

***Collaboration between University of Salford, School of Health Sciences
and Bridgewater Community Healthcare NHS Trust***

**The stories that people tell: receiving care from the
Trust**

Final Report

Research activities Sept 2009 – May 2012

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1 Introduction and background

This study was commissioned in 2009 by Ashton, Leigh & Wigan Community Healthcare (ALWCH) as a systematic approach to understanding the experiences of its service-users following implementation of the quality improvement strategy 'Programme Endeavour'. Specifically, the Trust was interested in addressing the question:

'What kinds of experiences have service-users had, during two years of service improvements, and what sense do they make of them, in the stories they tell?'

By listening to service-users' voices ALWCH was aiming to employ a creative way of understanding their experiences of service qualityⁱ. By listening to their *stories*, the Trust was joining a growing movement of researchers and health care providers wishing to give attention to first-hand, detailed accounts of peoples' experiences.^{ii iii} Unlike large quantities of numerical data collected by surveys, service-user stories, or narratives, enable detail, complexity and context to be explored.

1.1 Project plan and outputs: an overview

Over a period of two years, there have been three points of data collection (service-user interviews), analysis and reporting of outcomes.

	Liaison with Trust Recruitment of participants Interviews Analysis	Report to Trust
Round 1	Winter '09 – '10	Spring 2010
Round 2	Winter '10 – '11	Spring 2011
Round 3	Winter '11 - '12	Spring 2012

The research team has consisted of academic staff from the School of Health Sciences, University of Salford, primarily Dr Jackie Taylor and Angela Hook, but with additional team members as interviewing schedules demanded. All researchers were registered health care professionals with research passports. Ethical approval for the study was given by the Trust R&D ethics committee, and by the University of Salford Research Ethics Panel.

Early in the study a **Research Advisory Group** was established, to act as a source of peer review and advice and to offer a breadth of perspective to the project. The group met twice a year and consisted of two **experienced researchers** and **three service users**.

More detail about the background to the research, and the rationale for the choice of narrative analysis as methodology, can be found in the report from Round 1, whilst detail of the methods used for data collection and analysis can be found in each report.

1.2 Evolution of the research approach over the period of the project

1.2.1 Changing needs of the Trust

During the period of the study there have been significant changes in the health service nationally, and in the Trust. The original project aims were related to the impact of Programme Endeavour:

- To explore the quality of service delivery as it is experienced by service-users, with a particular focus on the ways that people make sense of what has happened to them through the stories they tell.
- To perform an analysis of narratives of patient experience for each of the 6 Care Groups to give feedback to ALWCH on the impact of their quality improvement strategies.

These aims were reflected, and met, in the report of Round 1. In the following winter, however, close liaison with Trust representatives responsible for service quality and for service-user experience indicated that a different approach was more appropriate, with slightly different aims. It was agreed that there was a degree of flexibility in the original research plan that would allow the research team to be responsive to the Trust's evolving needs, during a time of transition in the next year. This flexible approach would remain true to the original aims, whilst being sensitive to a context of Trust changes in terms of structure, personnel and activity.

In Rounds 2 and 3:

The aim of the study was to explore the quality of service delivery as it is experienced by service-users

The objectives were to

- Collect narratives about specific events from people who have received care from the Trust.
- Analyse the narratives with a particular focus on the ways that people make sense of what has happened to them.
- Develop a structured representation of how individuals experience community health care and what the key factors are that impact on their experience.
- Provide feedback to the Trust which will help it to assess how its aims for service delivery relate to how the service is experienced.

1.2.2 Changing focus of study

In **the first year** of the study the focus, as requested, was on each of the six Care Groups around which the Trust's service was newly structured in 2009. Each Care Group (**Long Term Conditions, Complex Community Care, Acute Care Closer to Home, Children, Young People and Families, Independent Living and Health and Wellbeing**) might be expected to be impacted on by Programme Endeavour's quality initiatives.

In **the second year**, it was requested by the Programme Endeavour Steering Committee that we focus on particular services: Acute Care Closer to Home (**GP Out-of-hours Service & Walk-in Centre**), Complex Care (**District Nurses & Support Services**), Children, Young People and Families (**Complex Care Nursing, Acute Care Nursing, Occupational Therapy & Physiotherapy**) and Long Term Care (**Community Matrons & Podiatry**). Some of these were services that had been under-explored in Round 1, or were undergoing transition.

In **the third year**, following liaison with the Trust Service-User experience representatives, we were asked to focus on those patients who had received community-based adult nursing services (**District Nurses, Community Matrons, Specialist Nurses, Cardiac, Respiratory, Diabetes, Continence and Dermatology**).

The different focus each year required a different strategy for the recruitment of people who would act as participants in the study. In the first and third years leaflets were distributed via front line staff to their face-to-face contacts. In the second study, recruitment strategies were designed to suit each service, so that leaflets were handed out by face-to-face staff, and were also left in clinics. Some recruitment was carried out in clinics, walk-in centres and 'out of hour' GP clinics, where interviews could be carried out immediately, to catch *ad hoc* service users. Apart from these, interviews were carried out in service-users' own homes by pre-arrangement.

1.2.3 Making sense

Common to each of the three rounds of the study was **the use of narrative analysis**. The small stories that people told about every health care episode delivered by the Trust were extracted and subjected to detailed analysis, so that we could understand better:

- what sense they made of the events
- what the events meant to them
- how they evaluated what happened.

The analysis of each narrative then contributed to a structured representation of how individuals experience community health care and what the key factors are that impact on their experience.

2 Findings at each stage

The detailed findings from each round of the study can be found in the respective reports. Here they are very briefly summarised and viewed together.

2.1 Round 1 – 2009-2010

A total of 141 narratives, told by 18 people, contributed to the findings.

Programme Endeavour was organised around 7 quality orientated work-streams, and the research team used these as a framework for understanding the narratives. In effect we were asking the question, of each Care Group, 'Is the service:

- responsive?
- accessible?
- informative?
- modern and technological?
- customer-focused?
- integrated and efficient?
- expert? '

In fact there was a range of evidence given by the research participants that these 7 service qualities were integrated well into their health care experiences. The majority of narratives told made positive evaluations of these 7 qualities, although negatives (poorer experiences) were also noted and highlighted in the report for Round 1. There were also some particular issues which emerged across the Care Groups, which we felt gave scope for consideration in the Trust, in terms of

addressing quality improvements. These issues, listed here, are discussed in more detail in the original report for Round 1.

1. Service-user expectations of a health-care episode
2. 'Going the extra mile' – a standard part of a health-care worker's job?
3. Helplessness and empowerment in health care
4. What is a professional?
5. Service-users as experts
6. Service-user responsibilities
7. Seamless care

2.2 Round 2 – 2010-2011

A total of 114 narratives, told by 27 people were analysed. We were asked to look at particular services. In this round of the study, we focused on the relationships that people have with the health care providers, at different levels. We found that people had attitudes towards and something to say about their relationships and interactions with individual health care workers, the service provision and the health service and health care in general.

We organised the findings of the study around four questions, each posed in relation to each of the services being examined:

- *What makes a good health care worker?*
- *What makes a good service?*
- *How do patients relate to the health service and health care generally?*
- *What makes a less than perfect health care experience?*

We were able to offer a synthesised 'vignette' to answer each of these questions, based on the narratives that people had told about their encounters with podiatrists, nurses, receptionists etc. As well as using the vignettes to understand what qualities people value, or do not, in their health care providers, we again identified some issues which appeared to be themes and useful topics for debate. These are discussed in detail in the Round 2 report and listed here:

1. What do people mean when they say . . .? How people use local language to describe and understand services
2. What relationship do people have with the NHS service providers?
3. Going the extra mile: making the individual feel special
4. Why don't people speak up when they have a complaint?
5. Coping with changing services

2.3 Round 3 – 2011 - 2012

In this round we analysed 109 narratives from 17 people who had received adult community nursing services. We realised early in the analysis process that the stories that we were hearing were overwhelmingly positive. The possible reasons for this are discussed in the Round 3 report. We decided to focus the analysis on the positive nature of the responses that we had had. If nearly everyone is telling us that the nurses are good, then what is it that makes them so good? What can we learn about what people value about the providers of their health care?

We learned that these good nurses are able to form **strong foundational relationships** very quickly. They make people feel **supported and 'accompanied' in their illness** and they clearly **make a difference to people's lives** and health. Also, we found that they appeared to be delivering an **individualised, bespoke service**, which people very much appreciated. Last but not least the nurses were perceived as being **more than professional** in their standards of knowledge, skill and caring.

The narratives were not all positive, and issues related to weekend working, the prescription of dressings and the timing of visits were discussed.

We also noted, in this round, how humour appears to help to mitigate some difficult circumstances and treatments.

3 Discussion and conclusion

This study, carried out over approximately 30 months, has adapted and evolved in response to the changing needs of the Trust. Each Round served a slightly different purpose, but each has provided a snapshot of services as perceived and experienced by our groups of 'mystery shoppers'.

The study has been carried out using an interpretive, qualitative design, in which people's stories of their experiences have given us access to the fine detail of health care provision in the Trust. The findings of each part of the study are not generalisable in the same way that a quantitative survey based on large numbers would be, but it offers a sensitivity to detail and context, and to the individual's uniqueness in his or her interaction with health care provision. Whilst not generalisable in the statistical sense of the word, the reader is invited to give attention to the resonance of the findings, asking themselves, '*does this ring true, is it meaningful to me, given my knowledge of the service?*'

We have uncovered some excellent, exemplary, examples of health care practice and professional, effective relationships. We have also heard people talking about times when they were dissatisfied and disappointed by what had happened to them. Because the research team stands outside of the Trust, it has enabled an objective distancing, but this also means that the team is not best placed to understand these findings in the context of the Trust, its structure, processes, activities and development.

There are clearly issues raised in these reports that offer scope for debate and discussion within the Trust, as well as the opportunity to learn from the strengths and weaknesses of the service that have been described by its users. Internal dissemination of the findings will enable care providers to reflect on how the service is experienced, and possible lessons learned.

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ⁱ DH (2009). High quality care for all: our journey so far. Department of Health: HMSO

ⁱⁱ Wilcock, P. M., Brown, G. C. S., Bateson, J., Carver, J., & Machin, S. (2003). Using patient stories to inspire quality improvement within the NHS Modernization Agency collaborative programmes. *Journal of Clinical Nursing*, 12, 422-430.

ⁱⁱⁱ Such as the University of Oxford / DIPEX's <http://www.healthtalkonline.org/>