

Collaboration between University of Salford, School of Health, Sport and Rehabilitation Sciences and Ashton, Leigh and Wigan Community Healthcare

The stories that people tell: receiving care from the Trust

**Report on round 2 of data collection and analysis
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Document prepared by:

Principle Investigator : Dr Jackie Taylor
PhD, MSc, BSc (Hons) DipCOT
Senior Lecturer in Occupational Therapy
University of Salford
j.taylor@salford.ac.uk

Project Lead: Angela Hook
MSc, BSc (Hons) DipCOT
Senior Lecturer in Occupational Therapy
University of Salford
a.hook@salford.ac.uk

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1. Introduction to the report

In the summer of 2009, Ashton, Leigh and Wigan Community Healthcare (ALWCH) identified the need to understand how its quality improvement programme (Programme Endeavour) was impacting on the experiences of those who are on the receiving end of its services. Further, there was a desire to develop this understanding by listening to the stories that people tell about their episodes of health care. To this end, this research was commissioned from the University of Salford.

This report is the second report from a series of three. It is a summary of the research carried out in the **second phase** of the project, between **September 2010 and February 2011**. The first report was presented to the Trust Board in spring 2010, and the third will be presented in spring 2012. A full timeline for the project is included in Appendix A. In order to avoid too much repetition some of the background information included in the first report will not be included here.

The importance of hearing patients' stories

Every individual has stories to tell about his / her experiences as a consumer of health care services. Each story, when examined closely, reveals the minutiae of events and interactions in context. A patient survey might show that 75% of the sample rated a service as good, but patients' stories will draw a picture of what made the experience a good one. With this knowledge, the health care provider can gain a greater understanding of the match between what people expect in health care, and what they think they receive. The use of patients' stories has become popular in recent years as a way of informing service improvement initiatives.¹²

Stories or narratives?

The term 'patients' stories' is often poorly defined. It is sometimes used to describe summaries of events that have happened to an individual, but they may have been précised (and possibly unintentionally changed) by someone else. In this study we use the more precise term 'narrative', to represent a story that is told by an individual about their own experience, and analysed from its verbatim form. In this way distortions are minimised, nuances are captured and the personal meaning of the events can be understood.

What is the usefulness of the study to the service provider?

Narrative analysis can provide important information to the service-provider about the values, priorities, expectations and perceptions of the service-user. This approach is a way of listening to the voices of a small cohort of 'mystery shoppers'. It is these voices that can help build a detailed picture of what day-to-day experiences of community services are like.

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

The objectives are 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.

¹ http://www.institute.nhs.uk/share_and_network/pen/add_your_experience_programme_story.html

² 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.

- Provide feedback to the Trust which will help it to assess how its aims for service delivery relate to how the service is experienced.

2. Design and Method: a brief summary

This is a qualitative, longitudinal study, designed to explore and understand service-users' experiences of health care during Programme Endeavour. A sample of service-users are being recruited and interviewed at 3 points over the two years:

Round 1	winter 2009-10	at the early stages of Programme Endeavour
Round 2	winter 2010-11	mid-way though (12 months)
Round 3	winter 2011-12	at the end (24 months).

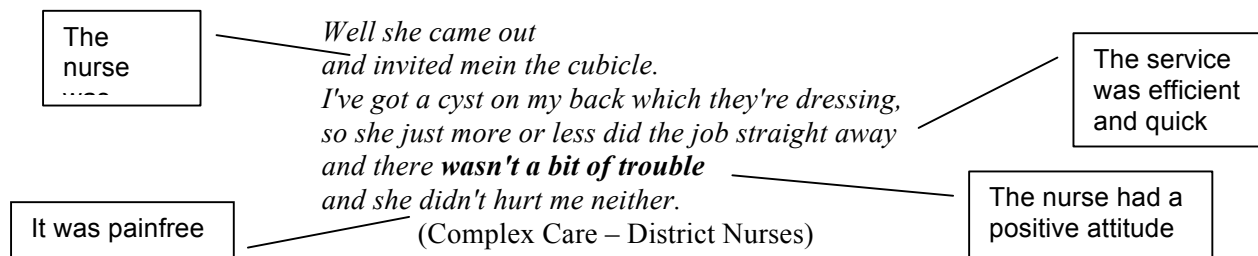
The sample of up to 90 service-users in total will be taken from across the service, a different sample (up to 30) being taken at each round.

In brief summary (**a fuller description of the research method can be found in Appendix B**), Round 2 of the study, reported here, has focused on service-users from services within 4 Care Groups:

Complex Care	<ul style="list-style-type: none"> • District Nurses • Support Services
Acute Care Closer to Home	<ul style="list-style-type: none"> • GP Out-of-hours Service • Walk-in Centre
Long Term Care	<ul style="list-style-type: none"> • Community Matrons • Podiatry
Children, Young People and Families	<ul style="list-style-type: none"> • Complex Care Nursing and Acute Care Nursing • Occupational Therapy and Physiotherapy

These services were selected by the Programme Endeavour Steering Committee. A range of strategies, negotiated with the relevant service teams, was tailored to maximise recruitment of research participants. 27 individuals were interviewed in total. A table showing the demographic characteristics of the sample can be found in Appendix E. Interviews took place in clinics or in service-users' own homes, when the individual was invited to talk about his or her recent health care experiences with ALWCH. The interview was unstructured. The service-user was asked simply to tell what happened; they were not asked to evaluate the service or give opinions. It was anticipated that, without being asked, the individual would tell narratives that contained an intrinsic evaluation.

Within each interview transcript, every narrative that an individual told was isolated and analysed to reveal its meaning. Examples of narratives, and their analysis, will be used as illustrations as the results of the study are presented and discussed, but here we include a small example. At first glance, this seems a simple, description of a visit to the District Nurse clinic. Speaking colloquially the service-user says '*there wasn't a bit of trouble*'. When the narrative is unpicked, we gain a clearer understanding of what she means by that, and how she has evaluated the service.



A single interview could provide up to 12 short accounts of health care episodes, with as much detail as the service-user chose to tell. In this way the experience of receiving health care, in all its everyday detail, could be better understood.

3. Findings

3.1. PART 1: How do people experience the services?

The narratives that people told were very human stories, describing and making comment on the services they had received, and their encounters with health care professionals. What emerged for us, in a powerful way, during analysis, was that these were stories about health care being delivered within the context of relationships. As human beings, the way in which we relate to individuals and services shapes our expectations and our experiences. 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.

Each Care Group will be presented separately below, each section being organised around these four questions:

- *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?*

The answers to these questions will be drawn from the analyses of the narratives of the people that we interviewed, and they will be presented as a synthesised narrative, capturing the essence of what was said. The first person statements are **not** direct quotes from the participants, they are constructed paraphrases, based on an interpretation³ of the meaning of a narrative i.e. each statement is a summary of at least one person's experience of receiving care. Where more than one person had a similar experience, these are captured in one statement.

The paraphrasing serves to *distil the essence* of what has been said and also serves to protect the identity of the narrators.

Note 1) the interviews did not contain these questions. These questions are being used here as a simple framework to present the findings. This framework has arisen inductively out of the analysis of narratives. The reader will find that some of the questions are not addressed for some of the services, because the issue did not arise.

Note 2) there is no claim made here that the people interviewed are representative of the total population served by ALWCH. These narratives represent the voices of some of the recipients of care in the last 12 months, who each have something legitimate to say about what the experience was like. They are our mystery shoppers.

³ Measures taken to enhance rigour in the study, and to verify interpretations are shown in Appendix B.

3.1.1. Complex Care - District Nurses

30 narratives, told by 10 people, were analysed. These tended to be quite short interviews, because they were obtained in clinic areas (for sources of recruitment see Appendix D), after people had been seen by a nurse. The overall picture is very positive.

What makes a good District Nurse?

*the girl that I've actually seen today, the nurse,
she remembered me from before,
which was very nice.
Hundreds of patients she must see
but she remembered me,
and it was very nice.
And again, very, very efficient, very nice, it's good.
You don't feel as if you're just a number and you're in and out.
(CC11)*

Some of the complex care service-users were very clear in their narratives about what good qualities individuals in the District Nurse team have. They are captured within the following synthesised vignette of a 'good' nurse, made from the analysis of the narratives:

A 'good' District Nurse

S/he makes me feel like a unique human being, s/he remembers me from last time and s/he sees me as a whole person. S/he looks beyond my immediate medical condition; s/he understands how it might impact on my life. I trust her/him to tell me the truth. S/he is efficient and quick and will try to make sure that the procedure won't hurt. S/he makes it clear that it is no trouble to treat me.

What makes a good District Nursing service?

Again, there were a lot of positive narratives told about encounters with the service. These far outweighed the negative comments. The essence of the positive stories that we were told is captured here, in this synthesis:

A 'good' District Nursing service

The service is very professional; the nurses are skilled and know how to look after my complex needs. They try different treatments to make me better. I'm not afraid of coming to see them; they have helped me overcome my fears. I respect them; they have a good attitude, they are friendly, they put you at your ease and tell it you straight. I like it that they give me information and help me to feel in control. They are quick, thorough and efficient, but they are there to give me emotional support, when it is needed. You can talk to the nurses like talking to a friend – you know you are in safe hands. I have appreciated having continuous care from one nurse.

They are a good team, they all work together, and they will go that extra mile for me, making sure that I have the means to get home safely, or making sure that I have their phone number.

How do patients relate to the health service and health care generally?

This was an unexpected feature of some of the narratives that people in more than one Care Group told us. Two individuals in the Complex Care Group talked about events that clearly displayed their views about the National Health Service and health care and how they felt one should relate to it. Clearly this does not represent the views and values of all, but this is

a perspective that a patient can bring into his / her own health care situation, and which has a bearing on it.

Relating to the Health Service and health care

As a patient, I have a responsibility to help the throughput of care, and not to waste time. The staff have a hard job, and if I can lighten their load with a joke or two, then I do. A bit of banter and friendliness help make the whole experience better for everyone. If my own appointment is delayed then I can accept it, because we all have a duty to recognise that some patient's needs are more urgent. If I could manage my own health care, then I would.

What makes a less than perfect health care experience?

Not everyone was completely happy with the service they received. Two people told narratives that found fault with the service. Again, this is a small number, but their narratives, in the context of this project, give them a voice. Interestingly, both people agreed on the first point made in the synthesised narrative below:

A less than perfect District Nursing service

They don't really take my personal circumstances and preferences into account when deciding whether to see me at home or in clinic. I wish I could speak up for myself, but it is difficult to and so I feel frustrated. Because I have mobility problems, moving care to a clinic further away is a problem. Also, the cubicles in the clinic don't feel very private.

3.1.2. Complex Care - Support Services

6 narratives were obtained from 3 people, about their encounters with the reception staff in the District Nurse clinics. These were predominantly positive stories. The service-users told narratives about the service, rather than particular individuals.

What makes a good reception service?

*Because I see Dr Z
so I have to ring there
and they're very pleasant, very helpful
and they always try to get me in,
Especially if I feel worse than what....you know
sometimes you need a doctor
and sometimes they say, 'oh we can 't get you in until such a day'
and I just say, 'well, I don't feel a bit well
and I'm living on me own', '
right, come in Mrs X'.
(CC7)*

Inevitably, encounters with reception staff are short, and sometimes over the telephone. People seem to be very clear about what makes a good reception service.

A 'good' reception service

The reception staff are pleasant, helpful, flexible and sensitive to my needs, even when they are having computer problems. When one of my appointments had been made in an unusual way, it wasn't awkward, it was no trouble and everything ran efficiently.

What makes a less than perfect health care experience?

But there are occasions when things run less smoothly, and people have told more critical narratives, as illustrated here:

A less than perfect reception service

When I try to make an appointment by telephone it is so frustrating to get an answering machine all the time. Also, once, when the service was moved about, I was told to go to the wrong place for treatment.

3.1.3. Acute Care Closer to Home - GP Out-of-hours surgeries

16 narratives were obtained from interviews with 5 people, who were all interviewed after they had attended the surgery, except one, who preferred to be interviewed in her home. The service-users' tales about their health care experiences were largely positive and we speculated whether this might be because, between seeing the doctor and being interviewed, little time had passed in which to reflect upon what had happened. This possibility was offered some support when the one individual interviewed at home gave a more critical account.

What makes a good health care worker in this setting?

The experience of attending an out-of-hours surgery is affected by the reception staff and the doctors. There were several qualities highlighted in the narratives that people appreciated, brought together here.

A 'good' receptionist

The woman who answered the telephone was really helpful and polite – she answered quickly, gave us all the information we needed and told us to come straight away. This was better than expected. She was very considerate; she listened carefully, and then offered me the option of a home visit.

A 'good' doctor

The doctor was thorough, nice and helpful and also included me in her/his thought processes – s/he explained everything s/he was doing. S/he gave me time, and treated me like a special individual, not just anyone. S/he has a joke and treats you like you're human.

What makes a good GP out-of-hours service?

A visit to this service is often made in response to a sudden need, and so the issue of how to access the service was the main focus here, mentioned by several people, usually positively, but not always.

A 'good' GP out-of-hours service

I woke up ill and I was pleasantly surprised to find that accessing the service was so quick and easy. It is easier than accessing my normal doctor. Also, once in the surgery, I didn't have to wait long.

What makes a less than perfect health care experience?

4 narratives were told by one person who found the experience of accessing the service, waiting to see the doctor and then seeing the doctor unpleasant. This individual is an exception amongst the other more positive accounts. She had had time to reflect before telling her stories, and had clearly visited the service more than once. These are not her actual words, they are a synthesis, made from the analyses.

A less than perfect visit to a GP out-of-hours surgery

The first time I used the service I was told I should have telephoned ahead of my visit, but this wasn't made clear on the web-site. The second time I went, I phoned ahead and was only asked for my name – it doesn't make sense to me. The wait in the waiting room can be very long and stressful. I can't make sense of what is going on, how long my wait might be, who all these people are and what they are doing. The staff make no effort to explain what is happening. One of those rolling displays would help to give information. The reception staff

don't think it's their job to make the waiting room less stressful. Also, I hate it when the GP doesn't introduce him / herself.

3.1.4. Acute Care Closer to Home - Walk-in Centres

7 narratives were obtained from interviews with 3 people who had attended a Walk-in centre. The interviewees gave mainly positive accounts of their experiences, although we must note, as in the previous service, they had had little time to reflect between using the service and being interviewed. Only one negative story was told.

What makes a good health care worker?

One narrative was told that related to the personal qualities of the staff in the Centre.

A 'good' health care worker

People here are friendly and down to earth. They aren't snobbish and they make you feel at home. They call me 'love' and I like that, it's part of Lancashire.

What makes a good Walk-in Centre service?

The service was seen very positively and was regarded by two people as being better than their GP service.

A 'good' Walk-in Centre service

I got a better service here than at my GP and I'd have to wait 3 weeks to see a District Nurse. I was seen sooner than I thought, and she was more thorough than I expected. The staff were professional; they knew what they were doing. The service is speedy, attentive and polite.

What makes a less than perfect Walk-in Centre experience?

*We had a couple of hours to wait
and then we were shown into a little cubicle
and the treatment we got was fine
It was just the waiting time was a lot
and it added to the discomfort*

*I know the waiting area was crowded
and some of the people were a bit loud and...
...at some point it was a bit uncomfortable, you know...
... with the actual people who were there, waiting...
It was a night appointment...
...and it was a bit uncomfortable*

*but I didn't have any choice in the matter, you know,
she needed attention
and you just wait
(ACCH 3b)*

This was the only narrative which told a less than positive story.

3.1.5. Long Term Care - Community Matrons

No service users were recruited to the research via the Community Matrons service.

3.1.6. Long Term Care - Podiatry

25 narratives were analysed, obtained from one hour interviews with 4 service-users. Each of the service-users told a variety of narratives, including very positive ones, and some negative ones. The positive ones tended to focus on the good relationships with friendly staff, and the efficacy of the interventions they received. The negative narratives were varied, but several of them featured problems that the interviewees perceived, with changes in the podiatry services.

What makes a good podiatrist?

All of the service-users described good relationships with the podiatry staff. The qualities which are valued are presented here, in this synthesised narrative.

A 'good' podiatrist

I find that I can have a nice chat or a bit of banter with the podiatrist while s/he is working on my feet. We have a good rapport and s/he is a good listener. S/he shows interest and makes me feel special. I have liked it particularly when I have had the same podiatrist over a long time, providing my long term care. I didn't mind it when s/he had to change an appointment once, because s/he was so polite about it.

What makes a good podiatry service?

The relationship with individual members of staff is important, and clearly impacts on the service-user's experience of the service, but a wider eye is cast across the service, also. These are some of the things that make a service valued by the service-users, presented in a synthesised narrative.

A good podiatry service

The service makes a difference to me, it provides relief, and I'm pleased because they notice problems that I wouldn't see myself. In fact they definitely do the job better than I do, or my daughter! I have found the service to be very flexible, accommodating my needs, for example when I need a particular appointment time. These things make a difference. It doesn't matter to me if I have to wait to be seen, because the work of the podiatrist is effective.

How do patients relate to the health service and health care generally?

*obviously you expect to wait.
I mean when I went up to Hindley,
I waited.
You know I mean obviously if you've got one in front of you,
you perhaps might have to wait ten minutes or whatever.
But in general, I think that's quite acceptable
in any sort of National Health,
yes excellent,
I think it's very good.
(LTC6)*

In more than one interview across the Care Groups people mentioned having to wait to be seen, but this was usually (not always) noted as acceptable. In the synthesised narrative below, comments from three different people are brought together.

Relating to the Health Service and health care

It's a good service, and I don't mind waiting for my appointment, because it is the NHS.

People get given health advice, but if we are honest, we don't always follow through on it, even though we might have intended to.

I think they are reducing services, but I think they should be focusing on preventative health care, not waiting for problems to arise.

What makes a less than perfect podiatry experience?

There were several concerns about the podiatry service, some of them related to service changes that had happened or were anticipated. They are brought together here:

A less than perfect podiatry experience

I found that changes in how the podiatry service operated confused me, and the continuity of care that I had from my podiatrist was broken. I had to choose between the podiatrist that I had been seeing for a good number of years, and one that was nearer home. The new system of having them moving from clinic to clinic makes them less accessible and appointments less certain. I used to have good care, but I now feel abandoned. I'm worried that the standard of my care is being reduced, and that I won't get such a good service from the community podiatrists.

Also I need clearer information. If I'm not given clear information, like names and phone numbers, then I can't phone about appointments, especially if I forget things and if the service moves around.

Also, I sometimes worry that standing with bare feet on the floor in the clinic, I might catch an infection, though I haven't said anything to the podiatrist, who I really like, I don't want her /him to think I'm criticising her / him.

3.1.7. Children, Young People, Families - Complex & Acute Care Nursing

8 narratives were analysed, taken from interviews with 2 people. The interviews were carried out with the mothers of children who had received care from the service, in their own homes. The narratives that were told, and, indeed, the interviews as a whole, were very positive.

What makes a good nursing service?

The interviewees tended to speak about the 'team' or the 'service', rather than individual members of staff (as we found in podiatry, physiotherapy and District Nursing), so we do not get a picture of a good children's nurse, so much as a good service. Here is the synthesised vignette of what makes a good service, constructed from the experiences told in the narratives.

A good nursing service

The nurses have been magnificent. They have helped me to make some extremely difficult decisions by giving me emotional support as well as all the information that I needed, and they gave me practical help, quickly and efficiently. Their help was delivered as and when I needed it. They made me feel important and treated me respectfully, like an equal partner. The nurses were flexible. They were willing to adapt what they had to offer to fit in with my needs. I trust them enough to leave my child with them.

They are great problem-solvers. They help to find solutions to problems, and then they move into action to put the solution in place quickly. I have seen them do this even when there has been a shortage of resources or staff.

The nurses are great when they visit. They help me to relax, because they know how to deal with my children, and with my own anxieties. Sometime I have worried that they will judge me as a bad mother, but they have understood and reassured me. They explain what they are going to do and they ask permission to do it. They make sure the problem is resolved before leaving us.

What makes a less than perfect health care experience?

Only one small narrative was told that had a negative connotation, but, in fact, this was told in order to illustrate how well the nurses coped with the problem.

A less than perfect health care experience

Sometimes there is a problem with a shortage of equipment, but this is the fault of the system, not the nurses. The nurses do everything they can to make sure it doesn't affect us mothers.

3.1.8. Children, Young People, Families - Occupational therapy & Physiotherapy

3 people volunteered to be interviewed about these services, and we extracted 22 narratives from the interviews. In general very little was said that was negative. Two people in particular were very happy with the services they receive. The third expressed some unhappiness and frustration in her narratives, mainly with the orthotics and appliance service. Although this service was not part of the focus for this round of the study, we have included the analysis of her narratives here, for information.

What makes a good physiotherapist?

Here, in this synthesis, some of the narratives painted a very vivid picture of the personal attributes of a physiotherapist that are valued.

A 'good' physiotherapist

When we are anxious she⁴ makes the whole situation less daunting. She talks to my child, and talks to me, so we feel welcome and comfortable. My child gets a bit fed up of seeing doctors and nurses, but the physiotherapist makes her feel special, so she loves coming for her treatment. The physiotherapist does the routine treatment well and she finds solutions to problems that crop up, but she also has additional skills that make my child love going to see her. She is like a friend; she comes over to chat to my child if we bump into her socially. She does not just provide a professional service; she is a good human being. My child loves her.

What makes a good occupational therapy and physiotherapy service?

*She used to go to a session
once a week for a few weeks;
I think it was for about six/eight weeks.
Intensive sessions;
she used to go for about an hour
and do things ...*

*simple things like fastening buttons and coats,
and things like that,
and it used to drive her up the wall
that she couldn't fasten her own buttons.*

*She'd literally ...
she got to the stage
where she wouldn't wear anything
that had got buttons on it
because she couldn't fasten them.*

*And she got so frustrated with it
so the day she managed to fasten a button,
it was like her birthday party.*

*It's just little things like that that make a big difference to her.
She can't do laces;
she struggles with laces no end,
but these days there's a lot of Velcro shoes,
and things like that, so it's not as important.
But the button thing, it was just great.
(CYPF3)*

When occupational therapy was featured, the narrative tended to focus on the service, rather than the characteristics of an individual. Here is the synthesised vignette.

A 'good' occupational therapy service

We have a long term relationship with this service, and it keeps my child 'ticking over' in terms of meeting her needs as and when they arise. When there is a problem, the occupational therapists are responsive. I have found them to be flexible, fitting in with my needs. They have an easy interaction where me, and my child's thoughts are central to treatment and decisions. They interact well with the medical treatment. Appointments are timed to fit in with botox injections, to facilitate treatment.

⁴ Although the physiotherapist and the child are not necessarily female in these narratives, the female pronoun has been used to avoid clumsiness in sentence construction

Occupational therapy has had a big impact on my child's life– it's the little things, like learning to fasten buttons, that can lead to independence and empowerment. They have started a group for young people to learn new skills and become more independent, and I think this is a great idea.

A 'good' physiotherapy service

In the long time in which my child has been attending, s/he has only had three physiotherapists. They tend to stay a long time, and I have appreciated the continuity of care and the relationships that we have built. The two that left, left for very good reasons.

How do patients relate to the health service and health care generally?

Only one short narrative had anything to say about this topic.

Relating to the Health Service and health care

As a parent, I think that I have an important role to play in making sure it all runs smoothly by co-ordinating appointments etc.

What makes a less than perfect health care experience?

One or two narratives were told that had small criticisms of the service. One interviewee wanted to share her stories about the orthotics service, and although we were not asked to focus on this, we have included it, for interest. This is one mother's perspective, summarised.

A less than perfect health care experience

In general

The parking at Platt Bridge is a problem, particularly for someone with mobility problems. Also, in relation to therapy appointments, it can be difficult juggling the demands of school attendance, clinic appointments and my child's level of tiredness. Through no fault of my own, we missed an appointment recently and received an impersonal and brusque dismissive letter. This was unacceptable from a service with which we have been involved, in such a positive way, for such a long time.

Orthotics and appliances

I get frustrated when people don't introduce themselves to me and my child, especially when it is not the same person that we saw last time. Also, people have conversations without including us, talking over our heads, even though we have been going a long time. I feel invisible, and it is hard to speak out about this.

It can very difficult to get appointments that are right for us, and getting adjustments to appliances can be a long drawn out affair, what with waiting for appointments to come up. I don't like seeing my child in discomfort during the long time it takes to get things done. Also, I can't understand why, when the appliance is delivered to the appliance office, they can't speed things up by phoning me to tell me it's arrived, instead of sending me a letter.

3.2. PART 2 – Some interesting themes to note

As the interview material was collected and analysed, several key issues and questions began to emerge. The analysis was *inductive* i.e. issues were not found because we were looking for them, but because service-users introduced them. The findings are participant-led, rather than researcher-led, although some interpretation has taken place.

What do people mean when they say . . . ?

The value of using narratives to understand people's experiences is that we are listening to fine detail, told in the individual's own words. People used words and phrases like 'no problem', 'professional', 'good', 'smashing', 'fab', 'helpful', 'no trouble' and 'spot on' in their stories. These are the words that local people use to describe the service. We can work out their actual meanings, for each individual, by analysing their narratives. This sounds fairly obvious, but the words have a deceptive simplicity until we get some understanding of their use, in context. An example of how meaning can be unpicked was given above, in section 2. Here is another example, in which the speaker, describing a visit to the GP out-of-hours surgery, describes the doctor as 'helpful' – but what does s/he mean by this?

*It was good.
He was very helpful.*

*He explained all the...
so as he was going through, examining,
he was telling her what he was doing and why he was doing it,*

inclusiv

*and then talked through what he thought it was
and what he thought it might be,
and what we should do
and how we should react to it.*

Transparent and

understandin

*He's given us a prescription
and been very helpful
so, yeah, it's been a really positive experience . . .*
ACCH3

Problem

The answer is in the rest of the narrative. 'Helpful' here means thorough, transparent, informative, understanding, inclusive and reaching a solution to a problem. Just what the patient wanted! Unpicking such words has enabled the synthesised narratives included above to be so rich and detailed. It is not enough to say that a service is 'good', the service-provider needs to know what this actually means, in order to learn from it.

What relationship do people have with the NHS service providers?

As in Round 1 of the study, some of the service-users made it clear that they did not regard themselves as being passive recipients of care. Some people regarded themselves as partners in planning and organising their care, and also, in being mindful of the welfare of the health care staff and other service-users. Some people positioned their understanding of their own personal health care experience against their understanding of the purpose, strengths, weaknesses and structures of the National Health Service.

Going the extra mile: making the individual feel special

As in Round 1, the analysis revealed some impressive examples of health care staff who 'go that extra mile' in providing an excellent service.

*She's just a fantastic person.
She does her job really well*

*and if we see her outside of working hours,
because I think she's a football fan,
just like (my child)
she goes up to X
and she'll talk to him,*

*but she's just...I'm not just saying it,
she's a **really good person**.
(CYPF 2 – Physiotherapist)*

This appears to contribute to a debate about what is a standard service, and what is exceptional. Is there a tangible difference between providing a service as a 'professional', or a 'human being', or between 'being a professional' and 'just doing a job'? There were several narratives in which people talked about being made to feel special. It was notable that, where the service provision was praised in high terms ('excellent', 'magnificent', 'fab', 'spot on') this was often largely as a result of the personal relationship and interactive skills of the health care provider, which seemed to overshadow the outcome of treatment, sometimes.

Why don't people speak up?

Another interesting factor that arose is that, sometimes, when faced with mild (or more significant) dissatisfaction with a health-care experience, people cannot always speak up about it. More than one person told the interviewer about something that they could not say to the health care worker involved. These are direct quotes:

~~~

*so I didn't like not to agree to it really, (CC3a)*

~~~

Yes, but not something you've felt able to mention? (interviewer)

No not really, I just don't bother , Only that one thing, there's only that one criticism. I don't want to put any extra work on them. (LTC2)

~~~

*And then you know you feel like saying*

*"is there something I would like to know?" (CYPF4)*

~~~

Not all individuals are unable to speak up, of course, but there is a point of discussion here, regarding the factors that might send someone home feeling frustrated that they did not mention something that impacted on their experience. The three direct quotes offered here suggest that factors such as politeness, feeling coerced and at a disadvantage, lack of personal assertiveness and not wanting to be a nuisance or give busy people more work might be involved.

Coping with changing services

It is of special note that the 'less than perfect service' section for podiatry included several mentions of recent service changes. These reactions might be those of people who do not like change, or they might be comments on a service that has become less convenient for some individuals. There was certainly an issue for at least one person about the long continuity of care from his/her podiatrist being disrupted by changes. We note this here because continuity of relationships and the quality of relationships has featured elsewhere in the report.

Considerations in the research

- 1) People who were interviewed just as they came out of receiving treatment might be more inclined to be positive about the service they have received. It was notable that most of the narratives we collected at the GP out-of-hours surgery, the Walk-in Centre and the District Nurse clinic were very positive, perhaps because people felt some relief and gratitude following treatment (our speculation). Two people from the same groups, who had chosen to be interviewed on another day, at home, gave longer, more negative interviews, although a third did not.
- 2) This study is not quantitative. The findings are not derived from numerical data. The focus here has been on meaning, detail, depth and context in the narratives that people tell. It is appropriate, therefore, that the data has been gathered from a smaller number of people than one would expect in a quantitative study such as a survey or an experimental trial. As a consequence, it is not claimed that this is a representative sample. Each experience told to us was a unique experience. This report offers our analysis of these experiences as an account of what it was like to be on the receiving end of ALWCH services for these people. In qualitative research findings, we sometimes talk about findings having a 'resonance' for the reader, who can ask themselves, '*does this ring true, is it meaningful to me, given my knowledge of the service?*'

4. Discussion and Conclusions

The findings of Round 2 of the study, offered above, provide rich and detailed material for the providers of community health care. The material has a usefulness in assessing the quality of service provision, and in understanding what it is like to be on the receiving end of care. **At one level** these findings give a simple qualitative evaluation of the services in question. Each service is provided with some rich information about its own provision. **At another level**, some interesting issues arise which can provide a focus for discussion across services, amongst those who strive to provide accessible, high quality services. When shared with service managers and staff the synthesised narratives will have resonance – they are likely to identify issues that they recognise, and perhaps some they have not thought about before.

What these service-users have told us about their positive, negative and neutral experiences of health care offers much to learn from. Within these descriptions of what makes a good health care professional, what makes a good service, how people relate to health care and what can make a service less than perfect, lies some excellent material for discussion, action and training.

The value and usefulness of listening to the first hand accounts of patients' experiences is increasingly being recognised. A recent **Ombudsman report to Parliament 'Care and Compassion'**⁵ bases its findings on the stories of 10 people, recognising that, though not perhaps statistically representative, their experiences were real, and must act as a focus for attention. Another recent report '**In their words: what patients think about our NHS**'⁶, based on patient's stories, has some findings in common with this one, relating to patient-staff relationships and staff attitudes impacting on the care experience. Unlike the report we present here, however, '**In their words**', produced by patientopinion.org.uk, was based mainly on the stories of people who chose to register their complaints on the website. This study has the advantage that experiences of health care have been collected from people who did not just want to complain, and who had small narratives of small everyday incidents and experiences to tell. There is value in listening to people who are not just

⁵ http://www.ombudsman.org.uk/data/assets/pdf_file/0016/7216/Care-and-Compassion-PHSO-0114web.pdf

⁶ <http://www.patientopinion.org.uk/resources/POreport2011.pdf>

reporting critical incidents and big events. The **NHS Patient Experience Network**⁷ offers other approaches to gathering patient experience.

5. Next steps

The research team will:

- Review the processes and outcomes of Round 2, in preparation for Round 3
- Find appropriate platforms for dissemination of the research findings
- Consider whether there are further questions raised by this round of the research that could be addressed next time

ALWCH may wish to consider:

- Whether there are further questions raised by this round of the research that might influence how we approach the next round
- Whether Round 3 could be designed in a specific way, for example
 - Recruiting participants, not directly from services, but by trying to engage the general public through the press, libraries, support groups etc
 - Repeating the approach taken in Round 1, where all 6 Care Groups were involved.
 - Targeting services known to have gone through significant changes in the last year
- Engaging with the NHS Institute for Innovation and Improvement, in relation to this work on patients' narratives.
- Whether these findings might have any impact on what is measured quantitatively

⁷ http://www.institute.nhs.uk/share_and_network/pen/add_your_experience_programme_story.html

Appendix A**Project timeline**

Project Line	Time	Jul 2009	Aug 2009	Sept 2009	Oct 2009	Nov 2009 2010 2011	Dec 2009 2010 2011	Jan 2010 2011 2012	Feb 2010 2011 2012
Complete costings and Project document for the Trust Board									
Preparatory work Ethical Approval									
Pilot interview and basic pilot analysis									
Liaison with Trust regarding recruitment of participants									
Data Collection									
Data transcription, Data Analysis									
Produce narrative analysis summary for each Care Group and dissemination									

Appendix B

Round 2 Research method

The research team:

Principal Investigator:	Dr Jackie Taylor (interviewing and analysis)
Co-investigator:	Angela Hook (interviewing and analysis)
Research assistants:	Heather Davison (interviewing)
	Viv Jones (interviewing)

All the research team members are academic members of staff at the University of Salford, and all are registered Health Care Professionals.

The study sample

The target was to recruit up to 30 people across these services. Each service being very different in the way that service-users are seen by the professionals, a flexible recruitment strategy was designed, tailored to best fit each service. The recruitment strategy was informed by close liaison with service managers and team leaders who could give best advice on the ways to access service-users in each part of the service. The range of recruitment strategies included:

- Inserts in routine survey letters
- Attending clinic waiting rooms
- Leaflets being distributed by health care staff

For more detail, see Appendix D.

Inclusion / Exclusion Criteria

- **Inclusion criteria**
 - o Being a person who has personally received health care, or whose child has received health care, within one of the six Care Groups of ALWCHC.
 - o Having used the service in the last 12 months (*in order that the service-user has a fresh 'bank' of memories to draw on*)
 - o Having the ability to engage in verbal conversation (*since the research method depends upon the telling of narratives*)
 - o Ability to understand and capable of giving written informed consent
- **Exclusion criteria**
 - o Being under the age of 18 (*the ways in which situations are perceived, recalled and recounted may be different in children*)
 - o Being unable to communicate in oral English (*with a translator, we would expect some altered representation of the original narrative, and this would distort the analysis, also the narrative form cannot be assumed to be the same in all cultures (Flick, 2009) and so validity may be compromised*)
 - o Cognitive impairment to the extent that the service-user cannot give accounts of their experiences (*since the research method depends upon the telling of narratives*)
 - o Those who have previously made a complaint or compliment about their health care in the last 12 months (*because this group may wish to use the interview to focus on this issue. The normal Trust complaints procedure gives them a process for having their specific complaint heard and investigated*)
 - o Those who are too ill to participate, or who are unable to consent for themselves (*it is important that the service-users are not vulnerable, and that they can understand what is being asked in terms of consent*)

Data collection:

Some people were interviewed in private rooms in clinics, and some in their own home. All participants were given sufficient information with which to give informed consent to take part in the study, and were advised that they could withdraw at any point, should they change their minds. After basic demographic data were collected, an interview was carried out, designed to prompt the service-user to talk about their recent health care experiences. Narratives about specific events were invited and encouraged, rather than generalisations, descriptions and opinions. Interviews were recorded digitally. A single interview might contain anything between 1 and 12 narratives.

Data analysis:

Interview recordings were transcribed and subject to analysis in the following stages.

- Narratives were identified within the interviews. A narrative, here, is defined as a small story, with a beginning, middle and end, about a particular event that happened, with a protagonist, action and consequence⁸. Each interview yielded several of these small stories (see Appendix F for details), each giving an accessible 'snap-shot' of an experience of health-care services.
- Each narrative was laid out in a way that reflects the pattern of speech and dramatic delivery of the story content⁹
- Every narrative has a point, or a meaning, which can be exposed by analysis of story plot and the narrator's use of an evaluative device.¹⁰¹¹ The extracted narratives were subjected to this type of structural analysis. In this way the meaning that each experience had for the narrator was interpreted.
- The meanings of the narratives were closely examined for common features and for potential clustering. The resultant categories provided a framework for reporting the findings.

Research governance and ethics:

Ethical approval for the study has been given by the Trust R&D ethics committee, and by the University of Salford Research Ethics Panel. Consent, confidentiality, data storage, risks and benefits have been given due and appropriate consideration throughout. The research team involved in interviews all hold a current research passport.

A university-based Research Advisory Group has been established, made up of colleagues with relevant research experience, service-users and the Trust R&D manager. The terms of reference for this group can be found in Appendix C.

A Trust-based research liaison group has been established to discuss and help the progress of the study.

Specific ethical considerations

- In order to interview people in District Nurse Clinics, GP out-of-hours surgeries, and NHS Walk-in Centres, interviewers carried out some recruitment in waiting rooms. The ethical implications of this were debated with the Research Advisory Group, and appropriate safeguards were put in place to ensure that people did not feel

⁸ Mattingly, C., & Lawlor, M. (2000). Learning from stories: narrative interviewing in cross-cultural research. *Scandinavian Journal of Occupational Therapy*, 7(4), 4-14.

⁹ Gee, J. P. (1986). Units in the production of narrative discourse. *Discourse Processes*, 9(391-422).

¹⁰ Labov, W., & Waletzky, J. (1966). *Narrative analysis: oral versions of personal experience*. Paper presented at the Essays on the Verbal and Visual Arts, Proceedings of the 1966 Annual Spring Meeting of the American Ethnological Society, America.

¹¹ Riessman, C. K. (1993). *Narrative analysis*. London: Sage Publications.

compelled to take part, and that informed consent and privacy issues were given due regard.

- Anonymity when quoting narrative material in reports must be given extra attention, as it is common for qualitative material such as this to contain clusters of features which, together, might identify the speaker. In these cases, not only names, but also events, may have to be altered.

Rigour in the study

Rigour was enhanced through several means with a view to monitoring subjectivity and the increasing credibility of the findings:

- Field-notes, reflective diary-keeping and reflective discussions were used to enhance transparency of process.
- Training sessions were carried out, so that the interviewers would all adopt a similar style and routine, in order to stimulate narrative telling.
- Reflective cross-interviewer discussions took place, to enhance transparency, and identify possible sources of subjectivity and bias. These also served to begin the analytic process.
- Initial analysis in this round was carried out by one person (JT). Each transcript, once analysed, was passed back to the original interviewer, for verification of the analysis. Alternative interpretations were discussed and consensus agreed.
- Foot-noting and comment-boxes were used to aid analysis and dialogue between analysts.
- Original narratives were revisited more than once during the summative analysis and formulation of findings.
- The summative analysis tables for each Care Group were shared with and verified by a second analyst (AH). Different perspectives were debated.

Appendix C

Research Advisory Group Terms of Reference

University of Salford
School of Health, Sport and Rehabilitation Sciences

Research Project with Ashton, Leigh and Wigan Community Healthcare

The stories that people tell: receiving care from the Trust

Terms of Reference for Project Advisory Group

Aims of the project:

1. 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.
2. To perform an analysis of narratives of patient experience for each of the 6 Care Groups to give feedback to the Trust on their quality improvement strategies.

The project timeline runs from September 2009 to February 2012

The role of the Advisory Group is to meet approximately two or three times in each year (once during April - Sept and once or twice during Oct - March) to:

1. Offer a breadth of perspective in the process and findings of the research project
2. Review the progress of the research project and offer feedback
3. Advise how the project may be strengthened and any weaknesses addressed
4. Facilitate and engage in problem solving as necessary
5. Comment on relevant reports produced during the project
6. Be a forum to share the emerging findings from the research
7. Suggest ways the emerging findings may be acted upon and disseminated

In addition it is hoped that members are agreeable to being approached for advice on an individual basis as the need arises.

Appendix D

Table showing services involved and varying methods of recruitment

Care Group	Service	Date of Meeting	Strategy agreed	Important dates	Other
CYPF	Complex Care	28.9.10	Send paragraph in survey letter for participants to call AH	Survey sent Oct 10	
	Acute Care	28.9.10	10 staff to hand out leaflets to service users to call JT if wish to volunteer	AH drop 500 leaflets 11 th Nov. Staff hand out commencing 15 th Nov until they run out	
	OT/Physio	Tel call: 8.10.10	To use the review lists to send a letter and request participants contact JT Trust to address the envelopes	AH get 50/50 =100 letters in prepaid envelopes to Helen Hollett 11 th November for sending out on 15 th Nov	
CCC	District Nurses	29.9.10	To be in 3 clinics Worsley Meynes, Leigh Lift and Claire House and recruit/interview	Claire House 6 th Dec 6-9pm Leigh Lift 10 th Dec 10-2 Worsley Meynes 13 th Dec 10-2	
	Support Services	29.9.10	To include in 2 of the above clinics as mentioned in other column. To be in Ashton Clinic for 3 rd	Ashton Clinic 9 th Dec. 10-2 Leigh Lift and Worsley Meynes will jointly consider Support Services	Ashton clinic not required
LTC	Community Matrons	6.9.10	Leaflet drop by staff. Staff collect completed slips and had to Marie who send in prepaid envelopes back to JT	AH deliver 150 leaflets 18 th Nov. to Marie. Hand out starts 22 nd Nov until they run out	No response
	Podiatry	6.9.10	Leaflets to be left in 3 clinics Boston House, Leigh Lift and Platt bridge with request to put in boxes	AH drop 150 leaflets and a box at each clinic 18/19 Nov and collect at end of each of 2/3 weeks. We can ask support staff to be responsible for the box and to draw people's attention to the leaflets.	No response Boston House Leigh Lift no box left due to middle of move Good response from Platt Bridge
ACCH	GP Out of Hours	31.8.10	Researchers to attend 2 sessions to recruit and interview	4 th Dec 9-1 and 8 th Dec 7-8pm	Only 1 clinic required.

	Walk In Centre	31.8.10	Researchers to attend	20 th Dec 10-3	Difficult to get people to stay to be interviewed
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Appendix E

The Study Sample: Demographics and Care Group Distribution table

Care Group	CYPF			CC	LTC		ACCH	
Service	Complex Nursing	Acute Nursing	OT & Physio	Disrict Nursing & Support Services	Podiatry	Community Matrons	Walk in Centre	GP out of hours
Age Range 21-83	40	26	30-45	60 -83	57-68		35 - 62	21 -41
Ethnicity	WB: 1	WB:1	WB: 3	WB: 10	WB: 4		WB: 3	WB: 5
Male Total: 7				3	2		2	
Female Total: 20	1	1	3	7	2		1	5
Employment Status	Unemployed/carer: 1	Unemployed	Employed ft: 2 Unemployed/carer: 1	Employed pt: 1 Retired: 9	Retired: 3 Semi-retired: 1		Employed ft: 3	Employed ft: 1 Employed pt: 2 Unemployed: 2
Job Titles ¹²	HGV driver, labourer, wages clerk, management and leadership advisor, surveyor, warehouse operative, chef, charging assessor, telephone engineer, shop owner							

Key:

H&W: Health and Wellbeing
 IL: Independent Living
 LT: Long term Conditions
 ACCH: Acute Care Closer to Home
 CC: Complex Care
 CAYF: Child and Young Persons
 WB: White British

¹² Presented randomly to protect identities, but to show heterogeneity of the sample

Appendix F**The number of narratives analysed, per service**

Care Group	Service	Total narratives
Children, Young People and Families	Complex care nursing	5
	Acute care nursing	3
	Occupational therapy & physiotherapy (and orthotics)	22
Complex Care	District nurses	30
	Support services (reception staff)	6
Long Term Conditions	Community Matrons	1
	Podiatry	24
Acute Care Closer Home	GP Out-of-hours	16
	Walk-in Centre	7
Totals		114