

Exploring attitudes towards and experience of the NHS in the North West

A REPORT PREPARED FOR NHS NORTH
WEST BY PICKER INSTITUTE EUROPE AS
PART OF "OUR NHS OUR FUTURE" REVIEW

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Picker Institute Europe

The Picker Institute works with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique combination of research, development and policy activities which together work to make patients' views count. There are three key strands to our work:

- Measurement - researching and evaluating patients' experience
- Improvement - leading initiatives that make improvements happen
- Policy - building evidence to inform health policy.

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1 Executive summary

1.1 Context

NHS North West (NHSNW) commissioned Picker Institute Europe, an independent health research organisation based in Oxford, to provide some input from staff and patients to inform their deliberations in response to 'Our NHS our future' (the 'Darzi' review).

The Picker Institute ran twelve focus groups with patients, staff and the public throughout the region exploring their experience and understanding of the NHS. They were asked their views, why they think the way they do and where they got their information from. They were also asked to form a view as to priorities for development of the NHS in the near future.

Focus groups are not opinion polls; they do not provide representative or transferable data. However, they allow exploration of the ways different groups feel about the issues under discussion, and why they feel the way they do. Debate about such broad subjects as the future of the NHS is not likely to provide specific remedies but to highlight areas for further work.

Part of the focus groups' time was used to ask participants to prioritise a number of cross cutting themes for the immediate attention of decision makers within the NHS.

1.2 Key findings

Patients in the North West are extremely proud of the NHS. Many feel it is under various kinds of threat and don't feel it is in safe hands. They feel very protective of it. People are very prepared to defend the NHS when compared to other health systems – almost all comparisons with overseas were positive. However (and perhaps because of this) they felt they had the absolute right to complain vociferously about it.

There was a general perception that the NHS is at its best when acting as an **emergency service or tackling major problems**. There was a belief that services for extreme or acute conditions have improved. There seemed to be a resignation that less 'serious' conditions inevitably involve longer waiting, less convenience and a generally poorer care experience. There was an understanding as to why people who could, would 'go private' in these circumstances. There was a general acceptance that the quality of service in a private hospital was better but there was little definition of what 'better' means. There was real irritation at NHS equipment (and staff) being used for private treatment. However, given the chance to prioritise "increasing role of private sector" as a concern in a prioritisation exercise, almost all the groups did not see this as one of the urgent priorities.

When considering other improvements, one area that was obviously of concern was being able to **access services** (especially in primary care). The participants had a mixed

perception of whether this is improving. Some extremely good experiences were mixed with and some extremely poor ones. In general, most patients and staff (with some very vocal naysayers) felt that things were improving. Some infrequent users of health services had had very low expectations and had been pleasantly surprised.

Universality (the idea of services being the 'same for everyone') of NHS services was viewed as very important by most people. However there were some examples of assertive (usually younger) individuals being able to navigate the system to their advantage. There were also several examples of people dipping in and out of the service (going private when it suited them) that seemed to be acceptable (although some of these individuals felt they were being disloyal). There was a general feeling that refusing treatment to people with 'poor' health behaviour (obesity, smoking etc) was not justifiable in a universal service.

People who had used **walk in centres** were extremely positive about them. **NHS Direct** tended to polarise opinion with some very positive experiences outweighed by some cases of extreme disappointment and dismissal of its value.

Some frequent or long term health service users, especially carers, were much more prepared to be critical of the NHS, although many of the very negative experiences reported took place some time ago. Some long term users and carers were very dismissive of the service as a whole but reported having had excellent care themselves – they felt that they were **lucky**. As is often the case, one poor experience is remembered and recounted whereas a myriad of good experiences go unnoticed.

The fact that the NHS is **free at the point of access** (many participants were clear that we all pay for it) appeared to be fundamental to people's sense of ownership of it. The erosion of this principle (ie that 'they' will start charging for it and 'we' won't be able to afford it) is a great fear for the future and seemed to define whether or not the service remains true to its roots.

People were **anxious about the future** of the NHS. The major concerns were (in no particular order):

- NHS acquired infections
- that the whole service will collapse
- the ageing population will put more strain on the system leading to a dilution and inevitable break up of the universal service
- technical advances will inevitably mean that more financial pressure will be brought upon the NHS
- the influx of immigrants was putting 'unfair' pressure on the system.

Patients were clear that they want to be **treated with respect** and taken seriously as they pass through the healthcare system. While they were prepared to overlook poor 'people' skills in nurses who were perceived as overworked and underpaid, they were not prepared to receive sub-standard 'people' skills from support staff or doctors.

The majority of participants knew people **who worked in the NHS**, many of whom painted a very negative picture of the state of the service. However the view that 'everybody thinks they are overworked and management is rubbish' was also prevalent.

Cleanliness and infection control was seen as fundamental to a quality service by a significant majority of participants. Some people refused to see it as a priority for improvement but rather a necessary condition for the service. It is worth noting, however, that this data was all collected before the high profile stories emanating from Kent about *Clostridium difficile* (CD) and from Lancashire about methicillin resistant *Staphylococcus aureus* (MRSA). Cleanliness and infection control appeared to be more important for those people who do not often use services (ie outside observers) than for regular, long term users who were more concerned about receiving the latest drugs and being able to access the treatments and therapies that they wanted.

Many saw the perceived increase in infection rates as the result of falling standards of cleanliness within the health service, and a lack of pride in working for the NHS. Some put the blame squarely at the door of outsourced cleaning services. Interestingly there was also a general acceptance that the public would put up with **more restrictions** – including restricted visiting, greater compulsory disinfection (more than just the use of hand gel) and so on if they were seen as to improve infection control.

People's **opinions of certain hospitals** or health services were fairly **immutable**. Uncovering what people mean by a 'good hospital' was hard work. Good clinical care – 'getting better', was taken by most people as a given. It was the way in which they are treated as people, and the environment they find themselves in, that people tended to remember. Most went on personal experience, recommendation, reputation and location. Nobody had accessed any kind of performance data to help them make any healthcare decision.

If people had a good experience in hospital that they perceive to be a 'poor' hospital they saw themselves as lucky or the exception that proves the rule. Similarly they were less confident about reporting bad experiences in a well loved institution, believing they must have been unlucky. Patients' discussions about what makes for a 'world class service' provided some thought-provoking material.

People who use the NHS occasionally had a higher opinion of it than those who are regular users – carers were the most willing to be critical. In general younger people were more willing to be critical of services than were older participants.

Access to services was clearly very important to participants and getting hold of a specialist service or therapy had caused lots of anxiety. Most recent experiences of accessing mainstream services had been positive although there were some extremely negative stories.

People defined 'having access' and 'waiting' in different ways. For many people the experience of having to wait was of supreme irritation (more so among younger and working people). Several people pointed out how much they appreciated knowing how and why delays were taking place.

Many participants flagged up the fact that they saw the NHS as being quite **good value for money** (perhaps in contrast to the expense of private or overseas medical costs). There was less emphasis than we might have expected on wastage within the service. In general the service was seen as under-funded and health service employees were seen as over-worked, underpaid and under-supported. This was not the view of staff within the service. There were several comments that money was being spent on the 'wrong' things,

although it was less clear exactly what this meant – possibly high profile projects and equipment rather than grass root services.

Whilst some developments were welcomed, almost all development proposals (whether for services or for new builds) were viewed **suspiciously** and the majority of people believe that all changes were likely to be driven by a desire to save money above all else.

There was a palpable sense of frustration and anger at the idea that some bits of the country (even within the NHSNW area) get better services than others, although few concrete examples were quoted. The notion of a '**postcode lottery**', even within the region, was a real grievance. The close proximity of Scotland and Wales, with their high profile differences towards care and prescription charges, for example, probably served to highlight these concerns.

Patients were clear that a high quality service is one in which people get better, where there is visibly high standards of hygiene and where they are treated with dignity and respect by trusted health professionals.

Overall, patients in the North West seemed to have the same priorities as people throughout the UK. They appeared proud of the NHS and felt that they 'own' it. They have mostly had good experiences of it but feel that they may have been lucky in this regard. However, they feel that it could perform better, want more visibly universal standards and are anxious about its future.

2 Introduction

NHS North West is playing its part in the national NHS Sext stage review: 'Our NHS, our future'. There are to be a series of events organised by the Department of Health, involving front-line NHS staff, patients and the public in discussions that will shape a national report in summer 2008 to coincide with the 60th anniversary of the NHS.

The national process is fairly prescribed but NHS North West was keen to organise some of its own activities in order to ensure that the outcomes from the "our NHS our future" listening exercise reflect the ambitions of NHS staff and the needs of patients across the North West. Picker Institute Europe conducted a research project as part of these activities.

This is the story of one part of that process of listening.

3 Background

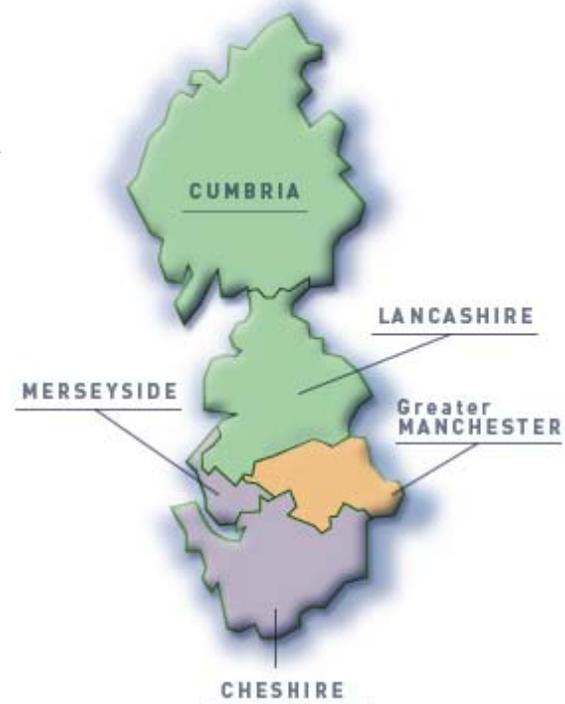
3.1 NHS North West

The North West Health Authority, known as NHS North West, was created in July 2006 as a result of 'Creating a patient-led NHS' initiative. Its predecessor organisations were the Greater Manchester, Cumbria and Lancashire and Cheshire and Merseyside strategic health authorities.

It is the largest of England's ten strategic health authorities with a population of more than seven million people, living in both inner city and rural areas. It is a diverse area with a wide range of social inequality.

The regional NHS budget is £9.5 billion, and the area includes 24 primary care trusts, 29 acute trusts, one ambulance, one care trust, and 11 mental health trusts.

Along with other regions the North West faces a number of public health challenges including cancer, teenage pregnancies, heart disease, obesity and the affects of excessive drinking.



3.2 The NHS Next Stage (Darzi) Review

A major review of the way the NHS delivers patient care is under way ahead of its 60th anniversary. Overseen by Lord Darzi, the NHS Next Stage review wants to hear the views of everyone with an interest in building a better health service.



Objectively the NHS has made huge progress nationally and locally over the last few years. Together with increased funding, the NHS has delivered demonstrably improved services for patients, including better cancer and cardiovascular diseases outcomes, and reduced waiting times.

However, the NHS also knows that despite these improvements it spent a lot of time talking about the means of change - payment by results, practice based commissioning, patient choice - and sometimes distanced itself from the ends - the things that really matter to staff and patients like safer, high quality care.

Lord Darzi

The Department of Health wants to use the 'Our NHS our future' listening exercise as an opportunity to take stock of what has been achieved; and to involve NHS staff and other stakeholders in a discussion about the next stage for improving NHS services.



Over nine months through to June 2008, a series of events will be organised by the Department of Health, to involve front-line NHS staff, patients and the public in discussions that will shape a national report to coincide with the 60th anniversary of the NHS.

NHS North West is organising their own activities to make sure that a North West vision for the NHS is developed that reflects the ambitions of their NHS staff and the needs of their patients. This research with patients commissioned in August 2007 forms part of those efforts.

NB The terms of reference for the NHS Next Stage review as announced by the Secretary of State for Health on 4th July 2007 appear at appendix 7

3.3 Picker Institute Europe

Picker Institute Europe is a registered charity with headquarters in Oxford. We work with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice. We undertake a unique

combination of research, development and policy activities which together work to make patients' views count.

Our activities include:

- ***Researching and evaluating patients' experience***
Measuring patients' experience using surveys and other methods to gain systematic feedback on the quality of healthcare. Original research is complemented by a suite of patient, staff, and public surveys to provide in-depth insight.
- ***Leading initiatives that make improvements happen***
Working with healthcare providers to use patient feedback to improve services. Our educational and development work encourages and supports health professionals in implementing change.
- ***Building evidence to inform health policy***
We use our research evidence to promote innovative, intelligent approaches to meeting patients' needs. We aim to make the views of patients and citizens count throughout health policy and practice.

The Picker Institute is an approved survey contractor to the NHS and the leading provider of patient experience surveys to NHS Trusts. We have obtained feedback from more than one million patients since 2000, as well as being involved in population, patient and staff surveys in other European countries. We have expertise in all stages of survey research including design, sampling, questionnaire development, execution (including online surveys), analysis and report writing.

As well as surveys, Picker Institute's researchers have expertise in all major methods of social research, including focus groups, depth interviewing and qualitative analysis; evaluation research; comparative cross-national investigations; and research on particular populations such as children.

4 Project details

4.1 Methodology

NHSNW wished to initiate some of their deliberations for the NHS Next Stage review by gathering the views of patients and other stakeholders across the region. They wanted a rapid assessment of how the NHS was viewed and what the priorities might be for development. These criteria lent themselves to a qualitative approach.

The Picker Institute proposed a number of focus groups to allow more creative and constructive discussion with targeted individuals in a short timeframe.

Focus groups are small group discussions, usually involving eight to ten participants. The discussion is led by a moderator using a topic guide (see appendix 1) to maintain the

focus on predetermined questions. The goal is to generate information about a carefully defined research issue. Data from focus groups helps to identify and clarify underlying attitudes and beliefs about the topic.

Groups work best if they are relatively homogeneous. In this case the defining features of the group make-up were geographical location and type of patient experience. We also separated out members of the public from NHS employees or associates.

Participants are generally unknown to each other. They are asked to give their informed consent and their expenses are paid, together with a small fee. Focus group discussions are best conducted in a quiet room, away from health service premises, free from distractions with refreshments available. The discussions are recorded and transcribed.

4.2 Method

The Picker institute offered to plan organise, run and analyse a series of focus groups throughout the region.

The screening and recruiting for the groups (sampling) was done after consultation with staff from NHSNW; they were particularly keen to hear from certain sections of the community, as outlined in the list below. Full details of the sampling strategy (screening) for the recruitment of participants appears at appendix 4. A synopsis is included below in tables 1 and 2.

People with recent experience of mental health problems	<i>Manchester</i>
People with recent experience of hospital care	<i>Manchester</i>
Parents of young children	<i>Lancashire</i>
People from BME communities with recent hospital experience	<i>Lancashire</i>
People with long term conditions aged under 45 years	<i>Merseyside</i>
People from BME communities with good health behaviour	<i>Merseyside</i>
People with long term conditions aged over 45	<i>Cheshire</i>
People 20 - 45 with good health behaviour	<i>Cheshire</i>
People 45+ with good health behaviour	<i>Cumbria</i>
Carers	<i>Cumbria</i>

Table 1: synopsis of focus groups with patients

Clinicians, NHS managers and partner organisations' reps.	<i>Newton le Willows*</i>
Clinicians, NHS managers and partner organisations' reps.	<i>Newton le Willows*</i>

**Groups took place at Haydock Racecourse as a central venue - recruitment took place throughout the region*

Table 2: synopsis of focus groups with staff clinicians and other stakeholders

4.3 Development of topic guide

As discussed earlier, the subject of the NHS is such a wide one that it was important to manage the discussions. Thus a topic guide was developed in order to channel discussions on predetermined questions.

Direction and context was taken from the work of the 'Our NHS our future' team at the Department of Health and a set of questions was developed by staff from the Picker Institute. These were sent to the team at NHSNW for comment thus a topic guide was developed. This guide appears at appendix 1.

4.4 Patient DVD

In addition to the above work the Picker Institute directly contacted the team at the Department of Health and secured a copy of their DVD providing some background information for the exercise. Serendipitously the video (2 ½ minutes) showing patients talking about their experience had been recorded outside hospitals in the North West and it made for an excellent and relevant scene setting exercise for the commencement of each focus group.

4.5 Card sort exercise

As part of the deliberations of each focus group Picker Institute staff designed a **card sort exercise**.

Fourteen potential areas for NHS reform were represented in cards and participants were invited as a group or a subgroup to rank them in to high, medium and low priorities. They were then asked to identifying their top three priorities for reform.

This provided an opportunity for refocusing the discussions and allowed a different basis for interaction between participants. It also presented priorities in a way that could be compared between different groups.

The results and a commentary on this revealing exercise appears at section 6 below.

4.6 Schedule, data collection and reporting

Data was collected from patients during October 2007 and from health professionals in mid November 2007. All material was digitally recorded and transcribed. Data were coded and analysed using a bespoke coding frame. Themes were developed, recorded and analysed and appear below, illustrated with participant quotes. We have not revealed any details of individuals who took part in order to protect their anonymity.

5 Results

5.1 Preface

Researchers spoke to a total of 74 patients and members of the public with varied experiences of healthcare across the North West. Almost without exception, people were keen to take part in the research in order to have their voice heard...

The NHS is out there and everyone has an opinion on it... so I thought it was a worthwhile discussion to come and take part in.

Most participants had strong opinions, wanted to be listened to and wanted their opinions to be acted upon.

Listen to the public... if they don't listen they will never get anywhere.

Mixed experiences – mostly not so good, so I am keen to make that known.

Many healthcare professionals we spoke to felt that the public were having much more influence over decisions within the health service than previously.

I think there is a greater involvement and I think people do feel we will listen.

However the public do not appear to share that sense of being listened to. In fact we detected a sense of ennui, a view that the public have been asked for their views before and that they have been ignored, or at least sidelined because of financial considerations.

They will just put it down – they are not going to listen. If it will save them money they will listen.

How many people have actually listened to what the public have said? – None

Are they using the NHS? [Do they know] how it feels day in day out for it to be your lifeline and part of your life and you haven't got that option?

Some of the contributors felt that the NHS is at a major crossroads and that decision-makers have one last chance to get things right before losing whatever trust that the public have left.

5.2 Ownership of and opinion of the NHS

We began each focus group with two very open questions “What does the NHS mean to you?” and “Do you value the NHS?”

These questions generated a range of interesting debate and some quite surprising instantaneous reactions. In general we got the impression that the NHS is in the background of most people's lives and that they don't think about it very much.

I don't use it very often but it is there at the end of a phone isn't it?

It is peace of mind to me – it is there to fall back on – it is there, it is free, you know how you are going to be treated.

I would like to think that it is a good thing rather than a bad thing because I am generally quite healthy – It must be so frustrating for those families and people who are generally poorly who have to rely on the NHS all the time to provide that care.

Well the true value is you don't know what you have had until it is gone or your miss it – but with it being there – even though it is at the end of complete criticism at the moment – good, bad or indifferent – it is there.

In the abstract the people regard the NHS with extreme pride and affection:

Whenever anybody mentions the NHS I think it is fantastic.

I think we are so lucky to have it.

However almost all see it as being flawed:

The theory of it is fabulous obviously, it is just...the finances are all over the place.

It needs a good shake up ... It was a good organisation – it is not any more.

I think the NHS at its best is fantastic. At its worst it is bloody awful but at its best it is fantastic. I think it is probably trying to do too much at the same time.

There were a large number of comments about the management in the NHS. Some of which were reflecting perceived wisdom:

Too many managers. Non productive, not required... get rid of the bureaucracy.

The complaints are more about those in suits than the medical staff

Too many chiefs and not enough Indians.

When you walk through the corridors there are so many people in business suits with clip boards.

There were some comments from participants that illustrated some understanding of the challenges facing managers in an organisation the size of the NHS:

The thing is that you don't see good management do you? Things just happen.

Good management is very important because often you see the effects of bad management.

But it appeared that the public in the North West have a low opinion of NHS management:

There is a lot of mismanagement in it.

Some clinicians were equally critical:

Some of the contracts that have been negotiated are prepaid whether they actually use the operations or not – enormous amounts of money have been top sliced from our budget to pay for a centre that nobody refers to and they are making money sitting on their bums doing nothing. Whoever negotiated that contract at the Strategic Health Authority should be shot

There were lots of comments about use of resources:.

They put a lot of money into it, but in the wrong things

The money the government has - they don't put in to it – they spend it on stupid stuff.

Time didn't allow much exploration of these views in detail, but they appeared to be a widely held belief. There were one or two descriptions of building work that had been undertaken only to be knocked down within a short time, and some less focused comments about the way in which high profile technical projects seem to be favoured over low profile services in the community. **There appears to be an opportunity for the NHS to communicate some of its spending decisions more clearly.** We noted throughout this project that the public has very little idea about the cost of NHS services and in general the public had erroneous notions of how much doctors and nurses earned:

A trainee nurse – how much is she getting? She's getting £90 pound a month.

Pay the doctors and nurses more.

The pay is not rising with inflation.

Even people who had negative feelings about the service they had experienced were prepared to defend it against other health systems:

It is still better, the system we have, even with its faults, than having no NHS.

I get cross when people talk about the wonders of the American system...It is OK if you have the money ... it just makes me so cross when people sort of wave the American flag in front of us and say we should be like them.

I think we need to be honest and recognise that it isn't perfect and there are problems and we need to try and address them. But I think we could lose it – we would then have the next 1500 years thinking why the heck did we do that?

Several of the people that we spoke to had had terrible experiences (some of them many years ago) that had completely clouded their opinion of the service. We had a sense that a bad experience sticks with people for longer and colours judgement much more so than did a series of good ones.

The last 3 years he was in hospital an awful lot and some of the treatment he received was heart breaking.

And now I have a handicapped son because of Carlisle I hate Carlisle – if anything is wrong with me I would go to Newcastle – I would hate to go in that place.

My husband died in the Royal, it was terrible, he got neglected, I am not going over the doorstep.

Even when people had had bad experiences often their reactions were not always ones of anger (although there were a number of terrible stories that generated righteous anger) but of **disappointment**. People felt that the service could and should do better and they felt disappointed and let down by it when it failed to meet their expectations. They felt let down by something in which they felt they had a stake and undoubtedly this is linked to a strong sense of ownership and pride.

We also asked whether people **valued** the NHS and, in general, we had confirmation that people did indeed value it very highly:

Oh yes I value it enormously I think it is marvellous.

I think there is a huge value in having a service that you can access free of charge to speak to a good healthcare professional...

However, people did not think about the NHS very often and did not value it on a daily basis:

I don't think we do value it because it is just something that is taken for granted that it is always going to be there and it is always going to give you what you need.

And although they felt very positive about it, they admitted to taking it too much for granted:

I think it is good – people cherish it – I suppose some don't – take the mickey out of it.

I think you do take it for granted. I don't know what would happen if it wasn't there – it would be a totally different kettle of fish really wouldn't it?

I value it enormously. On a personal level I feel it is an incredible security blanket that if I or any of my family fall ill, particularly with serious disease they will have access very rapidly to top specialists. And I think that is an enormous reassurance.

In general older people valued the NHS more than younger people:

I think it is a marvellous thing... my father told me when my sister was born they had to sell my mother's engagement ring and his motor bike because there was no NHS to get her in to hospital.

For many young people, especially those who were not using it very much, it was viewed as something 'in the background', to be proud of in the abstract, rather than as a service that they themselves had a stake in:

It is peace of mind to me – it is there to fall back on – it is there, it is free you know you are going to be treated.

Most people perceive the NHS to be in a parlous state and they don't have tremendous faith in the people looking after it:

I think it is something that we need to look after.

Many participants believed that the NHS was in crisis even though almost **everybody** we spoke to had had very good recent experience of it.

I have had no problems, none at all but you hear about all these people who do have them...

People who used it regularly (people with long term conditions and especially their carers) were however more willing to be critical of its services:

That creates a great deal of stress if the service isn't run properly - if you are having to constantly fight...

In the case of my mother when she was suffering with her knee pain and her hip pain there were a series of stages where she would have to go through assessment... Really my perception of it is that there was a bit of delaying tactic.

Interestingly people were willing to be critical of the NHS as a whole **even if their own experience had been good**. They just saw themselves as being lucky in that their experience had been atypical:

The individuals that we deal with are fantastic but they are under enormous pressure but I realise how very lucky we are to have this team.

I have had no problems myself but you hear stories don't you?

I think we are very lucky – and very lucky that we have Wythenshawe on our doorstep for the diabetes – I am insulin dependent and I have found it fantastic – wonderful service.

Many saw the NHS mainly as an acute or **emergency service**. The over-riding impression is that if you were in an accident or were seriously ill it was excellent:

I do think that the acute services do very well. The sicker you are the better the service you have.

But for less serious conditions the service was perceived as less than ideal, and some were willing to believe that this was almost deliberately so:

You go for a non emergency and you realise it is delaying tactics and they put you off for months and months.

The elderly are very poorly served and so are the mentally ill... so you are not so well served if you have got some chronic condition or if you are old.

Several people had telling experiences of the inconsistencies between different services:

I would say my cancer was much, much better than my having mental illness – no comparison.

This illustrated some of the major themes emerging from this research. Firstly, people perceived that the service for people with long term or less acute conditions is less good than it should be. Secondly, people believed that they are being given permission or even **encouraged** to 'go private' and this notion seemed to be quite well accepted. There was a sense that 'if you could you would', and implied that the NHS service was seen as a safety net, particularly for less acute conditions, for those who can not afford anything better. This challenged the concept of a 'cradle to the grave' universal service which people identified as one of the defining strengths of the service.

However our overwhelming impression was that the concept that NHS exists for everyone was a great source of pride:

You are safe in their hands- no other country has this – it is one of the things in this country you should be proud of.

Staggering in terms of value – what organisation could withstand the flack, agro, criticism that a service gets and yet is loved.

5.3 Value in being a universal service

Many participants had had experience of overseas health systems and a recurring theme was that whatever the shortcomings were of the NHS, a universal health service,, free at the point of access (see below) was a matter of great pride:

These plush hospitals in America and all these politicians say how good these American hospitals are, but what they don't tell you is that if you haven't got health insurance you are not going to that hospital.

Much of this pride was embedded in the concept of the service's universality, where everybody is treated the same:

The sense of equality as well – it is there – it doesn't matter what money you have – you go in there and you get treated for your condition.... and the beauty of it is that it is a multi cultural unit and it is not just driven by one colour and you have the feeling that you are totally comfortable no matter what background you are from.

However, there were a range of stories about people being able to get what they wanted (although they perceived it as 'needed' – an important differentiation that was highlighted

by many of the healthcare professionals) by being persistent, argumentative and generally having the skills to negotiate the system.

The thing is, with certain illnesses, you have got to be on the phone all the time, nagging all the time to get up the list or to find out when your operation is.

Over the course of six months – I kept going back to the doctors and he said “I will send you to the specialist – I don’t think there is anything but to stop you worrying.”

This sometimes meant paying for a private test or scan, which was a very common occurrence among our participants. This was sometimes accepted phlegmatically but sometimes caused deep resentment:

He said that if I hadn’t it would take about 8 months before you would get to see a specialist at the hospital even though I had already waited 6 months. He asked if I had got private medical insurance and I said “Yes I have”... I went back to work and rang and they said “Come in Monday morning”.

So we rang up and said because he was getting stressed, how much would it cost if we paid for this scan?... we said we would go private for the scan on the Tuesday and we paid £600 for this scan and we had just set up home we were not well off at all by any means – we didn’t have the money... he had his operation a week later. So basically that was an 18 month reduction in waiting times because we paid for that scan.

If we hadn’t paid for her to go and see the specialist to say to the NHS “You have got to give this kid the stuff” – we wouldn’t have got it – because we know it is expensive stuff. It is unbelievable.

There was no resentment or chagrin about this type of behaviour, which could be seen as queue jumping. But there was some annoyance at having to pay privately to use NHS equipment (see the role of the private sector below).

It was the same doctor and the same machine – unbelievable!

Another theme that we identified was the problems that many people had in accessing the service that they wanted. This was particularly true of the mental health service users:

I have had trouble accessing and getting the right kind of treatment.

The treatment I have personally received has been great. However, getting to that stage is like looking for a pot of gold at the end of the rainbow.

This was also a consistent complaint from carers and parents of children with disabilities:

As well as that emotional burden that you carry, you also have to find the strength to fight, if you like, to get what your child or what that person needs... it is an ongoing battle.

Another popular theme linked to the concept of universality was the challenge of rationing (see the Fears section below). Unbidden almost every group discussed the issue of whether NHS services would, or indeed should, become rationed to those who exhibited 'good' health behaviour. This proved a very challenging idea for most participants:

It is that concept of almost just deserving – who is deserving of the health care and that selection – we talk about smokers, talk about obesity, talk about drinkers and all these groups if you like – single out people with certain life styles as being less deserving of having access or free access or rapid access and I think that is a very frightening concept.

Most participants expressed distaste for the idea and felt that it would run counter to the guiding principles of the NHS. However this was one of the relatively few areas where we detected a difference between the attitudes of the public and health professionals. The call for good health behaviour to be used as a criterion for providing a health service was couched in terms of a debate about honesty:

I think we should be explicit about it. At the moment we are a bit dishonest – well we don't say to patients at all – we'll fudge the issue but I think from a public health perspective we should be saying "Actually smoking is bad for your health, but also it will restrict the access that you may get for treatment". "If you are over weight, it may restrict the access that you get for treatment".

There was agreement that the NHS was going to have to address the issue of rationing as a matter of priority, because of increasing demands and limited resources. When asked to elaborate, participants' greatest fear for the health service – collapse under the weight of expectation - was as high as the fear of having to pay for healthcare.

5.4 Free at the point of access

As might be expected, the 'free at the point of access' principle was fundamental to the North West public's view of the NHS:

I think for me there is a certain amount of morality in the access and the free nature of it.

It is important that it is free.

Come times of emergency you don't have to put your hand in your pocket - it is there.

Again, there was a sense in which the NHS was perceived as a safety net for those who could not afford anything better

It is important that it is free to people because there are always going to be people who cannot afford it.

Some interesting themes arose as part of a discussion, including whether the NHS is in fact free:

It's not free is it?... we all pay for it through our taxes don't we?

Or whether the public does, in fact, directly fund some parts of the health service. Dentistry services were a concern and caused much debate:

The cost of dental treatment now – it is just terrifying.

I am actually flying to South Africa on Thursday for some dental treatment – I need some treatment which will cost £9000 and it will cost me less than £2000 in South Africa.

There was extensive resentment at the feeling that people were being forced in to 'going private'. There was also a general belief that dentistry services available on the NHS were in some way poorer quality:

Now we go private for a dentist. Because you were getting different people coming over – this is no disrespect to anybody but obviously with the NHS you have got the downgraded service if you like – you got the trainees in a way.

Even when people had the same dentist that they had had under the NHS they were convinced that treatments and materials were superior under private care.

Another topic that provoked comment was that of paying for prescriptions. There were comments in Cheshire and Cumbria about the fact that 'over the border' prescriptions were free.

A prescription in Scotland doesn't cost you anything.

Participants did not appear irritated about this fact, but rather bemused by it. Some patients on the borders of the region felt that they were doubly hard done by; once for being in the North West and again for being away from the centre of NHS activity nationally.

I spoke to the GP and I heard it on the television about a drug for diabetes. "When will we get this drug up here"? He said "We won't because we are up in the bloody sticks."

One final theme that arose in the discussions about the importance of the NHS being 'free' was the renewed appreciation people had for the NHS once they had received or knew of treatment received, and paid for, abroad – especially in Europe or the USA. The very fact of having to pay (even if they were insured and would claim it back) as well as the size of the bill made people realise how much they valued the NHS:

Patients of ours have been in Florida on holiday and the children have fallen ill with ear ache and they come and say "I had to pay £60 to see the doctor and I had to pay £30 for the script – I won't moan so much about your injection."

There were several stories from people favourably comparing the quality of services they received in the UK to that which they had paid for abroad. There certainly seemed to be a number of opportunities to celebrate the quality and value of the NHS.

My mother was treated for cancer at Christie and received very, very good care and I am told the person that did the operation was probably one of the top people in the World – if it had been the USA she would have had to have been on a very good insurance policy to fund it.

Some healthcare professionals wanted to go further:

Some I think one of the things that the NHS doesn't do is turn around and tell anybody how much their course of treatment has cost. I think actually if people had a perception of the vast amount of money that is often spent in terms of treatments and things then there may be a little bit more respect. .

One effect of people having paid for private treatment seemed to be the crystallising of what good value they got from their taxes:

I know we only pay peanuts compared to what it really costs because it is subsidised by the NHS – I have had e-mails off people telling me to go to – I think – is it Poland? – go to Poland to get that work done! If you are going to pay private it will cost you

This feeling was reflected among staff:

I am not saying I want a World where patients are told “By the way Mrs Jones, on your discharge you have just cost the country £30,000 hope you feel good about that!” But also in that public perception I think there is no concept of what treatment can cost.

There seems to be a gap in the public's understanding that could be an opportunity for the NHS to exploit.

5.5 Perception of improvements – what works well

When we asked the question “what works well in the NHS”, participants' responses showed they were aware of major improvements in healthcare. In general people's first thoughts were mostly about services that they probably had not been in receipt of themselves, such as technological breakthroughs and highly complex clinical procedures:

Progress – heart transplants and test tube babies.

Incredible –something my grandparents could never have dreamed would happen.

There were also a number of recurring views that seemed to suggest that much of the investment resulting from the NHS plan has been noticed by the public:

Waiting times have definitely improved. We have got the two week cancer target which has led to an improvement.

I think the buildings and environments have improved enormously. There are still some really dreadful old Victorian locations but by and large both in primary care and in hospitals huge developments have been made

I think the big services that have received a lot of resources like cancer and other things have done hugely well – fantastically well.

I perceive that heart disease is much better.

While there appeared to be many reasons to be cheerful, as ever there was a sting in the tail:

Unfortunately my perception is that by prioritising those politically important things, they have de-prioritised mental health care, community services and maternity

There was a real appreciation of some initiatives that while less high profile are making appreciable and appreciated differences to people's lives:

I really appreciate some of the preventative things that have happened. My mother died of a stroke when she was young and my doctor now regularly monitors me to make sure the same doesn't happen to me

My mother who is 84, now has a community matron that I managed to put in place and that is working extremely well.

When I need an inhaler or when I am running out now I don't have to book in and wait for two weeks to get one – I can ring up and he will say it will be ready in the next 24 – 72 hours which is a great improvement for me because it saves me losing a day off work.

I am really impressed with what is happening in integrated care.

I had to go for a heart scan a few months ago – I just got a letter – and I just went along to the hospital and it was very quick – just went in and was scanned.

There were a number of very positive messages about waiting times:

Speaking from the point of view as an outpatient. I notice that you are getting seen a lot quicker. My experience has been that you get a time slot and the last time I went I must have been in and out within 20 minutes.

There were lots of comments about the positive impact of IT both from patients:

You can book your own appointment on your computer – brilliant!

...and from clinicians:

IT has transformed primary care. When I started in the practice I would routinely spend an hour at the end of the morning handwriting repeat prescriptions – it is

now computerized – the analysis of the drugs – the interactions, the warnings, patients' safety is enormously improved.

There were some very mixed messages about access to primary care. In general people were extremely positive and perceived that things had got better:

I never had to wait for an appointment now.

You can ring your doctor of a morning and 9 out of 10 times you are seen that day.

I just went into the drop in clinic and they sorted it out there and then – I was in and out within half an hour if that.

Been to the doctors a few times with him – and it is “Bring him down now – in a couple of hours” – in and out – no problem at all.

But a significant minority felt that things had got much worse – especially those who valued seeing a particular health professional:

There has been a time when I was trying to get an appointment for 3 months – I haven't got one yet – 3 months – every day I was trying to get an appointment – it was impossible.

I think access to Primary Care is poor at the moment – whether that is real or perception – I don't know. I think if you have a problem – go to the A & E department because you will be seen and you will be dealt with. You might have a bit of a wait but you will be dealt with. Access Primary Care and it will be a week to get to see the GP

I think the GP's have got worse. My doctors has got terrible – I can't get in for an appointment at all

The frustration of some members of the public that you get better service in some practices than in others in the same area was clear.

A number of new initiatives were raised by patients:

Choose and book was liked in general but people found that the system had, thus far, been unreliable.

Drop in centres were extraordinarily popular with those people who had made use of them

The Walk In Centre – that is fantastic.

I went to a Walk In Centre – can't remember what it was for but that worked well and the way they... IN OUT – BISH, BASH BOSH – which makes a hell of a difference because you don't have to sit and wait for an appointment. I thought that was a good thing.

I walked in – it was 2.30 pm – waited for 5 minutes and I was seen by the nurse consultant – she prescribed me some eye ointment and I was out of there all in all within 15 minutes – and I thought it was fabulous! I came out of there with a bit of a spring in my step because I thought that was really good.

It is worth recording that many patients (usually older people or those not working) could not see why you would need walk-in centres if you had a GP practice.

NHS Direct polarised opinion. People either sang it praises....

I think NHS Direct is brilliant – hardly anybody ever uses it – hardly anybody even knows about it.

....or could hardly contain their anger about it. The following statements were typical of many

I can't understand why money is being ploughed into that because that is the biggest waste of time. You ring up, you tell them your symptoms and they normally say "I will ring you back in a bit" and then they say "Go to the doctors or go to the hospital" which you were going to do anyway.

I think the NHS Direct service is a waste of money. You phone up and the idea of it is that they will basically give you an "over the phone" diagnosis but they never do... so for me that is a complete waste of money.

Both patients and staff expressed a view that they had seen improvements in the NHS over the last few years but both groups expressed frustration that the picture portrayed in the national and local media was almost always negative:

the problem is that we don't get the reflection in the media and I think we need it – there might be one thing gone wrong out of 100 but they will pick on that one. That really makes me cross.

I spent some time at Carlisle Hospital and the abuse and criticism it got! – You are sort of thinking millions have been spent in this locality with hugely improved facilities and very good services and yet day in and day out the local press and whoever it was that was wanting to knock it for political or other purposes just castigated it.

5.6 Perceptions of deterioration and what works less well

Having asked about things in the NHS that were working well, we went on to ask about those issues which were irritating to patients and might be perceived as deterioration in the quality of service.

Most people had perceived deterioration in dentistry services:

Something which has got worse over the years is dental care. That is a nightmare now isn't it?

Many reported that they felt that they still had to wait for too long for test results:

There is one thing that annoys me – if you have an x-ray – why it takes 3 weeks to get from the hospital back to your doctors?

I personally did live abroad and it was much better. The service, blood test in the morning, by 1 pm you have got them – the service was much higher, the quality – everything was much better.

When I had blood tests I had to go and see a specialist – the appointment was 2 pm and it was 4.55 pm when I got in to see the doctor, but he had got all the results of the blood tests, every one. He said “I am sorry you have been kept here so long but this is why I have kept you here so long because now I have got all your blood results” – so it can happen – they can get the results if they want to get the results.

There were a few examples of unacceptable waiting either for appointments or at A&E:

I had to go to counselling about two years ago I think there was a six month wait – it doesn't matter how bad you are – you can be suicidal but you have still got to wait six months.

I went in through A & E – the waits in the department were just terrible. Even though I was in a lot of pain I was sat there for quite a while.

As an out patient I think probably the thing that frustrated me most was the wait in clinics.

However, people seemed to expect very long waits. Again the picture given of waiting times was mixed with more experience of better-than-expected access than of poor service, however the perception of poor service was strong:

You hear about the NHS occasionally leaving people lying in corridors – you don't actually see it, you just hear about it.

Some patients bemoaned their having to access some services through their GPs:

[Everything] is based on the assumption that the GP is the gatekeeper to services

A Walk In Centre cannot refer you – he will refer you to go back to your GP.

Patient complained vociferously about the seeming inability of different parts of the NHS to communicate effectively with each other. This was true of GP practices and hospitals, of different departments within hospitals and of NHS organisations and partner organisations.

There is not much communication between different teams.

There were some profound things said about the attitudes of staff. Despite some complaints from patients (see the section about being treated with respect and dignity) the image of clinical staff and nurses remains extremely high (see the section about

attitudes towards staff). Interestingly much of the negative comment came from health professionals themselves:

There isn't that going the extra mile any more – and that's sad I think because I don't think the majority of people want to be like that.

I just think the whole value of the NHS has changed so much - you don't give the way you did because you get nothing, absolutely nothing back.

It is about targets now. It is like a political football – the quality aspects don't really seem to count very much.

It seems like every turn there is something else for you to jump over and I think people have just taken their bat home really and they go to work and they do their job and I think that feeds right through into the patient experience.

The perception that almost everybody had was that virtually every decision made in the NHS is based on **financial considerations**. We know from experience that, if asked, the public will almost always support investment in preventative work (although they are usually very unsure what the NHS should dis-invest in). However some patients believed that decisions are being made in the NHS that run counter to an 'early intervention' approach:

They wait until the situation has escalated and people do need surgery. That is obviously where most of the money goes in the hospitals is towards that serious stuff.

Finally, some participants took a much broader view of health services and discussed whether the system as a whole was achieving some of its professed aims to reduce inequalities in health (which would seem to be particularly marked in the North West).

There is still this huge polarisation between the "haves" and "have nots" and I cannot personally see that it is improving that much.

5.7 Funding

The NHS in the North West was seen as under-funded and the public seemed to believe that many of its frustrations are the result of parsimony on behalf of politicians and NHS managers.

It is not the individuals where our complaint is – it is the lack of funding.

I just feel that these professionals who are very good at their jobs are not getting the support through the funding. Whoever is working out these budgets are not doing it properly to cater.

We detected a sense of the North West being seen as the poor relation:

I know there are other areas where the NHS does not have a lot of money –

...and that although there is general distaste for private health providers there was a call for the NHS to be **more business like**:

If it was a business it wouldn't survive – like the BBC.

What was very clear was that the public believed that **every** decision made within the NHS is made on financial grounds, whether at the strategic level:

I know there are a lot of health services that have down due to lack of funding recently and people who live in a certain area have to travel maybe 5 or 10 miles out of town.

At the end of the day these centres wouldn't close down if the funding resources were there – again it is a scandal that they are closed down because of it.

Rationalisation means – “Make it cheaper” and saving money!

Especially in relation to the drugs because – I have heard in the news there is not enough provision of certain drugs – there is not the funding in place and certain people are not getting the drugs or are having to wait for them.

...or at an individual, clinical decision-making level:

It's as if the diagnosing thing is on the basis of “How much is it going to cost us for drugs?” Delaying tactics on things and I have seen it – I have seen it with my own daughter.

I have heard in the news there is not enough provision of certain drugs – there is not the funding in place and certain people are not getting the drugs or are having to wait for them.

They just wouldn't prescribe them –they denied knowledge of this particular drug that was in the newspaper.

Even registering with a GP was seen to be influenced by this criteria:

It is the same with the doctor's surgery –you have got a good practice manager he is not going to want people that are sucking that system dry – he will want those patients somewhere else.

There was total belief that **all** decisions about services have been, and will be, about saving money in an under-funded service. **Every change was seen as a cut.**

Staff seemed to be aware of this and were keen that decisions needed to be more transparent and expectations managed:

We have got a whole load of patients who are a bit suspicious really and when you want to make a change about something else they will say is this another one of these changes about saving money?

Funding and resources has to be a major thing doesn't it to get those right and to be clear about them and that in turn will lead into managing people's expectations.

I think there has to be a clearer understanding of what money is available, what it is available for and that has to be translated to patients and communicated to them.

In addition, some staff echoed the public's view that money was sometimes spent on the wrong things:

The trouble is we all perceive that we might get cancer, heart disease, none of us perceive we are going to get old or mental health problems. So people are happy to see millions spent on sexy cancer treatment, when actually making sure everyone has got a pair of slippers may be the best use of resources.

5.8 "Choice"

We talked at some length about what factors would affect peoples' choice of healthcare provider. The understanding of 'choice' tended to be about different treatment decisions rather than different hospitals.

Participants found it hard to engage with the idea of choice in healthcare *per se*.

They are going to get the money whatever – you have a bad experience but what are you going to do – go to Tesco? There is nothing you can do, you have still got to go there whether it is rubbish or not. They will still take your tax, they will still spend it – it is a monopoly – we have no choice.

This was especially true of those people who lived in communities that had only one hospital or practice available. However, they did comment about the desire to see particular doctors within their practice, or having to 'go private' for dentistry or other services.

In order to explore what makes patients choose one service rather than other the facilitators asked them to imagine that they lived equi-distant between two providers of a particular procedure or therapy they needed. This generated some interesting debate, the outcome of which was crystallised by one participant who said:

I'd make a choice based on reputation and location

Location was not viewed as just about physical distance – it was also seen as to be about how easy a place is to get to, the ease of access once you get there, parking and the option to use public transport. **Reputation** proved much more difficult to define, defend or even justify. Most patients would take the advice of their GP and use their personal experience, and that of their family and friends, when making choices. Beyond this messages from the local media influenced people's minds:

I hope I never have to go to the Royal. They don't seem to get good write ups these hospitals do they in the paper.

Almost nobody had done any 'research' about making a choice between hospitals, although there were some assumptions from professionals that this would become the norm:

Most of us now actually determine what we are going to do isn't it? Whether we are buying an IPOD or whether we are actually going for surgery. We look it up.

However we came across **nobody** who had accessed the wealth of data freely available on the internet, and other places, which objectively measure performance of local health providers.

Can you do that? You would do that if you had the time to do it...

I mean it is not like America unfortunately in that respect...they can ask the actual surgeon they are seeing, is there anybody better than you?... they find out and they can go on the internet and find the guy who has the most letters after his name.

Are there league tables of hospitals and things?

There were some comments about external NHS communications such as:

I am just thinking that when they have improved on services or as you say, if waiting times have gone down, they need to share that information. They should do an annual report or something.

It appeared that patients' 'gut feeling' about hospitals/doctors or other services were immutable, unexamined and very long standing:

I was there in Wythenshawe in 1970 - and they were perfect then, that was 37 years ago. They haven't really changed at all - still the same...

Exploring **why** people felt the way they did about certain services proved interesting, if very hard work. Everybody had a view about hospitals, whether they had personal experience of them or not:

If I was being taken in an ambulance I would beg them not to take me to the Royal because it is manky.

I wouldn't go to my nearest hospital - I would want to be dragged past it!

I think it has got a local media that is very happy to knock it. The public are very happy to feed the stories to the media to knock it - I think you can talk to people - "What do you think of the Royal?" and they will tell you how lousy it is and you will ask them "Well when were you in there?" and they have never been.

Exploring what participants meant by 'a good hospital', and therefore what would make them choose it over another, was less easy:

You just know don't you, you get good'uns and bad'uns...

This research probably confirmed a number of things. It appears people make decisions about healthcare based on the following order of criteria:

- **their own personal experience** *You know the hospitals in your area don't you? I would hate to go to another hospital out of my district.*
- **experience of family** *It's listening to Nelly isn't it?*
- **experience of friends** (with more credence being given to friends working within the NHS which were almost all negative) *I would say reputation because I had a friend whose dad had to go for a lung transplant and he went to Withenshaw and obviously they are well known for the transplant unit up there and he got fantastic care.*
- **their understanding gleaned from local media** *It is your local free papers and things like that – you always hear of things on the news.*

There were some very interesting revelations about what happened when people went against their instincts:

I always used to totally rule out Fairfield because for me it was just an inefficient hospital... Then I went to Fairfield and I had no problems in my experience there – it always seemed really organised, really well run – everybody that I had spoken to that had had either operations or treatment there had said it was fine, the surgery was good, the consultant was good, the nurses were good – they sorted the problem out

Exploring some of these experiences further may be beneficial for planners of NHS services.

The general acceptance was that 'private' offers better quality services than the NHS, especially when it comes to hospital provision. However, we had a number of examples of people who, for whatever reason, were holders of private medical insurance but who had used NHS hospital services. They had very positive things to say about their experience in NHS hospitals:

I was moving jobs and I'd missed some payments on the BUPA and I went to the doctors and he had me in Oldham Hospital that evening and I was really surprised by how good it all was.

He has got private with work and he didn't end up using it because it was an emergency – he snapped his Achilles and he had an operation literally there and then and the after care was just unbelievable. They gave him like the David Beckham boot free – it should have cost him £200/£300 – but they gave it to him free and they fitted him up and he went back every week and now he is having physio at the hospital. So we can't complain.

Low expectations were often exceeded and people were extremely pleased with the service they received. These felt like 'good news' stories that could be exploited by the NHS.

Where people had a high opinion of a hospital a poor experience was excused because staff were overstretched. What made for a good healthcare experience was rarely, if at all,

connected to resource issues. A reputation, good or bad, seems very difficult indeed to change.

The Christie, in terms of the treatment for my wife, compared to the Mac and the local services were all dreadful – absolutely dreadful – long waiting times, dealt with like second class citizens – you go into a highly prestigious place expecting to get treated well and were treated like cattle and appallingly. So the public perception is different.

I have got patients who say exactly the same thing – they didn't tell me that I wasn't going to get better, they didn't tell me that I needed this – but the public perception remains that Christie is wonderful.

We found that many patients at the periphery of the North West region do not perceive that they have any real choices in healthcare. Several healthcare professionals believed that this was actually a good thing:

I think there is also the burden of choice – choice is always talked about in terms of patient care work – it is a positive and actually when you meet patients a lot of the time they are burdened by that choice – it doesn't build confidence and it is an extremely difficult time and then they feel culpable for the outcomes because they feel like they have chosen it. It could be a very double edged sword.

It is not informed decision making is it? – it is burdening patients with a decision that they don't have the information to make.

5.9 The NHS as partner organisation

This was not an issue that we expected to hear much about. However a number of people passionately expressed the view that the NHS exists in a vacuum. It was seen as huge, unwieldy, extremely inward looking and resentful of liaising with other agencies.

I think it is massive, it is turgid and it is slow and it is incredibly closed...

Some partner organisations, especially those in the voluntary sector, felt that they struggle to be taken seriously by health colleagues:

The NHS – it is like trying to knock, scream, shout at the door. It really, really is. They just about talk to their partners in Social Care, the voluntary sector – they tolerate.

Several people told us that as a partner organisation in community development work the NHS was a difficult partner to work with.

A sort of amorphous organisation that is actually very difficult to communicate with and do business with.

At just about every meeting there is an empty chair that the PCT should be sitting in – that's our experience.

5.10 The role of the private sector

In the card sort exercise the card representing 'the role of the private sector' was given a low priority in almost every group. However some aspects of the private sector obviously influence people's negative feelings about the NHS.

There were some very strong feelings expressed by healthcare professionals about the private sector:

I think this is privatisation of the Health Service via stealth – I think it is being cherry picked at the moment.

I think it is absolutely disgraceful, I think it is undemocratic, I think it is happening by default, I don't think there has been any true debate about it, I have grave concerns as a practitioner about who these people are and what the quality assurance is.

There seemed to be a belief, also echoed by patients, that the service received from BUPA is better than the NHS. We sensed that people from lower socioeconomic groups and, possibly, people from Merseyside had concerns about the 'fairness' of this.

If you could you would wouldn't you?

We did not ask questions about health insurance but many people volunteered information about the topic:

I was in BUPA at one time at one time – I enquired about carrying it on but it was a fortune.

I pay for BUPA for me and my wife – costs nearly as much as my mortgage.

There was a belief that the NHS was the best (possibly the only) option for emergency medicine and for serious acute conditions:

If you have a heart attack I am sure the NHS is second to none.

Where using the private sector made sense to people (although many still felt it was unfair) was when they had non-critical conditions or elective surgery needs. It was then felt acceptable to 'buy your way to the next point in the queue'.

There was, however, anger at the idea of NHS equipment and staff being used, or even being made available but then not used, for private clients when there were long waiting times for NHS patients.

BUPA are using NHS stuff and they are stopping genuine people going in and using that stuff and who is paying for that stuff what they are using in operating theatres – US! If they want to set up as BUPA, set up as BUPA and bill their own hospitals and run them with their own people, don't use NHS people.

There was also quite a strongly held view that whilst people assumed the standards in the private sector were *generally* higher...

If you say you are having it done on the NHS people will say "Oh you will probably be OK".

....at the same time they were convinced that NHS cleaners supplied by the private sector had lower standards.

I just think an increase in privatisation and the standards would go backwards again.

There was anger at those people (who themselves also professed some guilt) who dipped in and out of the NHS – as well as with consultants who obtained tests and diagnoses privately but then dipped back onto the NHS lists. This was seen to be beyond the pale. In addition, there were a couple of examples of people with extremely serious, life threatening conditions who felt that they had had no choice but to pay for private scans in order to move their care forward through some bottleneck.

However, there seemed to be an acceptance that private sector healthcare, in the shape of private sector providers, had a role play to in healthcare:

I have no problem with private medicine – there will always be a need for it and I think where people feel they want to use that – I am quite happy to refer people privately

It has a bit of an image problem probably - you say "I am having to go on the NHS"- it is like a bit of a "I can't afford to have it done privately – I haven't got good enough insurance."

There were some gripes about feeling forced into using private healthcare and thereby paying 'twice':

You are actually paying twice aren't you because you are paying your taxes, your National Insurance and you are paying private. You are paying into a service that you are not fully using in some ways.

This sense of paying for everything twice (the first via taxation) was especially strong with regard to dentistry services (perhaps because most people had grappled with the problems of finding an NHS dentist or had given up trying):

Why am I suddenly paying £30 per month for dentistry? – where was my reduction in my taxes which used to be free dentistry? I think it is a con.

There was some real anger at paying for parking, televisions and telephones in hospitals (although in the card sort exercise facilities in hospitals including TV telephones and parking were **never** seen as a priority).

Why do we have to pay to park there? That is a real con that is – when the hospital was paid for out of your taxes – that to me is scandalous!

They have got like premium phone line rates and it is costing pounds to make like a ten minute call and it is absolutely ridiculous.

There was a widely held belief that the **privatisation of cleaning services in hospitals had led to a drop in standards** and a reduction in staff pride in the job (see cleanliness section below).

5.11 Cleanliness (and superbugs)

Cleanliness was consistently considered a high priority area for members of the public and fears and concerns appeared to be very real to the patients and public in the North West.

People are dying because of this...

There must be people going in there nervous thinking that they are automatically going to get MRSA.

However, we detected that cleanliness and infection control were more important to people who were **not** using the health service on an ongoing or a long term basis. It is possible that for people with long term conditions and their carers access to the latest treatment and drugs is a more important priority.

People perceived that problems with 'superbugs' were **directly linked to poor standards of cleanliness**.

It's all regarding cleanliness – you don't get MRSA in a private hospital do you?

Cleanliness and hygiene were seen as synonymous by the public. But NHS staff were far more sanguine and believed that 'superbugs' are a result of antibiotic use (and misuse) and are only loosely connected with cleanliness.

It has always been there and is partly because we are giving too many antibiotics

We have halved the incidents of MRSA in our hospital by changing antibiotic policy; we haven't employed any more cleaners

The public certainly perceived cleanliness (by which we think they mean things to be visibly clean) as being pertinent to a quality healthcare experience. They were happier when they **saw cleaning** happening.

I was in for four days and never saw a cleaner once.

I went to see him in the afternoon... all the lunch time dishes were still there. I just think of them as being dirty. I hope I never have to go in to the Royal Hospital – it is disgusting when I have gone to visit people but then I can't say for every hospital.

I want it to be clean, I agree the superbug thing is overblown but when I go in to hospital I want it to feel clean.

Almost all people believed that the outsourcing of cleaning to private companies had led to lower standards that were **directly** to blame for the rise in hospital-acquired infections.

If you sub contract out your cleaning, service is bound to suffer

They need properly trained NHS cleaners.

These contract cleaners, she was mopping the floor and not even moving the mop, she didn't move anybody's bed.

Many participants were quite clear about not blaming the cleaners themselves but rather the 'system'.

Your Eastern European lady doesn't give a toss whether she leaves it clean or not but she comes in and does her five hours and gets her thirty quid then goes home.

What you want is somebody on a decent wage who was responsible for cleanliness and could be held accountable for bugs coming in to their area – not just a cleaner.

There were many calls to **bring back matron** and there was a very strong perception that nursing staff used to take a role in cleaning and that no longer do:

It was part of their duties wasn't it?

This had changed partly, they believed, due to nurses being 'rushed off their feet' and partly because they are 'not allowed to'. Health service staff had a different view. They did not see short staffing as a factor influencing cleanliness or any aspect of healthcare delivery.

People declared themselves very willing to accept more rigorous bio-security measures such as restricted visiting, compulsory gel hand-washing and even disinfectant mats and so on. How effective these sorts of measures might be is debatable but patients may feel 'safer' with these sorts of measures in place.

People's priorities appeared to be affected by media coverage, and some were quite aware of this influence:

You might get three cases of MRSA out of how many million of people being treated throughout NHS Hospitals... you don't get the full picture.

In terms of MRSA it has been built up by the media as well. Yes it is more of a perception

They don't seem to get good write ups these hospitals do they in the paper.

There were a number of personal experiences of MRSA and at least two participants had lost somebody to the condition:

It wasn't until after I got home and I went to my own GP that I found out that I had got MRSA from the hospital.

A woman we knew died from it.

NB It is worth noting that all of our sessions with members of the public took place before the heavy media coverage of MRSA in Lancashire and CD in Kent.

5.12 Access to the latest drugs and treatment

The public, and especially patients with long term conditions, consistently gave access to the latest and drugs a high priority.

If you have got something serious and you are not getting the drugs then it is absolutely the most important thing to you isn't it?

However, some healthcare professionals felt that it wasn't the highest priority for the NHS and that better outcomes might be achieved by improving other services.

One or two patients were quite independently minded:

I am not sure that the latest drugs and treatment are necessarily the best.

...and this feeling was backed up by healthcare professionals:

It is about being evidence based isn't it? tested and appropriate.

However there was a general belief that many NHS organisations won't condone the use of the latest treatments or drugs because they are more expensive than less effective drugs or treatments.

We paid for a lot of treatments that my husband had – otherwise he wouldn't have got it because they wouldn't pay the money for his treatment.

There was a concern amongst participants that the North West was away from the centre of NHS activity and thereby the poor relation when it comes to new treatments or services. It is worth noting that this was not reflected in the views of staff.

5.13 Being treated with respect and dignity

Patients and the public (including healthcare professionals who had had a recent patient experience) all highlighted how important being treated with respect was to their sense of well-being.

There were a large number of extremely powerful comments to this effect, ranging from the general...

It would really help the recovery if they were treated as human beings by the doctors.

Being treated nicely and respectfully has definitely got to be an aid to recovery.

It is not personalised any more you are just a number.

...to the specific....

My husband was taken into hospital again – he was slightly confused as the disease progressed and the consultant came round and said in front of him – “Does anyone know if he wants to be resuscitated?” He was right there in the bed

I actually approached a nurse for shouting at an old man... It was disgusting the way she spoke to that old gentleman it really was.

One story illustrated two extremes of approach in one experience:

A few months ago I thought I had lost this baby that I am carrying now and the service that I had I can't fault. We rang the hospital because of an incident that I had with the pregnancy - a complication. Come straight in now – I went in and I had a fantastic doctor that sat on the bed – I had a thorough examination – he went through all my previous pregnancies and he was absolutely excellent. But in the next breath because it was a change of shift another doctor came in at that time – we had gone from a service where this doctor came in shook our hands and spoke to my husband – you were there as a couple – thoroughly explained everything, went through the examination, consulted a superior. This doctor walked in and started asking me questions again about my history which is very difficult, very upsetting, very emotional that this doctor had already done and you could see that this doctor was not comfortable, she did not introduce herself, who she was, she could have been Jo Bloggs off the street.

Patients (especially younger ones) seem not prepared to tolerate what they see as poor people skills in healthcare professionals, although to an extent some front line staff were excused (see the section about perceptions of staff below)

If you are not going to treat them with respect you shouldn't really be a doctor or a nurse.

Patients on a ward – they will tell you – “Oh God is she on tonight – oh it is going to be a terrible night”. And they just know – they can't describe it but they know.

Some patients called for more training in customer care:

Just research some better customer care skills.

But others thought that certain skills can not be taught:

I think it is with the individual to be honest – you can't actually teach someone to be polite.

Some patients appeared to recognise that front line staff were under so much pressure that allowances could be made:

They are so pushed and stressed with the long shifts and long hours.

but a lot of doctors – I know they are busy, especially doctors on wards – they are busy, they are overworked, they work long hours and they want to get the job done with.

This understanding was not extended to consultants or ancillary staff:

Do you notice the doctors always talk down to you? You couldn't possibly be on the same level of intelligence... they talk down to you – like a vet would do with an animal. That is the way it is.

All she needed to do was say "I am really sorry we are running really late do you mind waiting?" When I went up to the old bag – I wanted to swear at her – she said to me "You are not the only one here with kids" and ignored me.

For almost everybody we spoke to, being treated with respect was a fundamental part of whether or not they felt they had had a quality health experience:

If someone, from my experience, is not being treated with respect, that means someone is not really doing their job or their heart is not in it.

5.14 What makes for a quality health experience?

One of the questions we asked was "What makes for a world class service? How will we know when we have one?" There were lots of answers that could have been anticipated in advance:

People getting better.

Fewer complaints.

Less MRSA.

However the legitimacy of the question was raised a number of times:

I hate that term, "world class" because what does it mean?

Do they want the Health Service to be the best health service in the world or do they want it to be good on its own? Because you could have best of a bad lot without necessarily being world class.

The discussion about what would constitute a world class service ranged far and wide, but a number of key themes emerged. Speed of access to healthcare professionals was seen as extremely important, especially when patients were anxious:

Well from the beginning, the fact that after seeing my GP I was seen within two weeks – so that was good because I didn't spend months waiting and wondering.

Secondly, patients were concerned that different parts of the service should feel properly 'joined up' and that their journey through the system should feel seamless, linear and progress logically:

When I got there I was expected to be there – I was seen on time at the clinic and I was seen by the person that I thought I was going to see which is always nice.

When this fails to happen it is very irritating for patients, as is the simple breakdown of communications:

There is just no consistency and sometimes you feel that there is no communication within the people – the members of staff – that there should be.

We heard of several examples of this:

I was phoned up to say “Yes be there at so and so time” – which had to be 10 am – I got there for 9.45 am – I was told I should have been there for 9 am – so I have missed x, y and z tests. So I showed them the documentation – organisation is the pits.

Anything that has gone on at the doctors before you have got to the hospital and vice versa doesn't get transmitted or isn't accessible when you are there unless somebody sends a letter which gets lost.

It is absolutely down to the individuals that you come across from the clinic and all that kind of thing that you think actually I matter here and they have got the right notes and the right person – those kind of things really.

Several patients commented how they had appreciated the punctuality and dependability of the private healthcare services. Others valued being treated intelligently and being given information in a way that they could understand:

Everything was explained to me about what would happen and there was an opportunity to ask questions and things like that.

I was treated like someone with a brain and as a person and how this problem was affecting me. And then told when I would come in to have the treatment to the investigation and what would happen and that was fine.

Patients wanted to trust their health professionals:

At the end of it I felt like they actually knew what they were doing.

There were myriad comments confirming the idea that what made the difference for people was health service staff 'going the extra mile':

The physiotherapist we had went that one step further – she is the reason why my child is progressing so well

But often the 'difference' was simply being treated with dignity and respect.

The most important thing was that the people I came into contact with showed compassion and I don't mean compassion in terms of pity, I wasn't dying – not ill –

but actually being treated as somebody who was going into hospital for an investigation that could have turned out quite different to the way it did.

5.15 The public perceptions of health service staff

Despite patient stories of poor service and customer care, and clear messages about low morale from healthcare professionals, the public perception was of dedicated and overstretched healthcare professionals:

I think the majority of nurses are like that – you will get a minority who are...just there for the money or whatever but most people are there to tend and give 100%.

Go and sit in ICU for a week and then they would see how hard they work.

They are extremely short staffed everywhere.

I think they work extremely hard and extremely long hours – they are on their feet all day long – it is not an easy job.

These views were not always based on personal experience, however:

Short staffed, very overworked, underpaid... you see it on the news don't you?

They are very under staffed with doctors and nurses. Everybody says that there are not enough doctors.

We detected an unwillingness to blame front line staff, especially nurses, for poor service, who were excused because they are perceived by some as overstretched:

They are pushed to the limits.

The older nurses cannot deliver the service – how they were trained to deliver it – and there is so much pressure put on them that they feel they are not giving the patient care.

The public perception is clearly that good, caring healthcare professionals are being driven away from the service:

They don't want to be part of it any more and they are coming away from it. So they are actually losing the good nurses.

Nobody has ever given that opportunity to be best at what they are best at.

Just about everybody who has friends or relatives working within the health service had an unrelentingly grim view of it:

My son-in-law is a young doctor and for every place there are so many people trying. To get them to be doctors they treat them so badly. They expect them to do such a lot for so little and they are twisting them for money all the way.

She actually says is that nurses are not like they were years ago – they don't tend and care the same and it is all down to the bottom line of administration and money and things like that... that is what she finds in the NHS.

He says he spends most of his day cutting through red tape and filling in forms. He said it is not nursing any more and he absolutely hates it. 15 years ago he said it was what he wanted to do and he meant it but now he spends most of the day sitting at a desk and filling in forms.

There were comments about unreasonable conditions:

You can't challenge your boss if there is a wrong doing in the NHS or else you get sacked.

You have to sign a receipt every time you want to go to the toilet – you have to sign every time you want to go for a fag. It is all governed by red tape, bureaucracy and they literally cannot think for themselves.

Although one or two participants pointed out that everybody moans about their job:

I think that is the same with any job! If you go into any company they are all short staffed – other people say "Oh yes it is a great firm to work for" and the people who are working there will say "Oh it is not it is rubbish".

Everybody is short staffed – it doesn't matter what job you are doing everybody is short staffed.

and perhaps healthcare staff should not be surprised that they were entering a stressful profession:

It makes good news though doesn't it – the NHS. OK so some of them are stressed – it is like going for a job in a cold store and people thinking it is cold!

Most people perceive that NHS staff members are **underpaid**:

The guy I know is a doctor and he gets paid appallingly. He is doing a 12 – 14 hour shift for peanuts.

Pay the doctors and nurses more.

They need to pay the nurses some money.

However, this was one of the areas where the views of professionals differed from those of the public. Whilst the professionals we spoke to were clearly discontented with a wide range of things, not least of all the latest pay rise, none of them complained about their salaries and every professional with whom we spoke denied that there is currently a shortage of staff. This could be due to the fact, however, that we were talking almost exclusively to senior managers within the NHS staff cohort – we may have received different messages had we interviewed more front line staff.

5.16 Fears

We asked participants “**what are your fears for the NHS?**” The responses gave us a number of very strong themes:

- almost all people were very concerned about **hospital acquired infections** and felt that falling standards of hygiene were directly to blame
- virtually everybody (regardless of how highly they valued it) was concerned that the service was in **danger of collapsing** under the weight of expectation from an ageing and ever more expectant population.
- patients were anxious that the principle of **universality** of the health services being eroded and that **rationing** will become inevitable. Speculation that this might be based on the grounds of health behaviour was viewed as objectionable.
- most patients were extremely concerned about the erosion of the principle of being free at the point of access – if the NHS collapses they are convinced that many people will not be able to afford basic healthcare and they see the situation around dentistry services as being ‘the thin end of the wedge’.

Beyond these four key themes there were some other, less common fears.

Firstly, several members of the public felt that immigration was putting an ‘unfair’ and unsustainable pressure on health services. especially in the North West:

Can I just say – on the influx of immigration – more people coming to this country to work and stuff – it seems like our GP’s and our NHS has been clogged up.

There is a lot in the papers at the moment about the Eastern Europeans coming across – they are spending millions on interpreters and you are kind of thinking well that is a fear that all this money is going to be going on this sort of thing.

There were some very specific fears around the status of foundation hospital trusts from both the public:

One thing I’d like to understand is all this about Foundation Hospitals

and from staff:

One of the things that concerns me is that the Foundation Trust where I work is financially hitting the buffers ...nobody steps in to bail you out – you sink or swim. Now I don’t think the general public understand that and actually what happens if it does hit the buffers, are they going to close down a big hospital?

The future of local hospitals was a concern for the public:

Several hospitals have been closed around here people have to travel much further now.

There were also some more esoteric but heartfelt concerns shown by staff:

What are we training up all these clinicians for when there clearly aren't enough jobs for them?

My great concern is actually – what is the role of DGH? Because once you have taken out obstetrics, paediatric, A & E and so on. We are being used as a whipping boy... good for a spot of granny farming.

5.17 Desire for uniformity of services

A **key message** coming from patients in the North West for NHS managers was that the public desire uniformity in their health services:

Make the standard all over the country instead of pockets of good and pockets of bad. It should be standard – the whole country should be the same.

Inconsistencies between one practice and another needs to be sorted out.

Some departments you have got faith in, others you don't.

You found that because there wasn't a continuity with the treatment - you were told a different thing every time you went.

I have a choice of two hospitals where I live. One of them I wouldn't touch with a barge pole but the other one is fantastic.

I have got a very good GP – I am very lucky – so I can't fault the GP but the hospital – yes I can. They are just going down and down.

You get some fantastic nurses and doctors – no two ways about it – they are fantastic – and then you get some that shouldn't even be in the NHS.

On a personal level patients (especially older patients or people with long term conditions) value continuity of care from individual clinicians:

I saw the same dentist every time I went and he knew my family history. Same with the doctor actually, the village doctor – continuity – you would go in, they knew your history, they knew everything about your family without even looking at your card and now I haven't seen the same dentist twice for maybe the past 3 years. It is the same with the doctor.

The issue of **post code prescribing** was a topic that caused some irritation:

One of the main problems that needs to be sorted out and you read about it all the time is this post code lottery. The way that Primary Care Trusts across the country – they all operate differently. So somebody having a bad experience for some particular condition, operation or whatever, in one Primary Care Trust – may have a terrific outcome and nothing but praise - but in another one where they are spending more money on that.

I don't know how they split the resources depending on the kind of conditions or the number or ration of people they get coming into hospitals with various different conditions, whether it is spread that way I don't know. Maybe it is – but they do seem to operate differently. Some must be spending marginally more on something that may not affect you – where there is somebody across the border in another one is getting top notch service – very happy being treated totally differently and much better for the condition that you are being badly treated. So how are they going to level this playing field?

If you move across into Ellesmere your prescriptions don't cost you anything!

A prescription in Scotland doesn't cost you anything...

Consistently patients commented that they wanted the differences to be ironed out and to feel that they are having their 'fair share' of NHS resources.

6 Priorities for the NHS – the card sort exercise

6.1 Overview

Participants were given a card sort exercise which involved considering fourteen issues that were under consideration as priorities for the NHS Next Stage review and rank them as low, medium or high priorities.

Each of the 12 groups was then encouraged to nominate their top three priorities for concentration by decision makers in the NHS.

The priorities (see list below) were deliberately devised to be open to some interpretation in order to foster debate within the group. Participants were asked to come up with reasons for their choices. These discussions and the choices were recorded.

Priorities for discussion (in alphabetical order)

Access to out of hours services

Being treated with dignity and respect (including mixed sex wards)

Bureaucracy

Cleanliness and/or "superbugs" eg MRSA

Funding and resources

Getting GP appointments quickly

Getting the latest treatments and drugs

Having enough information (about NHS services and about their care)

Hospital facilities (car parking/TV and telephone charges/food)

Joined-up services

Numbers of NHS staff

Reducing waste and inefficiency

The role of the private sector

Waiting times for hospital treatment

6.2 Commentary upon the process

One group chose to break up into a couple of smaller groups but the other 11 chose to work as one. The exercise involved thrashing out compromises which resulted in several

participants who felt very passionately about individual issues feeling disenfranchised when out-voted.

In one instance an assertive individual refused to allow the group to create a rank order, believing 'they were all important' which undermined the process somewhat. However there was agreement about which of the priorities was important for delivering a quality health service so we have used those rankings as a proxy.

In order to amalgamate the results into some kind of an overall message we 'scored' the priorities in the following way.

Top three priority	score of three
High priority but not top three	score of two
Medium priority	score of one
Low priority	score of zero

While this was not intended to be a 'scientific' process and groups interpreted the instructions in different ways, there were nonetheless some clear top priorities (see table below).

NB It is worth noting that the groups with patients and the public all took place before the outbreaks of CD in Kent and MRSA in Lancashire hit the headlines in the autumn of 2007.

6.3 Results

Priorities for discussion in rank order of preference (Patients and the public)	
Cleanliness and/or "superbugs" eg MRSA	26
Getting the latest treatments and drugs	22
Funding and resources	22
Being treated with dignity and respect (including mixed sex wards)	20
Numbers of NHS staff	19
Waiting times for hospital treatment	18
Getting GP appointments quickly	14
Reducing waste and inefficiency	13
Access to out of hours services	11
Joined-up services	7
Bureaucracy	7

Having enough information (about NHS services and about their care)	4
Hospital facilities (car parking/TV and telephone charges/food)	3
The role of the private sector	2

Priorities for discussion (in rank order of preference) (NHS and partner organisations)	
Being treated with dignity and respect (including mixed sex wards)	6
Funding and resources	5
Getting GP appointments quickly	5
Joined-up services	5
Cleanliness and/or "superbugs" eg MRSA	4
Reducing waste and inefficiency	3
Hospital facilities (car parking/TV and telephone charges/food)	3
Getting the latest treatments and drugs	2
Waiting times for hospital treatment	2
Access to out of hours services	2
Having enough information (about NHS services and about their care)	2
The role of the private sector	1
Numbers of NHS staff	0
Bureaucracy	0

Appendix 1: Topic guide

Topic Guide for patient and carer focus groups

Equipment

- Pens
- Sticky labels
- Digital recorder
- Spare batteries for same
- Microphone
- Boxes/Elastic bands for card sort exercise
- Vouchers
- Consent forms
- Travel claim forms
- Refreshments (if appropriate)

Setting Up

Arrange chairs in a circle, with enough for all the participants, including the researcher(s). Ensure the recording equipment is accessible. Make sure no interruptions will occur and the neighbouring offices are quiet/doors shut etc. Have refreshments available. *(Be aware that it is Ramadan until October 13th)*. Ask all participants to write the name they want to be known by on a sticky label and attach it to their person. Ask all participants to complete the consent forms. Ensure sort cards are arranged in piles for each participant. Ensure pens and sticky labels are in the centre of the room and accessible. Explain location of fire escapes and toilets.

Introduction (10 mins)

Welcome everyone to the group. Explain that the aim of the discussion group is to find out about individuals' impressions of the NHS. Explain that the Department of Health is keen to learn as part of national programme of development.

Explain that we are carrying out similar group discussions elsewhere in the North West.

Explain that participants can have a summary version of the report if they would like (we need their contact details)

Emphasise that each participant should feel free to talk about his or her personal experiences, but only to the extent that he or she feels comfortable. Introduce your colleague (if present) and explain that s/he is independent of the NHS and is present only as an observer.

Say that the discussion group will:

- Last no more than 2 hours

- Involve a discussion around several topics led by the researcher
- Be recorded to ease later analysis: but note anonymity
- Will involve a card sort exercise

Explain about the recording: reiterate that nobody will be identified and all comments will be anonymous. Ask people to respect any confidences that are shared. Ask group to try not to speak “over” each other. **Ask group’s permission to switch on recorder.** Remember to check the recorder regularly to ensure it is recording properly.

Run the “our NHS our future” DVD [here](#).

Warm Up Exercise (10 mins)

To break the ice, facilitator to introduce herself/himself, welcome all to the discussion group, and ask each individual to introduce themselves, where they have come from and why they were interested in taking part in this.

Themed Discussion

Not all topics will be covered in any one discussion group: topics to be selected from the following list in light of priorities for NSF development and relevance to patients and carers involved in the discussion group. Facilitators will use additional prompts where necessary to clarify responses.

We need to get to what people’s values and beliefs are about the NHS. As well as understanding their attitude about the levels of clinical expertise they experienced. It is also about getting to the softer issues eg what makes them feel safe etc

The specifics the client is after are around improving quality and safety; extending access; reducing inequalities and continuous service improvement.

Prompting questions for first half discussion (40 mins)

- What does the NHS mean to you?
- Do you value the NHS? –
If yes why? If not why not?
- How do you rate improvements in the last 10 years?
What do you think currently works well? Why?
What do you think currently works less well? Why?
- When was the last time you accessed the NHS – hospital, GP, Pharmacy, Dentist – how did you rate that experience?
- What is the most important issue for you when you access health services?

- Do you know anyone who works within the NHS – what do they say about it?
- What are your main concerns for healthcare in the future?

Leads to...

Card Sort Exercise (~20 mins)

(To take place around half-way through the discussion.)

Explain that the purpose of the exercise is for participants to pick the three most important aspects for NHS development from their own experience, and to discuss the reasons for their choices.

Try to do exercise as a group (it can get difficult to control and otherwise)

Each theme is on a laminated card arranged in alphabetical order.

Ask focus group participants to sort the cards into 3 piles:

- Most Important
- Quite Important
- Least Important

Ask participants to talk about their most and least important items.

Note reasons for decisions and areas of dissonance.

Distinguish patients' and carers' choices and rationales if appropriate

Prompting questions for second half discussions (30 mins)

- What are the most important factors in delivering a high quality service?
- What would help demonstrate that the service is safe, effective and high quality?
- What actions would you like to see to tackle the spread of infections in hospitals?
- What are the current barriers to accessing health services?
- What makes 'world class' services? What are the criteria?
- Any final messages you'd want to send to the people responsible for the NHS?

...and finally

- Thank all participants very much for taking part in the discussion group. Reassure them that everything they have shared will be treated as confidential. Emphasise

how valuable their contribution is as a means of informing NHS policy. Ask them how they feel about having shared their experiences.

- Reiterate that they can have a summary report if they would like
- Ask them if they have any further questions.
- End the group. Switch off the recorder.
- Hand out payments to each participant. Arrange payment of any travel expenses.

Appendix 2: Focus group participants

1. People with recent experience of mental health problems	Manchester	2f 5m
2. People with recent experience of hospital care	Manchester	5f 4m
3. Parents of young children	Lancashire	4f 3m
4. People from BME communities with recent hospital experience	Lancashire	4f 1m
5. People with long term conditions aged under 45 years	Merseyside	3f 4m
6. People from BME communities with good health behaviour	Merseyside	4f 4m
7. People with long term conditions aged over 45	Cheshire	3f 5m
8. People 20- 45 with good health behaviour	Cheshire	4f 4m
9. People 45+ with good health behaviour	Cumbria	4f 4m
10. Carers	Cumbria	5f 2m

We spoke to a total of 74 patients

37 women

37 men

16 from a black or minority ethnic background

58 from a white background

Focus groups with clinicians, healthcare professionals and associated organisations

11.	Newton le Willows	4f 1m
12.	Newton le Willows	4f 1m

We spoke to a total of 10 professionals 8 women and 2 men all were white.

Appendix 3: Recruitment screener

Group 1 Mental Health service Users

Range of recent (within the last 2 years) illness/use of mental health services eg depression/bi-polar disorder etc with some mix of gender, ethnicity, age, severity of condition, mix of socio - economic group preferred but not essential

Group 2 People with recent experience of hospital care

Mix of gender, age, socio - economic group, who have stayed in hospital overnight within the last 2 years or as a day case patient or have had regular outpatient appointments within the last year

Group 3 Parents of young children (inc maternity/newborn)

Fathers and mothers with children under 9yrs and including min 1 pregnant woman and min 1 parent with baby under 3 months Mixture of socio - economic group/ethnicity preferred but not essential

Group 4 People from minority ethnic background with recent experience of hospital care

Individuals from minority ethnic background with a mix of gender, age, socio - economic group, who have stayed in hospital overnight within the last 2 years or as a day case patient or have had regular outpatient appointments within the last year

Group 5 People with long term conditions aged over 50 (older age group)

Mix of gender, socio - economic group, with long term/chronic conditions eg asthma/diabetes/chronic pain/cardiovascular conditions which affect their quality of life mix of ethnicity preferred but not essential

Group 6 General Population - aged 20-45yrs younger people staying healthy

Mix of gender, socio - economic group respondents who agree with the statements "I consider myself to be in reasonably good health" or " I take care of my health"

Group 7 People with long term conditions aged under 45yrs

Mix of gender, socio - economic group, with long term/chronic conditions eg asthma/diabetes/chronic pain/cardiovascular conditions which affect their quality of life mix of ethnicity preferred but not essential

Group 8 General Population - minority groups staying healthy

People from minority ethnic backgrounds with a mix of ages, gender, socio - economic group who agree with the statements "I consider myself to be in reasonably good health" or "I take care of my health"

Group 9 General Population aged over 45yrs staying healthy.

Mix of gender, socio - economic group respondents who agree with the statements "I consider myself to be in reasonably good health" or " I take care of my health"

Group 10 Carers including those with experience of looking after terminally ill relatives

Mix of male and females who are, or have been within the last three years, providing significant care for relatives or close friends beyond that which might normally be expected, some to have had experience of looking after terminally ill relatives/close friends

Identification of the healthcare professionals and associated stakeholders participating was undertaken by NHS North West.

Appendix 4: Terms of reference for NHS Next Stage Review

AS ANNOUNCED BY THE SECRETARY OF STATE FOR HEALTH ALAN JOHNSON MP ON 4TH JULY 2008

1. The NHS Next Stage Review will build on the progress made in delivering the vision set out in the NHS plan and the Government's reform agenda, to identify the way forward for a 21st Century NHS which is clinically-driven, patient-centred and responsive to local communities.
2. The review should engage with patients, NHS staff and the public on four critical challenges:
 - Working with NHS staff to ensure that clinical decision-making is at the heart of the future of the NHS and the pattern of service delivery
 - Improving patient care, including high-quality, joined-up services for those suffering long-term or life-threatening conditions, and ensuring patients are treated with dignity in safe, clean environments
 - Delivering more accessible and more convenient care integrated across primary and secondary providers, reflecting best value for money and offering services in the most appropriate settings for patients
 - In time for the 60th anniversary of the NHS, establishing a vision for the next decade of the health service which is based less on central direction and more on patient control, choice and local accountability and which ensures services are responsive to patients and local communities
3. The review should consider the case for a constitution of the NHS as the basis of a sustainable and lasting settlement that meets these challenges, enhances local accountability, secures value for money and protects the fundamental values that the NHS has always embodied.
4. The review should help support local patients, staff and the public in making the changes they need and want in their local NHS and make recommendations to the Prime Minister, Secretary of State for Health and Chancellor on how the NHS can best meet these challenges whilst delivering a publicly funded, comprehensive, affordable, high-quality service on the basis of need and not ability to pay. It will report by June 2008 with an interim report in October 2007.

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