand and improve the care experience of people living with long term conditions, It is vital that the experience of this growing group of people is not overlooked.

LTCAS Living with Multiple Conditions Event
In order focus attention on multiple conditions, LTCAS held an event in February 2011 which looked at the issues, challenges and potential solutions.

In Part 1 of this report, we highlighted the importance of 'measuring what matters' when carrying out experience-based improvement activity and this event was an important opportunity to share in the findings from two research programmes:

The National Research Programme into 'Multi-morbidity'
Professor Stewart Mercer, University of Glasgow.
The programme includes the development and evaluation of a whole-system intervention in primary care to help people live better with multiple conditions. To date the research has established important links between multiple conditions, mental well being and socio-economic deprivation.

Minimally Disruptive Medicine
Professor Frances Mair, Institute of Health and Well Being
This research programme made the distinction between 'illness burden' and 'treatment burden' and asked: How do we lessen the treatment burden?

Key take-home messages included:

- Treatment burden can outweigh illness burden, impacting on quality of life as well as treatment adherence
- Most people with multiple conditions will be on a range of drug therapies and will have little support to manage the interactions, which may not always be fully understood by care professionals
- Barriers to self-management are greater and signposting, or support to pursue other forms of support is needed
- The need for support from beyond the NHS is greater, including voluntary, social care, housing and employability services
- There is a greater likelihood of impact on mental well being and here simple but early interventions are known to be effective
- The work people have to do to manage their conditions includes illness (and treatment) work, everyday life work and 'biographical' work

When we reconsider the key factors known to influence experience, some of these take on additional significance and meaning for people living with multiple conditions, and a number of additional factors (denoted with *) emerge:

Transactional aspects of care – The 'What':

- Participation in decisions, feeling confident and in control
- Experiencing coordinated, joined up care (both across parts of the health service and with other services)
- Continuity of care *
- Access to care: goes beyond receiving prompt care and treatment to include appropriate triage and longer appointment times where needed *
- Combined care: fewer investigations / GP appointments / hospital visits *
- Combined or simplified treatment: simplified medication regimes *
- Signposting or support to pursue other agencies and support services including housing and employability services, plus psychological, social and emotional supports *

Relational Aspects of Care – The 'How':

- Relational dimension to continuity – building relationships over time *
- Being treated with respect - in a way that makes the person feel valued
- Being treated holistically – attentive to the emotional, psycho-social impact
- Being treated as a person – interest in 'biography' – the sense of self, personal identify and context in which the person manages
- Being treated with responsiveness to what matters in the wider context of his / her life
- Being a partner in care

Part Two:
Listening, Learning & Improving Together

Supporting people with multiple conditions will therefore be a true test of the person-centredness of future healthcare services.

The following 3 examples describe projects aiming to improve one of the factors influencing the experience of people with multiple conditions.

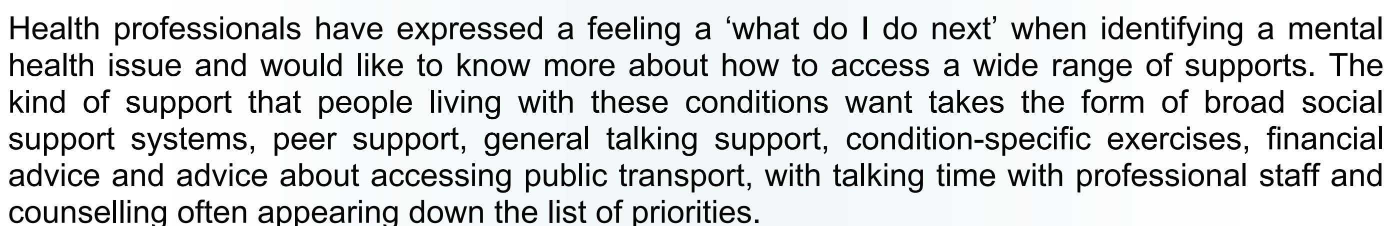
Polypharmacy Project: NHS Highland
People who are taking a lot of medicines or who are at particularly high risk of medication side effects are being invited to make appointments (where appropriate with their carers) at their local medical practice to discuss and review their prescriptions. A simple information leaflet has been developed and announcements about the review published in the local press.

Guidance has also been produced for practitioners on how to make safe and sensible decisions on prescribing in situations where extra thought and consideration is needed. The guidance highlights the benefits (or otherwise) of certain types of drugs when combined with other types of medication, particularly numerous medications, and provides further information which can be used to inform their discussions with people, to consider stopping medication or making changes, such as changing to a form that is easier to take (eg, once a day rather than three times a day). The reviews also aim to ensure that people are taking the correct medicines to get the best possible relief from symptoms and, where possible, prevent or delay deterioration.

Contact: Dr. Martin Wilson, Raigmore Hospital, email: martinwilson2@nhs.net

The Living Better Project: Attending to Emotional and Psychological Needs
Living Better aims to improve the mental health and well being of people living with diabetes, coronary heart disease and chronic obstructive pulmonary disease. The project is working with 5 community health partnerships and 10 GP practices across Scotland.

Living with one or more of these conditions has been found to cause both acute and chronic stress and impact people in a number of ways including:
- Shock of being diagnosed
- Feeling that family and friends don't understand the strains
- Lifestyle restrictions and frustration over lifestyle changes
- Accessibility / transport problems
- Loss of confidence
- Strains on relationships
- Frustration, anger, fear, guilt, embarrassment
- Financial worries
- Social isolation
- Loss of purpose in life



Health professionals have expressed a feeling a 'what do I do next' when identifying a mental health issue and would like to know more about how to access a wide range of supports. The kind of support that people living with these conditions want takes the form of broad social support systems, peer support, general talking support, condition-specific exercises, financial advice and advice about accessing public transport, with talking time with professional staff and counselling often appearing down the list of priorities.

A series of recommendations for community health partnerships have been identified, with a firm focus on greater local partnership working and recognition of the role of social support systems alongside staff awareness training. www.livingbetter-scotland.org.uk

The LTCAS report Emotional Support Matters reinforces and builds on the findings to emerge from Living Better. The report was informed through two discussion events attended by over 275 people, with small group discussions being held over a number of sessions. In particular, the discussions found that while delays in accessing specialist services is a recognised problem and the role of these services is crucial for some people, a broader range of less specialist but equally supportive services would meet the needs of many, with an emphasis on earlier, simpler interventions and an increased role for peer / social supports.

The LINKS Project: Signposting to Self Management Supports

One project aiming to equip GP practices with better local links to support services is the "LINKS project", drawn up jointly by the Deep End Project, the Long Term Conditions Collaborative and the Long Term Conditions Unit. The project is supporting a group of GP Practices working in areas of deprivation where GPs identified a wish for better connections and engagement with their local community and for using Practice and community resources more efficiently to provide more people with self management support.

The project is a discrete piece of work, using small tests of change to learn what can be achieved in a short time and the lessons which can be shared with other practices and more widely concerning both self management and community engagement.

Contacts: Christine.hoy@scotland.gsi.gov.uk; P.cawston@nhs.net and susan.bishop2@scotland.gsi.gov.uk

Part Two:
Listening, Learning & Improving Together

Experience of Children with Long Term Conditions

> **"I think that young people with long term conditions find it difficult to kinda speak out because they don't think they can. I think you're patronised more … People kind of make you feel as if 'oh well, they're speaking for me so I don't think I should speak".**

LTCAS: Seen and Not Heard

In attempting to understand and improve the experience of people living with long term conditions, it is essential to consider all age groups. Children and young people are recognised as having needs that are distinct from those of adults. Much work has already been carried out by LTCAS, both directly and by drawing upon existing research to understand the things that matter to children and young people. This includes requiring information available in forms that are meaningful to them, skilled communication with health professionals and support to make decisions and develop self management skills and capacity.

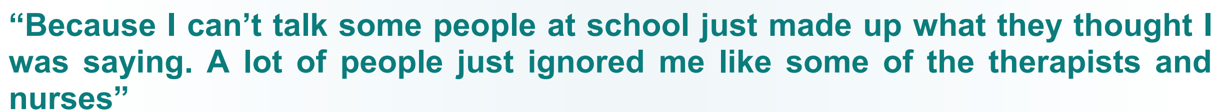
Compared to other Western nations, the health outcomes for children and young people are consistently poor in the UK, resulting in reduced quality of life and life chances, and a legacy of adult healthcare need. The experiences of children and young people must be included in experience-based improvement programmes.

fSDC and LTCAS Survey of Children and Young People

LTCAS and for Scotland's Disabled Children Liaison Project (fSDC) commissioned a survey of children and young people who are disabled and/or live with long term conditions to gather their experiences of school life, children's, leisure and other relevant services to determine how far and in what ways they are supported to enjoy a good quality of life and childhood/adolescence.

The survey questionnaire comprised standard questions relating to children and young people's quality of life plus two optional sections: one on the experience of attending school and the second on using other services. The second optional section revealed that the person respondents were most likely to have contact with outside of school was their doctor, followed by nurses and therapists. The likelihood of being listened to by people working in other services was much lower than the results for being listened to at school: only one in five respondents felt that their views were always listened to, with four out of ten saying they were sometimes listened to. The key issues for respondents were that health and social care professionals were perceived as pretending to listen or too busy to listen to them:

> **"It feels like the doctors and nurses are too busy to listen"**



"Because I can't talk some people at school just made up what they thought I was saying. A lot of people just ignored me like some of the therapists and nurses"

fSDC and LTCAS Research Briefing (2011)

Children young people can form a clear understanding of their care experiences, including but not limited to being listened to and involved in decisions. This point was reinforced through the findings of a pilot of the National Paediatric Toolkit by Greater Glasgow and Clyde in two inpatient wards and one outpatient clinic.

In a separate project, NHS Forth Valley worked with a graphic artist to create a poster incorporating the key messages about care experiences in hospital, including powerful quotes.

The National Paediatric Toolkit Pilot: Greater Glasgow & Clyde

The pilot tested an electronic survey tool developed in conjunction with staff at Alder Hey hospital. Two versions are available: one for children aged 4-11 and one for those 12 and over. The survey incorporates a carton character, Fabio the Frog, and is completed in the style of a computer game. Children and young people were involved in the design and testing of the tool.

Staff found the rapid turnaround and clear visual display of results conducive to measuring the impact of improvement actions Concerns about demands on nursing staff time to collect data proved unfounded, with the ward clerk and play leader both embracing the tool, the latter remarking that it integrated well with play activities. However, of particular interest was the finding that children as young as four demonstrated a clear understanding of what might be considered abstract concepts, such as being listened to and respect of dignity and privacy.

Contact: Marjorie.Gillies@ggc.scot.nhs.uk

This provided a vivid, colourful and constant reminder of the aspects of care that were viewed positively and not so positively by children and young people.

Living with a long term condition can of course have a significant impact on many aspects of a child or young person's life, not just the time spent in hospital or with healthcare professionals, In particular, mental health and wellbeing, educational opportunities and experience of being included alongside their peers are known to be important.

"[I would like to] have friends and go out at night [but I] don't have friends"

Views of Quality of Life from Children and Young People
Who are disabled and/ or Living with Long Term Conditions
for Scotland's Disabled Children and LTCAS Research Briefing (2011)

Part Two:
Listening, Learning & Improving Together

Children and young people need greater access to support – including peer support – to deal with the broad impact of living with long term conditions. Voluntary organisations play a vital role in providing information and support to children, young people and their families. Health professionals have an important role in signposting to relevant organisations, but may not always be aware of what's available, especially locally. Here initiatives such as the ALISS project have an important role to play.

Experience of Care Transitions

From Children's to Adult Services

The transition to adulthood is often a time of stress and uncertainty and a young person's management of their condition can be undermined as a result. Many young people and their families need additional support and understanding at times of transition.

There is also a distinct lack of age appropriate health services and settings for teenagers and young adults, which can result in them spending time in children's wards or alongside much older people.

As adolescents living with long term conditions move from child-centred to adult-oriented healthcare systems, transition should be a purposeful, planned process that addresses the medical, psychological, educational and vocational needs.

> **"I think if they just make it smooth, like a smooth transition without any chaos"**
> **Young person, Experience Based Design Cancer Pilot, NHS Lothian**

The following case study considers the application of experience-based improvement approaches to develop a new transition pathway.

Contact: Scott.Taylor@lothian.scot.nhs.uk

CASE STUDY: Transition from children to adult neuro-oncology services
This project was completed in Lothian as part of the Experience Based Design cancer pilot.

Approach: The experiences of teenagers and young adults were gathered, along with those of their parents and staff using a range of methods including clinic observation, questionnaire, in-depth interviews and staff discovery interviews.

Findings: The methods produced a range and depth of evidence which correlated with policy and clinical guidance around many key themes.

General Views on Transition
Views of teenagers and young people about transition were mixed and parents also recognised the need to move on, but still expressed reservations:

> *"I'm not sure I'd like him being in paediatrics at the age of 20!"*
>
> *"It's sort of a security blanket, knowing the nurses"*

The Care Environment
The waiting area in children's services was small and geared to small children, with entertainment options for teenagers and young adults less obvious. Equally young people attending adult services often spent time waiting alongside some extremely ill, disabled and scarred people. Attendees heard conversations about treatment consequences and witnessed an emotional rollercoaster being played out in front of them. Staff were concerned by this:

> *"Teenagers must end up wondering: is that going to happen to me?"*

Parents too commented on the importance of the care environment:

> *"She's been to adult services and didn't want to go back at all. But after a while she didn't feel right in the children's hospital either because she was the oldest. She didn't know where she belonged really".*

Young people also remarked on the unsuitability of both environments:

> *I don't like being in the clinic with wee kids.*
>
> *It does feel weird when you are sat in the waiting room because 90% of people are actually a lot older than you and you just feel a bit out of place*

Part Two:
Listening, Learning & Improving Together

CASET STUDY (Continued)

Empowering and Promoting Independence

There was a strong desire from staff to see teenagers and young people empowered to take ownership of their healthcare, including the need for age appropriate education. Some staff revealed perceptions of parents inhibiting independence and decision making. However, the majority of young people felt comfortable with the level of parental involvement. All interviewees indicated that their parents were always with them during consultations, that they were happy with this, and felt adequately involved:

> *It's difficult to take everything in. They are kind of like my second ear*

> *There might come a stage when there is a subject and I want to talk to the doctor alone. I'm sure mum would understand. She'd be quite happy to leave the room.*

Parents recognised the need for their children to own their own health care, but often found it difficult to become less involved:

> *I'm finding it quite hard letting go and letting her take responsibility, but I'm trying.*

Parents also expressed uncertainty about the extent to which they can get involved once transition has occurred:

> *Paediatrics are dealing with the patient and the family, whereas adult services are just dealing with the patient. I don't even know if I'd be allowed to go into the consultation.*

Timing of the transition was another key theme, with the consensus that this should occur when an individual is ready, rather than at a specific point.

Acting on the Findings

The results were presented at a service improvement event attended by staff members. Key quotes were presented on posters placed around the room and read by staff. Staff welcomed the feedback and commented openly on issues they were not aware of. The use of direct quotes was a powerful means of highlighting the impact of being seen in an unsuitable environment and also the issues around empowering and promoting independence.

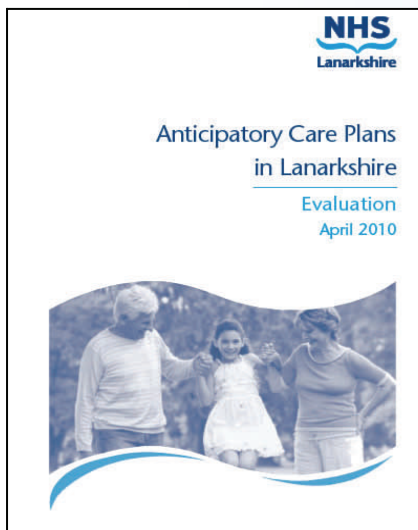
This was followed by a facilitated discussion to agree the best means of transition by drawing on the evidence plus the experiences and perceptions of young people, parents and staff, from which a set of actions and a timeframe of 30, 60 and 90 day review were agreed. Work on the new transition pathway and transition documentation has been completed as far as possible prior to running the first clinic for teenagers and young people.

Supporting Local Care Teams to Engage in Experience-Based Measurement and Improvement Work

Anticipatory Care Planning

Embedding Experience Capture in the Planning Process

Here the term Anticipatory Care Planning is used in the context of Advanced Care Planning, which aims to develop better communication and recording of decisions in the context of an anticipated deterioration in condition, thereby leading to care based on the needs and preferences of people reaching the end of life and carers. As such, ensuring a positive care experience sits very much at heart of Anticipatory Care Planning, but as a new approach, mechanisms for measuring experience in this sensitive context remain largely undeveloped.



When introducing the Anticipatory Care Planning approach within NHS Lanarkshire it was felt that the ideal place to test out the documentation and supporting guidance would be within GP aligned care homes.

In the course of conducting an evaluation of the approach, questionnaires were issued for completion by residents, relatives and staff and comments were also captured throughout the process.

Common emotions conveyed by residents and staff included relief and feeling less frightened:

"One day soon I am going to die. All I am really scared of is losing my mind. In the meantime, I feel better now that I have talked over what I want to happen when I am unable to make any decisions with my family and carers, and have written it down in my care plan".

Care home resident

"Thank you for helping me to make a very stressful situation more bearable".

Relative

Part Two:
Listening, Learning & Improving Together

During the course of the introduction, the Care Planning facilitator received many requests directly from relatives and care home staff for extra copies of the documentation for use themselves and by other family members.

Staff accounts captured growing confidence in engaging in potentially difficult conversations:

> **"Felt a bit uncomfortable at first as sensitive issues were discussed by residents, but was amazed at the type of information that was revealed. One of our 85 year old ladies confided that one of her wishes was to ride on the back of a Harley Davison motorbike. We got that arranged for her".**
>
> **Care home manager**

> **"I think at the beginning it's a very difficult conversation to have with anyone and it was quite a new thing for a lot of our staff to be doing, so in the early days it was quite difficult and we skirted around the issues and words to use and things like that, but what we've found is that once we've actually asked the questions some residents or relatives have said "Oh, I'm so glad you've asked. I think we should be proud of giving good end of life care"**
>
> **Care home manager**

The learning gained from this aspect of the evaluation was regarded as highly valuable and something that teams would seek to continue to build upon, but in an unobtrusive way, and without the need for questionnaires.

Here learning from the Talking Points: Personal Outcomes Approach was shared, namely the importance of ensuring that the process of measurement does not in any way detract from meaningful engagement. This becomes prerequisite in the case of care planning around highly sensitive issues such as end of life decisions. The Emotional Touchpoints approach, described below, also proved insightful, but with emotions and associated short narratives being recorded spontaneously during the course of the care planning conversation, rather than elicited through the use of emotion prompt cards. Staff accounts are also being recorded on a periodic basis.

The resultant approach is allowing the experience of the Anticipatory Care Planning process to be captured in a way that can be documented, reflected upon by individuals and local teams, and aggregated for reporting purposes as required without detracting from the Anticipatory Care Planning process. NHS Lanarkshire ACP Evaluation Report

Contact: Janette.Barrie@lanarkshire.scot.nhs.uk

Care Management

Using Emotional Touchpoints

Direct measurement of care outcomes can be problematic for people with a degenerative condition and many of the benefits of Care Management relate to the experience of care services delivery. There is therefore an understanding of the factors contributing to the care experience of this model of care. These include transactional factors concerning the monitoring of medications, access to information and education and provision a single and continuing point of contact, and relational factors in terms of advocacy and psychosocial support based on trust and mutual respect.

One community nursing team comprising 5 members of various grades trained in the Emotional Touchpoints approach identified Care Management as an area of care that could benefit from its application. Reference has been made to 'touch points' throughout this report, namely the key moments or sub-experiences that shape or colour the care experience overall. More specifically however, the concept of Emotional Touchpoints is a highly practical adaptation introduced by the Leadership in Compassionate Care programme to support use within busy care settings.

The approach is essentially a prompt mechanism for eliciting accounts focused on the emotional dimension of care experiences in a short space of time. A series of possible touch points that people may wish to talk about are presented on cards, with blank cards provided, allowing additional touch points to be added. Having identified the aspects of care that an individual wishes to talk about, a number of positive and negative emotion words, together with blank cards, are then offered to facilitate the discussion, giving permission to talk about emotions and feelings. This has been identified as:

> **"Probably one of the biggest challenges we face as Scots – to learn how to talk freely about our emotions"**
>
> **Nicola Sturgeon**
> **Foreword: Emotional Support Matters**

The use of Emotional Touchpoints has largely been confined to inpatient settings. To progress the work around the experience of care management, a tailored and reusable suite of training materials was developed, together with an Emotional Touchpoints Starter Kit. This comprises possible community care 'touchpoints', a bank of emotion words, a touchpoints stories recording sheet, and examples.

The touchpoints and examples were 'reverse engineered' from the suite of community care stories developed by the Digital Storytelling in Health and Social Care project. The identification of touchpoints was carefully considered and drew upon the learning from staff, the **It's All About Me** event, experience of care management and the emotional and psychological support needs of people living with one or more long term conditions.

Part Two:
Listening, Learning & Improving Together

As such, the touchpoints are not confined to key points of contact with healthcare services, but also pertain to aspects of day to day life where the care manager would be in a position to provide support, either directly or by linking with wider agencies.

Staffing changes resulted in the testing of the approach reaching a premature conclusion. However, the applications that were made were viewed as insightful and successful. One particular application not only generated evidence of the care experience that could be reflected upon, but also resulted in conflict de-escalation, highlighting unanticipated issues to staff and enabling steps to be taken that contributed to an improvement in the individual's mental wellbeing.

The approach was however deemed quite labour intensive, although this would not be unexpected in situations of complexity. There was a strong sense that the Emotional Touchpoints approach would be highly useful in the context of Care Management, although perhaps not for routine use by busy practitioners.

Contact: Karen.Barrie@nhs.net

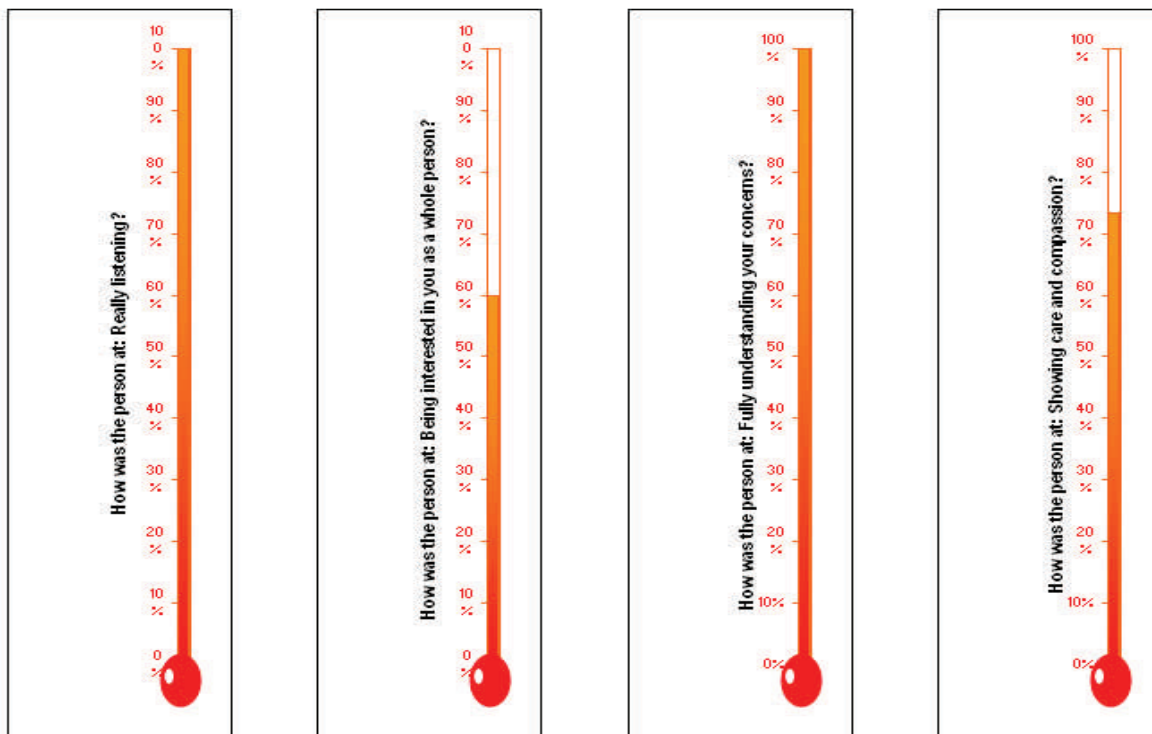
Ongoing Management of Specific Conditions

The Living with Your Long Term Conditions Survey

The Living with Your Long Term Conditions Survey has been described previously. Recognising its potential utility in different contexts, we developed a spreadsheet tool incorporating the questions from the survey to support local teams to evaluate the experience and outcomes of care for people living with long term conditions.

The survey combines a measure of the consultation itself, an enablement measure, a measure of key aspects of the support and care over the past 12 months and a measure of quality of life, together with demographic questions.
Recognising the increasing interest in rapid feedback mechanisms, the spreadsheet tool was designed to allow a subset of questions to be selected from the core set. Provision is also made for the inclusion of additional questions of local interest.

The spreadsheet generates a printable version of the questionnaire including all selected questions plus any additional questions. The tools supports capture of questionnaire responses from up to 15 respondents on a weekly basis and for a period of up to 52 weeks.



Run charts are also automatically created to track trends over time.

Testing with local teams confirms that tool is most applicable in the context of assessing the impact of person-centred interventions for specific conditions such as diabetes or heart failure.

The tool has been shared with Releasing Time to Care in the Community and is now being tested within neurology to support evaluation of the impact of the new generic neurological standards. Possible future opportunities have been identified within heart failure.

Telehealthcare {Palliative and Complex Care}

Care at Home Project: Digital Storytelling

Telehealthcare and children's services as two key areas where 'patient experience' was identified as having the potential to enhance ongoing improvement work. It's recognised that story has a vital role to play in improving the patient experience beyond simply supporting 'service improvement' in the narrow sense.

Staff identified the use of digital storytelling as a means of evaluating pioneering projects in highly sensitive care contexts (linking parents of newborns with neurological conditions with advice and support; linking carers of children with complex needs with specialist community paediatricians and linking the homes of children with palliative care needs to lead oncology clinicians) while also aiming to provide a therapeutic experience for the families involved.

As a result of delivering two digital storytelling workshops, Scottish Centre for Telehealth and Scottish Spina Bifida Association (SSBA) staff were trained in the approach. This has increased their capability to enable others to make digital stories to support evaluation, offering deeper understanding of patient and carer experience and at the same time increasing understanding of therapeutic applications of digital storytelling.

The Care at Home palliative care pilot concluded with the passing of the child, with the team receiving a national reward for the sensitive write-up of the pilot. The child's mother would very much like to create a digital memory, but is not ready yet. The team is convinced of the therapeutic value of the approach and is seeking to role out as an integral part of the programme.

SSBA hosted the training workshops, enabling their staff to take part. As well as creating digital stories to support the evaluation of the S.E.A. Change project, the SSBA has now set up a 'film club' to support youngsters to make their own digital stories as a fun activity and is already planning an 'Oscars' ceremony!

A full suite of resources to support the making and use of digital stories is available from the Care Story Library. The link to the Resource Kit is located in the top right-hand menu. www.carestories.co.uk

Supporting People Living with Long Term Conditions to be Partners in Improvement Activity

While many of the previous approaches are participatory in nature, the work stream also sought to support people living with long term conditions to become partners in improvement activity by providing training and support, and to identify other current models that foster participation. The examples that follow illustrate some of the quite different ways in which this is happening.

Experience Gathering and Improvement Activity

Resource implications have been cited as a significant barrier to engagement in experience data collection and use. In addition, concerns are often expressed that people who use care services will be reluctant to express dissatisfaction or share negative experiences with service providers. Volunteer story facilitators represent one possible solution. However, it is vital that appropriate training and ongoing support, including emotional support is provided.

Story Facilitation Training Case Study

Better Together linked with the Patient Involvement team in NHS Greater Glasgow and Clyde to develop and deliver training in the gathering of personal stories and in carrying out thematic analysis to identify priorities for improvement.

The team had conducted a lot of experience-based improvement work, but had found it difficult to identify areas for improvement within certain services such as cardiac rehabilitation, with people instead expressing their gratitude for 'a new lease of life'. It was felt that involving people living with long term conditions in collecting personal stories might result in qualitative differences in the accounts through their shared identity.

What's Your Story?

Volunteer Story Facilitator Manual

The training participants were people living with one or more conditions who were drawn from an existing network of people actively involved in local service improvement work, largely through membership of groups within Managed Clinical Networks.

As the participants were already actively involved in improvement work, extending the training beyond story collection to include identification of themes and action planning seemed a natural thing to do.

Part Two:
Listening, Learning & Improving Together

The training was conducted over 3 sessions, each lasting for 3 hours and combined lectures, discussions, hands on practical work and role play. Participants felt more confident about asking people to share their stories by the end of the training and a series of 'practice sessions' with fellow members of the network were planned to build on this. Understanding of issues of confidentiality, consent and governance also increased. A suite of reusable training materials has been developed and a full evaluation report will be produced. Training Manual

Case Study: NHS Lanarkshire Palliative Care Managed Clinical Network
Carer Experience Influencing Service Change

The Living and Dying Well action plan (2008) directed Boards to identify carer needs as well as those of people receiving palliative care. Discussions led to the suggestion that carers might prefer this to be carried out through face to face interviews. It was proposed that carers with similar needs should lead these discussions and be trained to carry out the interviews with other carers. This work recognises that a palliative diagnosis impacts the whole family.

The reasons for taking this approach were that people with similar experiences and a shared identity:

- Can establish a rapport
- This affects the quality of information gathered
- Are likely to know what to ask and how
- Could be empowered to use their unique knowledge

The initial reaction from carers was that they had related their experiences many times before and did not see a need to do so again.

However, when it was explained that this initiative was for carers to identify carer support needs there was much greater interest.

The main components of the work are:

- Provide interview training for former carers
- Support the trained interviewers to gather information about the experiences of current carers for people with palliative care needs
- Provide full support including debriefing and emotional support
- Work with interviewers to interpret the data gathered to inform service improvement

Contact: Helen.Alexander@lanarkshire.scot.nhs.uk

Managed Care / Clinical Networks (MCNs)

Managed Clinical Networks involve a variety of health staff and organisations from primary, secondary and regional health care working together to make sure that high quality, clinically effective services are fairly distributed to people with a given long term condition.

Involving people with experience of the particular condition is an important part of Network development. While there are a few examples of MCNs involving people in the collection and use of ‘patient and carer experience’ data to identify and inform improvements, as illustrated through the two previous case studies, the focus on ‘experience’ is a fairly recent development. Most networks do however have long-established ‘patient groups’, and people living with long term conditions and unpaid carers often play an active role alongside staff on service planning and improvement groups.

The following examples typify the responses received from Networks when invited to provide examples of experience-based improvement activity:

- Network activity encourages the involvement of people with long term conditions, carers and lay representatives in development of the Network
- Representation at meetings and on panels
- Feedback from ‘patient satisfaction’ questionnaires is reported to individual Health Boards to inform improvement
- Using personal stories as catalysts for change at events
- Discussion / world café events

During the course of the long term conditions work stream, the opportunity has been taken to attend several national meetings of MCNs to position ‘patient experience’ in the context of the NHS Quality Strategy, to increase awareness of the national patient experience survey data, and to outline the various methods that can be used to support experience-based service improvement activity.

Consulting people about the aspects of the care experience that matter to them represents an important advance in health care service improvement. However, achieving greater person-centred care requires a combination of consultation, user involvement and empowerment at individual and collective level. Each is important and inter-linked.

Managed Clinical Networks are well placed to encourage the use of experience data in developing high quality services and where such steps have been taken, the resulting action has been both effective and inclusive.

Part Two:
Listening, Learning & Improving Together

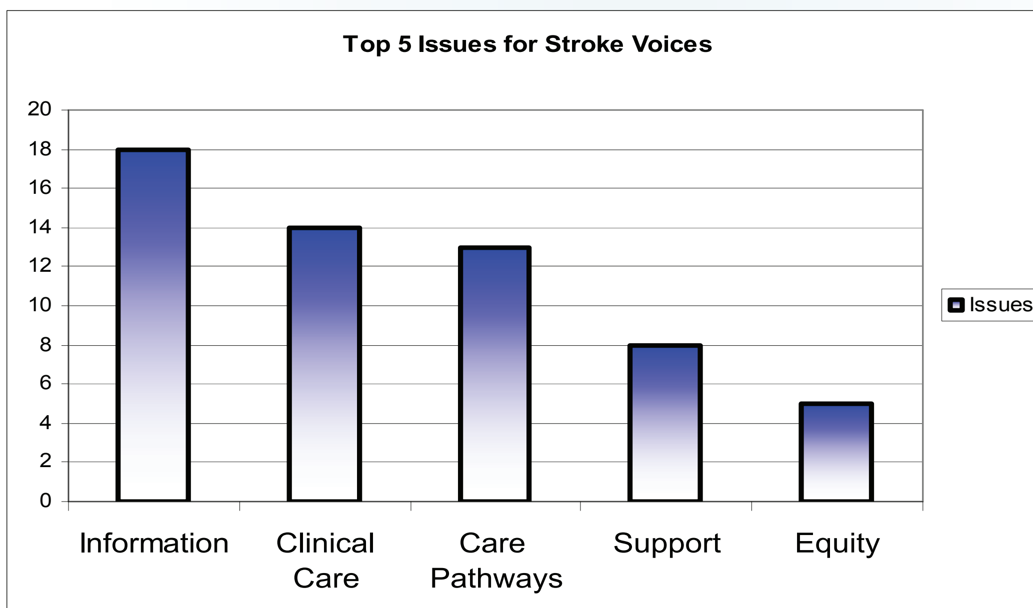
VOICES Scotland

There are many different ways that the voices of people who use care services can be heard. Consultation and gathering feedback is only part of the process.

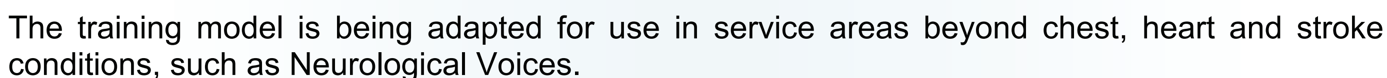
While approaches such as Experience Based Design seek to involve people in time-bound service improvement exercises, with the expectation that they need only bring knowledge of their own personal experience to the table, some people may wish to play a more active role in shaping services. Here, some individuals may need some support in order to build their confidence.

VOICES Scotland supports people living with chest, heart and stroke conditions to have their say and improve care services by giving representatives access to free training and support to improve confidence and skills to take part in national and local initiatives seeking to improve services for their condition.

A Scotland–wide network of representatives has been established and partnership working between the health services and Voices representatives are encouraged to maximise the benefits of the training. A database of issues and concerns identified through the training and taster sessions is also kept and used for feedback to relevant stakeholders.



While developing Stroke Voices, an inclusive approach was sought that would enable meaningful participation by people across every level of the spectrum of ability affected by stroke. The resultant series of three short workshops has huge applicability across a range of conditions.



The training model is being adapted for use in service areas beyond chest, heart and stroke conditions, such as Neurological Voices.

The Voices Scotland team is currently developing a 'Self Management Champions' module, which will initially be offered an extension to the current training provided by the Voices Scotland Programme for people living with chest, heart and stroke conditions. Once finalised, this module will be made available for other organisations to utilise. A carers-specific workshop has also recently been piloted, and a module for healthcare professionals is planned.

More information and guidance are available at: www.chss.org.uk

Service Pledge

The Breakthrough Breast Cancer Service Pledge is a ground-breaking tool to enable meaningful and useful involvement of people living with cancer in improving their breast cancer services. It is designed not only to evaluate the existing service, but also to allow the breast units to pledge to improve areas which people feel could be better. Through the use of a questionnaire, which is based on national standards and specifically tailored to each individual unit, the pledge is able to gain a high level of participation with response levels typically above 50%. More depth of evaluation is obtained through individual and in-depth interviews with people accessing the service. It also allows former patients the chance to represent their unit in the decision-making process to ensure the improvement goals pledged by the units are as meaningful as possible to people. This approach allows staff the opportunity to hear first hand what people value in their service, as well as the areas which could perhaps be improved. So far the Service Pledge in Scotland has been successfully piloted in the South of Scotland Cancer Network area, with a roll-out now taking place across Scotland. The pledge successfully combines the involvement and feedback process with actually improving services in a tangible way.

> **"I felt I was able, in a very small way to help the Service Pledge on behalf of Breakthrough, to allow patients to voice their opinions and feelings and also to assist hospital staff to understand that it sometimes is the small things in a hospital that make life easier for the patients. Sometimes the patients know themselves what is required to make life easier for them but they have no way of voicing this opinion. Sometimes you have to be on the other side of the fence from the professionals to see an obvious answer to a problem. I hope the Service Pledge was in some way a step in the direction of making life more comfortable for patients, and also alerting the professionals to the priorities of the patient."**
>
> **Service Pledge Volunteer**

For more information contact hazela@breakthrough.org.uk

Part Two:
Listening, Learning & Improving Together

Involving Children in Improvement Activity

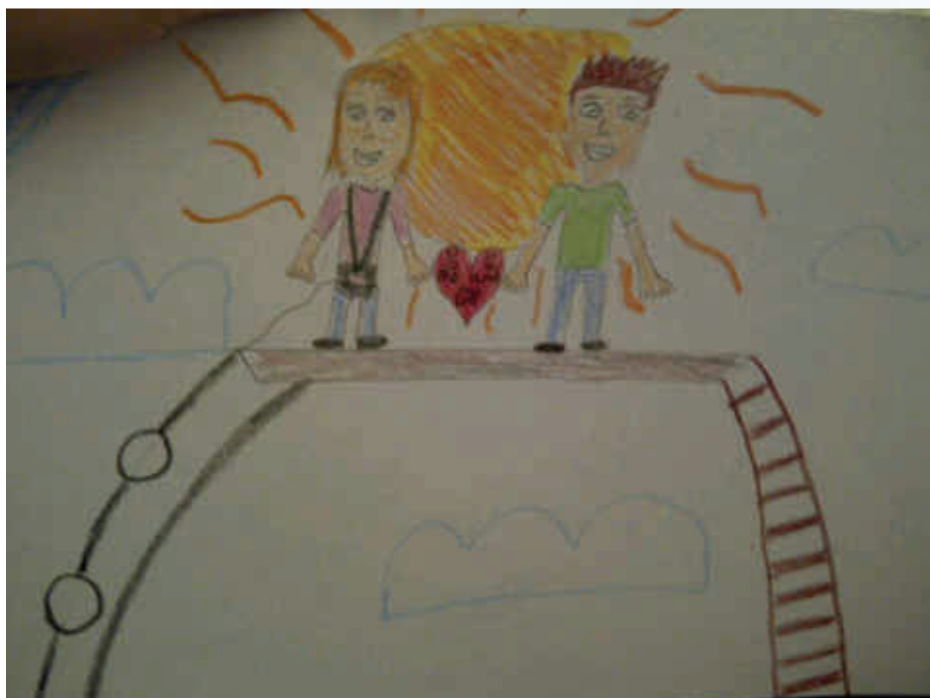
Children and young people should first and foremost be involved in their own care and decisions. Good practice should be built upon, for example the NHS Quality Improvement Scotland Asthma Standards were developed based on this principle and have increased the extent to which children and young people are supported to manage their own condition.

All organisations and services that affect children and young people should have structures and systems in place to respond to their ideas and priorities, and to work with them to bring about positive change. The development of the Asthma Standards was also participatory in nature, was taken forward in partnership with Children in Scotland, who can help organisations and services to involve children and young people in planning and improvement work.
http://www.childreninscotland.org.uk/html/par_con.htm

The Scottish Commissioner for Children and Young People also provides access to a range of information to support the active and meaningful participation of children including workshop resources http://www.sccyp.org.uk/

Learning from the Third Sector

A number of third sector agencies now routinely plan, review and evaluate services and approaches in partnership with the young people they work with. One simple yet powerful example is described in the following case study.



“Go Up High”

Having secured funding to build an adventure play area in the grounds of its centre at Cumbernauld, the Scottish Spina Bifida Association looked to ensure that this would be a facility that visiting children would really enjoy. They first consulted play experts, who advised that the top three things that children with physical disabilities enjoy are:

“Water, sand and swings”

Staff at the centre then brought together a group of children to check this out and when they asked them what they most enjoyed playing on when they visited a play area - what was it that made the experience a positive one - sure enough the answer that came back was:

“Water, sand and swings”

However, one of the play leaders remarked, “we’ve got a blank sheet of paper here; we’re asking the wrong question”. The children were then invited to draw a picture or write a story about what they would really like to be able to do when they visited an adventure play area.

The top two answers were:

“To be able to play on the same things as my brothers and sisters” and

“To go up high”

With a little imagination, both of these aspirations were accommodated.

This story highlights the possibilities that are presented when we focus on the things that people would like to achieve. In Part 3 we consider this in more detail when we take a brief look beyond experience to focus on outcomes.

Part Three

People Not Patients

Part Three:
People Not Patients

Moving Beyond Experience to Outcomes

> **"People spend such a lot of their time trying to manage their conditions. It can be easy to see them only in that dimension, but people are other things; they are mothers, they are fathers, sons, daughters, they are employees"**
>
> **Angela Donaldson, Director**
> **Arthritis Care in Scotland**

When we reflect on the different approaches investigated and tested out in Part 2, a number of recurrent themes emerge:

- The focus has expanded from gathering people's experiences of 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 in improving services.
- 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 themes signify encouraging developments in terms of our efforts to understand the experience of people living with long term conditions and to work together to make improvements to existing care services. However, they remain largely concerned with what current services do and how.

Yet we know that the experience of care for people living with long term conditions is inextricably linked with the extent to which these services, alongside other supports, enable them to live full and positive lives.

> **"Healthcare systems are in their infancy in putting the experience of the user first and have barely started to realise the potential of patients as joint providers of their own care and recovery"**
>
> **Department of Health (2010): Equity and Excellence: Liberating the NHS[20]**

We therefore take a brief 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..

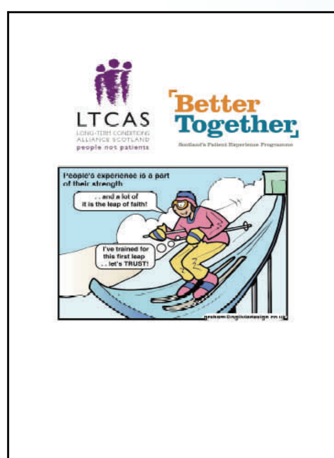
Part Three:
People Not Patients

Learning from Lived Experience and Expertise

People living with long term conditions have a unique understanding of how the condition affects their lives and how to cope with the symptoms. Sharing this experience and expertise can help others to manage their conditions better and to live full and positive lives.

In addition, listening to and valuing this lived experience helps staff at all levels to understand the impact of care and treatment decisions on the lives of those they work with and serve.

Interim Evaluation of the Self Management Fund



Most people with a long term condition lead full and active lives, with only occasional contact with health and social care services, and provide much of the care themselves. As self management will becoming increasingly important as people live longer, many with more than one condition, understanding and improving the experience of support for self management is crucial, demanding a holistic approach, closely coupled with the delivery of improved outcomes.

The interim evaluation of the Self Management Fund Project presented an important means of understanding the role that experience plays in informing self management initiatives and in identifying good practice.

Four themes relating to experience were identified from the analysis of the project evaluations, with peer support and learning from stories featuring prominently alongside using experience to inform service design and delivery improvements and measuring experience.

The findings have been shared through the publication of a special report, which helps make plain the important distinction between 'patient experience' and 'lived experience', as reflected in the measurement approaches. The report is available at:
http://www.ltcas.org.uk/self_basics.html#firstspecialreport

Supporting Professionals to Develop a Person-Centred Approach

Emotional Support Matters highlighted the importance of having an approach to setting goals that is meaningful to the individual and that recognises people's inherent ability to look after themselves and for recovery of their sense of wellbeing. This can represent a significant change in established ways of working for some practitioners and training and support may be required.

Case Study: Thistle Foundation Self Management Fund Strategic Grant

The Thistle Foundation was established in 1944 to provide accessible housing and medical support for disabled veterans so they could live in their own homes, with their families. While the Foundation's work has developed and expanded hugely since then, person centredness has always been very much at its heart:

> **"We recognise that each person is the primary authority on their own life, and we support people to lead great lives where they are in control".**

The Foundation's story is one of continual adaptation, based on learning from the people they work with. For instance, the Lifestyle Management Service was developed by listening to people's stories of "what works" and "what would the ideal service/facility look like". This led to creation of lifestyle courses, plus a supported supervised gym, cafe and spaces to organise peer support initiatives at the Foundation's centre in Edinburgh.

The next stage was the development of a peer co-facilitator programme and the expansion of Lifestyle Management courses across central belt Scotland. In the course of carrying out this work, much was learned about the benefits of peers, and people with lived experience are now actively involved not only in delivering courses, but in all aspects of service, keeping the health professional team connected to 'what matters' to people living with long term conditions.

Over time, the Foundation's approach has developed, with a shift from thinking about health behaviour change to addressing people's concerns and hopes, resulting in the adoption of collaborative, strengths based and outcomes focused approaches - solution focused approaches that help people to rediscover skills and strengths they may have forgotten they have.

Last year the Foundation was awarded a grant from the Self Management Fund to establish a consultancy and improvement resource to train and support public, voluntary and private sector organisations. The project aims to encourage a shift in culture towards person-centredness and holistic approaches. There has been a massive response and tremendous enthusiasm for the programme, with over 300 practitioners having now completed the training. Findings include great stories of supporting people with long term conditions better; signs of relief from therapy burnout and practitioners recognising their role in influencing colleagues' and in service redesign

A tool has also been developed containing 10 Key Ideas for stimulating self-reflection and discussion about ways of improving person-centred practice: 10 Key Ideas

Contact: Ross.Grieve@thistle.org.uk

Part Three:
People Not Patients

Working with People to Shape their Own Care

Talking Points: Personal Outcomes Approach

Talking Points is one approach to building the outcomes that service users and carers identify as important into everyday practice. It includes tools, guidance and training resources to:

- Support a focus on outcomes at assessment, care planning and review
- Enable information on service user outcomes to be systematically gathered during assessment and review processes
- Support organisations to use this information to improve outcomes at individual, service and organisation levels

Talking Points identifies three types of inter-related outcomes based on solid research evidence about the outcomes important to users and carers. Process outcomes are similar to those identified as key aspects of people's experience:

Quality of Life Outcomes	Process Outcomes	Change Outcomes
Feeling safe	Feeling listened to	Improved confidence
Having things to do	Having a say	Improved skills
Seeing people	Feeling respected	Improved mobility
Being as well as can be	Responded to promptly	Reduced symptoms
Living life as you want (including where you live)	Reliability	
Tackling discrimination/stigma		

These broad categories of outcomes provide a framework that can be used to structure conversations. A major consequence of the shift from thinking about 'outcomes' rather than 'needs' has been the recognition of the contribution of the individual and various forms of support, rather than always thinking solely in terms of what services can provide.

During care review, the outcomes identified during assessment and care planning can be revisited to establish the extent to which they have been met. Assessment data can be collated and analysed in order to establish relationships between different outcomes, aspects of services and the attainment of outcomes. This can be used to inform service improvement and redesign. By embedding 'process outcomes' within this overarching outcomes framework, it's possible to identify the relationships between the way in which support is provided and the attainment of quality of life and change outcomes. For staff, the approach can result in a change in practice:

Case Study: Just Listening

As a musculoskeletal physiotherapist, I tend to concentrate on backs, necks and knees and I've often only got 15 minutes per patient, so I do focus on what I see as the main problems. One lady, Jean, was recently referred to me and it sounded like her problems were musculoskeletal

I knew that Jean was 63. She had had a brain injury ten years before and had recently fractured her right foot as a result of a fall. Jean was in pain and this was limiting her mobility. She lived alone in sheltered housing and had a care package in place. I had been informed that Jean was 'not coping'. In the car on the way to visit Jean, I was compiling a list of problems:

Pain; Mobility; Range of movement; Mental abilities; Care provision

Before I arrived, I was already finding a virtual solution to all Jean's problems. The primary thing was to get her up on her feet a bit more doing a bit of exercise to get that foot moving.

Well, things turned out differently. Jean was a charming lady, very much aware of her situation. And we sat and talked. And what Jean told me was first and foremost she really wanted to go to her daughter's for Christmas, but couldn't see how it would work as she couldn't walk.

Her care package had recently been cut from 5 to 3 visits. Her carers have half an hour to get her up, washed, dressed, walked through to the living room and breakfasted. Jean has IBS and frequently has accidents during the night. She was very upset that the carers had other people to look after and she was making them late. The care manager had discussed her care prior to the fall and promised Jean that it would not be reduced. It was reduced and had not been re-evaluated since the fall. She loved her lunch club, but she wasn't going. Her foot was too sore to walk and she "didn't really feel like it anyway!"

Jean's priorities looked a bit different from the list I had compiled:

Worried that she wouldn't get to her daughter's house for Christmas
Distressed that carers were having to rush
Upset that her care package had been changed despite reassurances
Lonely because she couldn't get to the lunch club
In pain

I couldn't resolve all of these issues but could see that some of Jean's 'outcomes' could be improved. The final list of 'interventions' was:

Just talked; use the wheelchair more; review care package

I walked out of there leaving a much happier lady. My eyes were opened to the importance of *just listening* to what people want.

Part Three:
People Not Patients

Extending Choice and Control: Shaping and Selecting Support

Self Directed Support

Self Directed Support is seen as having a major role to play in making the cultural shift from treating people as passive recipients of services to respecting their rights as citizens to become actively involved not only in shaping, but also in selecting the support they receive. It means giving people choice, and also the option of control, recognising that while this option should be available to all, it must be imposed on none.

Self Directed Support is defined as:

> **"The support individuals and families have after making an informed choice about how their *individual budget* is used to meet the outcomes they have agreed"**

It therefore relies upon an outcomes focused approach to care assessment and review that is founded on the principle of co-production, such as that described for Talking Points. While this approach has becoming increasingly familiar in social care contexts, it is less prevalent in health and the use of health monies towards SDS packages remains extremely limited.

Self Directed Support in Health is being piloted in NHS Lothian, focussing on:

- Raising awareness of SDS with target groups and NHS staff
- Establishing clear criteria where healthcare is offered through an SDS model of delivery following clinical assessment
- Working in partnership with local authorities towards establishing complimentary systems to support SDS
- Exploring how resources from other health budgets can be released to support ongoing SDS.

Initially the pilot is identifying people in receipt of healthcare funding from the complex care budget who wish to receive aspects of their healthcare via Self Directed Support on an on-going basis.

Thereafter the pilot will work with stroke survivors deemed ineligible for a complex care budget, but where short-term interventions have been assessed as a clinically appropriate means of supporting re-ablement and self management. These individuals will be given the option to receive part of their healthcare as a Direct Payment delivered through their local authority systems.

For more information contact: Allie.Cherry@luht.scot.nhs.uk

Experience and Community Assets

Thinking about different ways of working together in a person-centred way to improve care experience and outcomes requires a different way of thinking about what we mean by 'support'. The LTCAS 2010 conference posed the question: **''How can we achieve person centredness for people living with long term conditions"?**

The following key themes emerged in response:

partnership; trust and listening; risk and the role of communities

There was a strong sense of the need to empower families and communities as key resources to enhance the health, wellbeing, quality of life and opportunities that people with long term conditions enjoy. Much as focusing on the strengths and assets within individuals has brought about new ways of working together, focusing on the strengths within communities can enable communities and service providers to work together to tackle local issues.

Case Study: Perth and Kinross Healthy Communities Collaborative

The Healthy Communities Collaborative is an innovative project that seeks to improve the health of older people in local communities and tackle health inequalities by combining community development principles with collaborative methodology. The ethos of the Collaborative starts from the assets that older people bring and the outcomes they wish to achieve for themselves, their families and community, and involves continuing collaboration with professional staff, with a focus on localism and forging links with various forms of support from within the community, statutory services and the voluntary sector as appropriate.

Across the area a growing number of local teams of older volunteers are now running local lunch clubs, walking groups, exercise classes for different abilities and social groups, some of which are held within sheltered housing complexes. Support is provided to varying degrees by a small team of health professionals, and some local teams are now self-sustaining. Team meetings are also held to identify and progress local improvement projects using Plan Do Stay Act cycles in which volunteers are trained. Speakers are often invited to attend for instance to raise awareness about early identification of dementia or to prepare people for the digital switchover. Mutual support aspects are valued by members, staff and stakeholders and the model provides a refreshingly positive picture of ageing.

Better Together recently had the opportunity to support the Joint Improvement Team (JIT) in conducting an independent evaluation of the Collaborative. The full report and the executive summary are available from the JIT website.

Part Three:
People Not Patients

This resonates with the growing interest in the following concepts:

Health Assets: Any factor or resource which enhances the ability of individuals, communities and populations to maintain and sustain health and well being. These assets can operate at the level of the individual / family or community as protective and promoting factors to buffer against life's stresses [Anthony Morgan 2009]

Co-production: Delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours

Community Capacity Building: Activities, resources and support that strengthen the skills, abilities and confidence of people and community groups to take effective action and leading roles in the development of communities.

There is now a growing conviction that in many areas we need to re-think models of public service delivery, which have tended to be based on 'doing things to' people to 'fix' their deficiencies, often engendering a culture of dependency. By contrast 'assets approaches' recognise individuals' and communities' strengths and assets, and support them to use these to manage their own circumstances and so achieve sustainable improvements in their lives.

In response to this conviction, an inception event for a Scottish Assets Alliance was held on 13 December 2010. This event, organised jointly with the Scottish Community Development Centre and Long-Term Conditions Alliance Scotland, saw a gathering of some 90 stakeholders, bringing together people already using asset-based approaches with influencers from across the public and third sectors.

A report summarising the event proceedings is available at:
http://www.ltcas.org.uk/documents/AssetsAllianceScotlandEvent13Dec2010Reportpdf.pdf

As we move forward, it is important to situate work to improve experience and outcomes within the context of this 'new' approach to designing and delivering services.

Future Directions

We need to build on the work progressed through this work stream and adapt it to address the challenges of gathering and using experience for all, including people from marginalised communities.

To continuously improve quality, outcomes and ensure our services remain fit for the future, we need to embed and mainstream practical approaches for rapid feedback of experience from people who use care services, unpaid carers and staff. This will provide meaningful level 3 quality indicators to complement results from the Better Together surveys.

Towards Person Centred Care

To provide greater integration and coherence as we implement the Quality Strategy this work will now be progressed by the Person Centred Delivery Group.

Future challenges to be considered include:

- To develop approaches that capture experience and outcomes within an integrated health and social care context
- To develop and test methods of using this data to improve practice and the quality of health and care treatment and support
- To tailor approaches in order to evaluate experience across the life journey –from early years to end of life care - and to extend reach to gap populations and to health
- To support NHS Boards and their partners to use experience data to redesign and commission services
- To support QIS/HISD in developing and testing experience-based level 3 quality outcome measures including development of PROMs and PAMs
- To inform commissioning of future national surveys on patient experience

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.

> **"People must always come before numbers. Statistics, benchmarks and action plans are tools, not end in themselves. They should not come before patients and their experiences"**
>
> **Robert Francis QC**
>
> **The Mid Staffordshire NHS Foundation Trust Inquiry[1]**

The report from Health Service Ombudsman[2] 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.

Definitions

There is no universally accepted definition of **'patient experience'**. Indeed there is a tendency to confuse concepts that may be related but are not synonymous.

Patient Feedback

A generic term for any information gathered directly from people in relation to their care or treatment. Collection, analysis and reporting about a very recent healthcare interaction, often using hand-held devices or online channels, is often described as **Rapid Patient Feedback.** When information is collected at the point of healthcare interaction it is described as **Real-time Patient Feedback.**

Patient Satisfaction

This is feedback from people about how satisfied they felt with their care or treatment. Typically, people are asked to rate their care using broad categories such as 'poor', 'good' or 'excellent'. Patient satisfaction measures can help to monitor trends over time. However results can be difficult to interpret given the wide variations in individuals' expectations of care and the lack of a clear indication of what needs to be done to improve care.

Patient Experience

This is feedback from people about what actually happened to them during the course of receiving care or treatment, which also reflects the person's emotional response to their care. It is a combination of what actually happened (the transactional aspects of care) plus how they felt about the way they were cared for or treated (the relational aspects of care). The term is often used as a convenient form of shorthand and the need to understand the experiences of carers, relatives and other supporters is implicit.

Lived Experience

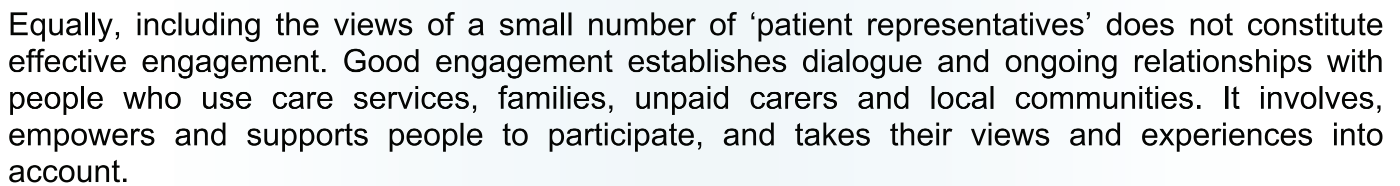
This is the information, knowledge and expertise a person has in relation to any aspect of their life and the extent to which it is affected by their condition(s). It spans their quality of life, function, health and wellbeing, coping strategies and ways of managing their condition(s) in order to live a richer and fuller life.

Empathy

In the context of care encounters, empathy is an ability to understand the person's situation, perspective and feelings (and their attached meanings); to communicate that understanding and check its accuracy; and to act on that understanding with the patient in a helpful way. Empathic encounters improve experience for both the patient and practitioner.

Patient (and Public) Engagement:

Patient feedback is just one element of patient and public engagement and sits well down the ladder of participation[21].



Equally, including the views of a small number of 'patient representatives' does not constitute effective engagement. Good engagement establishes dialogue and ongoing relationships with people who use care services, families, unpaid carers and local communities. It involves, empowers and supports people to participate, and takes their views and experiences into account.

Co-production:
A mutual relationship developed through meaningful engagement.

Outcome:
This is the impact, effect or consequence of a specified treatment, care and support, service or policy. It applies at the level of the individual, service or system. Outcomes are concerned with goals and with the 'why', rather than 'what' we do.

Patient Reported Outcome Measures (PROMS):
Standardised validated sets of questions used to measure patients' perceptions of their health, functional status and their health related quality of life. Generally used before and after care or treatment, they generate *change outcomes* that reflect the extent to which the intervention has worked from the patient's perspective. A frequently used generic PROM is the EQ5D. This set of questions measures the person's perception of mobility, ability to self-care and to perform usual activities, and their self-assessed levels of pain / discomfort and anxiety / depression.

Personal Outcomes:
Personal Outcomes approaches record the goals, aspirations and priorities of individual users of care services and subsequently evaluate the extent to which these are met**.** One example is *Talking Points.* This is based on a co-production approach that acknowledges the role of the person in deciding and achieving the outcomes important to them. Talking Points personal outcomes include *quality of life measures, change outcomes* and p*rocess outcomes. Process outcomes* reflect the impact of service process and are closely aligned with the core set of factors influencing patient experience, but expressed in terms of impact on the individual.

References

1. Speech at the publication of the final report. 2nd March 2010 Available at: www.midstaffsinquiry.com

2. Care and Compassion? Report of the Health Service Ombudsman on 10 investigations into NHS care for older people. Available at: http://www.ombudsman.org.uk/__data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf

3. Darzi, A. 2008. *High quality care for all: NHS next stage review final report.* London: Department of Health

4. King's Fund, Point of Care: Seeing the Person in the Patient, London (2009)

5. Dr. Foster Report (2010) Patient Experience: The Intelligent Board Report

6. Health Care Quality Strategy for NHS Scotland (2010). Scottish Government

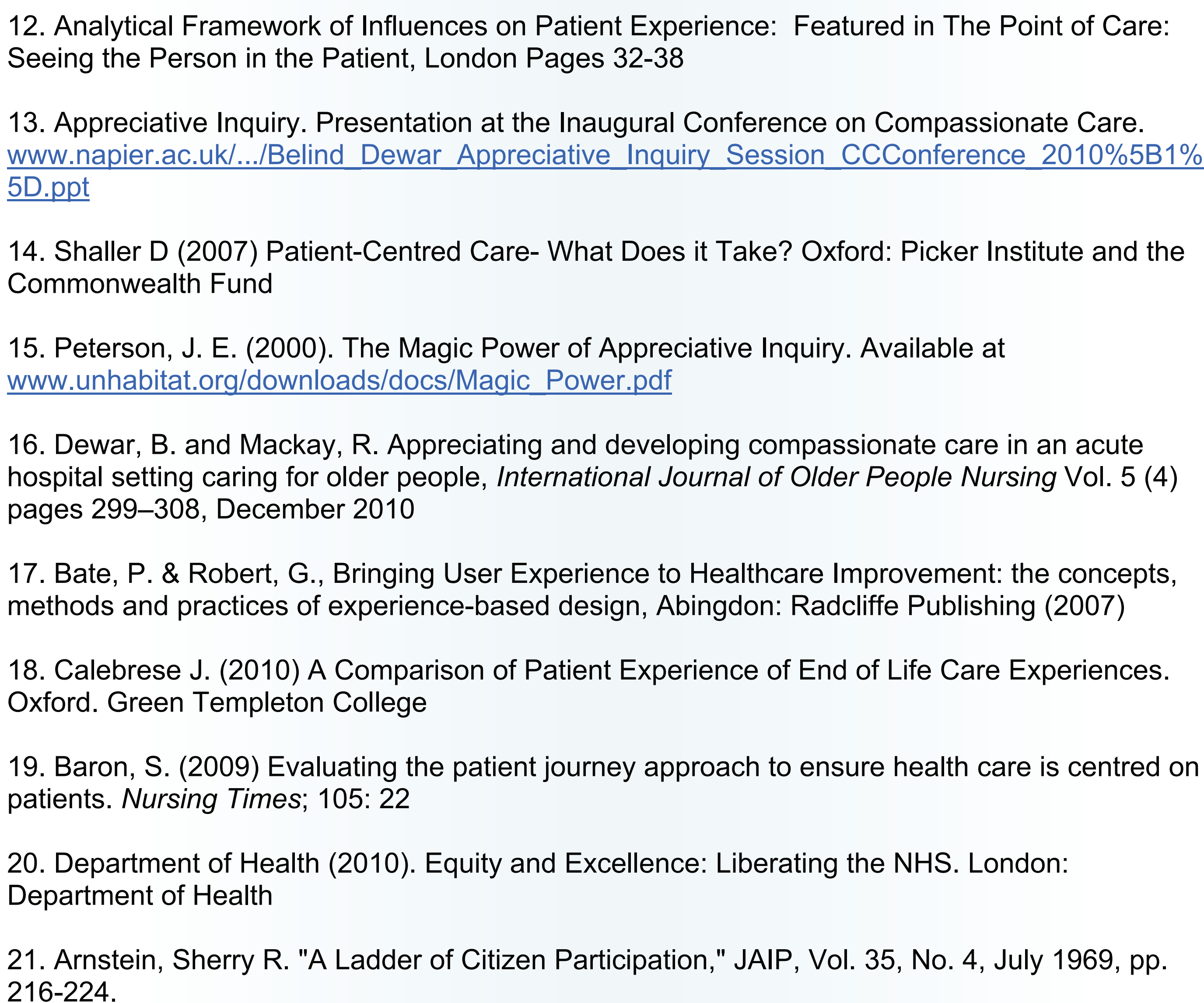
7. Crossing the Quality Chasm: A New Health System for the 21st Century, Institute of Medicine 2001; Frontiers of Performance in the NHS II, Ipsos Mori 2008; Core Domains for Measuring In-patients Experience of Care, Picker Institute Europe, 2009; Key Domains of Experience of Hospital Outpatients, Picker Institute Europe, 2010

8. Flemming, M. (2008) Patient Safety Culture. The How-to Guide for Measurement for Improvement. Available at: http://www.mtpinnacle.com/pdfs/hq8SI_fleming.pdf

9. Department of Health (2009). Understanding what matters: A guide to using patient feedback to transform services. DoH, London. Available from: http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099780

10. Miller E. (2010) Talking Points Personal Outcomes Approach – Personal correspondence

11. The Model for Improvement: Langley GJ, Nolan KM and Nolan TW (1992) The foundation of improvement. Silver Sptrin MD, API Publishing



12. Analytical Framework of Influences on Patient Experience: Featured in The Point of Care: Seeing the Person in the Patient, London Pages 32-38

13. Appreciative Inquiry. Presentation at the Inaugural Conference on Compassionate Care. www.napier.ac.uk/.../Belind_Dewar_Appreciative_Inquiry_Session_CCConference_2010%5B1%5D.ppt

14. Shaller D (2007) Patient-Centred Care- What Does it Take? Oxford: Picker Institute and the Commonwealth Fund

15. Peterson, J. E. (2000). The Magic Power of Appreciative Inquiry. Available at www.unhabitat.org/downloads/docs/Magic_Power.pdf

16. Dewar, B. and Mackay, R. Appreciating and developing compassionate care in an acute hospital setting caring for older people, *International Journal of Older People Nursing* Vol. 5 (4) pages 299–308, December 2010

17. Bate, P. & Robert, G., Bringing User Experience to Healthcare Improvement: the concepts, methods and practices of experience-based design, Abingdon: Radcliffe Publishing (2007)

18. Calebrese J. (2010) A Comparison of Patient Experience of End of Life Care Experiences. Oxford. Green Templeton College

19. Baron, S. (2009) Evaluating the patient journey approach to ensure health care is centred on patients. *Nursing Times*; 105: 22

20. Department of Health (2010). Equity and Excellence: Liberating the NHS. London: Department of Health

21. Arnstein, Sherry R. "A Ladder of Citizen Participation," JAIP, Vol. 35, No. 4, July 1969, pp. 216-224.

If you require this report in another format please contact:

Better Together: Scotland's Patient Experience Programme
Scottish Government
GR St. Andrew's House
Regent Road
Edinburgh EH1 3DG

Email: patientexperience@scotland.gsi.gov.uk

Telephone: 0131 244 4841

Website: www.bettertogetherscotland.com