

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

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

**Report on round 3 of data collection and analysis
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1. Introduction to the report

In 2009, Ashton, Leigh and Wigan Community Healthcare (now the Bridgewater Community Healthcare NHS Trust) 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, by listening to their stories. To this end, this research was commissioned from the University of Salford. Since then changes have taken place within the structure and activities of the Trust and so the focus of this study has developed in line with these changes. Some flexibility was agreed at the start of the project, which has enabled the research to meet the evolving requirements of the Trust. The project team has worked with the Trust to identify specific services to be the focus of investigation at each stage. This report is a summary of the research carried out in the **third phase** of the project, between **September 2011 and April 2012**. The first report was presented to the Trust Board in spring 2010, and the second in spring 2011. The project timeline is included in Appendix A.

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.¹

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: to explore the quality of service delivery as it is experienced by service-users

The objectives were to

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

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

2. Design and Method: a brief summary

This is a qualitative study, designed to explore and understand service-users' experiences of health care. A different sample of service-users have been recruited and interviewed at 3 points over two years:

Round 1	winter 2009-10 (at the early stages of Programme Endeavour)
Round 2	winter 2010-11
Round 3	winter 2011-12

In brief summary (*a fuller description of the research method can be found in Appendix B*), **Round 3** of the study, reported here, has focused on service-users who were in receipt of community-based adult nursing care. Specifically, we were asked to look at services provided by **Community Matrons, District Nurses and Specialist Nurses (Cardiac, Diabetes, Continence, Dermatology, Respiratory)**.

Recruitment and data collection

During the period 16.1.12 to 16.2.12 nurses from the services listed above were asked to hand out invitations to take part in the research to every patient contact that they made. This was not the ideal method of recruitment, but it was agreed between researchers and the Trust contacts that it was the best method, given ethical and practical constraints. 34 number of people offered to take part in the project by returning the recruitment flier or by telephoning. Of these 34, several changed their minds about taking part, some could not remember filling in the form and some thought that they had already taken part by filling in the form. No-one was recruited from the Specialist Diabetes or Respiratory services, but all the others were represented, albeit by small numbers in some cases.

18 individuals were interviewed in total, but the data from one could not be used as the audio-recording was spoiled. A table showing the demographic characteristics of the sample can be found in Appendix C. Interviews took place in service-users' own homes. The interview was largely unstructured, with the participants simply being invited to talk about recent community nursing experiences. **It was anticipated that the individual would tell narratives that contained an intrinsic evaluation of the events recounted.** A single interview could provide up to 15 accounts of health care episodes, though these were not always relevant to this study. At the request of the Divisional Director participants were also asked how the service could have been better.

Note: This is not the type of research that requires data from a large number of participants. The converse is true. We required fewer people who each yielded rich and detailed data. There is no claim made here that the people interviewed are representative of the total population served by Bridgewater. 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.

Analysis

Every narrative that an individual told about community nursing services in this Trust was isolated and analysed to reveal its meaning. Analysis focused on

- What point the individual was making in the narrative (what was the point of the story?)
- What did the individual emphasise as important about the health care episode?
- The detail of the events, their context and the individual's understanding of them.

Examples of narratives, and their analysis, will be used as illustrations throughout the report. In addition, in this round of the study some attention was given to

- the role played by humour in these health care experiences
- some of the extremely positive things that people said about their nurses and
- ways in which the participants thought the services could be improved

3. Findings

In total, we heard 109 narratives about the care and services that had been received from these community-based nurses. **These narratives were, with very few exceptions, overwhelmingly positive.** It must be noted here, and this will be discussed further in section 4, that the recruitment strategy (in which nurses helped us to recruit participants from their own case-loads) may have resulted in a skewed sample. This strategy might have resulted in a bias towards participants who had mainly good things to say. Having noted this possibility we approached the data with this thought in mind *'It looks as if these people think these nurses are very good indeed. What is it that makes them so good, in the patients' eyes?'* Service evaluations often focus on what is weak in order to determine how it might be improved. **It is also important to focus on what is good, in order to find ways that it can be maintained, learned from and generalised across the service.**

The first section below, **Part 1**, examines those narratives that help us to understand this, and also summarises non-narrative parts of the interviews which give evidence of a much appreciated service. **Part 2** addresses those narratives that were not so positive, and summarises the comments that people made about how the service could be better, for them. The final section, **Part 3**, is a short exploration of the ways in which humour appears to play its part in health and health care, for the people interviewed.

Throughout this section extracts from illustrative narratives will be used. The narratives chosen for inclusion are, we believe, typical of what several people in the sample were saying. Code names have been given to individuals according to the service they were receiving (**CM** / Community Matrons, **DN** / District Nurses, **SpCar**, **SpDerm**, **SpCon** / Specialist Nurses). Where necessary, any identifying words and phrases have been changed or omitted to protect anonymity.

3.1. PART 1: 'we just can't praise them highly enough'

Without exception, the nursing services under examination (Specialists, Community and District) received high praise. To understand this better we sorted the narrative meanings into **five categories**, which emerged from the data and from our ongoing field-notes and reflections.

3.1.1. Category 1: a strong foundational relationship

'And when I see her face comes there, my face must light up'. CM1

It became clear from a number of the narratives that most of the nurses showed considerable skill at developing a good relationship with their patients very quickly. Within the context of that **strong foundational relationship**, difficult and intimate treatments can be negotiated and delivered, reassurance given, problems solved and needs identified and met. 13 of the participants told stories that evidenced a good relationship with their nurse (which is not to say that other 4 did not have good relationships, just that they didn't tell narratives that evidenced it). The nature of these strong foundational relationships can be captured in this list of narrative meanings.

Narrative meanings	Number of Narratives
They're always happy, despite working under a lot of pressure	6
They are never impatient or irritable	2
Reliability and trust	3
We have a good relationship	4
We can have banter	4
S/he maintains professional boundaries	1
S/he respected my knowledge	3

All of these qualities were seen in all 3 groups of nurses, except the last, which was a point made in 3 narratives told by 2 patients of the Specialist Cardiac nurses. These nurses seem to be skilled in assessing the level of knowledge and understanding of the patient, and their self-perceived needs.

SpCar3-8

*and she said do you know what the drugs are?
And I said yeah I know what all the drugs are for
and when to take them
and what have you and all that –
that's fine and is there anything you want me to do?
And I said well no*

It would appear that nurses in all three groups were seen as being able to engage quickly with the patients, in a good humoured way, despite the pressures of their jobs. This good humour, often accompanied by 'banter' was often interpreted by the patient as having a good or special personal relationship with the nurse.

CM2-4

*So, but, I'm on very good terms with her,
and she's... there if anything I want to know about,
in the sickness way, you know...*

*I give her a ring
and she....she'll come and see you
You know, she's been very good to me.*

SpCon1-1

*They are all very friendly.
Some are more...
are a little bit more talkative than others
but they have all been friendly.
And we have had a bit of a laugh
sometimes like the chap who come last week
I didn't hear him come because I was in the bedroom
and he went round the back and he was shouting my name.
So I am at the door shouting I'm here.
So we had a laugh about that,
but on the whole they have all be very pleasant.*

DN7-1

*and then when they come in they're always dead chirpy
and what have you,
asking you how you are and everything
and they get all the dressings out,
XX puts all the dressings out on the settee
so they're all laid out ready for them
and then they start treating my legs.
We have a good chat and a bit of a laugh
and what have you.
They're scrupulously clean and hygienic*

Some narratives were told that emphasised the value placed on reliability and the ability to trust the nurse.

CM1-4

*You don't get a follow up off your specialist or anything when...
so she got me a follow up to go for this scan and whatever.
She's done...she's the only one really I can trust.*

3.1.2. Category 2: not alone with this illness

*'But she was very good and she still is.
Made sure I knew she was always there'. SpCar5*

The patients that we interviewed were people who had experienced serious, and often, long term and complex health problems. We learned that this can be a lonely journey fraught with anxieties and uncertainties for the individual and their carers. There was an overwhelming impression given that an important function of all three of these groups of nurses was to be there for people – accessible and supportive, on this journey. Having access to these nurses means that the patient is **not alone with this illness** (or, indeed, not alone in negotiating the complexities and difficulties in the health care system). The narrative meanings that explicate this further are listed here.

Narrative meanings	Number of narratives
S/he was there for me / us	11
They're at the end of the phone	6
S/he supports us in many ways	5
S/he negotiated with the GP /doctor on my behalf	6
S/he keeps an eye on my general health / aware of my health status	5
S/he taught the carer how to look after person's health care	2
S/he allayed my anxieties	6

For some people it was enough to know that the nurse would be dropping in or could be reached at the end of a telephone, to discuss health concerns and anxieties. Others told narratives about times that the nurse had offered practical support.

DN14-2

*and I was a bit reluctant to ring them
because I know there are more important people,
but they all said, 'honestly, you must never hesitate to ring us'
and they have always been good.*

SpCar2-5

*And she got all them blister packs.
She opened them all
and took all the tablets out that wasn't relevant
which she is...
she is really good, she is,
if you could just see her,
you would understand what I mean.*

Some people also told us how a nurse had taught them to care for their own health. There was also a general reassurance to be gained by knowing that the nurse was constantly monitoring the individual's health status, sometimes noticing a change before the individual him/herself did.

CM1-3

Podiatrist.

They come every four days.

They are okay.

It don't take them so long

but I told her about this toe a few times

but she says it is alright.

Just keep their eye on it.

But my nurse says

ask her tomorrow when she comes

if I need anymore antibiotics

because if it is infected then I will.

Patients of the District Nurses and the Specialist Cardiac nurses sometimes told how the nurse had given reassurance about specific anxieties related to the illness.

DN14-5

The other week when they were that busy

it was quarter to eleven when someone came.

She said to me 'we are busy tonight'.

I said I understand but she said, 'but no, somebody will come.

Honestly, somebody will come'

.....

so anyway she called in just to put my mind at rest really over this blood.

They have never said no ever, night or day.

SpCar1-11

She was calm –

I suppose it's part of their training for the job, I don't know,

because I've only met the one, and she was reassuring –

everything about her.

Before you'd even got on the phone to her,

after you got to know her a few times

and had spoken to her a few times,

you knew that when you were dialling her number

there was no problem;

there was no fear or anything like that.

She would sort it out –

you felt completely confident,

even though she's not there looking at me,

she's down the phone-line somewhere –

3.1.3. Category 3: making a difference*'she's got me where I am'. DN17*

The participants that we spoke to told several narratives which conveyed a sense of the **real difference** that these nurses had made to their lives. Lives were improved by speedy and knowledgeable responses, sorting out muddles and confusion and by easing access to other health care provision.

Narrative meanings	Number of Narratives
S/he put me in control of my health care	8
S/he gave me confidence in my own body again	1
Responded speedily	7
If it weren't for the nurse I'd have ended up in hospital	1
S/he did better for me than the doctor did	2
They sorted my pain / discomfort	4
S/he sorted my medication out	3

It was notable that the patients of the Specialist Cardiac nurses and the District nurses told of how they were shown how to take control of their own health and/or health-care.

SpCar2-6

*I could use that (walker) going out.
But she says, go for a short walk on that,
and anytime you feel breathless or tired,
sit down on that.
She says don't think you are being soft.
Sit down and rest.
And that's really [unclear 13m02s]
because I can only explain it...
it's so hard because I don't know what,
I could run miles and miles and miles once upon a time.
But I can see that's stopped now
and I know my limits.*

SpCar5-8

*there was no pressure about losing weight
because I know I'm two stone overweight
with giving up smoking –
two and a half stone.
But the benefit of giving up smoking
as far as she was concerned
far outweigh for now
the extra weight I'm carrying
so she was pushing me that way you know
and it was only a gentle push –
it was nudge more than anything.
But again I made the decision to start a diet
and so again another positive from a negative*

The speed and skill with which the nurses intervened to alleviate problems was also recounted in several narratives, and was always much appreciated.

DN8-5

*And yes, two days it took
from me actually saying can we have one of those?
And then the bloke knocks on the doors
and says I have brought your mattress.
.....
And they got me some cream for that as well.
....
So really to wrap it up,
we have had a very, very good service from the District Nurses.
I can't praise them highly enough
because they have done so well for us.*

DN1-10

*I couldn't sleep.
I told the carer when I went to get up in the morning
and he told me 'come on, we'll phone the District Nurses',
so I didn't phone
he phoned
and they came near enough the ...*

*I'm sorry it was during the night, late on at night ...
when he came before tea-time
I said 'I can't put up with this',
and he phoned them
and they came that night and changed it*

Interestingly, two stories were told, by different participants, which showed that they felt that the nurse could respond to their health needs better than their GP could.

CM1-2

*because I had a water infection
and I was going funny.
.....
She rang my doctor
and he would not send me away (to hospital).
But she said
well I am sorry but I think she needs to go away
because she is very ill.
And it was a good job I went
otherwise I would have been dead.
Because ..I was seriously ill after that..*

3.1.4. Category 4: a bespoke service*'there was nothing that girl couldn't solve' SpCar1*

Delivering nursing care to such a wide range of people, each with unique, and often complex, needs, requires the ability to tailor the service to the individual. It was clear from many of the narratives told to us that patients could give evidence of a '**bespoke service**' designed for their specific needs. The list of narrative meanings below gives an indication of the individualised nature of the care given.

Narrative meanings	Number of narratives
S/he's a problem-solver	7
S/he gets things done for me, sorts things out / S/he was efficient and thorough / All my needs were met	12
S/he dealt with other health care professionals / services for me	3
S/he makes us feel special	2
It was a personalised service / flexible to meet my needs /very helpful	7

We were told many narratives that illustrated how simple, sudden and or complex problems were speedily solved, often to the pleasure and surprise of the patient, and certainly to their benefit. Some examples are given here.

CM2-1

*(I cared for my wife for many years)
it was a long time.
I collapsed at the end.
And she (the Matron) got me [laughter]
sorry, meals on wheels,
and district nursing
and one or two other things
and they worked out very well.*

DN6-1

*but I have done it at least a couple of times, forgot (my appointment)
She has even now,
she puts it on my mobile phone,
the appointment.
and it like rings ten minutes before,
because it is only just round the corner.
So I can get there fine.*

Part of that problem-solving process often involved dealing with other health care professionals on the patient's behalf. Sometimes this was simply to support or advocate for the individual, and sometimes (notably amongst the Cardiac Nurses) it was to use specialist knowledge to discuss drug regimes with the doctor.

SpCar5-3

*Explained everything about my medication,
went through each different tablet I was on.
She was a bit worried about my blood pressure*

*and she was talking about putting me on other medication,
she said what I will do is get in touch with my GP
and she actually contacted the surgery
and put her ideas forward.
My GP wanted me to stay on a tablet I'd been on
but the hospital took me off and put me on another one,
so she wanted one tablet to buffer my medication for my heart*

3.1.5. Category 5: a professional and much more

'She's not doing it because it's a job' SpDerm1

In previous stages of this study, it has been remarked that health care staff in the Trust often go that 'extra mile' to provide a good service and to meet the patient's needs. Some of the people we interviewed were very aware of the highly professional care that they were in receipt of, and also often acknowledged that it was beyond their expectations. They recognised that they were receiving care that was **professional and much more**.

Narrative meanings	Number of narratives
She is knowledgeable and skilled	11
She seemed to go that extra mile for me / she did far more for me than I expected	4
Good care / good service /Superb care	6
She's special, brilliant	2

The high level of professionalism, knowledge and skill being employed by their nurses was noted by those on the receiving end of care from Community Matrons, District Nurses and Specialist Cardiac nurses, often with a degree of pride, and perhaps a sense of privilege. The fact that similar stories were not told by those receiving care from Continence or Dermatology nurses may simply be due to recruiting only one person from each of these services.

CM2-8

*And then she thought...
a few months ago,
she decided they weren't strong enough,
so she had a word with (the doctor)
and it opened the doors and....*

I think she's fairly high in the nursing profession, you know,

We heard stories that told of the 'extra mile', and how this was perceived and appreciated.

DN6-3

*It's not just come and sit down and jab and out.
No. She's great.
She takes care.
She does look after people.
Because you can tell it's not only me.
There are loads of cards up to her...
Thanking you.*

And I sent her one as well.
 I sent her a birthday card.
 Because I thought well it is only a little thing
 but she has gone a long way out of her way for the family, [unclear 5m47s]

 and we talk football and he's a United fan.
 So and we get on good.
 We really get on good.

DN2-1

I tell you how good she is,
 I got a phone call from the district nurse (inaudible 2.22)
 she said, "YY, it's district nurse here, ZZ,"
 I said, "Yeah."
 She said, "Why're you not in clinic?"
 Because I live alone and I'd not –
 I said, "I'm not in."
 She said, "Yes, you are."
 She said, "No, you're not."
 She said, "I've looked at the wrong place."
 I looked at my card I said, "No, I'm not in."
 But you see they were checking on me which is good.

3.1.6. Qualities and attitudes: why the nurses are valued

The study has focused on hearing narratives, i.e. self contained stories about health care events. As we familiarised ourselves with the interview transcripts, however, there were sections and phrases that we thought could not be ignored, in terms of some of the evaluative comments made by the research participants, about the nursing service they had witnessed and experienced. We present these here because we feel it is important to acknowledge them. They are listed in two sections: descriptive phrases about the qualities, attitudes and behaviour of the nurses, and a listing of things that are valued. These are all verbatim phrases taken from the interviews of 9 of the participants and need no further analysis or commentary.

My Nurse:

- just helps me and got me through./ **she's got me where I am.**(DN)
- talks to you and tells you and asks you things and whatever. / both myself and my wife were amazed at the attention I've had and to be honest we **just can't praise them highly enough.**(DN)
- she tells us little things (DN)
- is **always there for us.** (DN)
- is ever so pleasant. (DN)
- knows it all, it's as simple as that./ they have all been spot on/ **there was nothing that girl couldn't solve.** / Where somebody might say, 'well, I'm not sure about that, leave it with me and I'll get back to you', there was never that (SpCar)
- is so down to earth and she has **no airs and graces** (CM)
- is **always cheerful and positive** (CM)
- is available at the end of the phone.(CM)

I value my nurse(s) because:

- As I say I'll reiterate it again **they do a brilliant job.**(DN)
- Because they've been **absolutely fantastic** (DN)

- *they are all good.(DN)*
- *they do their job very well. (DN)*
- *It is **just like a friend** calling every week (DN)*
- *they have done so well for us.(DN)*
- *They are now treated like friends of the family. (DN)*
- *it is a nice experience, it is nice to see them (DN)*
- *she is **brilliant**. (CM & Spcar)*
- *she is **the best**. (CM)*
- *She's the only really that I could trust.(CM)*
- *when I see her face comes there, my face must light up. (CM)*
- *as soon as I saw her, as soon as she started coming it clicks with you. (CM)*
- *She is just **everything to me**, anyway (CM)*

3.2. PART 2: The service isn't perfect

The narratives that people told about the nursing services were largely complimentary, but some difficulties and faults were drawn to our attention. During the interviews we did not, initially, probe for opinion and evaluation. Instead we just asked the participants to tell us about their contact with the nursing services. As narratives were told, each individual made sense of what had happened, and offered a perspective without being explicitly invited to. In **section 3.2.1** we summarise the 9 narratives which evaluated the services, finding them less than perfect. Towards the end of the interviews we asked the participants whether the service could be improved, and how. Several people told us it could not be improved. As DN6 said

'How can you change something that is perfect? Like I said earlier in the interview, if it's not broke, don't fix it. And it's not broke.'

But some people did offer some ways in which they could imagine that the service they had received could be better. These are shown below in **section 3.2.2**

3.2.1. 3 types of narratives that suggested perceived problems

9 narratives (7 participants) suggested that there were problems with the service that was received, although it should be noted that most of these participants also told positive narratives. Of the 9 narratives discussed in this section, 3 were told by one person. In order to protect the anonymity of the individuals concerned, the services that they talked about are not identified.

The problems that were revealed by the narratives fell into 3 types: weekend availability (2 narratives); quality of service (3 narratives); systems (4 narratives).

Weekend availability

2 individuals expressed concern or commented that the nursing service which was so supportive during the week, was not available at the weekends, although it was clear that telephone messages left at the weekend were quickly responded to on the Monday morning.

*The only ...
well, it's like everywhere else I suppose,
it didn't happen that way,
I didn't need to ring ...
well, I knew it would be a waste of my time to ring in at weekends.*

It will be noted that, the way the participant expresses this is a very delicate manoeuvre which begins with *'The only..'*, as if s/he is going to make a complaint, and then, almost in a protective and

accepting way, adds the phrase ‘*well, it’s like everywhere else I suppose*’ – acknowledging the ubiquitous Monday to Friday way of working, and then, also protective, ‘*it didn’t happen that way, I didn’t need to ring ...*’ and then continuing to say, quite honestly ‘*well, I knew it would be a waste of my time to ring in at weekends*’. In this short piece of speech, the nurse is protected from criticism.

Quality of service

Two people told narratives that indicated that it caused them problems because they did not know what time a nurse might come to see them.

*Turn up whatever time,
that's one of the things that I think needs to be improved upon.
Officially it's from half past eight until five o'clock
and you're sat (waiting for your treatment)
....
and you're sat from half past eight until five o'clock
waiting for them to turn up*

This particular person argued that, if supermarkets can predict the time-slot when they will make a home delivery, then maybe the nurses should be able to do this.

Another participant made the point that, whereas in the past s/he had been seen by only a small number of District Nurses, nowadays there are more nurses, and the perception was that this might impact on continuity of care.

Systems

We heard one narrative in which the speaker seemed to be confused about a follow-up appointment to have tests and see a nurse, but this confusion may have been related to the individual, rather than a general problem for the service. It is probably worthy of note, however, that 3 narratives were told, by 3 different people, about the complicated and lengthy way that prescription of dressings is carried out. Here are two cases, from two different services:

Case 1

*She would put the prescription in when we went on a Tuesday
and when we went back ...
say on the Wednesday / Thursday ...
and go to the chemists ...
because she had taken it to her..... senior
it would mean that she could give us the prescription
but we couldn't pick it up till the day after
I have come back with loads of boxes haven't I?*

Case 2

*From what I understand
officially they're not allowed to put the prescriptions in.
The sister can make the prescriptions out
and then they've got to hand that back to you.
So my wife would have to go out
because she doesn't drive,
to go to a chemist
to put the prescription in
and more than likely they won't have what you actually want
and the quantities*

*because she went one day on the bus right...
...and they came out with these bin bags full of stuff...
And she said like
flippin' heck I'll have to get a taxi,
so she had to phone up for a taxi to get her home.*

3.2.2. How the service could be improved

We asked the participants how the service could be improved. Some of these suggestions had already been revealed in the narratives, but they are all listed here, in the speakers' own words.

- *she's only available Monday to Thursday. They're not available seven days a week, are they? And as you know with illness or whatever....it could come like a Saturday, Sunday, any old time that you don't expect it. You know, it doesn't conform with working hours. (CM)*
- *I think I would like more of them. I am not a political person but I think the NHS is as such the last thing that the common man has got in this country and with it being so good to me, I treasure it. So I might be very biased in a lot of respects, but no. I don't like to hear stories that they have just taken two nurses off from round here and so forth. I don't think it is fair on the people that are left because that gives them less time to sort of do what they would like to do. And of course in my opinion, it just clags the system up. And I don't like it. I don't like the idea at all. It is the same with the hospitals and so forth. Because if you've had as good experiences as I have had, you want to preserve it for other people. (DN)*
- *Perhaps if they had more people doing it, in that case they would be able to provide ... like, when we rang up it was just after tea wasn't it? Well, she is in the middle, she is overloaded, she can't give you a time, she just says 'I'll be there somewhere round before midnight'. If there were more feet on the ground she could get to you quicker. (DN)*
- *but the poor old girls that came in the beginning they're under too much pressure, they're seeing too many clients in so short a time. and I felt embarrassed at...not trying to prolong the visit but I didn't want to mither her too much about what was going on which is wrong because I should have done. (DN)*

As mentioned above, some people thought that no improvements were needed. Here is one example.

- *I think she covered...obviously I hope...it's the first one I've had and I hope it will be the last one and I've never been here before but I can't think of anything in my situation that she could have done any better or anything extra she could have done. (SpCar)*

3.3. PART 3: Illness, humour and nursing care

"my sense of humour, that is what keeps me going" (DN14).

This was not part of the remit of the study, but on this round of data analysis, as on the previous two, it struck us, that humour had a large part to play in these health care situations.

We witnessed humour being used:

a) as a way of talking about a condition or situation

Some of these patients have been through, and are still going through, very difficult health problems, often accompanied by painful, intimate or intrusive treatments. Black humour, or sometimes music hall / seaside postcard humour appear to have their usefulness in helping people to deal with these situations. One very elderly participant, with complex health needs laughed as s/he said *"you'd think I was dying or something!"*. Another participant laughed, told how s/he was recognised by the specialist nurse after a previous episode of care *"because she said 'I know you'.... And then she said 'oh your bottom'"*

b) within the nurse-patient relationship

Several of the participants talked about the banter that goes on between them and the nurses. This seemed to be the case particularly with the District Nurses, who are, perhaps, performing 'hands-on' intimate treatments within the strong foundational relationship discussed earlier. Such relationships appear to be sustained well by good humour and joking.

- *"They have got to know me because they don't.....it is just friendly banter and we joke...it is a good relationship with them"*
- *"Yes. But I have a banter with them all"*

Patients sometimes expressed their concern for the stress and hard work of their nurses, and try to do things to make their life easier; they are caring for their nurses, as one participant expresses here

- *"and we have a bit of friendly banter, a bit of a laugh Because ... I find by doing that it makes their day a little bit easier"*

Older patients of the District Nurses might also engage in a little teasing – all ways to engage well, in a professional relationship which has clear boundaries, but is also based on human caring and interaction.

- *"I said yeah if I had been younger [Laughter] ...and I pull her leg like I'm going to chase her..."*
- *"and I rib her a lot and she keeps saying I'll get you one day"*
- *"I don't know whether to beat him or whether to throw him out the door"*

c) as professional disposition

Several of the participants indicated that they felt that good humour was an essential quality for nurses to have.

- *"the sister or ward manager or whatever she's called right, was choking off the staff for spending too much time laughing and joking with the patients and to me that is all part of the care you know"* (this was a narrative about nurses in another Trust)

Other participants gave evidence that their nurses do have good humour, and so meet this essential requirement.

- *"...they don't know and they're still happy and chirpy"*
- *"it gets me how they manage to always be so cheerful and positive..."*
- *"they come in, they're professional but they have a laugh and a joke"*
- *"She is not huffing and puffing as if to say...she is all happy....well when I say happy, she was in a good mood"*

We noted that, whilst the patients of the Specialist Cardiac Nurses spoke highly of their professionalism, knowledge and skill, little was said about humour. No assumptions can be made, but we speculated whether this is because of the slightly different relationships with these patients, based on health education and reassurance.

4. Discussion and Conclusions

4.1. What were these service users saying?

In this round of the 24 month study the focus was on listening to the voices of those patients who had been on the receiving end of care from Community Matrons, District Nurses and Specialist Nurses (Cardiac, Diabetes, Respiratory, Dermatology, Continence). Unfortunately no participants were recruited from the services of the Specialist Nurses Respiratory and Diabetes.

The overwhelming impression was of a set of nursing services that are highly valued and appreciated. The research participants told narratives that indicate that the nurses are able to quickly build a **strong foundational relationship**, tailored to a particular patient, within which treatments, health education and monitoring can be delivered efficiently and effectively. The nurses made themselves accessible in terms of their approachability, good humour and patience and by regular visits and being at the end of a telephone. The participants (and their carers) reported feeling supported and **not alone** with the difficulties and anxieties presented by living with complex, life changing health problems.

We heard many narratives in which the research participants told of how the nurses had **made a real difference to their lives**, for example by alleviating pain, responding to problems quickly when needed, and, perhaps most importantly, helping people to take control of their own health. There is a high degree of complexity and subtlety in the nursing services offered by the women and men who deliver them. This is shown in the nature of the relationships they make and maintain with their patients, and also in the flexibility and variety of their methods, interventions and interactions. We gained an impression of a **'bespoke' nursing service** designed to meet many different needs. Such a bespoke service could only be delivered by professionals who are very skilled and knowledgeable. Further, we heard various narratives about how the nurses were perceived as **professional, and much more**.

Of course, there were narratives told about imperfections in the service, and these are summarised in section 3.2.1. The perceived need for a **weekend service** was mentioned, and some bemusement expressed by 3 people about the **system for the prescription of dressings**. We noted that when people told narratives, or made comments about problems that they perceived, they made it clear that they were not criticising their own nurses. If anything they were very loyal to those delivering direct care to them, often speaking in a protective way. When asked how they felt the service could be improved, many people took this to refer simply to their own nurse, and could find no fault. Three participants, however, suggested that, at an organisational level, the service could be improved by **increasing the number of nurses**. Interestingly, here their loyalty was displayed again; they proposed this in order to reduce the stress and workload of their nurses, rather than to enable more patients to be seen.

The very positive evaluation of these nursing services which has come through in this study must be understood against the background of a less than perfect recruitment process. Participants were recruited to the project by nurses handing out information fliers to them. This may have skewed the recruitment towards those who have something positive to say. But even if this is the case the positive stories that we heard cannot be discounted. In the privacy and confidentiality of the interviews, people might have consciously, or unconsciously, presented a poorer image of the nursing services. In fact, people were complimentary, loyal and defensive of the nurses. This suggested **three possibilities** to us. (1) That there was genuinely **little negative to tell**. (2) People might volunteer to take part in this type of research, and say positive things, **to show gratitude** for their recovering or maintained health. (3) People might **fear the loss of services** that they value.

4.2. How to make best sense of these findings

a. Understanding qualitative research in context

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 nursing 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?'*

b. The context

As a research team we can strive to give an honest and rigorous account of what we did and what we found. To make full sense of what these users of the Trust's services are saying, however, a good understanding of context is needed. Here, context is taken to include:

- The Trust, its systems, structure and processes
- The Trust and the ways in which it is evolving
- Health care and nursing generally
- What it means to be a resident of this area and part of its community and history

5. Next steps

The researchers:

- Would wish to disseminate the findings of this study to those who would be interested:
 - Nurses
 - Service-users
 - Trust managers
 - The public
 - Other academics

ALWCH/Bridgewater may wish to consider:

- The best use that can be made of the findings of this round of the research in relation to
 - The service itself
 - Staff training
 - Service-user liaison

Appendix A - Project timeline

Project Time² Line	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 and dissemination								

² As planned at the start of the project. Some necessary and negotiated adjustments were made as the project developed and circumstances demanded

Appendix B - Round 3 Research method

The research team:

Principal Investigator: Dr Jackie Taylor (interviewing and analysis)

Co-investigator: Angela Hook (interviewing and analysis)

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

The study sample

The target was to recruit up to 30 people across these services. The recruitment strategy was informed by close liaison with team leaders who advised on the number of leaflets to distribute, and when to do this. For more detail, see Appendix D

Inclusion / Exclusion Criteria

- **Inclusion criteria**

- o Being a person who has personally received health care from community nursing services
- 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 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:

Following receipt of the project recruitment flier, people volunteered themselves into the project either by filling in their contact details and posting them back in a stamped addressed envelope, or by telephoning the Principal Investigator direct. Following this, the individual was telephoned to see if they were still interested and then they were sent a full project information leaflet. A follow-up phone call ascertained that they understood the project aim and requirements and arrangements were made for an interview. People were interviewed in their own homes. 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 15 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 consequence³. Each interview yielded several narratives (see Appendix E), 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 content⁴
- 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.^{5 6} 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 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 in the early part of the group). The terms of reference for this group can be found in Appendix F.

Specific ethical considerations

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 in order to monitor subjectivity and increase credibility of the findings by:

- Field-notes, diary-keeping and reflective discussions were used to enhance transparency.
- 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.
- Each transcript was analysed independently by the two researchers 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 during analysis and formulation of findings.
- The summative analysis tables were shared with and verified by a second analyst. Different perspectives were debated.

³ Mattingly, C., & Lawlor, M. (2000). Learning from stories: narrative interviewing in cross-cultural research. *Scandinavian Journal of Occupational Therapy*, 7(4), 4-14.

⁴ Gee, J. P. (1986). Units in the production of narrative discourse. *Discourse Processes*, 9(391-422).

⁵ 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.

⁶ Riessman, C. K. (1993). *Narrative analysis*. London: Sage Publications.

Appendix C - The Study Sample: Demographics table

Service	Community Matrons	Specialist Nursing				District Nursing
		Cardiac	Respiratory	Diabetes	Continence & Dermatology	
Age Range 56-94	83-94	56-75			75-76	62-80
Ethnicity	W/Br: 2	W/Br: 4 W/ENG : 1			W/Br: 2	W/ENG:5 W/Br: 3
Male Total: 13	1	4			1	7
Female Total: 4	1	1			1	1
Employment Status	Retired: 2	Retired: 5			Retired: 2	Retired: 6 Unemployed: 1
Job Titles	Removal Business, Fire Service, Shopkeeper, Foreman in manufacturing, Prison Officer, Nursing, Process Worker, Cotton Mill worker, Warranty Supervisor, Facilities manager, Train Driver, Care Assistant, Newsagent, draughtsman, Telephone engineer, coal miner, cleaner, voluntary worker					

Appendix D - The distribution of recruitment leaflets

Area	Leaflets sent to	Number sent to staff
Community matron	Boston house, Wigan health centre, Frog lane, Wigan WN6 7LB	60
District Nursing	Ashton Clinic Queens road Aston In Makerfield WN4 8LB	12 packs of 75 leaflets
Specialist nursing- cardiology /respiratory /diabetes /dermatology (adults)	Long Term Conditions, Boston House, Frog Lane, Wigan WN6 7LB.	400
Specialist Nursing continence	Hindley Health Centre Liverpool Road Hindley WN2 3HQ	50

Appendix E - The number of narratives, per service

Service	Number of participants	Total number of narratives⁷	Narratives about community nurse services
Community Matrons	2	16	15
District nurses	8	60	44
Specialist Nurses ⁸ <ul style="list-style-type: none"> • Dermatology • Continence 	2	14	11
Specialist Nurses <ul style="list-style-type: none"> • Cardiac 	5	53	39
Total	17	143	109

⁷ Some of these were about in-patient service health care, and some were about other non-health related life events

⁸ Dermatology and Continence are combined here, to help to protect participant anonymity

Appendix F - 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.