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 1 of data collection and analysis

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1 Introduction to the report

This is the first report in a three part research project which began in September 2009 and will end in March 2012. This report is written to summarise the findings of the project to date. It is not a full and detailed research paper, which would be inappropriate at this stage. Some references to government documents and academic articles are included, to support the approach taken in the study, but these by no means comprise the full set of resources informing the study.

The intended audience for this report are the commissioners of the research, so, although some orientating background is given with regards to Programme Endeavour, this is brief.

The report begins by describing the context and rationale which have given rise to the study, followed by a brief description of the method used for data collection and analysis. The findings will then be presented and discussed. The final section will provide a summary conclusion.

> *NB Although the term 'patient' is frequently used in relevant Department of Health documents, the term 'service-user', arguably more appropriate for community -based services, will be used throughout this document.*

2 Background

2.1 Improving health care quality

'Quality is the silk thread that is being stitched into the very fabric of the NHS'. (DoH, 2009a p4/5).

Both the Darzi report (DoH, 2008) and good practice create a push for health care providers to find new ways of improving the quality of their services. Not only should quality be improved, but government drivers, such as the Darzi reports, have flagged up the need to measure and record the quality of care which is delivered, so that improvements can be demonstrated. One of the key areas identified in the definition of quality outlined in 'Transforming Community Services' (DoH, 2009b) is that of the service-user's experience.

While some quality improvements, such as those focusing on safety, can be measured numerically and relatively objectively, trying to access the service-user's experience of quality presents different challenges. The complex, contextually sensitive experience of the individual is less tangible and measurable. One of the challenges for health care providers, then, lies in finding creative and effective new ways to understand patient experience (DoH 2009a).

Ashton, Leigh & Wigan Community Healthcare (ALWCH), the autonomous provider arm of NHS Ashton, Leigh & Wigan Primary Care Trust (PCT), has embarked on 'Programme Endeavour,' a two year programme of quality improvements in service delivery, throughout their areas of community-based health care provision.

ALWCH services are delivered across the following six Care Groups (restructured in 2009)

- Long Term Conditions
- Complex Community Care
- Acute Care Closer to Home
- Children, Young People and Families
- Independent Living
- Health and Wellbeing

Each Care Group has its own sub-structure of organisation designed to incorporate and integrate the work of a range of health care professionals, to meet the specific needs of particular groups of service-users.

Programme Endeavour, will '*affect every aspect, no matter how small, of our services'* (ALWCHC, 2009, p10), and is organised around seven major work streams. The work streams, listed below, are designed to positively impact on the service-user experience:-

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

2.2 Listening to service-users

Finding a way to collect and capture the experiences of health care service users is challenging, but important. Safety outcomes may be improved and the effectiveness of interventions improved, but a service-user may still come away complaining about his / her experience (Wilcock, Brown, Bateson, Carver, & Machin, 2003). There are various ways that feedback about experience can be elicited. Survey questionnaires are quick and easy to administer to large numbers and offer some ease of analysis, but they have two significant disadvantages. They tend to capture superficial information, leaving little room for the respondent to elaborate with detail. Also, they ask questions which have been predicted as being important by their designer, but which may not be what the respondent thinks is important. The respondent is thus doubly constrained: he/she cannot give answers which reflect depth and complexity of experience, and he/she cannot give answers which fall outside the expectations of the researcher.

A method which addresses both of these constraints is the use of service-user narratives. There is a growing tradition of listening to, and analysing, the stories that people tell about their experiences (Riessman, 2008). People use story-telling in everyday life to tell others about their experiences, to make sense of them and to give a perspective on them. People do not tell stories without intending to make a point. By encouraging people to recall and recount stories, we can obtain ‘snap-shots’ of their experiences, including all the detail that the narrator thinks is relevant.

This method of research is developing outside of, and inside of health care research. The importance of narratives have been acknowledged in clinical interventions (e.g. Greenhalgh & Hurwitz, 1998) and in influencing service planning (e.g. Bate & Robert, 2007) but there is also potential for their use in exploring and understanding what it is like to be on the receiving end of services. Minimally structured interviews in a comfortable environment can be designed to promote the recounting of memorable stories about experiences, enabling the service user to bring to the fore what they consider to be important ‘*no matter how small’* (ALWCH, 2009, p10). This enables individuals to have a voice, and to tell stories which may otherwise remain untold, but which are important in the evaluation of the service. It is a little like inviting mystery shoppers to talk in detail about their experiences, in a way which is unfettered by researcher-led agendas.

Whilst the presentation of patients’ stories as a way to understand patient experience has become increasingly popular in recent years, the stories which are used are often those written by health service staff, based on anecdotes. These have their value, but a research study which aims to gain access to accounts of actual experience will need to focus on verbatim accounts which have been minimally altered (Riessman, 1993). These are a rich source of information and the analyst can focus attention on context, on meaning and on those taken-for-granted aspects of services which may have become invisible through familiarity (Greenhalgh & Collard, 2003). Through systematic analysis of the narratives, (Riessman, 1993; Taylor, 2008) the researcher can better understand the nature of the event and what meaning and impact it had on the individual’s perception of the health care service. This is valuable information for a health-care provider to have, when attempting to understand what it is like to be on the receiving end of services.

ALWCH wishes to understand the experiences of service-users during Programme Endeavour and so has commissioned this study which aims to address 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?*’ This qualitative information will supplement other quantitative measures (e.g. outcome measures and surveys) which are in place.

2.3 Aims and purpose of this research project

- 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.

3 Design of the study and method

This is a qualitative, longitudinal study, designed to explore and understand service-users' experiences of health care provision during the two year programme of service quality improvement, Programme Endeavour. A sample of service-users will be recruited and interviewed at 3 points over the two years: **round 1** at the early stages of Programme Endeavour, **round 2** mid-way though (12 months), and **round 3** at the end (24 months). The sample of up to 90 service-users in total will be taken from across the 6 Care Groups, a different sample (up to 30) being taken at each round.

The data collection, analysis and findings reported below are from **Round 1.**

3.1 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.

3.2 The research team:

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

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

3.3 The study sample:

Recruitment leaflets were distributed (approximately 1000 per Care Group) during January 2010. Service-users volunteered to take part by contacting the Principal Investigator. Project information was then sent out, and an appointment made to interview the individual, usually in their own home. 19 people volunteered, although 1 person withdrew before interview, so a total of 18 people were interviewed and included in the study. The demographics of the sample, and their distribution geographically and across Care Groups can be found in Appendix 1.

Some of the approaches taken and issues arising, in relation to the research process, are summarised in Appendix 2, in which the list of recruitment inclusion and exclusion criteria can also be found.

3.4 Data collection:

Interviews were carried out by Jackie Taylor, Angela Hook and Anita Williams. Before each interview began, the project was discussed and informed consent confirmed by signature. Some simple demographic information was collected. Typically the interview lasted an hour, although this varied. Interviews were carried out in a relaxed, informal way, with a flexible schedule that allowed for an 'active' conversational interaction

(Holstein & Gubrium, 2004) to take place. By this means, participants were encouraged to talk freely about their health care experiences. Narratives about specific events were invited and encouraged, rather than generalisations, descriptions and opinions. In some cases, a third person joined the interview (e.g. a partner) and occasionally contributed to the construction of a narrative. Interviews were recorded digitally.

3.5 Data analysis:

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

- Narratives told about heath care experiences from ALWCH were identified and extracted, as were narratives about non-ALWCH health care experiences. This latter group included experiences with a range of services including other Trusts, in-patients, ambulance services, A&E and also GPs. An early decision was made to include these for analysis. The rationale for this decision will be discussed later.
- 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 consequence (Mattingly & Lawlor, 2000). Each interview yielded several of these small stories (see Appendix 3 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 content (Gee, 1986)
- 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 (Labov & Waletzky, 1966; Riessman, 2008). The extracted narratives (colour-coded for ALWCH and non-ALWCH) were subjected to this type of structural analysis. In this way the meaning that each experience had for the narrator was interpreted. Two simple and short examples of what narrative meanings looked like are included here, from 2 different service-users in the Independent Living Care Group

    1. *How does she make sense of what happened? The staff were sometimes too kind and she had to take control of her progress and independence. The story seems to be about how she appreciated their kindness, but she wanted to do for herself.*
    2. *How does this person make sense of what happened? She has found information out almost by accident, at the Job Centre and on her GP’s notice board. Her implication appears to be that she might not have found out about services that were of benefit to her.*

- The meanings of the narratives were closely examined for common features and for potential clustering. At this point, rather than pursuing the emergence of a new, and possibly unhelpful, organisation of the findings, a decision was taken to map the meaning of each narrative account onto the 7 work streams against which ALWCH might wish to evaluate the quality of its service.

In **summary**, each narrative, or story, that each service-user told, about their health care experiences, had a meaning. These meanings were examined for evidence to address these questions:-

Is the service:

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

Each narrative could yield information to help provide an evaluation of these factors, from the perspective of these 'mystery shoppers'.

4 Findings

The total number of narratives extracted for analysis are summarised in Appendix 3.

This section will begin with a brief overview, giving a context for understanding how these narratives are situated in the participants' overall lives. Then the findings for each Care Group will be given, in terms of which services were discussed, and whether people had positive, negative or neutral experiences. Finally an examination of narratives about non-ALWCH services will be made, in order to understand what meaning people made of those experiences.

Small narratives and big life narratives

In everyday conversation we all tell narratives to describe and make sense of our experiences. These 'everyday' narratives range from the mundane and the small (*'the check-out operator was a little rude, and I told her'*) to life-changing, large narratives ('*this is how I met my wife'*). Each small narrative that we tell is just a small episode in the larger narrative which makes up a whole life story.

When these ALWCH service-users were interviewed, some of their narratives were small and 'mundane' and some were dramatic and life-changing. Even the most skilled interviewer would find it difficult to prevent the telling of a narrative about the admission to A&E with a heart attack which preceded input from the cardiac nursing services. Often, the 'big' life-changing narratives provide the backdrop for the small ones. This is important to note because early in the study, it was decided that the 'life-changing' narratives and others which were concerned with non-ALWCH services could not be ignored. They were included for four reasons:

(i) because they sometimes provided a contextual backdrop, helping to make clear sequences of events

(ii) they might help us to understand an individual's previous experience of health care services. These might influence perceptions and reactions to services offered by ALWCH. Also, people do and did make comparisons between various services

(iii) the other reason why they have been included is because these participants' experiences of other services, when analysed, may have something to offer ALWCH in its endeavour to improve service quality

(iv) some of the narratives concerned the interface between ALWCH and non-ALWCH services.

Presentation of results

The report will now consider each Care Group in turn. For each Care Group a summary is presented of our interpretation of how people made sense of the services they received. The first person statements are **not** direct quotes from the participants, they are constructed paraphrases, based on an interpretation[1] 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.

> **A cautionary note: how the findings are best understood**
>
> A note of caution must be inserted here. No attempt has been, or can be, made to quantify the data collected in the interviews. Some people told many narratives and some told few, some Care Groups had several service-users who volunteered, and some had only two. In all, the study is with a small number of participants who cannot be deemed to be representative of all service-users. In fact, the very fact that the narrative accounts are contextually situated, means that they are unique experiences, and so not generalisable. The value of the material presented here is that various experiences are offered up for service managers and front line staff to consider, as indicators of what might be viewed as good quality or poor quality services. 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?*'
>
> The feedback given here, for each Care Group to consider, may relate to only a small part of the service (depending on where volunteers were recruited from), and so it cannot be taken as an overall evaluation of the whole Care Group. The value here is in listening to service-user voices, and considering their value in relation to the quality of any part of the service. What an individual says about one part of the service could be considered in relation to its application elsewhere.

The tables presented below for each Care Group map the sense that participants made of their experiences onto the 7 quality work streams. The voices give food for thought, and possible actions to follow through. They act as indicators for a service that people would value and prefer.

Also included for each Care Group is a small section of a narrative to illustrate some of the things that people said[2].

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[1] Measures taken to enhance rigour in the study, and to verify interpretations are shown in Appendix 2.

[2] The quote for Complex Care is the only one with a slightly negative tone. It is included because it has a short, simple message

4.1 Health and Wellbeing Care Group

and when I started I thought
I don't want to do this,
the first couple of times,
and with her talking to me
and more or less her feeling
what I was feeling,
we were getting through to each other
***She's been great** and she has got **me** back*
HW5, about counselling

A total of 18 narratives were analysed from 5 participants, who all had stories to tell about receiving services. The majority of the narratives were about counselling services, but some were also told about ear syringing, smoking cessation (and related pharmacy services) and a district nurse. The majority of narratives evaluated the experiences positively. Negative evaluations were given in relation to a particular pharmacist (in relation to smoking cessation), and in relation to not understanding why counselling ended after 6 sessions.

	positive evaluations	**negative evaluations**
responsive?	It's meeting my needs It's making a difference S/he left her number with me	6 appointments is not enough for me I had to wait to get an appointment
accessible?	The appointment time fitted in with my needs I was able to self refer S/he saw me at ground floor level The GP suggested it I was able to phone up for an appointment after I'd been discharged	I don't want to have to travel too far Not all GPs refer to counselling It just ended after 6 weeks
informative?	I'm learning to understand myself	
modern and technological?		
customer-focused?	S/he had a sympathetic ear We were getting through to each other S/he saw first hand how things were for me and took me seriously	S/he tries to intimidate me S/he makes me feel powerless It was like s/he didn't want to know
integrated and efficient?		One service doesn't necessarily work in the same direction as another (pharmacy / GP)
expert?	There was a good outcome	

	- S/he has the skills to do the job - S/he made me realise what my problem was - S/he seems to have made the problem go away	

4.2 Complex Community Care Care Group

> *I had my catheter removed by a District Nurse;*
> *which I was dreading*
> *because, you know, it's really*
> *firmly stuck in.*
>
> *Unfortunately,* ***nobody explained to me***
> *that it was held in by a little balloon.*
> *So, when they take it out, all they do is extract the gas.*
> *I didn't know this;*
> *CC2*

Within this group two service-users participated in the study, telling 7 narratives about ALWCH services, including the lymphoedema service, the hospice staff, a district nurse and the Trust Board. Some negative evaluations were made, these tending to be around perceptions of people not being given enough information to allay anxieties about treatments, procedures and stages of illness. In counterbalance to this, there were positive evaluations, as listed below.

	positive evaluations	**negative evaluations**
responsive?	- They have tried alternatives, to problem-solve - S/he helped me straight away - S/he helped me to help myself - They helped me put the idea into action	
accessible?	- I could just pick up the phone to contact him/her	
informative?	- S/he had prepared me for what might happen, so I was ready	- I wish the procedure had been explained to me, I wouldn't have worried - She wasn't given the information she needed
modern and technological?		- The splints and supports are problematic
customer-focused?	- Despite the limited resources, they have tried hard to help me	- S/he didn't allay my anxieties - They didn't think to tell her what

	• S/he worked as a partner with me • They took my ideas for service development seriously	she needed to know • They wear a uniform and that puts me off
integrated and efficient?		
expert?		

4.3 Acute Care Closer to Home Care Group

> *Well, I found out that …*
> ***one of the most beautiful things** I saw …*
>
> *This is where the difference comes in.*
> *They work as a team.*
>
> *Everyone helps the other one out all the time*
> *and this is what I noticed with them.*
> *All the time.*
> *Especially when two of them come.*
> *They work like a team.*
>
> *They know what they're doing.*
> *They've a good chat; a good laugh;*
> *this, that and the other;*
> *they accept everything and get on with the job*
> *ACCH1 about Hospital at Home*

Narratives were collected from two people who participated from this Care Group. Between them they told 14 narratives. One individual told only two of these narratives, about experiences of a walk-in centre. The other was a voluble individual, who had had longer term, and complex involvement with a range of services, including district nursing, occupational therapy and Hospital at Home. This particular individual evaluated the Hospital at Home service very positively, in comparison with the District Nurse service. (NB this is one person's perspective, and may be based on a particular issue). Some of the narratives seemed to convey a meaning which could not be captured under the seven work streams identified by ALWCH, although this is open to interpretation. An eighth category of 'other' was opened up containing some positive evaluations when the service-user felt that he was given responsibility within the treatment, or when he felt the professional had shown a human side. Third in this category was when the service user felt that his expertise as a patient was recognised, in a role as 'teacher'. All three of these narrative meanings occurred more than once, across Care Groups.

	positive evaluations	**negative evaluations**
responsive?	• The walk-in centre was there when I needed it, because I couldn't see a GP	

	• S/he made the appointment to suit my needs	
accessible?	• It was open early in the morning, when I needed it, I could just walk in	
informative?	• They explained to me why they couldn't give me anything • S/he was on holiday, so I decided I didn't need her/his services (a neutral evaluation)	
modern and technological?	• S/he checks the equipment meticulously	
customer-focused?	• Being flexible was clearly no trouble • They are good humoured • S/he treats me with respect • S/he was interested in me	• s/he was poor at timekeeping • S/he was a bit casual • s/he behaved as if I should be honoured to have her visit
integrated and efficient?	• S/he was punctual • They are efficient • They work as a team • S/he works very hard • They have an impressive routine	• S/he was disorganised and forgot my appointment
expert?	• The diagnosis and advice was right • They know their job • I trusted their judgement • I have confidence in them • They took the opportunity to learn about my other condition	• They didn't identify that I had a problem, and there were very serious repercussions for me • I couldn't trust his/her judgement
other?	• S/he lets me take some responsibility in my treatment • S/he is a human being • I could teach him/her about my condition	

4.4 Children, Young People and Families Care Group

No participants emerged within this Care Group.

4.5 Independent Living Care Group

you have confidence in her
Well she's caring and she listens.
She's caring and she listens.
And she's watching all the time
for if anything is wrong.

She's experienced, she knows if anything is wrong,
she can see you staggering and things like that,
she knows when to stop and when to start
and that's a good carer and good nurse.

Not somebody, 'come on do this and do that, do the other'
somebody who gets into your mind
and makes you obey them
because you've confidence.
If you've no confidence in your carer or nurse that's it.
But once ***you have confidence in her****...*
IL5 about a community health development worker

28 narratives were collected from 6 people in this Care Group. Overall these were very positive. The services included in the narratives were the chronic fatigue syndrome service, community occupational therapy and physiotherapy, POPPS, district nurses, the community health development workers and a community matron. A walk in centre was also commented upon. There is a cluster of comment about the difficulties finding out about and accessing CFS support. There are also a range of very positive comments about the qualities of health care staff. These include an interesting comment about staff who go that extra mile to help someone. This type of comment arose elsewhere, and will be discussed later. Again there were some narrative meanings which could not be easily classified and so were put into an 'other' category. One or two of these relate to the service-user's role in his / her own health-care and also as an expert in his / her own condition. There is something here, also, about service-users observing health-care staff, and appreciating a professional persona, when appropriate, but noting that they are also human (and therefore possibly more accessible, and forgivable, if they are less than perfect).

	positive evaluations	**negative evaluations**
responsive?	• They were there when I needed them • They offered rapid solutions • They meet my specific needs • The GP referred me, when I asked her/him to • S/he was helping me to solve my problem • I've gained a lot from the service	
accessible?	• It was near to home	• I found out about it by accident, no-

	• It was open when I needed it • I could contact them if I needed to • They're at the end of a phone	one told me • I found out from a friend, not my GP • My GP referred me to the service, but I had to take the lead • The GP was a bit dismissive
informative?	• S/he gave me a lot of information, but I knew most of it	
modern and technological?	• S/he was thorough	
customer-focused?	• I was given choices • The care was designed round my needs • I was involved in planning what happened • S/he went that extra mile to help • They would try to help if I asked them • They've listened and understood and I feel valued • They were helpful • S/he was flexible • S/he is caring and she listens	• My condition isn't always taken seriously • They asked me to do something that I physically couldn't
integrated and efficient?	• I was referred quickly to another service • The whole thing flowed, with no obstacles • There was good referral between services • There were links to other useful services and groups • They worked together to help me	• The GP was dismissive at first
expert?	• S/he is helping to increase my independence • S/he didn't do too much for me – s/he let me do it myself • The diagnosis was spot-on! • Here was someone who knew something about my condition • They covered a lot of relevant topics • S/he is helping to improve my condition • S/he is observant • S/he can deal with a crisis • S/he knows when to stop and when to start • I have confidence in her /him • She spotted a problem that the doctor missed and knew how to treat it	• S/he didn't tell me anything new

	• S/he knew how to examine me • S/he wasn't afraid to disagree with someone else's opinion	
other?	• The service user has obligations too • The quality of my life has been improved • S/he has an air of authority • I can help to teach students, because I have expertise • Health care staff are only human	• Other patients didn't turn up, and so the session was a waste of resources

4.6 Long Term Conditions Care Group

Husband *I'll sum it up ... she is* ***a very professional person****.*
Husband *Knows her job, and carries it out very well. That's all I can say.*

LT2 *She's truly concerned about you.*
If she can help, she will do.
And if she can't,
she'll try to find somebody who can.
LT2 about a cardiac nurse

Three people contributed 10 narratives to this section. The narratives described experiences involving diabetes nurses, cardiac nurses, continence nurses and a podiatrist. The narratives invariably had positive evaluations of the experiences. One participant had had one bad experience of not being able to access District Nurses in an emergency, but this did not taint his overall positive view of the service. Again, there was a narrative which described a member of staff going out of her/his way to help someone, and again we see the service users talking about their own role as patient experts. In this Care Group, and in one or two others (mainly non-ALWCH services), participants told narratives about services not communicating well with each other.

	positive evaluations	**negative evaluations**
responsive?	• My specific individual needs were met • S/he did what needed to be done	• If they are sometimes not there when I need them, then I lose confidence in the service • They didn't have enough staff on when they were needed
accessible?	• S/he is available at the end of the telephone • I could choose a closer clinic • We get our diaries out and make an appointment there and then	

informative?	• S/he explains options and procedures	
modern and technological?		
customer-focused?	• My knowledge and expertise about my condition was recognised • S/he adapted the intervention to meet my unique needs • S/he could have joke • S/he adapted her / his communication style to me • S/he is confident • S/he gets things done • S/he goes the extra mile • She tried to help me sort the communication problem out • S/he encourages me to monitor my health • S/he offered me a choice	
integrated and efficient?	• S/he communicates effectively with other services • It is an easy way to make appointments, with a diary	• One service didn't seem to speak to another
expert?	• S/he sorted the treatment out • S/he offered sensible, knowledgeable advice	
other?	• I was recognised as an expert and potential teacher • I am glad to be responsible for my own health monitoring	

4.7 Non-ALWCH narratives

In the course of telling about their experiences receiving care from ALWCH services, the participants invariably told other narratives about the care they had received from other services. This occurred despite interviewers focusing on ALWCH episodes. There appeared to be various reasons for this:

1. They sometimes appeared to include these narratives, as suggested above, because some of their health care and illness episodes were dramatic and acute, and had to be aired, given this opportunity to talk about them to an attentive listener.
2. Sometimes these narratives were told to provide context and history for the narratives to be told about receiving community health care from ALWCH. Without this context, the significance of the ALWCH narratives was less likely to be understood.

3. Non-ALWCH narratives were also told sometimes, to illustrate issues concerning the interface and communication between services (sometimes efficient, and sometimes very poor).
4. Sometimes they were told because service-users find it difficult to make the distinction between one service-provider and another. In these cases interviewers tried to probe to identify the service-provider.

Tables showing the non-ALWCH narratives for each Care Group are shown in Appendix 4.

Perhaps because some people recounted dramatic episodes of health care, and perhaps because highly emotional events are more likely to be recalled and told, many of the non-ALWCH narratives had meanings which were negatively evaluated. It must be noted here that, had the interviewers spent time probing for ‘normal’ or ‘good’ experiences of heath care outside of ALWCH these tables might have looked different.

> ***A cautionary note***
>
> Within each of the Care Groups people were interviewed who are long term users of health care services, and some of these told many narratives. Because of this, a word of caution is again inserted that the qualitative phrases in the tables cannot be weighed quantitatively. Several of the narratives may have come from just one disgruntled, or very satisfied, person. What the phrases do provide are a collection of snap-shots of experiences from ‘insider’ sources, most of whom showed astute powers of observation, and an effort to be fair with their observations.

It will be noted that some of the narrative evaluations shown in the tables in Appendix 4 overlap with those made about ALWCH services whilst some are unique to specific services (such as patient transport, for example). The non-ALWCH narrative evaluations are included in the report because may have something to offer to ongoing quality improvement work streams in Programme Endeavour.

5 Discussion

In this section, attention will be given to some of the key issues and questions that have arisen in this first round of the study. The intention is to contribute to the ongoing process of Programme Endeavour by introducing some service-user voices into quality improvement activities. This should provide supplementary information to quantitative survey material. This report will focus on the first aim of the research project, which is 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’. The second aim, examining the impact of quality improvement strategies, will be addressed as Programme Endeavour progresses.

As the interview material was collected and analysed, several key issues and questions began to emerge. These were noted, usually, when it was observed that more than one person had had similar experiences, and made a similar sense from them. The analysis was *inductive* i.e. issues were not found because we were looking for them, but because participants introduced them. The findings are participant-led, rather than researcher-led, although some interpretation has taken place.

5.1 Service-user expectations of a health-care episode

For some of the research participants the standard of health care that they received from ALWCH was above their expectations, and for some it was below. What became apparent was that different factors in an individual's life history might influence how these standards are set. If someone had previously had a 'bad' experience as a service user (perhaps in the Trust, or perhaps elsewhere), then their expectations might be low and they might then be pleasantly surprised by what others would deem as 'standard' practice. For one participant the simple fact that one of his health care visitors was always punctual was compared very favourably with another who was not.

The expectations of care from ALWCH were also influenced by those who had experienced private health care, in this country and abroad. The failures and drawbacks of private health care were considered, as well as the benefits.

People made comparisons not just between services, but also between the past and the present. According to different participants appointment systems have deteriorated, honesty from doctors has improved and some services are further away than they used to be.

There was also a range of comments, from different people, about being reluctant to access health care services. Without further research one can only speculate whether this is about not wanting to be a 'nuisance', wasting people's time, not wanting to have invasive treatments, or not wanting to enter a system where, as a patient, one might be powerless (this latter probably applies to in-patient care, rather than community care).

5.2 'Going the extra mile' – a standard part of a health-care worker's job?

When a member of the health care team picked up a phone to make a call to solve a problem, or went out of his or her way to clear up some confusion about medication, then some participants felt that they had been given some extra special service – that the health-carer had 'gone that extra mile' to help them. These were occasions that merited inclusion in a story told about health care. These occasions mattered particularly when the individual felt abandoned by others, or felt powerless or confused in the system.

The question arose, however, on examining the narratives, as to whether what some people feel is 'going that extra mile' should, in fact, be considered a normal part of a health care worker's job. Should a service-user need to feel gratitude or surprise upon receiving good health care? Alternatively, why should we not recognise the merit of a member of staff who does something above and beyond the normal call of duty?

5.3 Helplessness and empowerment in health care

Some contrasting narratives were collected which demonstrated how vulnerable and powerless people can feel when on the receiving end of health care, and also how empowered and influential they can feel. Some people spoke about what it felt like to have different health carers giving contradictory advice, or having no one person taking responsibility for solving a problem. This latter situation was described by more than one person in relation to poor communication between services, or Trusts (lost records, test results or appointments), when they had to chase things up, or thought they were forgotten or lost in the system.

Impressively, more than one person described how they stopped a health care professional administering a wrong treatment by being assertive, having to explain their condition and its implications. This appeared to be easier for some to do than others.

Clear demonstrations of formalised service-user empowerment was given by examples of committee membership, having input to ALWCH service developments or by having suggestions for innovation taken seriously.

5.4 What is a professional?

People seem to have very clear views about what attributes a ‘professional’ should have. Some of the narrative extracts quoted in section 4 can be unpicked to construct the ‘ideal’ professional. This person (based on just four narrative extracts) would be a good team-worker who gets on with the job, who can have a chat and be good humoured but is always busy getting the job done. S/he is accepting, caring, listens and is observant. You can have confidence in her / him, because s/he knows when something is wrong, is concerned and will help. S/he knows her/his job and does it well, taking initiative when needed. This person is not bossy, but knows how to get you to co-operate.

These service-user-participants have high expectations of health carers, but they do not appear to be unrealistic ones. Importantly, more than one participant told narratives about how it was acceptable, and perhaps comforting, to see that the busy professional also has a human side, meaning that they do not have to be perfect all the time!

5.5 Service-users as experts

Several of these participants were long-term service-users who often had contact with a wide range of services because of long term or complex health conditions. It is not surprising, then, that there were individuals who felt that they had something to offer in teaching staff and students about aspects of their condition, and their treatments, equipment and medication. Several narratives were told about staff who had brought students to learn from the individual, or when the individual had offered some good-humoured tuition. One got the impression that, for at least one person, it felt as though they were offering something back to those who gave care. Also, one had the sense that they felt that they were being treated as respected and knowledgeable partners in the care relationship.

5.6 Service-user responsibilities

On a similar vein, some people told narratives which gave their perspective on their own roles and responsibilities in their own health care. One person felt that she was under an obligation to make herself well, to repay the good services she had received from so many people. Another took pride in keeping accurate and scientific records of his progress, to share with his nurse. Having a role in one’s own health care might be much more humble than this. More than one person told how they insist on cleaning their own rubbish bags away, after dressings have been changed, and several made it clear that they regarded that they had a clear role in planning treatment, making choices, and working towards recovery.

5.7 Seamless care

A range of obstacles in the delivery of ‘seamless’ care were identified in the narratives. Some of these have been mentioned already. People told of waiting for appointments, fearing they had been forgotten, missing test reports and letters, miscommunications between services and no communications between services. Sometimes different advice was offered by different services, and one participant noted (non-ALWCH services) that her GP and pharmacist didn’t appear to be working together to help her, one obstructing the work of the other.

Non-ALWCH services could impact on the work of ALWCH services, for example the GP can act as a conduit towards services such as the CFS service or counselling, or can act as a barrier, by not referring or being dismissive. More than one person described finding out about services through friends or notice boards.

Perhaps not impacting so much on ALWCH services, more than one person indicated that patient transport services caused much disruption in relation to clinic appointments, and also occupied a lot of time in waiting around. One person had to spend an extra night in hospital because his transport home did not arrive.

The discussion topics introduced here are unlikely to be a comprehensive list. Individuals working within ALWCH will approach the data summary tables with different knowledge and understanding and, inevitably, be able to make different links and generate different ideas.

6 Conclusions

This report, based on Round 1 of a three part research project, has described and discussed the sense that a sample of service-users have made of experiences they have had whilst receiving health care service from ALWCH and other providers. Broadly, the findings have been presented in three parts. **Firstly**, evidence about ALWCH services, from the 141 narratives, has been mapped across the seven work streams representing aspects of a good quality service. Whether participants found services to be responsive, accessible, informative, modern and technological, customer-focused, integrated and efficient and expert can thus be assessed. **Secondly**, attention was given to what people said about their experiences of health care outside of ALWCH services, in order that relevant information can be taken, and lessons learned. **Finally**, seven particular issues which emerged from the data were presented and discussed, for further consideration.

The report has taken the narratives told by service-users in five of the six Care Groups and used them as a basis for understanding what it is like to be on the receiving end of the service. This has value, clearly, to ALWCH, within the context of Programme Endeavour. It is also important to note that these are the types of stories that people are likely to share with friends, relatives and the person sitting next to them on the bus, contributing to the public image of the service, and the expectations of other users.

7 Next Steps

The research team will:

- Review the processes and outcomes of Round 1, in preparation for Round 2
- Give particular attention, in collaboration with the Programme Endeavour leads, to the issue of recruitment of participants to the project
- Complete the establishment of a research advisory panel
- 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 could be addressed next time
- Whether Round 2 should be targeted in a specific way, to collect narratives on certain aspects of the service, for example, or drilling down to explore particular issues. (There is some flexibility within the original parameters of the project proposal to be responsive to need)
- Whether these findings might have any impact on what is measured quantitatively

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1.1 Appendix 1

The Study Sample

1.1.1 Demographics and Care Group Distribution table

Care Group	**H&W**	**IL**	**LT**	**ACCH**	**CC**	**CAYP**
Age Range 37-80	37-77	41-80	56-77	34-68	60-66	
Ethnicity	WB: 4 White Welsh:1	WB:6	WB:3	Black African:1 WB:1	WB:2	
Male Total: 9	2	3	2	1	1	
Female Total: 9	3	3	1	1	1	
Employment status	Employed FT:1 Unemployed:1 Student: 1 Retired:1 Retired(medically):1	Employed FT:2 Employed PT:1 Unemployed:1 Retired:2	Retired: 1	Employed FT:1 Retired: 1	Retired:2	
Job Titles[3] (current and previous)	Chef, Systems Analyst, Pipe Fitter, Site Manager/Gym Instructor, Colliery Nurse, District Nurse, Engineer, Installation engineer, Catering, IT Support, Chartered Engineer, Paediatric Nurse					

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

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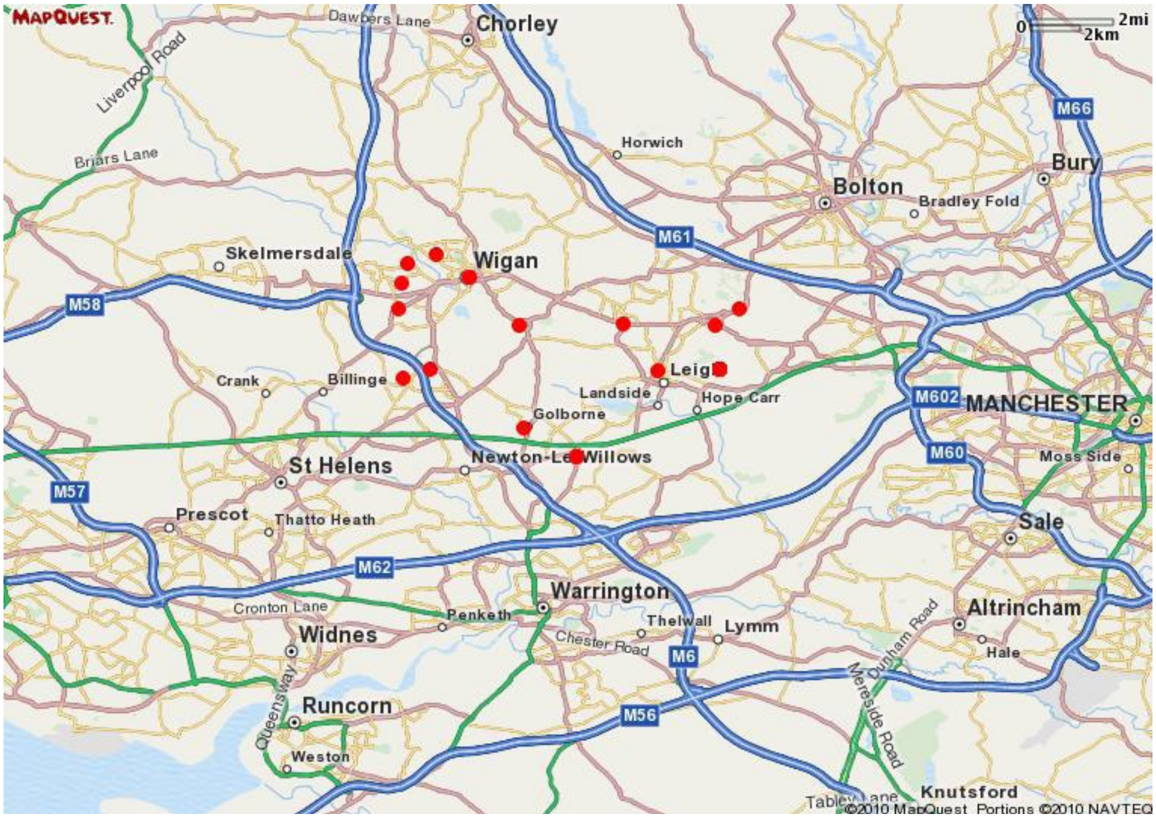
[3] Presented randomly to protect identities.

1.1.2 Geographical distribution



1.2 Appendix 2

The Method (Round 1) - Approaches and issues

1.2.1 The study sample

- The project and recruitment leaflet was discussed in detail with each Care Group Manager. This enabled the particular features of each Care Group to be taken into account in the leaflet's design, and also enabled a plan to be formulated for distribution of leaflets within each Care Group.
- Some discussions were had with regards to not including children as interviewees (methodological issues around the analysis of children's narratives)
- The intended week for distribution was the week beginning January 4th 2010. Unfortunately extreme weather conditions (snow) prevented this. Distribution was thus delayed and recruitment carried out over a longer period of time.
- Leaflet distribution and recruitment relied, to a large extent, on front-line health care staff, during face to face contacts.
- Recruitment was slower and less prolific than expected. It is not unusual to have slow recruitment, but additional factors were at work here, including the snow, and the recruitment deadline on the leaflet becoming misleading after the deadline was extended because of the snow.
- Some Care Groups, and particular services with Care Groups, are represented better than others.
- No recruits emerged from the Children and Young People Care Group.
- The reasons for volunteering to take part in a research project such as this are interesting in themselves and might include altruism, having something specific to say or even loneliness. It is also possible that some of the staff handing out leaflets were more persuasive than others.
- It is of note here that people were excluded from the study if they have made a formal complaint or compliment about the Trust in the last 12 months. This was in order to exclude those who might have a single, narrow focus in the interview.

1.2.2 Inclusion / Exclusion Criteria

- **Inclusion criteria**
  - 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.
  - Having used the service in the last 12 months (*in order that the participant has a fresh ‘bank’ of memories to draw on*)
  - Having the ability to engage in verbal conversation (*since the research method depends upon the telling of narratives)*
  - Ability to understand and capable of giving written informed consent
- **Exclusion criteria**
  - Being under the age of 18 (*the ways in which situations are perceived, recalled and recounted may be different in children*)

  - 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*)
  - Cognitive impairment to the extent that the participant cannot give accounts of their experiences (*since the research method depends upon the telling of narratives)*
  - 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*)
  - Those who are too ill to participate, or who are unable to consent for themselves (*it is important that the participants are not vulnerable, and that they can understand what is being asked in terms of consent*)

1.2.3 Ethical considerations

- The usual ethical issues were addressed
- 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, or, indeed, omitted from reports.
- Anonymity, in this study, has been afforded to service users and health care staff who feature in the narratives.

1.2.4 Rigour in the study

Rigour was enhanced through several means:

- Field-notes, reflective diary-keeping and reflective discussions were used to enhance transparency of process.
- Training sessions were carried out, so that the 3 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
- Analysis training was carried to ensure a consistent approach across analysts.
- Each interview transcript, and the extracted narratives were analysed by one member of the research team, and then by a second, for verification of interpretation. Alternative interpretations were discussed and consensus agreed.
- Foot-noting and comment-boxes were used to aid analysis and dialogue between analysts.
- The whole research team contributed to discussions regarding the synthesis of the whole set of narrative analyses into a meaningful framework.

1.3 Appendix 3

The number of narratives analysed, per Care Group

Care Group	**ALWCH**	**non-ALWCH**	**Totals**
HWB	18	18	36
CC	7	7	14
ACCH	14	2	16
CYPF	0	0	0
IL	28	15	43
LTC	10	22	32
Totals	77	64	**141**

1.4 Appendix 4

Health and Wellbeing Care Group - Narratives told about non-ALWCH services

The services which were talked about here were GPs, hospital doctors, A&E, qualified and unqualified ward staff and outpatient clinics. These comments are from four participants

	positive evaluations	**negative evaluations**
responsive?		• I had to fight to get an appointment • It was a poor treatment outcome • They're not solving my problem • They're approaching my health care wrong • Sometimes they promise treatment that isn't delivered • They didn't give good care to a very ill patient • I'm still waiting for an appointment to come through
accessible?	• You can get appointments after working hours	• You can't have anything at one surgery that's not offered across the borough
informative?		• I felt that the doctor deceived me into taking the pills • The messages can be confusing • Nobody tells you what is going on • They just left us to it
modern and technological?		• They pay lip service to cleaning
customer-focused?	• I had input to treatment decisions	• They think no-one is ill at weekends • My views weren't taken into account • They appear to be indifferent to people's health crises • They're on computers or chatting while people are waiting • They abused their power • S/he said something cruel about a patient

		• S/he defended a badly behaved patient • I didn't feel safe, and they did nothing
integrated and efficient?		• Non-family carers should be listened to • No one service is taking responsibility for helping me • They appear to be sticking to the A&E 2 hour time rules rigidly, which doesn't serve the patient well.
expert?	• An experienced nurse assessed my situation accurately and responded rapidly	• I'm getting confusing messages • They didn't take my expertise into account
other?		• They have to realise that I am an expert in my own heath care • They don't do the job they are paid to

Complex Community Care Group -Narratives told about non-ALWCH services

The services which were talked about here were a hospital consultant, private health care, hospital-based cancer services, GP and hospital x-ray. These comments are from two participants only.

	positive evaluations	**negative evaluations**
responsive?	• Once I was in the system, it all ran smoothly • The organisation responded to feedback • They met my need immediately	• The NHS was too slow, so I went private
accessible?	• I was concerned and they gave me an appointment the next day (cancer)	
informative?	• In the old days they weren't always honest like they are now	
modern and technological?		• S/he didn't understand my condition, so I had to explain
customer-focused?	• Patient representatives were listened to and were influential in bringing about change	• In the old days they thought it was okay to lie to the patient
integrated and efficient?	• I was passed to the appropriate service quickly	• Appointments were being cancelled • Poor communication and a lost report between services delayed the test results and causes stress.
expert?	• I have confidence in their expertise because they treated me successfully before • A quick diagnosis was made	• S/he was going to carry out a wrong treatment, so I stopped them

Acute Care Closer to Home Care Group - Narratives told about non-ALWCH services

The services which were talked about here were A&E, in-patient surgery, hospital physiotherapy. These comments are from one participant only

	positive evaluations	**negative evaluations**
responsive?	• They responded quickly to my emergencies	
accessible?		
informative?	• They showed me what it would involve, before I go through it myself.	
modern and technological?		
customer-focused?		
integrated and efficient?		
expert?		• Nothing they did solved the problem. In fact it got worse

Independent Living Care Group - Narratives told about non-ALWCH services

The services which were talked about here were mental health in-patients, mental health community, alcohol services, ward staff, unqualified ward staff, private health care, patient transport services, ambulance service, theatre staff, hospital doctors. The comments are from 4 people.

	positive evaluations	**negative evaluations**
responsive?	• The ambulance service responded well • S/he referred me on quickly	• They never had my things ready for discharge • There was no ambulance when I needed one
accessible?	• S/he was talking my language and I was listened to • I was seen at home	
informative?		
modern and technological?	• They dealt with me with all their equipment • They'll use keyhole surgery	
customer-focused?	• They didn't judge me • S/he was punctual • They helped me retain control	• S/he didn't explain why she was doing it • I wasn't treated with respect • S/he patronised me • Things were organised round the system, not the service user
integrated and efficient?		• Waiting for Patient Transport makes a half hour appointment last half a day
expert?	• S/he helped me to feel better • They knew what they were doing • I feel I'm in safe hands	• I was given conflicting advice
other?	• I know that health care staff are only human	• I found that private health care doesn't necessarily mean better health care • I was reluctant to access the service, I didn't want to waste their time (neutral, not negative)

Long Term Conditions Care Group - Narratives told about non-ALWCH services

The services which were talked about here were hospital physiotherapy and podiatry, patient transport services, hospital nurses and doctors, ambulance services, GPs, hospital waiting lists, outpatient appointment booking, pharmacist. The comments were from three participants, each of which had many experiences to draw on.

	positive evaluations	**negative evaluations**
responsive?	• My needs were met	• I wasn't ill enough to be treated soon
accessible?	• Patient Transport is not available when needed. • PTS are short-staffed • PTS don't work weekends • They've made it very difficult to book appointments	• I would have had to wait for treatment so I went private
informative?	• The reason for the treatment was clearly explained to me	
modern and technological?	• I was told what the latest thinking is • I was put through systematic investigation	
customer-focused?	• Staff will have a joke • Staff are flexible • I felt like I was at the centre of treatment planning • She was friendly • It was explained to me in language that I understood • She was told off for not being courteous	• I had my time wasted • Things seem to be organised for the system, not for the patient. • I was forgotten • She/he was rude to me • They didn't help me. • The appointment booking system is frustrating and time-wasting
integrated and efficient?	• The GP and pharmacy work well together	• Because PTS doesn't run on time, the appointment times mean nothing • I had to organise the appointments and chase them up • There was poor communication and misunderstandings between the Trusts • He hadn't read my notes • They kept sending me in and out of hospital with no diagnosis • Departments didn't communicate with each other • I wasn't given a follow-up appointment • I seem to fall between services • The new way of booking

		appointments is worse – the old way was perfectly good
expert?	• He showed his knowledge was up to date • S/he made an accurate diagnosis • S/he made a quick diagnosis with confidence • My GP knew how to get what was needed	• He didn't know why I'd come for the appointment • He was going to give me the wrong drug • They weren't getting to the bottom of the problem
other?	• She remained calm and polite under difficult circumstances • She was firm with other staff	