

# Development and Pilot testing of the NHS Acute & Specialist Trust Young Patient Survey 2004

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## **1 Executive Summary**

This report outlines the research carried out by the Picker Institute Europe to develop and pilot test a survey for young patients and their parents<sup>1</sup>, for use in the NHS patient survey programme.

### **1.1 Aims**

The aims of this work were:

To identify the issues that are important to young patients and their parents during their stay in hospital.

To devise questions that address patients' and parents' concerns and that can provide actionable feedback to trusts carrying out the survey, so that improvements in the quality of patient care can be achieved.

To refine the existing Picker Paediatric Survey (2000) for use as the survey instrument in the national survey programme.

To check whether any important items were missing from the original Picker questionnaire and to develop new questions covering any topics which were not adequately covered.

To identify patients' top priorities among the topics covered in the survey.

To pilot test the sampling methodology and check whether the trusts were able to draw a sample of patient discharges and attendances which met the criteria for inclusion in the survey.

To use the experience of the pilot study to refine the survey guidance to be issued to all acute trusts and survey contractors.

To report the pilot survey findings back to the trust.

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<sup>1</sup> We have used the term parents as shorthand to include mothers, fathers, carers and other adults with responsibility for caring for a child or young person.

## **1.2 Methods**

The key stages were:

Focus group discussions with patients.

Discussions with project sponsors, Commission for Health Improvement (CHI), on the scope of topics to be covered and the information which might be required for the calculation of performance ratings.

Development of new questions based on issues raised by patients during the focus group sessions.

- Cognitive interviews (face-to-face) to check patients' understanding of the questions.
- An 'Importance Study' to ask young patients or their parents about their recent experience by completing a short survey to rate topics in terms of their importance.
- Refinement of questions based on all of the above to develop the pilot questionnaire.
- Consultation with CHI and NHS trusts to develop the sampling procedures.
- Mailing of a pilot survey to 800 young patients from two NHS trusts (400 patients from each trust) with two follow-up reminders to non-responders.

## **1.3 Results**

The focus groups highlighted key issues that were important to the young patients in NHS hospitals. The draft questionnaire was developed to address these issues and face validity was tested. The young patient questionnaire was sent to 800 young patients, or their parents, who had been an inpatient or day case at two NHS trust hospitals and an importance survey questionnaire was sent to 100 young patients or their parents.

## **2 Focus Groups**

### **2.1 Introduction**

The qualitative stage of the development process was conducted in two stages – the initial stage took place in April 1999 in Edinburgh. Five focus groups were conducted with parents and children. There was one group with parents of under-9-year-olds and the remaining four groups were with children. These comprised one group for each gender in each age group (9-11 years and 12-13 years).

Using the results of these focus groups, the initial Picker Paediatric Survey (2000) was developed for parents to complete which incorporated issues raised by both parents and children at these focus groups. This questionnaire was designed to be completed by parents of children aged 0-15yrs who had stayed overnight in hospital. The detailed results of these focus groups are outlined in Appendix 1.

The second part of the qualitative work took place in August 2003. Further focus groups were carried out with the aim of refining and improving the pre-existing questionnaire so that it was suitable for 12-17 year-olds to complete themselves as well as parents of children of all ages, and to ensure that issues of importance to older children were incorporated in the questionnaire.

### **2.2 Methods**

Following a literature search and re-evaluation of the existing Picker Paediatric Questionnaire, a topic guide to be used for the focus groups was compiled (Appendix 2). Patients were asked to discuss their recent experience in hospital and the discussion was structured around the following topics:

- Perceptions of hospital
- Going into hospital
- Staying in hospital (ward, routine etc.)
- Doctors / Nurses / Other staff
- Tests & Treatment
- Pain
- Leaving Hospital

Participants also took part in word association games and a card sort exercise, to help them prioritise areas of importance to young patients.

The discussions were moderated by an experienced female researcher, and were recorded on audiocassette. The tapes were transcribed and analysed, with the research team taking care to ensure that any information that could identify individuals was omitted from the report.

## **2.3 Participants**

Focus groups were held in Slough and Maidenhead with 12-19 year-olds (at this stage, the upper limit of the survey had not been finalised). A number of methods of recruitment were attempted including posters in schools, but the timing of the research coincided with the end of the summer term, so response to these was limited. In the end, a recruitment agency was used to recruit the patients.

In this second stage of the research, four focus groups (2-4 participants in each) and one face-to-face interview were conducted. All participants were aged 12-19 years and had stayed at least one night in hospital. In total, 14 young people were involved in this phase, of which nine were aged 12-15 years and five were aged 16-19 years. Four females and ten males participated, taking part in either single or mixed sex groups.

Most participants had stayed on a children's ward, with the exception of four, all of whom were aged 16 or over and had been placed on an adult ward. There was a mixture of elective (planned) and emergency admissions, and the length of stay in hospital varied between one night and two months. Some of the participants were regular visitors to hospital for more long-term conditions, whereas others were visiting hospital for the first time.

## **2.4 Results**

### **Going into Hospital**

#### **Emergency Admissions**

Of those who went to hospital as Emergency admissions, a few had travelled by ambulance, but their recollection of the experience was limited, as they were often unconscious or too ill to remember any details.

*I don't know, I was in too much pain*

*I'm not sure, I think I lost consciousness because I wasn't aware of what was happening*

Others had been driven to the Emergency department by a parent or teacher. In general it was felt that response to the initial call for an ambulance was good and the ambulance staff's treatment and attitude were both praised.

*When I was in the ambulance I had a woman in there and she was trying to make me laugh, and I would probably have laughed usually but not at that point. She was asking me what football team I supported but I wasn't really bothered at that point but at least she was trying to keep my mind off breaking my leg and that.*

Once they had arrived in the Emergency department, they generally felt that they were seen quickly, although one patient was kept waiting on a trolley for 8 hours in casualty for a bed to become available on a children's ward.

*I was waiting in there for 8 hours to be put somewhere but they didn't have any room in the children's ward and they were going to put me in an adult ward, but they didn't because there were loads of old men and that....*

Some patients had been seen in a special children's A&E and they felt that they had been dealt with quickly and efficiently.

### **Planned admissions**

Most of those who underwent planned operations had felt nervous and apprehensive while waiting to go into hospital.

*I was nervous and a bit worried because I was having an operation*

*..because I didn't know what they were going to do to me because I would be asleep*

One of the younger patients had visited the hospital prior to the operation, to meet the staff and talk to the doctors about the operation, which had been very reassuring and useful to them.

*..she just explained what would happen when I arrived and what was going to happen while I stayed at the hospital which was useful.*

Some felt that they would have liked to have been given the opportunity to visit, but it was not offered to them. However, not all patients felt that this was something they would have liked.

*You see them long enough while you're there, you don't want to see them before as well.*

One patient was given an information pack prior to the operation, although this was thought to be more aimed at the parents rather than the child, and they found this frustrating.

*I think it was meant for my mum...it was me who was going in for the operation, not my mum*



## Staying in hospital

During this part of the discussion, the ward environment was discussed in detail. This included:

- Décor
- Noise
- Ward routine (including visiting hours)
- Entertainment facilities
- Facilities for parents
- Food

It became clear that those who had stayed on a children's ward had a very different experience to some of the older patients, who had stayed on an adult ward, so these experiences have been separated.

### Children's Ward

#### *Separation of age groups*

One of the main issues that arose about the children's ward was that the teenagers were not separated from the babies and younger children. The teenagers felt very strongly that this should happen, particularly as most were kept awake at night by noise from the younger children.

*At [Hospital A] there used to be a teenager side and they had a younger side and they have put them both together now and when you have been in there for a day and want to sleep and there are little kids sitting next to you shouting...*

*There were toddlers shouting all through the night because they were in pain...there was no door or anything like that just an open wall...*

*I had this boy opposite me and he was screaming.*

*The babies would sleep all day and be awake all night.*

*It was also felt that the two age groups had very different needs and that they wanted to be with people of their own age, for companionship.*

However, some participants, particularly the younger ones, felt that it was also important to remember that their needs were different to adults' needs as well.

*..being treated like an adult to a certain extent, but you are still a kid so you don't just want to be watching telly but you want games as well*

*You don't understand some of the things that the adults do.*

Most agreed that the ideal solution would be to have an adolescent ward for those aged 12 or 13yrs upwards in addition to the children's ward for the younger children.

### **Décor**

In general the wards were felt to be generally clean and brightly coloured with pictures of football teams or pop stars up on the walls.

*...but they stick things up like posters... to keep my mind off my leg.*

*They had pictures up on the wall – like football or pop music – assuming that everyone likes this as not everyone likes football or pop music.*

Some also felt that some of the décor was too 'babyish' for their age group.

*The room you go in is really babyish as it had Piglet and Tigger up on the walls*

*..it was full of Disney characters as there were younger children...I'm older so it's a bit babyish really.*

Some felt that they were being treated like 'babies' due to the use of safety features such as bed guards and window locks.

*The other annoying thing is that on the beds they pull those things [the bed guards] up and when you have got no one there they are hard to get down.*

The wards are really hot but the windows only open about that much so you can't get out...

### **Ward routine**

The ward routine was thought to be fairly strict – some thought that visiting hours should be available 24 hrs and that mealtimes should be more flexible. Breakfast was thought to be too early and some mentioned that they were woken up quite 'roughly'. For those who were less mobile, it was sometimes difficult for them to get to the lunch trolley to choose their food.

*It was horrible – we had to wake up about 6 am in the morning.*

*They would wake me up at 7 o'clock for my breakfast, and I reckon that's out of order really. When you can't go to sleep as it is and then get woken up when you do get to sleep.*

*..the way they wake you up – they're too rough...she was opening my eyes for me.*

*For lunch and dinner you had to get up and it was really painful for me to get up so my Mum went and got it and she didn't even know what I wanted as you don't even know what is up there or whatever it's going to taste like.*

*I would have liked to have eaten when I wanted because when they came I wasn't really hungry so I only had a little bit.*

A few children mentioned that the wards were cleaned at inconvenient times.

*I think, though on your wards they should have cleaning time, because I was getting knocked about by some woman cleaning with this big buffer thing and she knocked my drip over and I had a drip in my arm and my drip came out.*

*I didn't like the cleaner. Because she had this big floor polisher and she came right up to my bed and it was quite noisy and it was quite annoying because she was working around me.*

### **Entertainment Facilities**

All commented that the main entertainment on their ward was television. Some mentioned that they had their own television, with telephone and internet access (limited), but others had to share a television with others or had to use a communal television room.

*I think you should have TV's for each bed because if you want to watch something, you can't really watch it because you have people asking you to turn it down, don't really want to listen to that, don't want to watch this or that.*

Some commented that they would have liked to have had access to a video player as well.

Most also had access to board games, and Playstations and Nintendos were extremely popular, although there were not always enough of these available.

*I thought that the Nintendo that they had was really good, because that was new to it and I put my name up for it but I never got it. As soon as I went in there my Mum put my name down and then as soon as I left they said you can use the Nintendo now and I was on my way out so I didn't get to use it.*

*I still got bored because lots of the time the games were taken up.*

It was generally felt that the toys should be separated, with the baby toys kept separately in a different room. A games room, especially designed for this age group, with a pool table, table football, stereo, etc was a popular idea with all participants.

One patient mentioned that the ward had a playroom, but that it was locked and he was never given access to it.

*When I went in they had everything like toys and a pool table and mini football but it was shut throughout all my stay.*

### **Facilities for parents**

Most of the patients had one parent stay overnight in hospital with them, which was reassuring for the children, particularly the younger ones.

*I think if my Mum hadn't been there I would have been scared.*

*Yes parents are allowed to stay – friends aren't. I'd rather have my mates than my Mum.*

Although parents were generally made welcome, some felt that the facilities for parents needed to be improved, particularly for those who were admitted as emergencies. There was not much space, food was not provided for them and they sometimes had to sleep in an armchair due to the lack of spare beds and sheets.

*It was complicated because I was in a small room and there wasn't much space for her.*

*We had a picnic blanket but the chair, you know you get those cotton chairs that are really itchy, she had to sleep on that.*

For visitors the food wasn't free so my Mum didn't get anything to eat because she didn't have any money and she couldn't leave me and get someone to come here because it was past visiting hour.

One child's parent had access to a 'parents room', which was thought to be a good idea.

*They have got a parents room and they have got a bath and shower in there... and they have got a sitting room for adults as well and parents if they wanted to go and sit down.*

### **Food**

Most of the younger ones agreed that the food was not good – the problem seemed to be not so much the type of food they were offered (some had eaten pizzas and roast dinners) but the quality of the food (overcooked vegetables, not fresh etc.)

*I'm all right with vegetables just not ones that are all soggy and mushy like it's come out of a tin or something like that.*

*I had chips, can't remember anything else – I couldn't actually taste much of the food as it didn't have much taste.*

*It always tasted nasty.*

The system for choosing your meals was also criticized.

*It was weird how they did your food – because they give you a menu and you tick what you want but you wouldn't actually get that until tomorrow so I'd tick what I wanted for the day and then they said "you are going today" so the geezer that was there tomorrow had what I wanted today!!!*

## **Other issues**

### ***Privacy***

This was not a big issue among the participants - most felt comfortable when being examined, although this may have varied according to the sensitivity of their medical condition. Parents were usually present for examinations and curtains were almost always drawn round the beds as a matter of course.

*It's just a routine to close the curtains.*

*...obviously if it was a more sensitive area then I would have liked a bit more privacy but I didn't really care to be honest*

*I think if it was a personal matter then they would be a bit more private but with a broken arm ....*

One child mentioned that they would have liked a little more privacy when talking to the doctor in the playroom.

*Before I had the operation, just to get everything sorted, there was a man that came in and he just got a chair out and talked to us but we didn't think that was very good because everyone was listening and it is none of their business really and we thought it would have been better if he had taken us into another room and discussed it there.*

### ***Security***

Security on the children's ward was mentioned by a few patients. They did not feel that they, or their possessions, were totally safe on the ward and that anybody could walk onto the ward at any time.

*They should have better security...when I was in hospital in Wales a man got in the hospital and was roaming round and they had to get the Police in to get him out.*

*I think they should have a security thing like airports...anyone could walk in with a knife or a gun under a coat. There is hardly any security because by the time the Police get there, there could be people dead.*

One patient also mentioned that there were other parts of the hospital where they did not feel safe.

*I have to have casts built for my shoes and that is in the mental ward, underneath it, they should have it in a better place...I didn't feel very safe having to go through there...all that separates you is a different set of doors.*

### **Adult Wards**

Those who had stayed on an adult ward, of whom there were four participants, generally seemed to have a more negative view of hospital. The word association exercise brought up words such as *death, dying people, old people, illness*, although they all felt that they would not have wanted to be on a children's ward.

It had been quite a daunting experience for some – they had been exposed to the 'reality' of hospital life, some having to share a ward with pensioners, or very sick patients.

*I didn't want to go in that ward because there was loads of old people – they honestly looked like they were dying.*

*Pretty much dead or dying, pensioners, there was one crazy man who kept talking to himself, he was probably 90 + and there was some other blokes who were probably about 60..it was pretty discouraging seeing as we were placed in the same category as dying people.*

*Next to the toilet there was a special toilet and this man had no legs and he was really old and he just left the door open and I had to see this man lying there with no legs.*

### **Noise**

Patients also found it hard to sleep on the adult wards, due to the noise from other patients.

*There was a crazy man who kept talking to himself in the middle of the night and I couldn't get to sleep.*

*I had a weird man and he kept screaming all the time.*

There were no overnight facilities for parents on adult wards, which some would have liked.

*Well Mum stayed with me the whole time but a man brought a chair – like an arm chair – didn't have a bed or anything just arm chairs – I don't think they could really fit a bed there.*

There was also a lack of entertainment on adult wards in comparison to the childrens' wards. Some did not have televisions, or the patients had to pay to hire them.

*I asked for a TV and he said that wouldn't arrive until Monday*

### **Boredom**

This seemed to be prevalent throughout their stay and all felt that more could have been done to alleviate it.

*It was just so boring, the most boring time I've ever had in my life. Time goes so slow – I went to sleep and woke up and I'd been asleep for only half an hour. I was just so glad when they said I could go home now.*

*If they are not going to do anything to entertain you, surely they should have longer visiting hours.*

*Not much to do except eat and watch people die.*

### **Food**

The **food** on the adult wards seemed to be slightly more acceptable than that on the childrens' wards.

*It wasn't bad actually – better than aeroplane food.*

### **Staff**

#### **Doctors**

When asked to describe their **ideal** doctor, the patients, particularly the younger ones, had quite strong views on what a doctor should be like, mainly based on their own experiences.

Most agreed that doctors should **explain things** clearly and use **simpler language**

*Some of them just stand there and just speak in their medical terms and you can't understand and they use the same tone all the time they don't even try to brighten you up or anything. They speak too fast as well.*

They should be **friendly**, with a sense of humour, and **not 'grumpy'**.

*...have a sense of humour and be able to make people laugh and that.*

*A few of them, mostly the young ones, I think are a bit moody.*

*..you want to be happy, you don't want to have to look up at a tall, grumpy man.*

Doctors should also have a food fashion sense:

*Some of them come in really goofy ....ties up to their chins...*

*They should also be **hygienic** and **careful** – some had found the doctors to be a bit 'rough'.*

*In the plaster room they are not too careful with you – they are lifting your leg up and bending it and I was saying aah..... and they were saying "does that hurt" – they are not too careful.*

Patients also need to be able to **trust** them:

*I would like to be able to trust them and put my faith in them.*

They also felt that there should also be more of them and doctors should **inform patients** if they are not going to be able to keep to an appointment.

*If a doctor is not going in that day they should ring the people that he has got an appointment with and tell them, because I had to go for an appointment and get up early and the doctor wasn't even in.*

*There was only one doctor and it was packed and that doctor had to run around and do the whole stuff and I think they should have spare doctors so if a doctor is ill there are spare doctors to cover it, so one doctor is not doing all the work.*

Above all, it was felt that doctors need to have **knowledge** about their condition and they 'need to know what they are doing'.

*Doesn't really bother me as long as they know what they are doing.*



When discussing their condition with doctors, most felt that the doctors spoke mainly to their parents. Whilst most of the younger ones seemed happy about this ('because I didn't really understand what he was talking about'), and some were too ill to take part in discussions, some of the older participants felt that they would have liked to have been **more included in discussions** with doctors themselves. They felt that it was their body and therefore things should have been explained to them.

*They were talking to my Mum, they didn't actually tell me what they were going to do apart from when they were going to inject stuff.*

*It's not my Mum who was going to have the operation though is it? It's me – Mum doesn't need to know really does she? All she needs to know is that I'm having my tonsils taken out and that they are going to do it properly.*

*Every time I saw my doctor he said things like "it's healing nicely" to my Dad and not to me.*

Some also felt that the doctors did not spend enough time with them and they did not have always have enough time to ask them the questions that they wanted to.

*Yes I did have questions and they did answer them but a bit rushed sometimes.*

*Yes rushed and they paid more attention to my parents.*

*Sometimes I would have liked to have had an in depth talk to him but that might just have been because I was lonely – I'm not sure.*

Even the parents struggled at times to understand what was being said to them, because the doctor would use lots of **medical terms**. Some had also been given conflicting advice.

*I didn't understand a thing they were saying. My Mum didn't even understand it. They speak to you like you know what they are on about, like all the medicines and that.*

*They should put it in layman's terms.*

*First of all I had one doctor telling me one thing and then basically I had two different doctors telling me different things so I didn't know what was going on. One doctor said I can just put this together and hopefully it will heal and the next one said I needed plates in it and another person said I needed rods in it so I didn't know what was going on.*

In addition, some had experienced difficulties understanding some of the doctors' accents.

*The first doctor was English so I could understand him but the second two I honestly didn't understand a word they were saying...because of their accent – where they were from – I just couldn't understand them.*

Most seemed satisfied that their doctors were quite knowledgeable about their condition, although it was felt that they maybe did not appreciate how much pain they were in.

*They know all about it but they don't know the pain you are going through.*

*They think it hurts but it really does hurt.*

### **Nurses**

Patients were asked to describe their ideal nurse. Again, they had quite strong views about what a nurse should be like.

Most of the male participants agreed that nurses should be **young** and **attractive**.

*My Dad thinks the nurses should be a bit more good looking...I think the same.*

*I think you need a fit nurse looking after you.*

*Sometimes if you've got an old nurse she can be quite stroppy with you.*

They also felt that they should be **well presented** – they did not necessarily need to follow a strict uniform, but they should not be scruffy.

*I think some of them, they come in, I know they can't help it, but they come in, in a right state and their hair is all messed up.*

Nurses should also be '**nice**', **friendly** and '**bubbly**'. They should also be approachable and reassuring and it should be down to them to comfort patients if they felt scared or worried.

*They should just try and make you relax.*

*The nurses are easier to approach than doctors as well.*

*The nurses were nice but with the men it was just like "oh be a man".*

However, some of the older boys felt that they did not always want to be 'mothered'.

*I felt that some of them were kind of mothering me a bit too much.*

*A couple of them seemed a bit patronizing as well.*

Nurses were also seen as '*mates*' and someone who you can **have a chat with** to 'pass the time'.

*I like to be able to talk to the nurses – like friendly and happy everything – they are like mates and not nurses because they are there every day and you don't see anyone else.*

*... someone to chat to as you haven't got anything else to do.*

It was also felt that sometimes the nurses did not know enough about the patient's condition, and they often struggled to answer questions. In particular, participants felt that the nurses should be given more responsibility for medication and pain control.

*The nurses didn't seem very professional – it was like a ... don't know really – there were loads of people that didn't know what the hell they were doing.*

*I don't think they knew what was going on really....they knew I had a broken arm but I don't think they knew how bad it was or anything.*

*Sometimes if you ask if you can have something for the pain, they say I don't know I'll have to ask this doctor – they should know and then it would be easier wouldn't it?*

*Obviously they need to know what they are doing but know their medicine times and if someone needs their medicine they have to know when to give it.*

It was also important for nurses to tell the patients what they were doing, even for simple procedures such as taking a temperature.

*She came along and she just stuck a thermometer down my throat and she didn't tell me what she was going to do and she made me sick every time she did it and it really hurt and made it sore and everything.*

There were some comments that the **nurses were always changing** so it was difficult to get to know them. They also needed to spend more time with the patients, not always be rushing around.

Other staff that were praised included play leaders and porters.

## **Pain Control**

**Pain control** was very important to these patients. They felt that both doctors and nurses should be more careful when treating them, and try to understand the pain they were going through. They should also check regularly to see whether they wanted more **pain relief**.

*Unless they have experienced it they can't actually understand how much pain you are in.*

*Adults can sometimes take the pain and might not be given the drugs to take away the pain but if you are a kid you can't really take the pain as it hurts too much.*

*Whether they realised it was time for pain relief or whether she asked for it, some were on the ball and others weren't so we had to ask.*

One teenager on an adult ward was able to control his own pain, by using a self-administered morphine supply.

*The first 3 / 4 days I was on a thing with a button...most of the time I was using that to get to sleep – that was what I was using it for – they tell you that you can press it as many times as you like but it only gives you a certain amount.*

## **Leaving Hospital**

Most patients were relieved to be going home, and they felt that it was easier to rest and recover at home.

*I felt more comfortable being at home than in the hospital.*

*I was glad to get outside and get some fresh air.*

*It's a lot easier really to be at home because you feel more you really...you feel more relaxed and things and you've got your family there to help you.*

However, one or two felt that they were not yet ready to go home, and that they had been rushed a little.

*It was a nice feeling but then I thought it was a bit too soon because it was only the first day I had got out of bed and had physio and they were already sending me home.*

*I feel that because it was Saturday they just wanted to close the ward down and there was only 3 of us on the ward on the Friday night.*

One patient had wanted to stay in hospital because he had enjoyed it so much!

*...the attention and stuff and people being nice to you and the telly being straight in front of you, your own private thing, that was nice.*

All the older children were pleased to be going home due to boredom.

*It was just so boring, the most boring time I've ever had in my life..... I was just so glad when they said I could go home now.*

Whilst one or two patients were given discharge packs, some felt that they were not given enough information on discharge.

*I was given this discharge pack which had information about after your stay and everything and all the numbers. .. the contact number for the children's ward and other numbers.*

*All they said to me was not to get it wet.*

*I was given a booklet.*

One patient commented that they had to contact the physio dept themselves and make an appointment because the hospital hadn't done it for them.

### **Card Sort Exercise**

Participants were asked to sort a number of statements (see Appendix 3) into two piles in terms of what the most and least important factors were when staying in hospital as an inpatient. They were then asked to pick three factors from the *most important* pile as their top priorities.

When asked to pick the three most important aspects of hospital care out of 20 statements the aspects that came out were as follows (11 pairs/individuals took part in card sort):

- Doctors/nurses who know a lot about my illness (7)
- A clean ward and clean toilets (6)
- Being given medicine when I am in pain (4)
- My mum or dad being able to stay with me in hospital (3)
- Having things to do on my ward (3)
- Being given enough information about my illness (3)
- Doctors/nurses who I trust and can talk to if I am worried or scared (2)
- Having my special needs (e.g. diet) looked after (2)
- Hospital food that I like (2)
- Not being on a ward with adults (1)

## Questionnaire

One group were asked what they thought about the development of a questionnaire designed for 12-19 year olds. They felt it was important that they were not 'patronised' by using words such as 'wicked' and that it should "*Just try and be adult – just normal*".

They also felt that maybe 12-19 years was too broad an age range, as there were big differences between a 12 year old and a 19 year old.

*12 – 19 is probably a bit too broad an age range – I think there is a massive growing up period in this age range in this period...*

*...because 19-year olds are out working and some have even got their own houses.*

When they were asked what it should look like one teenager pointed out:

*...as long as it gave us a chance to express our opinions I don't really care.*

## **2.5 Summary of key findings from Focus Groups**

### **Admission**

- Children were generally seen quickly in the Emergency Department although they were sometimes kept waiting for a bed on a ward.
- For those admissions which were planned, some children (particularly the younger ones) would have appreciated a visit to the hospital to meet the staff and find out more about the hospital.

### **Children's Wards**

- All felt strongly that very young children and babies should be separated from the older children and teenagers within the children's ward as they have very different needs. However, it was also felt that older children should be treated differently to adults.
- Children's wards were generally decorated brightly, but it was too 'babyish' for some.
- A more relaxed ward routine would have been appreciated, with more flexible visiting hours and mealtimes.
- Television was the main source of entertainment, and although the Nintendos and Playstations proved popular, there were not enough of these so it was difficult to get a turn. A games room for older children was a very popular suggestion.
- Parents were made welcome on the wards, but were not always given the facilities they needed to stay overnight, with some having to sleep on chairs.
- Hospital food was not very popular, and was generally thought to be tasteless and overcooked.
- Privacy was thought to be respected most of the time - curtains were pulled round for examinations and parents were nearly always present.
- Some felt that security should be improved on children's wards to make them feel more secure.

### **Adult wards**

- Those on adult wards had a more negative view of hospital life and had often had to share with very old or very ill patients.
- There were no overnight facilities and not much entertainment provided, so most were very bored.

### **Staff**

- Doctors should:

- explain things more clearly
- be friendly and with a sense of humour
- have a good fashion sense
- be hygienic and careful
- be trustworthy
- more of them
- be knowledgeable

They should include the young patients more in discussions and spend time with them to answer their questions. They should also try to appreciate the pain they are going through.

- Nurses should:
  - be young and attractive
  - be well presented
  - be nice, friendly and bubbly
  - be mates
  - be more knowledgeable and have more responsibility for medicines
  - tell patients what they are doing

### **Pain Control**

- Pain control is very important – doctors and nurses should be more careful and should check up on the patients more regularly.

### **Leaving Hospital**

- Most were relieved to leave hospital, although some felt a little rushed.
- Information given on discharge could be improved.

### **Priorities**

- The most important three aspects of hospital care for these patients emerged as:
  - Doctors/nurses who know a lot about my illness (7)
  - A clean ward and clean toilets (6)
  - Being given medicine when I am in pain (4)

### **Questionnaire**

- Young patients would welcome the chance to express their views but it was important that they did not feel patronised. The fact that they were being asked for their opinions seemed to be important to them and the appearance and design of the questionnaire was of less importance.



## **2.6 Development of Questionnaires**

- As a result of the focus groups, two parallel questionnaires were designed: a parent or guardian version for those with children aged 0 -11 years, the other for young patients 12 -17 years to complete for themselves. The content of these questionnaires was identical and had been refined following cognitive interviews, to ensure that the views and concerns of the upper age group had been covered.
- The upper age limit was reduced to 17 years from 19 years after taking into account the fact that those patients aged 18 years or over were eligible to take part in the Adult Inpatient Survey which was also being carried out in 2003/04.

### 3 Literature Review

Published literature and grey literature were used to inform this survey development. The main sources are listed below:

- Listening, Hearing and Responding – Department of Health Action Plan: Core Principles for the involvement of children and Young people – June 2002
- Healthy Futures: A consultation with children and young people in Camden and Islington about their health services – February 2002 – Liabo, Curtis, Jenkins et al
- Open Consultation with Children and Young People for Children’s National Service Framework – a) National Children’s Bureau, London (Oct 2002) b) Buxton for Youth, Buxton, Derbyshire (Oct 2002) c) Rheged Visitor Centre, Penrith, Cumbria (Nov 2002)
- Summary of findings from focus groups conducted with pupils in primary school for the NSF.

## 4 Testing the draft questionnaire: cognitive interviews

### 4.1 Introduction

Cognitive interviews were carried out to look at the clarity of language and ease of completion of the two questionnaires and to test the 0 -11 parent & guardian version and the 12-17 young patient version of the questionnaire.

### 4.2 Methods

Ten cognitive interviews were conducted during October 2003. These were carried out in two geographical areas to cover experiences of young patients from different NHS trusts. The interviewees were recruited via a recruitment agency and were identified by networking in the local area. The patients were aged between 0-17 years-of-age and had been inpatients or day cases in the last year. Table 1 shows the age range of young patients and interviewees. Parental consent was gained for the young patients aged less than 16 years-of-age who were interviewed.

**Table 1 - Ages of young patients and who were interviewed**

<b>Interviewee</b>	<b>Age of young patient (Years)</b>
Parent	4
Parent	4
Parent	5
Parent & Young Patient	10
Parent & Young Patient	10
Parent & Young Patient	12
Young Patient	14
Young Patient	14
Young Patient	15
Young Patient	17

### 4.3 Results

The following amendments were made as a result of the cognitive interviews:

### Added questions

Two parents said that there was no A&E for children at the local hospital – the children were transferred straight to the ward. A new question was therefore added:

**Question 2 (V6):**

**When you arrived at hospital where did you (and your child go first)?**

- 1  Straight to a ward
- 2  Accident and Emergency Department

Three of the parents mentioned that they were bothered by the noise during their child’s hospital stay. As a result of this a question was added to the ‘Parent and Carers’ section of the questionnaire.

**Question 88 (V6):**

**Were you ever bothered by noise from other patients?**

- 1  Yes
- 2  No

### Re-ordered Questions

It became clear after several interviews that some of the questions were not relevant to young patients that had been a day case. As a result of this a question was moved and modified and a skip option applied.

Question 76 (V4) became Question 23 (V6):

Questionnaire version 4	Questionnaire version 6
Q76. For this latest admission to hospital, did you (your child) stay overnight?  1 <input type="checkbox"/> Yes  2 <input type="checkbox"/> No, I (she/he) was treated as a day case	Q23. Did you (your child) stay overnight in hospital?  1 <input type="checkbox"/> Yes → Go to 24  2 <input type="checkbox"/> No → Go to 28

### Response categories added

Response categories were changed or added as a result of cognitive interviews with both parents and young patients.

Questionnaire version 4	Questionnaire version 6
<p>Q17. Were there enough toys and/or entertainment facilities on the ward?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I (my child) was not well enough to use these facilities</p>	<p>Q16. Were there enough toys and/or entertainment facilities on the ward?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I (my child) was not able to use these facilities</p> <p>5 <input type="checkbox"/> I did not need/want to use these facilities</p>

Questionnaire version 4	Questionnaire version 6
<p>Q18. How would you rate the toys and/or entertainment facilities on the ward?</p> <p>1 <input type="checkbox"/> Very good</p> <p>2 <input type="checkbox"/> Good</p> <p>3 <input type="checkbox"/> Fair</p> <p>4 <input type="checkbox"/> Poor</p> <p>5 <input type="checkbox"/> I (my child) was not able to use these facilities</p>	<p>Q17. How would you rate the toys and/or entertainment facilities on the ward?</p> <p>1 <input type="checkbox"/> Very good</p> <p>2 <input type="checkbox"/> Good</p> <p>3 <input type="checkbox"/> Fair</p> <p>4 <input type="checkbox"/> Poor</p> <p>5 <input type="checkbox"/> I (my child) was not able to use these facilities</p> <p>6 <input type="checkbox"/> I (my child) did not need/want to use these facilities</p>

Questionnaire version 4	Questionnaire version 6
<p>Q19. Did you (your child) have a chance to see a play leader during your (his/her) hospital stay?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> I (My child) did not need/want to see a play leader</p>	<p>Q24. Did you (your child) have a chance to see a play leader during your (his/her) hospital stay?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p> <p>3 <input type="checkbox"/> I (My child) did not want/need to see a play leader</p> <p>4 <input type="checkbox"/> I did not know that there was a play leader</p>

Questionnaire version 4	Questionnaire version 6
<p>Q23. Did you think the visiting hours were..?</p> <p>1 <input type="checkbox"/> Not strict enough</p> <p>2 <input type="checkbox"/> About right</p> <p>3 <input type="checkbox"/> Too strict</p>	<p>Q26. Did you think the visiting hours were..?</p> <p>1 <input type="checkbox"/> Not strict enough</p> <p>2 <input type="checkbox"/> About right</p> <p>3 <input type="checkbox"/> Too strict</p> <p>4 <input type="checkbox"/> I did not know the visiting hours</p>

Questionnaire version 4	Questionnaire version 6
<p>Q23. While you were (your child was) in hospital did nurses give you (her/him) emotional support and comfort when you (she/he) needed it?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p>	<p>Q38. While you were (your child was) in hospital did nurses give you (her/him) emotional support and comfort when you (she/he) needed it?</p> <p>1 <input type="checkbox"/> Yes, definitely</p> <p>2 <input type="checkbox"/> Yes, to some extent</p> <p>3 <input type="checkbox"/> No</p> <p>4 <input type="checkbox"/> It was not necessary</p>

#### 4.4 Conclusions

The questionnaire was revised and amended in light of the interviews and new drafts were then tested in subsequent interviews. None of the cognitive interviewees raised any objection to the length of the young patient questionnaire.

## 5 Importance Study

### 5.1 Introduction

The aim of the importance study was to identify the issues most important to young patients (or their parents) who had been inpatients or day cases within the last six months.

### 5.2 Method

100 importance study questionnaires were sent out to young patients or parents of younger children, from two NHS trusts. The questionnaire consisted of 43 statements derived from the young patient draft questionnaire. The first mailing consisted of a covering letter and questionnaire. The second mailing was a short reminder note and the third mailing consisted of a second reminder letter and another copy of the questionnaire. The initial covering letter and second reminder letter were printed on trust headed paper and signed by the trust's Chief Executive.

### 5.3 Results

A total of 51 completed questionnaires were returned. 72.5% of these were completed by the parent or guardian of the young patient as shown in Table 2. The remainder were completed by the young patient or a combination of the young patient and parent.

**Table 2 - Who was the main person who filled out the questionnaire?**

<b>Response Option</b>	<b>Frequency (n=51)</b>	<b>Percent</b>
The young person who was a patient	4	7.8
The parent or guardian of the patient	37	72.5
Both young person and guardian together	10	19.6

The number of participants that ticked "most important" for each statement is shown in Table 3. They are sorted in descending order, so the statements considered to be most important are at the top of the list.



The four most important issues for young patients and their parents or guardians were:

- Confidence and trust in doctors
- Confidence and trust in nurses
- Doctors giving me information I could understand
- Being involved in decisions about my care and treatment

The four least important issues identified by young patients and their guardians were:

- The ward being nicely decorated
- Getting a chance to see a play leader
- Visiting the hospital and meeting staff before admission
- Having a choice of admission date

#### **5.4 Conclusion**

The results of the importance study confirmed findings from the focus groups and confirmed that the most important issues to young patients and their parents were addressed in the young patient questionnaire.

**Table 3- Number that ticked “most important” for each statement**

<b>Statement</b>	<b>Number of respondents that ticked most important (n=51)</b>
Confidence and trust in doctors treating me	48
Confidence and trust in nurses treating me	48
Doctors giving me information I could understand	46
Being involved in decisions about my care and treatment	46
Nurses giving me information I could understand	45
Clean ward	44
Having a chance to discuss worries or fears with a doctor	43
Getting pain killers when I needed them	43
Feeling safe and secure on the ward	42
The surgeon telling me what would be done in my operation	42
Being told about danger signs I should watch for regarding my illness or treatment after I went home	40
Being told about side effects of medicines to watch for when at home	40
Having a chance to discuss worries or fears with a nurse	39
Doctors and nurses working well together	39
Being given the same advice from all members of staff	38
Having enough nurses on duty to care for me	38
Being given an explanation about how to use the medicines when I went home	38
Being informed of who to contact if worried about my condition or treatment when at home	38
Being treated with respect and dignity	37
Getting help quickly when I used the call bell	35
Being given an explanation about what the medicines were for	35
Being given emotional support and comfort from the nurses when I needed it	34
Not having my admission cancelled by the hospital	32
Privacy when being examined or treated	32
Being told by a doctor or nurse how I would feel after surgery	31
Not having to wait too long on the waiting list	29
Good food	29
Friends and family being allowed to visit	23
When leaving hospital, being told when I could return to my normal activities	23
Privacy when discussing my condition or treatment	20
Being told how long I would have to wait for a bed on a ward after arriving at hospital	19
Having help organised by the hospital for when I was at home	19
Enough toys and, or entertainment facilities	17
Not being bored	17
Being on a ward with people my own age	15
A quiet ward	14
Good quality toys and, or entertainment facilities	14
Being discharged from hospital at the time I expected	13
Being offered help with my education	11
Having a choice of admission date	9
Visiting the hospital and meeting staff before admission	9
Getting a chance to see a play leader	7
The ward being nicely decorated	5

## **6 Mailed Pilot Surveys**

### **6.1 Introduction**

Before using the questionnaire in the National Survey Programme, it was essential to test the face validity of the questionnaires, sampling method and data collection method in the pilot surveys.

### **6.2 Methods**

Ethical approval was granted for the pilot study by the North West Multi-Centre Research Ethics Committee (MREC) on 30<sup>th</sup> October 2003.

Two trusts (A and B) participated in the pilot study. A sample size of 800 young patients – 400 from each NHS trust was required. The sample of patients was drawn from the hospital patient record system by the two trusts.

The sample included patients aged 0 to 17 consecutively discharged alive or who attended as day cases up to and including 31<sup>st</sup> July 2003 for Trust A and 30<sup>th</sup> September for Trust B. The following exclusion criteria applied:

- Deceased patients
- Any patient aged 18 or over
- Maternity patients
- Psychiatry patients
- Patients admitted for termination of pregnancy
- Private patients
- Current inpatients
- Patients without a UK postal address
- Patients who were only admitted to a Neonatal Intensive Care Unit (NICU) or a SCBU (Special Care Baby Unit).

The trusts ran a check using both their own records and the NHS Strategic Tracing Service to confirm that the sampled patients were alive.

### **6.3 Survey administration**

The first mailing consisted of a covering letter and questionnaire. The second mailing was a short reminder note and the third mailing consisted of a second reminder letter and another copy of the questionnaire. The initial covering letter and second reminder letter were printed on trust headed paper and signed by the trust's Chief Executive.

The first questionnaires were posted on 20<sup>th</sup> November 2003 for Trust A and on 14<sup>th</sup> November 2003 for Trust B. The final cut off date for inclusion of returned questionnaires was 26<sup>th</sup> January 2004.

All questionnaires (both returned completed and returned undelivered) were returned to the Survey Advice Centre, rather than to the trust. Logging returns and data entry were carried out at the Survey Advice Centre. The FREEPHONE helpline for handling enquiries was staffed by the NHS Survey Advice Centre, but callers were asked to give the number on their questionnaire, rather than their name and address. Calls were logged using this number to ensure that reminders were not sent out to people who had called to say they did not wish or were unable to participate.

The survey report supplied to the trust presented anonymised survey results, so that clinical staff could not identify any individual respondents.

#### **6.4 FREEPHONE calls**

Covering letters enclosed with the questionnaires included a FREEPHONE number that patients could call if they had any questions, queries or complaints about the survey. There were 20 calls to the FREEPHONE concerning the young patient pilot survey. The calls can be categorised as follows:

- 17 calls were from parents of young patients whose only experience of being an inpatient was at birth. (An error at Trust A meant that some young patients had been incorrectly included in the sample).
- 1 call from a parent to say that the young patient was recently deceased.
- 1 call about how to complete the Young Patient questionnaire.
- 1 call about a questionnaire that was addressed to the wrong person.

#### **6.5 Results**

The pilot Young Patient survey achieved a response rate of 58.0% (after adjusting for questionnaires returned undelivered, deceased patients and those patients considered to be ineligible), with 380 completed questionnaires returned. The response rates are shown in Table 4. Trust A had included newborn babies as an inpatient experience resulting in 133 patients becoming ineligible to take part in the pilot study. Following discussion with Trust A these young patients were identified and were removed from the sample resulting in a real sample size of 267.

**Table 4 - Response rates to pilot survey**

<b>Response outcome</b>	<b>Trust A (n=399)</b>	<b>Trust B (n=400)</b>	<b>Total (n=799)</b>
Completed useable questionnaire	125	255	380
Returned undelivered	4	5	9
Deceased	0	1	1
Opt out	14	5	19
Ineligible	133	1	134
Not returned yet	123	133	256
Sum denominator	399	400	799
<b>Raw response rate (%)</b>	<b>31.3%</b>	<b>63.8%</b>	<b>47.5%</b>
Adjusted denominator	262	393	655
<b>Adjusted response rate (%)</b>	<b>47.7%</b>	<b>64.9%</b>	<b>58.0%</b>

Note. Raw response rate is the number of completed questionnaires returned as a percentage of the total sample size (799). The adjusted response rate was calculated by removing questionnaires which could not have been completed (those returned undelivered or where the respondent was notified to be deceased or those considered ineligible) from the denominator.

### **Response bias**

It is possible that respondents might not be representative of all patients who have used NHS trust services, so certain groups might be under-represented. For example, it is possible that some age groups might be more likely to respond than others.

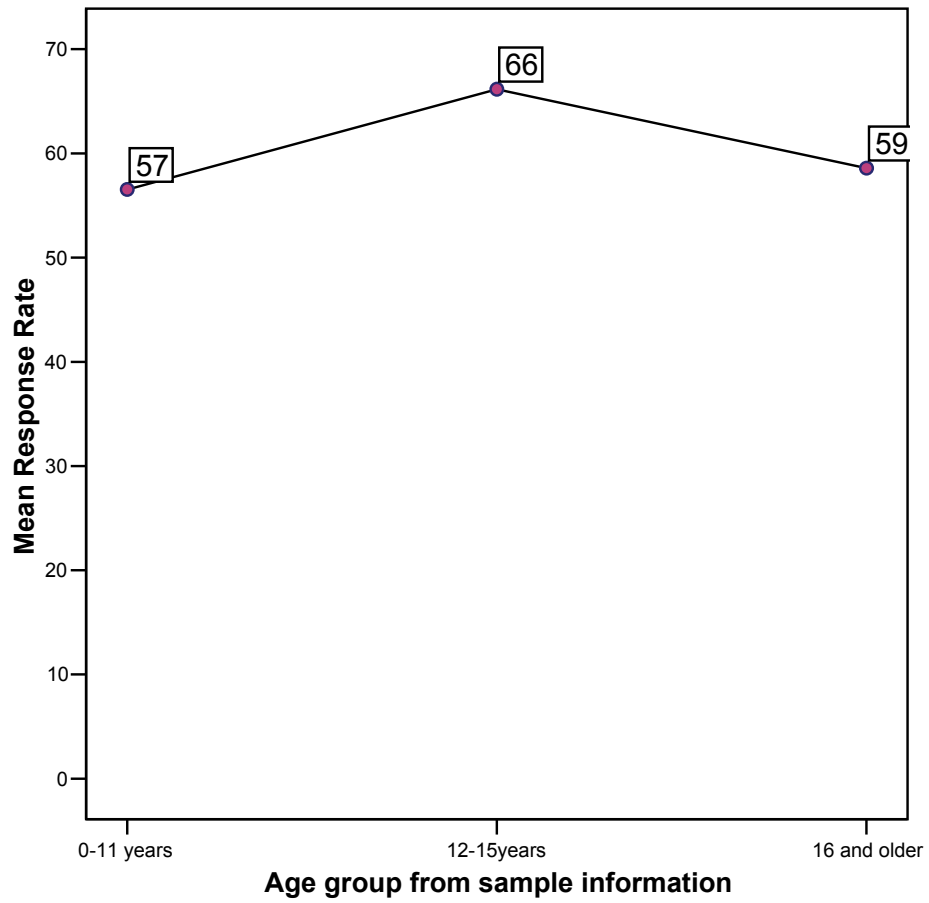
### **Ethnic group**

It was not practical to investigate non response by ethnic group because there were very small numbers of non-white patients in the samples for the two rural trusts that took part in the pilot. Also, there was incomplete information on ethnic group in the samples supplied by the pilot trusts. The proportions of respondents were 94% White British at Trust A and 97.6% at Trust B.

### **Age**

We divided the sample into three age groups for analysis – 0-11, 12-15 and 16-17 years of age. The sample from both trusts combined consisted of 421 young patients aged between 0-11, 65 young patients aged 12-15 years and 169 young patients between 16-17 years. The mean response rates for these age groups are shown in Table 5. It can be seen that the response rate for the 12-15 age group is slightly higher than the other two, but the difference is not statistically significant.

**Table 5 – Mean response rate by age**



### **Gender of patient**

The number of male young patients in the overall sample was  $n=345$  and the number of female young patients  $n=310$ . Response rate between the genders of young patients was not statistically different.

## Respondents

Sample characteristics are shown in Table 6.

**Table 6 - Basic characteristics of sample**

Sample characteristics	Combined Trust samples (n=380)
<b>Gender</b>	
Male	51.1% (194)
Female	48.9% (186)
<b>Age</b>	
Age 0-11	66.9% (254)
Age 12-15	25.0% (95)
Age 16-17	7.6% (29)
Missing data	0.5% (2)

**Table 7 - Ethnic groups of young patients**

Ethnic group	Frequency (n=380)	Percent
British	359	94.5
Irish	2	0.5
Any other White background	7	1.8
White and Asian	1	0.3
Pakistani	2	0.5
Bangladeshi	2	0.5
Any other Asian background	2	0.5
Caribbean	2	0.5
Missing	3	0.8

**Table 8 - The main person who filled in the questionnaire**

Response Option	Frequency (n=380)	Percent
Young person who was a patient in hospital	47	12.4
Parent or guardian of the patient	253	66.6
Both patient and parent, guardian together	78	20.5
Someone else	1	0.3
Missing	1	0.3

## Response frequencies

The questionnaire was designed to investigate young patient's experiences. The topics have been grouped into 11 sections:

- Admission to hospital
- The hospital and ward
- Doctors
- Nurses
- Your [child's] care and treatment
- Pain
- Operations and procedures
- Leaving hospital
- Overall
- About you[r child]
- Parents and parents

The results data presented here are from the two pilot trusts combined.

### ADMISSION TO HOSPITAL

#### Q1 Was your (your child's) hospital admission planned in advance or an emergency?

Response Option	Frequency (n=380)	Percent
Emergency, dialed 999, referred by GP or NHS Direct	97	25.5
Waiting list or planned in advance*	252	66.3
Something else	20	5.3
Missing	11	2.9

\* If "Waiting list or planned in advance", respondent went on to answer questions 5 but not questions 2-4.

#### Emergency or immediately referred

#### Q2 When you arrived at hospital where did you (you and your child) go first?

Response Option	Frequency (n=380)	Percent
Straight to ward*	24	6.3
Accident and Emergency Department	92	24.2
Missing	264	69.5

\* If the child went "straight to the ward", respondent went on to answer questions 10 but not questions 3-9.



**Q3 Following arrival at the hospital, how long did you wait before you were (your child was) admitted to a bed on a ward?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Less than 1 hour	9	2.4
At least 1 hour but less than 2 hours	33	8.7
At least 2 hours but less than 4 hours	25	6.6
At least 4 hours but less than 8 hours	14	3.7
8 hours or longer	3	0.8
Can't remember	5	1.3
I/We did not have to wait	2	0.5
Missing	289	76.1

**Q4 How organised was the care you (your child) received in A&E or medical Admissions Unit?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Not at all organised	7	1.8
Fairly organised	53	13.9
Very organised	31	8.2
Total	91	23.9
System	289	76.1

All respondents went on to answer questions 10 but not questions 5-9.

### **Waiting list or planned admission**

**Q5 How do you feel about the length of time you were (your child was) on the waiting list before admission to hospital?**

<b>Response Options</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Admitted as soon as thought was necessary	179	47.1
Should have been admitted a bit sooner	53	13.9
Should have been admitted a lot sooner	10	2.6
Missing	138	36.3

**Q6 Were you given a choice of admission date?**

<b>Response Options</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	67	17.6
No	164	43.2
Don't know, Can't remember	16	4.2
Missing	133	35.0

**Q7 Was your (your child's) hospital admission date changed by the hospital?**

<b>Response Options</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
No	176	46.3
Yes, once	64	16.8
Yes, 2 or 3 times	6	1.6
Yes, 4 times or more	1	0.3
Missing	133	35.0

**Q8 Before you were (your child was) admitted, were you invited to visit the hospital and meet the staff?**

<b>Response Options</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes and we did visit	161	42.4
Yes but we did not visit*	24	6.3
No, and we would have liked to visit*	16	4.2
No but we did not want to visit*	42	11.1
Missing	137	36.1

\* Respondents went on to answer question 10 but not question 9.

**Q9 Did visiting the hospital and meeting the staff help you (your child) when you were (he/she was) actually admitted?**

<b>Response Options</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	95	25.0
Yes, to some extent	60	15.8
No	9	2.4
Missing	216	56.8

**All types of admission****Q10 Did you feel that you (your child) had to wait a long time to get a bed on a ward?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	19	5.0
Yes, to some extent	57	15.0
No	302	79.5
Missing	2	0.5

## THE HOSPITAL AND WARD

**Q11 For most of your (your child's) stay in hospital, what type of ward were you on?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
A children's ward	324	85.3
An adult ward	22	5.8
An adolescent or teenager ward	21	5.5
Other	13	3.4

**Q12 What type of ward would you (your child) prefer to stay on**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
A children's ward	290	76.3
An adult ward	16	4.2
An adolescent or teenager ward	60	15.8
Other	5	1.3
Missing	9	2.4

**Q13 In your opinion, how clean was the hospital room or ward that you were (your child was) in?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Very clean	195	51.3
Fairly clean	159	41.8
Not very clean	24	6.3
Not at all clean	2	0.5

**Q14 How clean were the toilets and bathrooms that you (your child) used in hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Very clean	163	42.9
Fairly clean	163	42.9
Not very clean	24	6.3
Not at all clean	4	1.1
I (She/he) did not use a toilet or bathroom	22	5.8
Missing	4	1.1

**Q15 In your opinion did the ward look nicely decorated?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	189	49.7
Yes, to some extent	162	42.6
No	28	7.4
Missing	1	0.3

**Q16 Were there enough toys and or entertainment facilities on the ward?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	239	62.9
Yes, to some extent	87	22.9
No	18	4.7
Not able to use facilities	11	2.9
Did not need or want to use the facilities	24	6.3
Missing	1	0.3

**Q17 How would you rate the toys and or entertainment facilities on the ward?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Very good	160	42.1
Good	123	32.4
Fair	51	13.4
Poor	14	3.7
Not able to use the facilities	9	2.4
Did not need or want to use the facilities	22	5.8
Missing	1	0.3

**Q18 Were you ever bored during your (was your child ever bored during his/her) stay in hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, most or all of the time	21	5.5
Some of the time	156	41.1
Hardly ever or not at all	195	51.3
Missing	8	2.1

**Q19 How would you rate the hospital food you were (your child was) given?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Very good	40	10.5
Good	114	30.0
Fair	98	25.8
Poor	56	14.7
I (She/he) did not have any hospital food	71	18.7
Missing	1	0.3

**Q20 Did you feel that the hospital ward was a safe and secure place?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	306	80.5
Yes, to some extent	71	18.7
No	2	0.5
Missing	1	0.3

**Q21 Were you (was your child) ever bothered by noise from other patients?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	132	34.7
No	245	64.5
Missing	3	0.8

**Q22 Were you (was your child) ever bothered by noise from hospital staff?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	29	7.6
No	351	92.4

**Q23 Did you (your child) stay overnight in hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	283	74.5
No*	94	24.7
Missing	3	0.8

*\*If "No", respondent went on to answer question 28 but not questions 24-27.*

**Q24 Did you (your child) have a chance to see a play leader during your (her/his) hospital stay?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	180	47.4
No	42	11.1
Didn't need/want to see a play leader	40	10.5
Did not know that there was a play leader	20	5.3
Missing	98	25.8

**Q25 Were you given help with your (was your child given help with his/her) education while in hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	73	19.2
No, but it was needed	17	4.5
Did not need help with education	189	49.7
Missing	101	26.6

**Q26 Did you think the visiting hours were....?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Not strict enough	5	1.3
About right	229	60.3
Too strict	6	1.6
Did not know the visiting hours	42	11.1
Missing	98	25.8

**Q27 Did you feel friends or other relatives were welcome to visit you (your child)?**

<b>Response Option</b>	<b>Frequency</b>	<b>Percent</b>
Yes, definitely	247	65.0
Yes, to some extent	31	8.2
No	4	1.1
Missing	98	25.8

## DOCTORS

**Q28 Did doctors give your parent or guardian (you-the parent or guardian) information about your (your child's) care and treatment in a way that they (you) could understand?**

Response Option	Frequency (n=380)	Percent
Yes, definitely	297	78.2
Yes, to some extent	72	18.9
No	10	2.6
Missing	1	0.3

**Q29 Did doctors give you the patient (your child) information about your (his/her) care and treatment in a way that you (he/she) could understand?**

Response Option	Frequency (n=380)	Percent
Yes, definitely	173	45.5
Yes, to some extent	98	25.8
No	24	6.3
It was not necessary	83	21.8
Missing	2	0.5

**Q30 If you had any worries or fears about your (your child's) condition or treatment, did a doctor discuss them with you?**

Response Option	Frequency (n=380)	Percent
Yes, completely	235	61.8
Yes, to some extent	99	26.1
No	10	2.6
I did not have worries or fears	36	9.5

**Q31 Did you have confidence and trust in the doctors treating you (your child)?**

Response Option	Frequency (n=380)	Percent
Yes, always	325	85.5
Yes, sometimes	52	13.7
No	3	0.8

**Q32 Did doctors talk in front of you as if you were not there?**

Response Option	Frequency (n=380)	Percent
Yes, often	16	4.2
Yes, sometimes	62	16.3
No	302	79.5

**Q33 In your opinion, did the doctor(s) who treated you (your child) know enough about your (her/his) condition or treatment?**

<b>Response option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
All the doctors knew enough	237	62.4
Most of the doctors knew enough	102	26.8
Only some of the doctors knew enough	24	6.3
None of the doctors knew enough	7	1.8
Can't say	10	2.6

## **NURSES**

**Q34 Did nurses give your parent or guardian (you - the parent or guardian) information about your (your child's) care and treatment in a way that they (you) could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	289	76.1
Yes, to some extent	78	20.5
No	13	3.4

**Q35 Did nurses give you the patient (your child) information about your (his/her)care and treatment in a way that you (he/she) could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	178	46.8
Yes, to some extent	96	25.3
No	16	4.2
It was not necessary	90	23.7

**Q36 If you had any worries or fears about your (your child's) condition or treatment, did a nurse discuss them with you?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	200	52.6
Yes, to some extent	109	28.7
No	19	5.0
I did not have worries or fears	50	13.2
Missing	2	0.5

**Q37 Did you have confidence and trust in the nurses treating you (your child)?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, always	290	76.3
Yes, sometimes	86	22.6
No	4	1.1



**Q38 While you were (your child was) in hospital, did nurses give you (your child) emotional support and comfort when you (he/she) needed it?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	175	46.1
Yes, to some extent	82	21.6
No	15	3.9
It was not necessary	106	27.9
Missing	2	0.5

**Q39 Did nurses talk in front of you as if you were not there?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, often	8	2.1
Yes, sometimes	45	11.8
No	327	86.1

**Q40 In your opinion, were there enough nurses on duty to care for you (your child) in hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
There were always or nearly always enough nurses	229	60.3
There were sometimes enough nurses	125	32.9
There were rarely or never enough nurses	23	6.1
Missing	3	0.8

**Q41 In your opinion, did the nurses who treated you (your child) know enough about your (your child's) condition or treatment?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
All of the nurses knew enough	165	43.4
Most of the nurses knew enough	142	37.4
Only some of the nurses knew enough	39	10.3
None of the nurses knew enough	9	2.4
Can't say	23	6.1
Missing	2	0.5

## YOUR CHILD'S CARE AND TREATMENT

**Q42 Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you (your child) during your hospital stay?**

Response Option	Frequency (n=380)	Percent
Yes, often	19	5.0
Yes, sometimes	115	30.3
No	243	63.9
Missing	3	0.8

**Q43 Was your parent or guardian (were you as a parent or guardian) involved as much as they (you) wanted to be in decisions about your (your child's) care and treatment?**

Response Option	Frequency (n=380)	Percent
Yes, definitely	292	76.8
Yes, to some extent	73	19.2
No	13	3.4
Missing	2	.5

**Q44 Were you the patient (was your child) involved as much as you (he/she) wanted to be in decisions about your (his/her) care and treatment?**

Response Option	Frequency (n=380)	Percent
Yes, definitely	143	37.6
Yes, to some extent	97	25.5
No	15	3.9
Not able to be involved	121	31.8
Missing	4	1.1

**Q45 How much did your parent or guardian participate in your care, such as feeding or bathing?**

Response Option	Frequency (n=380)	Percent
Not enough	3	0.8
The right amount	262	68.9
Too much	17	4.5
It was not necessary	94	24.7
Missing	4	1.1

**Q46 Were you (were you and your child) given enough privacy when discussing your (your child's) condition or treatment?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, always	264	69.5
Yes, sometimes	93	24.5
No	17	4.5
Missing	6	1.6

**Q47 Were you (was your child) given enough privacy when you were (she/he was) being examined or treated?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, always	315	82.9
Yes, sometimes	51	13.4
No	11	2.9
Missing	3	0.8

**Q48 When you (your child) needed help from staff in using the bathroom or toilet, did you (he/she) get it in time?**

<b>Response Option</b>	<b>Frequency</b>	<b>Percent</b>
Yes, always	97	25.5
Yes, sometimes	45	11.8
No	8	2.1
I (he/she) did not need help from the staff	223	58.7
Missing	7	1.8

**Q49 When you (your child) needed help from staff in eating meals, did you (he/she) get it at the time it was needed?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, always	48	12.6
Yes, sometimes	29	7.6
No	13	3.4
I (he/she) did not need help from the staff	283	74.5
Missing	7	1.8

**Q50 How many minutes after you (you and your child) used the call button did it usually take before you (he/she) got the help you needed?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
0 minutes, right away	34	8.9
1-2 minutes	78	20.5
3-5 minutes	47	12.4
More than 5 minutes	10	2.6
Never got help when using the call button	1	0.3
Never used the call button	205	53.9
Missing	5	1.3

## **PAIN**

**Q51 Were you (was your child) ever in pain?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	247	65.0
No*	125	32.9
Missing	8	2.1

\* If "No", respondent went on to answer question 54 but not questions 52-53.

**Q52 During your (your child's) stay in hospital, how much of the time were you (was your child) in pain?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
All or most of the time	49	12.9
Some of the time	140	36.8
Occasionally	63	16.6
Missing	128	33.7

**Q53 Do you think the hospital staff did everything they could to help control your (your child's) pain?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, definitely	180	47.4
Yes, to some extent	59	15.5
No	13	3.4
Missing	128	33.7

## OPERATIONS AND PROCEDURES

**Q54 During your (your child's) stay in hospital did you (your child) have an operation?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	269	70.8
No*	108	28.4
Missing	3	0.8

\* If "No", respondent went on to answer question 62 but not questions 55-61.

**Q55 Before the operation, did the surgeon explain to your parent or guardian (to you the parent or guardian) what would be done during the operation?**

<b>Response option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	238	62.6
Yes, to some extent	27	7.1
No	2	0.5
It was explained by someone else	2	0.5
Parent or guardian did not want an explanation	1	0.3
Missing	110	28.9

**Q56 Before the operation, did the surgeon explain to you the patient (your child) what would be done during the operation?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	154	40.5
Yes, to some extent	51	13.4
No	12	3.2
It was explained by someone else	6	1.6
Not able to understand	44	11.6
Missing	113	29.7

**Q57 Before the operation, did the surgeon explain the risks and benefits of the surgery to you (you- the parent or guardian) in away that you could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	216	56.8
Yes, to some extent	40	10.5
No	7	1.8
It was explained by someone else	1	.3
Did not want an explanation	2	.5
Missing	114	30.0

**Q58 Before the operation did the surgeon or any of the other doctors answer your questions about the surgery in a way that you could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	205	53.9
Yes, to some extent	42	11.1
No	3	.8
It was explained by someone else	1	.3
Did not have any questions	19	5.0
Missing	110	28.9

**Q59 Before the operation, did a doctor or nurse discuss your (your child's) worries or fears about the surgery or operation with you the patient (your child)?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	117	30.8
Yes, to some extent	52	13.7
No	16	4.2
It was explained by someone else	5	1.3
Did not have worries or fears	24	6.3
Not necessary	55	14.5
Missing	111	29.2

**Q60 Before the operation, did a doctor or nurse explain accurately how you would feel after surgery?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	133	35.0
Yes, to some extent	100	26.3
No	36	9.5
Missing	111	29.2

**Q61 After the operation, did the surgeon or any of the other doctors explain how the operation had gone in a way you could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	213	56.1
Yes, to some extent	42	11.1
No	14	3.7
Missing	111	29.2

## LEAVING HOSPITAL

**Q62 Do you feel you were (your child was) discharged too early, at the right time, or too late?**

Response Option	Frequency (n=380)	Percent
Too early	26	6.8
At the right time	331	87.1
Too late	21	5.5
Missing	2	0.5

**Q63 On the day you left hospital, was your (your child's) discharge delayed for any reason?**

Response Option	Frequency (n=380)	Percent
Yes	121	31.8
No*	255	67.1
Missing	4	1.1

\* If "No", respondent went on to answer question 66 but not questions 64-65.

**Q64 What was the main reason for the delay?**

Response Option	Frequency (n=380)	Percent
Had to wait for medicines	53	13.9
Had to wait to see the doctor	31	8.2
Had to wait for an ambulance	5	1.3
Something else	28	7.4
Missing	263	69.2

**Q65 How long was the delay?**

Response Option	Frequency (n=380)	Percent
Up to 1 hour	15	3.9
Longer than 1 hour but no longer than 2 hours	35	9.2
Longer than 2 hours but no longer than 4 hours	47	12.4
Longer than 4 hours	21	5.5
Missing	262	68.9

**Q66 Did a member of staff explain the purpose of the medicines you were (your child was) given to take at home in a way you could understand?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	223	58.7
Yes, to some extent	30	7.9
No	4	1.1
Did not need an explanation	11	2.9
Not given any medicines*	108	28.4
Missing	4	1.1

\* Respondents went on to answer question 69 but not questions 67-68.

**Q67 Did a member of staff tell you about medication side effects to watch for when you went home?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	114	30.0
Yes, to some extent	43	11.3
No	49	12.9
Did not need, want explanation	63	16.6
Missing	111	29.2

**Q68 Were you given enough information about how to use the medicine(s) e.g. when to take it, how long you should take it for or whether it should be taken with food?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, enough information	217	57.1
Some, but not enough	27	7.1
No information at all, and I wanted some	3	0.8
Did not need, want any information	24	6.3
Missing	109	28.7

**Q69 Did a member of staff tell you about what danger signals you should watch for after you (your child) went home?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	186	48.9
Yes, to some extent	68	17.9
No	49	12.9
It was not necessary	64	16.8
Don't know, can't remember	12	3.2
Missing	1	0.3



**Q70 Did someone tell you when you (your child) could carry on your (his/her) usual activities, such as playing sport or returning to school work?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, completely	174	45.8
Yes, to some extent	72	18.9
No	39	10.3
It was not necessary	92	24.2
Missing	3	0.8

**Q71 Did hospital staff tell you who to contact if you were worried about your (your child's) condition or treatment after you left hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	332	87.4
No	28	7.4
Don't know, Can't remember	20	5.3

**Q72 Did hospital staff arrange the services you would need after leaving hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	109	28.7
No but these services were needed	35	9.2
It was not necessary	234	61.6
Missing	2	0.5

## OVERALL

**Q73 Did you feel that you (you and your child) were treated with respect and dignity while you were (she/he was) in the hospital?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes, always	310	81.6
Yes, sometimes	62	16.3
No	8	2.1

**Q74 How would you rate how well the doctors and nurses worked together?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Excellent	147	38.7
Very good	162	42.6
Good	51	13.4
Fair	15	3.9
Poor	5	1.3

**Q75 Overall, how would you rate the care you (your child) received?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Excellent	174	45.8
Very good	154	40.5
Good	41	10.8
Fair	8	2.1
Poor	2	0.5
Missing	1	0.3

**ABOUT YOU (ABOUT YOUR CHILD)**

**Q78 Do you consider yourself (your child) to be disabled?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	78	20.5
No	295	77.6
Missing	7	1.8

**Q79 How many times have you (has your child) been admitted to hospital in the past six months?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Once	292	76.8
Two or three times	55	14.5
Four times or more	1	0.3
Missing	32	8.4

## PARENTS AND CARERS

**Q82 Were you able to buy cooked meals for your self on the hospital premises?**

Response Option	Frequency (n=380)	Percent
Yes	318	83.7
No	47	12.4
Missing	15	3.9

**Q83 Did you have access to tea and coffee making facilities while you were on the ward?**

Response Option	Frequency (n=380)	Percent
Yes	322	84.7
No, but I would have liked them	30	7.9
No, but I did not mind	19	5.0
Missing	9	2.4

**Q84 Did you ever want to stay overnight with your child?**

Response Option	Frequency (n=380)	Percent
Yes	238	62.6
No*	124	32.6
Missing	18	4.7

\* Respondents went on to answer question 88 but not questions 85-87.

**Q85 Were you ever given the chance to stay overnight when you wanted to?**

Response Option	Frequency (n=380)	Percent
Yes, always	229	60.3
Yes, sometimes	5	1.3
No	7	1.8
Missing	139	36.6

**Q86 How would you rate the facilities for parents or guardians staying overnight?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Excellent	55	14.5
Very good	59	15.5
Good	62	16.3
Fair	43	11.3
Poor	14	3.7
Missing	147	38.7

**Q87 Were you offered a bed near your child?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	219	57.6
No, but I would have liked it	8	2.1
No, but I did not mind	6	1.6
Missing	147	38.7

**Q88 Were you ever bothered by noise from other patients?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	107	28.2
No	253	66.6
Missing	20	5.3

**Q89 Were you ever bothered by noise from hospital staff?**

<b>Response Option</b>	<b>Frequency (n=380)</b>	<b>Percent</b>
Yes	42	11.1
No	320	84.2
Missing	18	4.7

**6.6 Findings**

The face validity of the questionnaire was supported by the quality of responses received and the small number of calls about how to complete the questionnaire that were made to the FREEPHONE. Following the pilot study there were some minor amendments to the questionnaire.

Questionnaire version 6	Questionnaire version 9
<p>Q82. Were you able to buy cooked meals for your self on the hospital premises?</p> <p>1 <input type="checkbox"/> Yes</p> <p>2 <input type="checkbox"/> No</p>	<p>Q82. Were you able to buy cooked meals for your self on the hospital premises?</p> <p>1 <input type="checkbox"/> Yes, as often as I wanted</p> <p>2 <input type="checkbox"/> Yes, but not as often as I wanted</p> <p>3 <input type="checkbox"/> No</p>

The front cover of the questionnaire for young patients aged 12-17 years had a section added:

**Who should complete the questionnaire?**

The questions should be answered by the young patient with the help of the parent or guardian if necessary. The questions should be answered from the young patient’s point of view’.

As a result of Trust A selecting newborn babies the guidance manual was changed and a new exclusion criteria was added.

## **7 Appendices**

### **7.1 Appendix 1- Lothian focus group report**

# LOTHIAN UNIVERSITY HOSPITALS NHS TRUST

## FOCUS GROUPS REPORT

Steve Bruster, Sarah-Jane Lilley, Maria Lorentzon, Nick Richards

London, September 1999

## **Preface**

The information contained in this report is based on qualitative research (focus groups) with a relatively small number of former patients.

Picker Europe uses focus groups (and in-depth and one-to-one interviews) to assist in the development of questionnaires. These methods aim to provide a neutral setting in which participants are encouraged to express their own views, in details, with little prompting. A moderator or interviewer probes and seeks clarification from people on what they say, if required.

Because focus groups are by nature exploratory, concentrating on the richness and variety of experience of relative small numbers of people, they cannot be used for making generalised assumptions. Their strength and purpose lies in identifying a range of uses and perspectives which can be followed up in further, more representative investigations. Therefore, this report graphically illustrates the main issues and problems raised by former patients in the Trust but does not attempt to quantify them.

Questionnaires will be designed to reflect the priorities of patients as revealed in the focus groups and will subsequently be distributed to a random sample of over 5,000 in-patients to enable reliable, representative information to be obtained on the issues raised.

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# Summary

## 1. Summary

Focused group interviews were carried out with recently discharged adult in-patients, women using maternity services, child patients and their parents from the Royal Infirmary, Western General Hospital and Royal Hospital for Sick Children.

This report describes in detail the themes and issues raised by participants in the groups in three sections: adults, maternity and paediatrics.

Three principal themes emerged across the 3 groups: treatment, staff and the hospital environment, with a number of positive and negative comments made in each area.

### **Treatment**

**Overall**, patients described a sense of powerlessness, a loss of dignity and a feeling of being intimidated and vulnerable.

Before being admitted some patients, including those in hospital for maternity care, described how useful the **pre-admission** visit had been, allowing them to meet all the staff. Pre-admission information was also thought to be very helpful.

On **admission**, some patients reported having to wait a long time (sometimes in a bed in a corridor) until they were admitted to the ward. They found this upsetting or humiliating. Other patients were admitted almost immediately.

A number of patients found their **continuity of care** compromised by having to move ward often, this was quite distressing for some of them. Women in hospital for maternity care complained of being dealt with by too many different staff throughout their pregnancy.

**Information and communication** caused the most comment. Patients complained of constantly being asked the same questions, they found the ward rounds intimidating, sometimes had difficulty finding information about their condition or treatment, or were given contradictory information by different members of staff. Some patients complained of being given too much information.

Some patients having **surgery** had a clear and detailed explanation from the surgeons and anaesthetists of what would be done, however other patients were left very much in the dark. Similarly not all patients were told how the surgery had gone.

**Test** results were not always reported back to patients, particularly negative results, and this could cause them anxiety.

There were contrasting experiences regarding **pain management**. Some patients had their pain well controlled throughout their stay and others had problems getting medication at the appropriate times. Parents of children being treated expressed concern that they were not fully informed about the medication used.

## Summary

Patients were often unsure of who was **coordinating** their care and who to turn to in case of problems. They also indicated that they would not complain about their treatment as this may affect their future care.

Parents of children being treated expressed the need for more **emotional support**, as anxiety levels were very high. The support however on the cancer ward was noted as being particularly good.

On **discharge** from hospital, the principal complaints were about waiting to be discharged (because of a delay in the pharmacy) and the lack of information given to the patient's GP. However, a number of patients commented on how well the discharge had been planned and coordinated, although some found the amount of verbal information given to be too much to take in and would have preferred more written information.

Women discharged from the maternity ward felt that they were not given enough information about being able to cope at home with a small child.

### Staff

In general terms very positive comments were made about doctors and nurses.

Overall, doctors were thought to be first class, although some patients found them rather detached and cold and it was noted that doctors were not always available at convenient times.

Nurses were also rated very highly overall. Patients often related problems to a shortage of nurses, or the presence of agency or contract nurses on the ward. Particular praise was reserved for nurses on high dependency wards, although patients noted that they were slightly arrogant and gave less personal care. Nursery nurses were praised for their practical, hands-on approach. The principal concern was that nurses did not have time to sit and talk with patients.

Patients on adult wards were particularly critical of care assistants/auxiliaries who were just "doing a job" and had no real concern for patients. However, positive comments were made by children about the care assistants.

Medical students did cause some concern for patients, although they appreciated the need for medical training. Patients were not always asked if they could be visited by students, found it intimidating and overbearing to be visited by so many at a time and found it tiring to be visited all the time.

One patient particularly appreciated the pastoral care, commenting that she could always manage to get hold of the priest when she couldn't get hold of the surgeon.

# Summary

## Environment

Patients made negative comments about mixed-sex wards, ventilation problems, poor signs, noise, difficulty in sleeping, telephones and buzzers not working, privacy problems, poor cleanliness and hygiene and food.

## Conclusion

A number of important issues were raised by patients regarding their hospital stay and their treatment. Many of these issues can, and will, be developed into questions which will be included in the questionnaires mailed to a large sample of patients from the Trust.

The main issues to be included in the survey will be those on which **only** patients are the best qualified to comment. Patients, for example, are expert witnesses to the health care process – admission, continuity, information, communication, education, emotional support, involvement of family and friends, physical comfort and discharge. They can also comment with authority on the staff they had contact with. All of these issues will be covered in the questionnaire.

However, some of the issues raised by patients, although important, can be measured in other ways. These tend to be issues related to the hospital environment, such as ventilation problems, signs, telephones, and televisions. For example some patients commented that the buzzers or call buttons don't always work, this can be measured by technical staff periodically checking that buzzers work, rather than asking patients whether they work.



# Introduction & Background

## 2. Introduction & Background

### 2.1 The report

Picker Europe has been commissioned by the Lothian University Hospitals NHS Trust to carry out a programme of study to measure patients' experiences of health care, so that hospital staff may improve the standard of care they provide for their patients. The main research tool will consist of detailed questionnaires mailed to recently discharged in-patients at home, asking them a series of questions about their stay in hospital.

This document is the first of two preliminary reports on the development and testing of the questionnaires to be used in the survey. It contains an analysis of focused group interviews with recently discharged patients. Its primary purpose is to inform the design of the questionnaires, by highlighting the kinds of issues that are important to patients in the quality of care that they receive at local hospitals. A subsequent pilot study report will address the testing and refinement of questionnaire design.

The main body of this report is a description of a range of issues raised by a small number of patients, illustrated by verbatim quotes. The experiences related by the patients, and thus the report, should not be seen as representative of all patients and should not be generalised to the whole Trust. However, the experiences described by individual patients provide evidence of areas for further investigation, and their comments illustrate what it was like for them to be patients at the Trust.

### 2.2 Focus groups - background

The advantages of questionnaire surveys are well known, and include the ability for findings from representative samples to be statistically inferred across whole populations. However, the rigour of survey design method requires that respondents be presented with pre-determined question and answer options. Therefore, it is important that such questions address issues that are likely to be relevant and recognisable to the target population.

Picker Europe uses focus groups and in-depth interviews with local patients to assist in the development of its questionnaire surveys. Characteristically, these methods aim to provide a neutral setting in which participants are encouraged to express their own views on a subject. Patients are asked to discuss what happened to them during their stay in hospital from admission to discharge: what their experiences were, and what they considered to be the most important things about their time in hospital. The interviewer (or moderator) probes and seeks clarification from patients on what they say. In the case of focus groups, the interaction between individuals can enhance the range of issues and perspectives collected.

Because focus groups are exploratory and concentrate upon the richness and variety of experience of relatively small numbers of patients, they are rarely used for making more generalised assumptions. Their strength lies in identifying a wide range of issues and perspectives on the care that individual patients receive, which can be used for further investigation.

# Introduction & Background

## 2.3 Focus group - details

Three questionnaires are being modified for use at Lothian University Hospitals NHS Trust based on the groups and interviews. They are:

- Adult in-patient
- Paediatric (questionnaire to be completed by parents/guardians)
- Childbirth/maternity

Groups and interviews were run from 19<sup>th</sup> - 22<sup>nd</sup> July at Central Edinburgh Library and were moderated by Mrs. Kit Ward, an experienced group moderator.

Samples of patients, discharged in April 1999, were sent letters from Dr. Charles Swainson and Picker Europe inviting participation in the groups. Adults or children wishing to participate telephoned Picker Europe on a freephone telephone number. Participants were paid £10 to cover their expenses.

The participants contributed to the groups in confidence and names of participants are not known to the Trust – any information which could identify individuals has been removed.

### **Adult in-patient**

Three adults groups (one male only, one female only, and one mixed) were planned. In practice, no females were willing or available to attend the mixed group, so two male groups and one female group were run. The sample was chosen to be broadly representative of patients from the Royal and Western hospitals in terms of age and of admission type (planned or emergency admission).

### **Paediatric**

For the paediatric questionnaire, separate groups were run for both children and parents.

For children aged 9 or under, a group of their parents was run (all mothers).

Four groups of older children were run - boys aged 9-11, boys aged 12-13, girls aged 9-11, girls aged 12-13.

### **Maternity**

One group of women who had recently used hospital maternity services.



# Adult in-patients

## 3. Adult in-patients

### 3.1 Treatment and the treatment process

The principal focus of the group discussion was what happened to patients during their stay in hospital, and in particular their treatment.

Patients made a number of general comments about what it is like being a patient in hospital.

They described a feeling of powerlessness:

*You have no power. You're in their hands and there's nothing they can do about it; not that it worries you, because you're being looked after; you know you're being looked after. You still get a feeling that there's nothing you can do about it.*

a loss of dignity:

*It's terrible trying to keep your dignity when you're in hospital, it's a waste of time! [laughs]  
Oh yeah, definitely.*

and a feeling of being intimidated and vulnerable:

*It's a bit intimidating, a hospital, a big hospital, like that, where you're – you're, you know, you go in and you sit down in that place and you're waiting for your turn, and the consultants are all in little rooms along the corridor. And one comes out and shouts your name, and then you go in ... You're sort of, there's a slightly intimidating, um, atmosphere.*

*You're very vulnerable when you're lying there.*

*The people that were there were just really, really intimidating.*

Patients also made more specific comments about aspects of their care and treatment:

#### 3.1.1 Pre-admission

Some patients with planned admissions commented on how useful they had found a pre-admission visit in terms of helping to allay their fears and anxieties, and giving them an opportunity to meet the staff who would be treating them.

*I was also invited for a pre-admission visit right and met representatives of every single person that would – The nurse, the theatre sister and the, one of the senior house officers – and was told absolutely everything that would happen, down to having a great debate about what I was prepared to sign on the dotted line for, including being told that there would be a medical student present in the theatre, and only one, and did I have, y'know, did I want to give permission to be examined, since they've all got to practice these things. Ehm... So I felt I knew a lot.*

*I knew exactly what I was going to do and how long I was going to be in and what exactly the surgery entailed.*

*I think within four weeks I got a letter to come and see [NAME OF DOCTOR GIVEN], the surgeon who was performing my surgery, and I had meeting with him. He explained me basically what was going to happen, as to where the cuts or the incision would be, and there was a liaison sister as well with him.*

## Adult in-patients

*So, I mean, I appreciated what they had done with the liaison officer and sister got in touch with me, saying: 'Look, this is my personal number; if you have any problems – if you change your mind. Thought that was a very good experience, but then I get there, I got there, and it was a totally different experience.*

Patients who had received written information before admission (booklets, posters etc.) found these to be very helpful, well written and informative.

*I had paperwork, eh, booklets and posters telling me all about what was actually going to happen. They were very, very helpful, even the surgeon was very nice, very good. They handed the brochures and they tell you to take it home and read it, and, of course they, they tell you the facts first, you know, what, what, what's what, and then they tell you what's happening with you, where you get, what happens when you get done and, the medical care, the kits and all that that they give you.*

*Where to go to – 'You'll be met by,' and I've got to hand in this letter to what was it, the Central Admissions or something. And, 'Then you'll be taken to the ward and you'll be handed over to,' um, 'to a nurse who will show you your bed' and that sort of thing. This was all contained in the letter. And it's quite informative; –It's very good, uh-huh.*

*Well, they give you a booklet and ...and it tells you more or less what's going to happen to you when you arrive, when you arrive. ..It's – for someone who's been in hospital, as I have, you know, a couple of times, it's fairly obvious what it's all about: you know, there's nothing new in it; it's quite well put, you know, put together. Very informative. Information for all other patients and visitors: what to bring with you' – this is very good. It also gives all the telephone numbers of the wards, if – you know, which particular ward, so your relatives can phone up and find out how you're getting on.*

Some patients, however, reported only being able to get information when they specifically asked for it, or that they had to research their condition themselves:

*I... only got answered what I asked, and knew what to ask only because I'd researched and knew a lot about it, coming from the Western into the Royal. But, er, if I hadn't been the sort of person to say: 'What's going to happen? Who's going to do this? How am I gonna feel afterwards?' I would have known nothing.*

*If I hadn't asked, I wouldn't have known. I was given very scant information. I was just told I was going to have two surgeons: one opposite, one operating at the tail end, one operating and the tummy end; I would experience a few, a bit of pain for a few days, but they hoped everything would be all right.*

*I knew nothing, except what I had researched myself and asked about. If I had waited for the hospital to tell me I'd have known nothing.*

### 3.1.2 Admission – emergency

Patients admitted as an emergency reported being somewhat confused by what was happening to them:

*I wasn't planning to go in: I was taken in under emergency. I wasn't told anything. Everyone else seemed to know, sort of, other things... everything just seemed to be done behind my back.*

*I just wanted to know what had happened to me, you know.*

A patient admitted via A&E described the humiliation of waiting in a hospital corridor for over an hour for a bed before being admitted:

## Adult in-patients

*Yeah... I got left on a stretcher in the corridor just while they had a chat and went and got a cup of coffee, and then wheeled me off somewhere else. About an hour, just lying doing nothing. Was nobody... coming to tell you what was happening or anything? No. Nobody at all. It was humiliating. Because there were just people walking past, just looking at you – it was just... not very nice. Just in a corridor. They're all walking past you and... just giving you sort of odd looks and then stopping and chatting with the doctor who was with you and then sort of just... Don't know, it just seemed really humiliating.*

### 3.1.3 Admission – booked

Some patients with a booked admission also reported having to wait to be admitted to the ward. One patient who had been advised to arrive at the hospital at 10am was not admitted to the ward until 4pm that day. Patients found this to be quite traumatising, and it made them feel extremely anxious, worried and scared:

*Yes, I was prepared, but now when I reached there my experience was totally, totally different. I was very disillusioned; I was totally... I don't know how to put it, but I was very hurt when I went there, because the day I was supposed to come in on the [DATE GIVEN] and ten o'clock was my admission. Anyway, I eventually got there – ten o'clock sharp – saying I didn't want to be late. It was six o'clock in the evening before I got a bed. All day I was in the waiting room, right – my husband was with me. and as it is you're so worried, you're so tense at what's going to happen to you, and the last thing you need is to be put in a waiting room. And I wasn't the only one. A lot of people were with me in the same situation. Six o'clock before we were given a room – that's the length of time. I asked what was the reason. The person has been discharged but nobody's come to pick him or her up.*

*I had to go and ask them. I said, 'Can you please tell me, why am I sitting in the waiting room? And if that was the case, why did you call me at six o'clock when you know the certain time that patients are supposed to be discharged. It was enough waiting for me: I was ready to walk out. Nerve-wracking, you said. Yes, and I referred to the person who was there, you know, the ? or whoever you can call on duty: I said, 'I feel like walking out. I don't care. Because I've been traumatised even before the surgery, because that four weeks itself was a bit traumatising experience for me, so you see what a disaster having to come back.' I've been doing all this – they were suspecting it was ?? clots or they were expecting me to have cancer. So that was ... worrying.*

*I didn't have as long a wait, but I certainly had to wait a long time to actually get to bed. I was very nervous about what was going to happen, and on a couple of occasions, asked if somebody could sit down and talk to me: 'Well, we'll get back to you in just a minute: we're busy at the moment.' Nobody ever got round to coming and sitting and talking to me. My partner had to get back to work, he could not stay with me, so I was sat on a chair by the nurse station, waiting for a bed, with nobody to talk to, worried out of my mind, almost in tears.*

Other patients, however reported no such problems

*No. I was... told to come in at eight o'clock in the morning because I didn't want to come in the night before. And I certainly arrived at eight, and fortunately I was taken first, so that – I had to get myself measured up for my anti-embolism, stop this quite quickly, but no, and I was – it was that kind of ward. I had the ward sister on the phone to me at home and leaving me a message confirming that after I'd been to the outpatients', which ward it was and what time I was to come, and making sure I had the date of the pre-admission visit as well. So my experiences were totally different from anybody else's.*

*I don't know. I certainly knew that there had been in the past complaints about the gynae' wards at the Royal, and I think people had made their views known about that, and they had done everything in their power to make it easier for people to be admitted, and while the*

## Adult in-patients

*surgeons are certainly men, this ward is entirely staffed by women . I consider myself very fortunate in that respect.*

### 3.1.4 Continuity

A number of patients commented that they had been moved from ward to ward (“from pillar to post”) during their stay:

*Well, I was, I was, I was shunted, I was shunted back and forth when I, you know, when I got better and that, before I was in the, the men’s ward, and then after the operation, the care ward, and then there was the time, a couple of weeks after that, the side ward, and then back into men’s ward, you know, just as you go up there.*

*In the Monday morning, whipped off to the operating theatre, and you waken up in a recovery room. Now, that was on the Monday night. On the next day, that was the Tuesday, I was then moved to a side, a side ward, a little ward. The reason for that – emergencies are coming in. So they whipped me out. Everything had to come with me – all the gadgetry and everything else. Then, er... I was only in there for about four hours; a television and everything, it was marvellous, you know, I thought it was just great. It’s adjacent to the operating theatres obviously. And they decided to move me again, and there was an argument in front of me about where I was to go and what could they do about it. Anyway, they decided I was going to go back to Ward 37, which was through a rabbit-warren right the way down to the basement, you know – not the basement, the ground floor – to this place. I was a bit upset about that, because I – I’m supposed to be not very happy about this because I had a serious operation; twice, actually: they whipped me back into the operating theatre after the first operation something went wrong. I thought, This is no way to, you know, to handle me, moving me and pushing me about like this. So, down all the stairs and all the lifts and everything and into Ward 37, and into... the same room that I had started off in. I couldn’t remember how long I was in there – I think it was one night. Taken out of there, put into another little room, which really wasn’t a ward you know, it was – there was no window in it. It was just a door with a glass top; there was nothing in it – it really was a store room. I was put in there. For one night. Taken out of there and put into the other four berth, where I stayed till the Saturday. Altogether, I was in six different rooms in the six days.*

*Moved me out of one ward, the orthopaedic one, which is mixed – ?? in there, settled; then we were moved to a bigger ward. I was there for two days and moved back to the side-ward. And then after my operation, the lady next to me was going to be moved, and refused: in fact, filled out a complaints form. So I said I would go: anything would be better than no buzzers, no phone. So I was out to Ward Four, and then they were wanting to move an old lady of eighty-nine after a couple of days. So I said I would go. It was going upstairs to Ward Eleven, I think; surgical. And the nurse eventually said ‘If you go up there, you’ll never see an orthopaedic surgeon, because my wound had been bleeding from eight o’clock that morning; about seven they looked at it; decided it should be cleaned and I should stay where I was. But you couldn’t really move an eighty-nine year old. I mean... It’s too upsetting. This was her third or fourth move.*

Patients found this to be quite upsetting:

*All this moving about all the time was very distressing.*

*I was a bit put out over all this. I felt I was just being pushed from pillar to post. But all right, maybe they ?? more sort of serious case, but I don’t know.*

*Well, you’re in your bed and they trundle you along with the porters grumbling [laughs] – they always grumble about having to do this, you know,. ‘It’s not in the schedules’ and all the rest of it. It’s... It’s a funny, it’s not a – it’s not a pleasant experience to be moved about from room to room – six different rooms in the six days – I thought that was a bit off.*

## Adult in-patients

Patients also commented on the fact that they were often moved around within the ward without explanation - this caused particular distress for one patient's partner who thought she may have died:

*And back to the moving about, I wasn't actually moved ward to ward, but I was moved four times within the ward I was in, which very much traumatised my partner – he arrived on the ward to visit me and couldn't find me. He thought I'd died, because I was expected to be not well, and racing round looking for somebody: You know, and I mean, he thought they'd shipped me off in the metal box. You know, and that happened four times.*

*It wasn't a case of they keep you near the nurses' station while you're seriously ill and then they move you. No, I think I was just moved because they felt like it, because it had nothing to do with how ill you were.*

However, not all patients were treated this way, and one noted how good it was to see the same team of nurses all the time.

*I was just transferred from the major heart care unit to the ward and then I stayed there.*

*And there was two teams of nurses, and there we got the same people coming back on, so you weren't fazed with, y'know, seeing completely different faces every day.*

### 3.1.5 Information about their condition

Patients had differing requirements regarding the amount of information they needed about their condition. Some patients wanted, or expected, to know every detail:

*I wanted to know everything. It's nice to be given the option of saying 'No, thank you, I don't want to know.' It's nice to be given that option.*

*You expect them to tell you what's going to happen.*

*You know, I like to know what's happening to me body and that, you know?.*

*I would have probably really have, you know, just lay there and say, "Well I'm in the right place for being treated well," you know, like, you know but eh, I just felt I, I was just sitting there all day, and nobody come and said, you know, "This is eh, we've figured out, you know, this is what happened to you so far...".*

*Well, I, I wanted to know what was happening to me, you know, like I mean I woke up blind, I couldn't remember much, you know like, you know I could remember my wife's name, that's all I could remember at the time, and nobody was giving me information, you know, I was asking nurses and they'd say, "Oh, just wait, the doctor'll be coming round," you know, like I'm sat all day waiting for the doctor to come. And the first time I seen the doctor was on the Thursday.*

*I was just completely different, I knew nothing. I had to ask to see a doctor on the Thursday, to find out what was actually happening to me, I asked the nurses and that, they said, "Oh, ask the doctor," and I never seen the doctor all Thursday, I didn't know what, nothing, you know, they didn't help me at all.*

*You were led blind – they expect you just to cope with what was put in front of you.*

*Your arms and legs are all flying around everywhere, and they give you an injection, well I had them five times, within three quarters of an hour, you know, it was never explained to me*

## Adult in-patients

*what.....what was wrong, you know, like what the injections were [R4 coughs] I found out later the injections were, but em, you know like eh, I was never told what was, what caused that... Yeah, I would, yeah, you know, more information, maybe, you know.*

Other patients, however, didn't always want to be told:

*Oh yes. You want to be told but you don't want to be told too.*

*I really didn't want to know, I just wanted to be out of there.*

*Don't always want to know what is going to happen.*

*This funny thing – when you're in hospital you're apt to take, accept what they're saying and you don't ask any questions. I found that you don't really want to know too – you know, you don't want to sort of ask too many questions.*

### 3.1.6 Ward rounds

A number of patients found ward rounds to be rather intimidating (see also medical students 3.2.4)

*It's very intimidating and it's very annoying, 'cos you don't really want to say anything, 'cos there's – everyone's taking notes and everyone's asking you different questions.*

*Then a big group of student doctors would come and look. At one they were just like – there was something like fifteen people standing round my bed asking me questions, and I was, and you're tired and you just, it's not that nice.*

*Yes, some of them were because... well, they'd all come in at once and, like, shut the curtains and ask me all these questions, and it was... You didn't really want to answer them because there were just so many people watching you. Like... writing down everything you said, so, you just, you didn't want to say anything so you just stayed quiet.*

Ward rounds were not always at convenient time.

*Saw a consultant after breakfast, sort of breezed in, but you were in the middle of washing, or after lunch: they didn't seem to have set round or a particular time of day so you were always either coming out of a sleep or... not fully awake when they were doing their rounds, that's what I felt.*

One patient did, however, approve of ward rounds.

*The ward round. Yes – and they went round twice, twice a day to see how you were doing.– I think it's good.*

## Adult in-patients

### 3.1.7 Communication

Patients raised a number of issues regarding communication.

A commonly expressed view was that patients felt that they were always being asked the same questions over and over again by different staff.

*Yeah, every ten minutes there was someone else in that would come in and say 'I'm whoever' and 'Tell me everything,' and then you'd have to go over it again.*

*There were always people coming up and asking the same questions, that's the medical staff, I don't mean treatment medically, they were very good, but they seem to ask you the same questions over and over again, your name, and, I made some comment that my indigestion was caused by cucumbers, and I got this repeated to me time and time again, it's... I thought, why can they not just have a laptop with all this information on it and save having to go over the same information again?.*

*Yes, every time I've been in this hospital, I have been asked the same questions two or three times, em, at least, it does seem that every different branch of the care area asks, are required to ask you details, the physiotherapists, the nurses, the doctors, em, any other branch.*

*It's really very very depressing to – repeating and repeating and repeating.*

Patients related this to the fact that all the information should be available in the hospital record.

*What, what annoys me about that is, they've got your, your, your em, your folder, now what your folder is, is your medical history in it, and they just say, your doctor's coming round in the morning, your usual doctor, you know, coming round, then all of a sudden, "Can I bother you, Mr Smith? Eh, now, how did this start?" All over again, through what the lad says, he goes away, and there'll be another after it, "Is it alright if I bring some students in, Mr Smith?" It's just never-ending, it's never-ending.*

*What I found particularly depressing is repetition. As I said before, you have to repeat everything from day one to the day you've been admitted to the day... Once you have written it down, what is the need for repetition? As [NAME GIVEN] said, they write everything down, so I assume the doctor or whoever has come can read. He's got the file in his hand, so why does he want me to repeat time again and time and again and time and again as to what's wrong with me – 'Right, how do you find it? What's wrong? What do you think is wrong? Do you do this? Do you believe ??' – but everything is in the book.*

*But I still maintain that they should be able to, instead of coming round and finding out what's wrong with you, how it started and that, there it's there in black and white.*

*Read the notes.*

One patient found it quite disconcerting that everything she said was being written down.

*Eh, everything I said was written down, which annoyed most, 'cos I wasn't told that, and it was all used against me later, and I found that very irritating. I was quite intimidated by everything.*

One Asian woman commented on the fact that another Asian women had problems communicating with hospital staff.

*I don't have any problems where language is concerned, but there was one Asian woman just across from me, and she had no command of her English language, spoke all broken English.*

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*So either her children or husband, whoever, whether they stayed in their own room or were forced to stay by the woman because she couldn't converse.*

Another patient was concerned that his medication had been changed without his knowledge.

*There were a couple of instances where the medical staff, not nursing staff, but the, the doctors, the doctors who were the team on duty at the time, but not the ones actually performing the operation or what have you, did on, on a couple of occasions actually change my drug therapy without either discussing it with me, or, or telling me they'd changed it, and, em, that did disturb me.*

*What, what did that make you feel, this lack of information? Well, I felt they could certainly have been a lot more reassuring to me— I mean, I'm not a person that frightens or scares easily, but a lot of people are, and had they been facing the same was me, would have been terrified. You know, it really was quite – I was running blind. I really didn't know what I was facing.*

### 3.1.8 Surgery/Tests

Patients had differing experiences regarding the amount of information given to them before an operation. Some patients had a detailed and useful discussion:

*I think for me personally it was – I think I was also able to ask them things that I wanted to know; you know, I'd also been primed by some people as to what to ask – do you know what sort of operation? You can ask – and I felt I could ask about how much anaesthetic I wanted, and the theatre sister said, 'Tell the anaesthetist you don't want this, you want this.' [laughs] So I think I was primed and quite reassured about the kind of surgery I was gonna have.*

*Well, I knew what was going to happen, yes. The, the...em, consultant came and saw me, and the anaesthetist came and saw me after they'd something they had done some machine tests on me. And they both came to, to discuss the whole thing with me. And then the night before the op, the anaesthetist came by and then I seen probably the registrar of the ward came and said – You knew exactly what they were going to do.. You know, the anaesthetist was particularly good – in fact there was two, two anaesthetists came to see me. They, they, they just explained exactly what you were going to go through, and that was it.*

*As I say, as I say, when I'd went in, I'd had the week's test, tests, when I went back in on the Wednesday for the operation, before that, the surgeon came in, and the doctor came in, and they just explained to me what was happening with it, and, you know, how long it would take, probably, to, after I get it, it'd take a minimum of so many months before I could go back for the reversal.*

However, for some the discussion with staff was clearly insufficient:

*He'd come to sort of check my lungs and everything, make sure I was fit for the anaesthetic, and very roughly went through what was actually going to happen. But, I mean, I, I woke up with a ten-inch scar across my tummy that I didn't expect to have. You know, I thought they were gonna sort this end and put a hole here. I didn't expect to find this huge big scar as well, you know? I just didn't know it was gonna happen until I woke up and found out.*

*Yes. They never told me at all – nobody had mentioned that my prostate was going to be removed, and I found that a wee bit strange: afterwards you're told it's gone.*

*The surgeon who was going to operate spoke to me. No, it was about an hour before I went down to the theatre. Being kept waiting to not know what's, not know what's going to happen. I mean, I had a good idea of what was going to happen because of my own research, because of asking people. But it certainly wasn't volunteered from the medical side at all.*



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One patient reported having to demand to speak to the surgeon before the operation:

*Because I had asked to see him. I said there were a few things I wanted to put at rest. He wasn't going to come and see me if I hadn't asked.*

*The consultant, when I, when I pinned him to the bed sort of thing 'Stay here and talk to me, tell me what you've done.' Because they didn't exactly – they weren't exactly sure what they were gonna have to do to me. I would have been a lot calmer, a lot easier in myself. Er, more able to face it; less of a nervous wreck. And I think, had I been... more stable mentally before the surgery, I would have recovered quicker after it.*

Another patient commented on how helpful it had been to talk to someone before the operation:

*Somebody did sit with me, for about fifteen minutes before I went down to theatre the next morning. By that stage I was so traumatised I didn't speak to anybody, but she just sat aside to me and listened to me say nothing, but yes, she did sit at the side of me until I went down to theatre, which was really good, yeah.*

After having had a test, one patient commented on how anxious she was having not been told the result:

*The one complaint I had was about the radiologist at the out-patients' clinic, who told me nothing about what she actually saw in the scan, and had me thinking there was something else wrong with me than there actually was.*

Another patient reported good care after their operation:

*No, well, so many people came, and doctors came to see you after the op, you know, every day you were testing satisfactorily and all the tests they did, y'know, were satisfactory and they let you out in eight days.*

### 3.1.9 Pain management

Patients had differing experiences regarding pain management. One patient was given very useful information about pain before being admitted:

*Certainly in terms of pain management I got a leaflet from my pre-admission visit which said, you know, that you must not be in pain; you mustn't allow yourself to get – because it actually won't help your recovery.*

Some patients appeared to have their pain well controlled. One patient commented that the self-feed morphine drip was particularly useful:

*Yes, I was given painkillers when I wanted. In fact, before the surgery, the night before that when I had the talk with the anaesthetist and he told me that 'Would you like some sleeping tablets?' I said, 'I'm having, y'know, nightmares just thinking about it.' He said, 'Would you like some –' He was an excellent man, really– because I'm not actually diabetic but I'm on the watch: if I don't take care with my diet. So this time I pointed it out that this is worth mentioning, because I don't want any complications: because of stress my sugar level is up. So I mentioned to the anaesthetist at that point that I am not diagnosed a diabetic, but my sugar level tends to go up. So he said, 'well, that's fine.' I told him, 'Just in case there is some complications at that point.' He said, 'That's fine.' He was very good and gave me all the relevant information I was wanting, apart from when I was going to ?? ask a few other illnesses which I have thought about but I didn't know much about. Because he was such an*

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*easygoing guy that you could ask him about anything, and he told me, 'Would you like something – sleeping tablets?' I said: 'Fine.' He gave me, he must have prescribed such good ones that about fifteen minutes later I don't know where I was. Well, I'm going to be restless: this painkiller – sleeping tablets are just not going to work. The morning I was refreshed as anything, because I'd put my anxiety to rest, you know?.*

*They were always asking you 'Are you in pain?' They were always checking on you, all the time. Too much.*

*That was it, but the time I'd actually got the pain management - about six o'clock, could I please have – 'cos I had a sore back. 'You can have it whenever you like. What do you want?' And that was responded to.*

*I was actually put on a self-feed on morphine when I first came out of surgery which they give you for the first twenty-four hours, you know, and you feed your own morphine; that's fine and then that came off.*

Some patients did report problems in this area particularly when having to wait for pain relief, with the timing of medication, the strength of medication, and the fact that qualified people were not always available to prescribe medication.

*Pain management Doesn't exist.. Supposed to do drug rounds six, ten, two, six, ten; they do drug rounds breakfast, twelve o'clock and six o'clock. And at twelve o'clock, those that are due their ten o'clock drugs get them late and those that are due the two o'clock drugs take them early. Because they only have the time to do a breakfast, a lunch and a tea-time drug round. So you have to organise your pain management. There was one day I was in an amount of pain; I'd already had the drugs that had been prescribed for me, but they weren't enough; and I was told that I would have to wait till the surgeons came out of theatre to have something written up to manage my pain. Two hours later I was given a morphine shot and they were peeling me off the ceiling by that point. When the surgeon eventually got up the ward, when I insisted that they found somebody to come and write me up with some painkillers that would actually kill my pain, the surgeon came up and was appalled that I had been left in the pain that I was in, rather than the nurses call someone to come and do something about it.*

*Where do you think that went wrong? Who do you think was responsible for that cock-up? The nurses. The nurses. Because the surgeon within seconds wrote it up: he didn't know I needed it until he was told, and he wasn't told for two hours. And it was all a lot of codswallop that they were all in surgery, no one could be called and the house officer was not qualified enough to write up the pain management I needed. A whole load of codswallop. They were just too busy to do anything about it: too busy to even make a phone call saying 'Can you come and write up something for Mrs Smith.' Took me two hours on one occasion. From that point onwards, I only had to go snap and it was there, because the surgeon was so disgusted with them..*

*I actually spent two hours waiting for a morphine shot at one point.*

*It might have been a case of because of the strength of the drugs that I needed, you know: it was a case of only certain people were actually qualified to prescribe what I needed. I was told he was in theatre and couldn't write it up.*

*If you did ask for strong painkillers you just got paracetamol. And hydrocodeine, something, dihydrocodeine, and people say 'Oh, you should ask for relatives to bring you them.' Painkillers. Or sleeping tablets, because you could not sleep.*

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### 3.1.10 Co-ordination of care

Patients were concerned that there was no named person in charge of their care, and no one clearly in charge of the ward.

*It would have been nice if there was somebody where you could say 'Listen, I've asked so-and-so and I understand she's busy, I realise, I don't mind waiting a wee bit, but this is now getting a bit silly.' You know, and it just went on and on. And there wasn't anybody who would actually at some point say: 'Right, do something about this.' It just got shipped round, it really was. Everybody just passed the buck.*

*Yes. I didn't realise – I mean, there didn't seem to be a central figure in charge of the ward at all.*

*No, I couldn't sort of say 'There's Nurse Jones' or whoever. There was no lynchpin on the ward at all.*

*That's – 'cos we had a kind of keyworker type system on our ward: they would come on in the morning, and it was usually the staff nurse. The sister would be there but it was the staff nurse; and then there would have been another nurse underneath that, and a student attached to each team: the staff nurse would come and say 'I'm on today, so if there's anything you want it's me or Catherine or whoever.' Quite a different sort of experience.*

*I couldn't pin down one particular person to ask for strong painkillers.*

Although one patient had a very clear explanation:

*Well, I think – what the surgeon said to me was, the consultant said, 'It's like this: I control things in the theatre, but Sister [NAME GIVEN], the ward is her province and I must consult with her about when you're going to be admitted.' And I think that's exactly how it was.*

### 3.1.11 Discharge

Patients reported contrasting experiences regarding their discharge planning.

One patient was particularly frustrated to have to wait several hours for their medication to be delivered from the pharmacy before being discharged:

*I was prepared and couldn't get home for hours... Like I had to wait hours to get in the bed, I had to wait hours to get home. I was told I was going home on a set day, but it took five hours to get my drugs from the pharmacy so that I could be discharged.*

Some patients found their discharge to be very well coordinated and planned. Some were given verbal information, which they welcomed:

*Yes. My after-care was better than the hospital care. I was advised what to do and how to take care of things at home, and what's the problem and what to panic about and, you know, what's to be expected.*

*No – On that same subject, though, I do recall now that on the Friday before the admission, you were interviewed by – I don't know whether it was a nurse or whether it was some social side, you know, a social... what do you call it, some sort of person – asking masses of questions about your home environment: 'Do you have stairs? Have you difficulty in this and that and the next thing? Have you a shower? Have you a bath?' You know, all the personal things, so they have a picture of you. And in my case it was 'Yes; No' and they were perfectly all right, okay. The same questions were asked again after the operation: somebody else came*

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*around, you know, a nurse and asked – a big ticklist of all the things, asking more or less the same questions– Obviously they were concerned to know what, how you would be able to cope with being back home again.*

*Everything at home was beautiful. Was excellent, yes. brilliant aftercare, both from the ?? nurses and from my GP, from my family; I could not have wished for better care. Had I got the care in hospital I got at home, I would have recovered a lot quicker than I did. But then, despite the care I got at home, I had a relapse, which wasn't anybody's fault – it wasn't the hospital care fault, it wasn't the care at home's fault; it was just one of those things. You know, I developed a twist in my bowel; I developed a bowel obstruction, and I was rushed back in, back in in the middle of the night.*

*Em, they, they eh, whichever, whether it was a physiotherapist or an occupational therapist or a doctor or a nurse, the appropriate person always took the time to say, 'Well, these are the things you're going to need to think about', em, 'this is, this is what we can do for you, this is what we recommend, and this is why'.*

*No, they, laid on an ambulance to take me home, em, I was blind in this eye, since it happened, it's never returned, you know, and eh, the doctor came round on the Tuesday when I was getting ready to go you know, he, he told me more about what's happened to me than all the other doctors, he was just a junior doctor, really, you know? And he told me what, what I needed to do about losing weight and things like that, you know, my weight was a big... you know, what would happen to me, so, as I say, I've lost.*

However, some patients found too much verbal information was given, and would have liked something in writing:

*It was all verbal and I forgot half of it.*

*Obviously they're spinning this much information past you, and you're already ingrained traumatised, worried about how you're going to cope when you get home, and it goes in one ear and... some of it stays but not very much.*

*It would be nice if they'd give you that sort of thing to take home with you: 'Look out for these things; we're not saying you're going to get them but look out for them; these may happen, and if they do, call your doctor, call us', you know?.*

Patients waiting for test results commented that these took a long time to reach them, and their GP:

*Well, what I found was that the aftercare results are not very good, once you're discharged. I mean, I don't expect them to run after me – not at all. Once I'm discharged, that's it. They did not write my results to my GP for a month.*

*For a month I kept phoning; I went and I said, 'I had to phone after seven days; they told me that after seven days your results would be in, blah-blah-blah.' So I said, 'Instead of me – I know you people are busy so instead of me calling you up, because I'm anxious, I'll wait. I won't be calling again and again, just chancing my luck if the results are in. So once the results are on the table, would you kindly call me and let me know. So that's only one phone call you have to make and I don't have to bother you as much.' They said: 'Fine.' They did call me, but my GP was not informed – in fact, I was diagnosed with tuberculosis. This is what the diagnosis come up. And a month after I had been diagnosed, my treatment wasn't started, because my GP didn't know what was wrong with me. A month! Now, and this is the point I brought up with my GP – when I ask for six months' extension, suddenly they jump down my throat, saying no, they don't want to leave it so long. 'So why have I been left for one month when I've been diagnosed with something?' Does that make any sense? He says: 'No.' To today, I have not had a screen – that's two months I've been diagnosed; my course is finished.*

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*I was discharged on the first of May; this letter to my doctor is dated the first of May, to tell my doctor what had happened – this was moved, et cetera et cetera. And it says at the end, 'We will follow him up once the results of his biopsies, which we expect to be benign, are known.' Now, I've never been – no one from the hospital has followed me up at all. My doctor got this letter and he just filed it away. I got the feeling that nobody wants to know. The operation's finished; it's done; you're sort of in limbo. And you're told, of course – you get a, you get a sheet advising you the kinds of thing you must avoid doing like heavy lifting and all that sort of thing, exercising; if you've got a large wound across your abdomen, then you've got to exercise, you know – ??, you get all that. But that's all. Now, I would have thought that the, um, someone in the hospital – the registrar or the senior consultant or whoever, would have wanted me to go in, perhaps have a chat and see how it's getting on. Now, it's now twelve weeks – twelve weeks since that operation, and nobody from the hospital has indicated they want to see me; yet in the letter it says, 'We will follow him up once the results of his biopsies are known'. Well. I went to my doctor and I said, 'What about this?' He says, 'Oh yes, I've got a letter from the hospital says that your biopsies were clear; everything's all right.' That was weeks and weeks and weeks and weeks ago. I think somebody's falling down.*

*I went back to the hospital – I went back to my GP: shortly after coming back home after... I went to see him, to let him know what had happened, because I'd received a copy of that letter, and I was very upset about that letter because it mentioned nothing about the operation. All I told you was that there were no complications; that everything was all right, and so on and so on. Nothing about the, the sort of traumatic experience that happened in the operating theatre. So I sort of got the feeling that they don't want the GP to know about it: that this is something that the hospital authorities want to keep to themselves. Now, I may be a bit... wrong about that, you know, but it's, it's most peculiar. This is why I went back to my GP and I told him what had happened. You know, when you find that... when you find the, the senior staff nurses phoning your wife to tell you that things are a wee bit dicey and you had a large blood transfusion and he's had to go back into the operating theatre, and then later on the surgeon tells your wife that you're holding – 'He's holding his own', you get the impression that it was a serious business, but my doctor wasn't told anything about that. All he's been told is: no complications; there's what to do. Now it's this I think is a fault. My GP is not in the picture, or was not kept in the picture.*

Patients expressed differing views on whether they were ready to go home or not.

*I wasn't really prepared to go home but I just wanted to go home.*

*I would have liked to have been comfortable enough in hospital to have stayed a while longer. I mean, I have been having to learn to use colostomy bags and all those sort of things – would have liked to have been there, but because of my care I just needed to get home. So I learnt more at home than I did in the hospital.*

*I didn't feel comfortable enough to want to stay until I felt well enough to go home – does that sound stupid? [laughs].*

*Yes, because of all the trauma and the hassles and the nursing staff and the filth of the place and the food... I just wanted to go home.*

*It might have been an idea to have sent me off to convalescence somewhere; it was never offered.*

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### 3.1.12 Fear of complaining

Although several patients felt that they had legitimate cause for complaint about their treatment, they expressed concern that doing so may effect their future treatment.

*You're afraid to open your mouth and say anything to anybody, because you think: God, I'll just make it worse. I'll just shut up and put up with it. You do. You're afraid to open your mouth.*

*I'm frightened of repercussions. I mean, the cataract I had has not been and may not be my last one, and I might have to go back there again. And I don't want anything to influence what little bit of care I do get when I go.*

*I don't know. It's... you have a feeling that you're powerless: there's nothing you can do. I mean, you don't want to complain – the last thing you want to do in a hospital is stand up and complain.*

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## 3.2 Staff

### 3.2.1 Doctors

Opinion was divided on doctors, with some generally positive comments:

*I thought the em, the treatment by the medical staff was first class.*

*So I told him no, I didn't know what lymph nodes are, and he explained me all whatever the... relevant explanations were. – He was very pleasant. He was very pleasant.*

*The surgeons are wonderful.*

However some patients noted that they were rather detached or cold, and tended to lose interest once their operation was over:

*The attitude of the surgeons or the registrar or the senior - : there was a detachment, rather... unhelpful .It was a case of: 'Right, you're in for – you're in for an operation; you have the operation and that's it finished.' After that it's nurses that will look after you.*

*And I was a bit concerned by the fact that I only saw the senior consultant once, and that was the day after the operation when he came back, and he said, um, 'Oh, your prostate was a very large one – it was a certain size,' and he just walked off and left me. So, it was, the most important thing of all was the size of the – the removed prostate.*

*The surgeon. I had – I had asked to be given this information to – I had asked to be told how bad my cancer was going to be, and had put my affairs in order, made my will, made my peace with everybody before I went into the hospital, because I knew it was going to be big surgery. But –knowing that I was facing that, I think I would have expected a lot more TLC than I got.*

Additionally it was observed that consultants were not always available at convenient times:

*Saw a consultant after breakfast, sort of breezed in, but you were in the middle of washing, or after lunch: they didn't seem to have set round or a particular time of day so you were always either coming out of a sleep or... not fully awake when they were doing their rounds, that's what I felt.*

*When you got the consultant by your bed you could ask him anything and he would answer, if you were compus mentus at the time: you know, when you're flying high on morphine and what-have-you, you're really not able to ask anybody anything. You know.*

*The surgeons are wonderful but you, you've got to pin them down to get them to talk to you.*

### 3.2.2 Nurses

In general terms the nursing staff were rated very highly by patients:

*The nurses, the staff nurse, everybody I could not fault them. I just couldn't fault them.*

*The, the, the ward sister usually had... her fingers well on the tab for each patient: she knew exactly what was wrong with the patient and what treatment the patient was to get. Very very astute, these sisters on the ward that I was in.*

*The nursing staff, the professionally qualified nursing staff were all very good, em, the medical staff were all first rate.*

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*Never, I was always, whenever I needed anything, it was there in a few minutes, to be honest.*

*They would come and ask me, 'How are you? Do you want anything to eat or do you want any painkillers?'*

*There was plenty of staff around and everything, and the care was really good: they came and they sat, they constantly came over to my bed – in fact, a little bit maybe too often – to check: 'Are you okay? Are you feeling okay? Is there anything we can do for you?' You know, they were really good.*

However some patients observed that problems were due to a shortage of staff, and they also drew a distinction between staff nurses and agency nurses:

*So the nurses they hadn't got time. There was not time.*

*The staff are lovely; there was just not enough of them.*

*The nurses, such as there were, the qualified staff were very competent people. There wasn't enough of them – the place was full of agency nurses, student nurses who hadn't a clue what they were doing.*

*My visitors used to sit and talk to her as well, because she used to sit at the side of me. And when I was up and mobile, I would sit and – just to keep her by the bed because the staff were too busy and had too much to do to look after her.*

Particular praise was reserved for nurses on the high dependency wards, although patients noted that they were slightly arrogant and gave less personal care.

*..in a high dependency ward, where you're looked after by two nurses. They're all the senior staff nurses. There's a label on them. And, you know, you can see they're really the tops.*

*Oh, no. Erm, let's say that in high dependency ward, they're so efficient that they don't – It's the difference between – in an ordinary ward with a nurse, they're more friendly; these, these super, erm, nurses. They're a wee bit standoffish in some way, because they are the elite. Some of them are very nice. Some of them are a wee bit arrogant, you know: they're sort of, 'We're the tops.'*

*No; when you're in this ward, you're not terribly... compos mentis. You're a wee bit under the weather, they treated you more as a cypher rather than a person, because that's what they were there for.*

One patient held very strong views about the nurses, in one ward in particular

*I felt they were shocking nurses, especially in Ward 37.*

Patients noted that nurses were not always available to sit, listen and talk to patients:

*I mean, it should be common nursing practice to actually sit and talk with the patients and discuss what's going to – happen to them and go through what's going to happen and what they can expect to wake up to, and that sort of thing. And to give a basic question-and-answer session if they need it.*

*It was nice that the priest was there to listen, but I think it probably should have been the nurses' job to listen. To give me the care and the counselling and the support I needed, you know? Only because Father [NAME GIVEN] has been at the Royal for so long, he has picked up a lot of the medical knowledge and knows a lot of what people are going through; you know, I mean, but he's not medically trained, you know?.*



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*I found that quite difficult – 'cos I mean, part of my, part of my surgery – God makes you wonderful whatever state you're in, but I mean, my backside was sewn up and the whole of my belly, and I was feeling a bit like a freak, you know – and it's not something you can sit and discuss with a sixty-year-old priest. You want to talk to a nurse who has seen lots of people go through it, who's used to helping people cope with this and making them feel good about themselves.*

*Well, she came over and, like, talked to me, and... she just... She wasn't as patronising as everyone else.*

Two patients were kept waiting for some time when they had called for assistance.

*Sometimes if you're in the ward and you were needing attention, and you pressed the bell, you could bloody press it for ever! 'Cos sometimes they were short-staffed.*

*And you know, you complained because you're waiting for a call for twenty-five, half – twenty-five minutes, half an hour, and you felt if you complained any more, you just wouldn't get one.*

### 3.2.3 Auxiliaries/Care assistants

Patients had little of a positive nature to say about care assistants.

*Certain types of staff were not perhaps as considerate as they might be about creating, not to create unnecessary noise. Well, in particular, people supplying tea, coffee, table cleaning...Shouting to each other across... ...shouting to each other, and to an extent, some of the, they're now called care assistants.*

*I thought some of the auxiliaries who were in, who were being the sort of, the back-up if you like, were just doing a job, they wanted the curtains opened at six o'clock in the morning, they wanted the tea trolley, the medical, all these trolleys came round.*

### 3.2.4 Medical students

Patients clearly had a great deal of contact with medical students. Some patients appreciated the reason for this:

*these people we're talking about are your up and coming doctors in a couple of, three years time and that, so they've got to know.*

The point was made that patients were often asked for permission before being seen by medical students:

*Well, you were asked, but you know, it wasn't forced on you. They asked you first – a doctor would come along and say 'Do you mind if a couple of Third Year students came along and discuss the case? It would be helpful to them'.*

*Oh yes, of course you're asked, and I said 'No, no: I don't mind. Not; as I say, you'd need to, there'd need to be a reason for you to refuse, and I could only put that down to embarrassment or being unwell and not wanting to be bothered with people prodding you about.*

## Adult in-patients

One patient, however, was not always asked:

*Well no, 'cos they just sort of invited themselves round and stood there. I don't know; there wasn't really anything I could say.*

Patients did, though, find that they were visited too often by medical students, and that this did effect their privacy:

*It's just never-ending, it's never-ending.*

*they take your privacy away, you have no time to yourself.*

*Yeah, every ten minutes there was someone else in that would come in and say 'I'm whoever' and 'Tell me everything,' and then you'd have to go over it again, and then a big group of student doctors would come and look. At once they were just like – there was something like fifteen people standing round my bed asking me questions, and I was, and you're tired and you just, it's not that nice.*

*I mean, you've got them coming in, you know, doctors, nurses, students, I mean, coming in all times of the day.*

Patients also found this to be intimidating or overbearing

*It's very intimidating and it's very annoying, 'cos you don't really want to say anything, 'cos there's – everyone's taking notes and everyone's asking you different questions.*

*That, em, I mean, I, I have and always have had when I've been in hospital quite regular and considerable numbers of students milling around, now it's not something that bothers me, and I've made it clear that it doesn't bother me, and it's open season while I'm there, but a number of people have commented to me that, eh, they find it a little bit overbearing, and, the, I, also have commented that they don't like to say no, and eh, it, I mean it seems to me that it might be, it might be easier, em, for people if there was a slightly different system of introducing students into the ward, or, if em, if people were given a better opportunity to say whether they really did mind or not, 'cos someone, somebody arriving at your bedside with two, three or four students and saying, "Ah, Mr Beveridge, do you mind if we bring some students round?" Now if, as I've said, for me the answer is no, they're there, that's fine by me, but if they're, if they're there and you don't want them to be there, I think it's fair that some people have said that they find it quite.*

One patient reported it disconcerting to have their condition discussed in front of them.

*I had this sort of goitre and they all looked at me and said 'Yes, I would operate on that one,' and they all nodded: they all said they wanted to operate. But of course, they never operated at all. But it's a wee bit disconcerting to, to find that a student doctor or a student surgeon is suggesting the certain things that should happen to you [laughs] you don't know anything about, you see: that's one of the problems.*

One patient had particular problem with a blood test carried out by a medical student:

*I had my x-rays done, which may be very well a regular thing; now, when they asked me for my blood test I told them my veins are very difficult to get to. So instead of sending somebody who was qualified – and not in the sense that I'm not going to challenge them – but they sent somebody, a learner doctor or whatever. The way he poked me, there was blood everywhere but in the syringe. And you should have seen his face as to what he's done. The whole pillowcase was covered.*

## Adult in-patients

*It was the same when they took the needle out. They took the needle out from here after the anaesthetic and everything, after the surgery was over – it was like a fountain of blood. And my son is – He went out, he couldn't see the side of it, because – She said, 'Just press it.' I said: 'Look, I've told you that this is a very – I've still got the mark on either arms' – I was bruised, I was completely bruised, and he couldn't stop apologising. I said, 'But I told you. First you made a mess here – I told you you will not get one here, 'cos this is a problem I have always, you can't find. You want to take one from here.' He wouldn't listen to me. He done that, made a big mess, all blood all over the place, and then the other one, he just bruised me just as bad. I said, 'Do you ever listen to the patients?'.*

### 3.2.5 Pastoral care

One patient made some particularly interesting comments about the pastoral care available to her in contrast to the expected medical care.

*The one good thing about the Royal was pastoral care. I'm a Roman Catholic and at any given time they would find a priest for me. The priest sat and listened to most of what the staff should have sat and listened to.*

*Yeah. And he, he was really good. You know, he would always come, he was always there, you know, and they would phone him for me: I think, I suppose, while the priest's talking to her, she's not bothering us. They could always manage to get hold of the priest when they couldn't get hold of a surgeon.*



# Adult in-patients

## 3.3. The Hospital Environment

### 3.3.1 Mixed sex wards

There was a strong feeling from patients that mixed sex wards were a bad idea.

*Mixed wards - It creates embarrassment to both males and females: not a good idea at all.*

*I was only in the mixed ward for my second, my return visit when I was in the twenty-four hour acute surgical ward, and by its nature it's a mixed ward, because you're only there twenty-four hours and then you're moved somewhere else. I don't think it works at all. You don't have enough privacy and you don't want to ask for the commode – and I don't even like male nurses, frankly. I mean, bringing you the commode and things, kind of – they seemed to resent it to somehow. Er... I mean, I can't, you can't be against male nurses, obviously, but I don't like the experience – and in fact, the government's going to stop all this mixed wards.*

*You were the only girl in your ward? It was quite scary, because... a lot of the men were sort of probably about sixties or older, and, ehm, like a couple of them – one of them I think had senile dementia and he just like – he'd just sort of lie naked on his bed and just wander around naked and the nurses would kind of go.*

*Although they had difficulty with one of the showers in the men's ward: anybody that needed a shower before an op had to be escorted through the ladies' ward, eh, to get in to have a shower. It was embarrassing for any of the ladies – it was usually very early in the morning in any case; probably about half past six, seven o'clock – 'We'll take you to the shower before the ladies get up.'*

*Because once you're out of surgery, you're not aware what part of your body is covered, what is showing – you're not constantly going to fidget with the nightie, whether something is hanging out or something. No, it is just – I think people do feel very comfortable that they are all the same.*

### 3.3.2 Heat, ventilation

Patients often found the hospital too hot and badly ventilated.

*Yeah, I felt it very, very hot in the wards, especially the side ward I was in, you know, like the recovery ward, you know I felt it too hot.*

*Aye, the ventilation is terrible in some wards.*

### 3.3.3 Signs

One patient had particular difficulty in finding her way around the hospital

*There were not enough signs – I suppose everybody must have experienced how to get to the central admissions; it was like a crystal maze.*

## Adult in-patients

### 3.3.4 Noise

Of major concern to a number of patients was the issue of noise, which impacted on their ability to sleep:

*The earlier one, it was just linoleum and all night, [makes sound of shoes on hard floor] clip-clip-clip-clip-clip-clip-clip and I thought, oh God... This time, the whole place had been carpeted, which makes a great difference.*

*There were no quiet spells, even at night, when you were desperate to have a dark area to sleep in, there were lights on, people coming in all the time, I felt that the design of a lot of the wards could be rethought, to give you an area where you'd still be visible, but you could have a quiet area, if you wanted to sleep, or be quiet, you didn't have to have daylight, or people intruding when you were trying to get well.*

*You were stuck in a ward with a television all day – no remote control. No way of shutting it off.*

*One night, they had an industrial hoover out at quarter to twelve. I couldn't believe this. I asked the woman in the next bed what did she think it was; and she asked and they said it's a hoover, because they can't clean these big corridors until very late at night. Couldn't believe this; I had never experienced this in my life before.*

### 3.3.5 Difficulty in sleeping

Lack of darkness and lack of privacy also prevented people from sleeping - patients reported that being able to pull the curtains at night would have helped

*Hard to sleep, well, I like a darker room, I wasn't used to somebody else snoring and, em, movement in the ward, em, it really wasn't dark enough, and you never really got two or three hours during the day that was.*

*I'd have been quite happy to have had the blinds or curtains pulled at night round my bed so I could sleep better, but that was never an option.*

One patient noted that sleeping gave him a great boost in helping him to get better.

*That's, the point I was going to make following what, eh, what you said earlier, sleeping is one of the things which I found to be a great boost, em, eh, helping me to overcome, and to actually, eh, get better, I found sleeping difficult, partly as a result of kickback, there were drugs to be administered late at night and early in the morning, but apart from that, eh, sleeping during those times I found, eh, to be difficult, and I found that to be a constant and quite serious, eh, hurdle to overcome.*

Another patient felt that being roused at 6 a.m. was unnecessary:

*I think I would probably echo a few of the comments which were made about em, maybe designs of wards, and noises, eh, etc, and I suppose it might be good to have quite adequately designed wards, inherently there are a number, a number of people around you, and not everybody sleep silently from ten o'clock at night 'til eight o'clock in the morning, em, I do feel that being roused at six o'clock in the morning is, perhaps, just a little unnecessary, I know it's not as bad, or as rigidly enforced as it used to be, but it still, em, personally, I would have found it quite an advantage to be able to doze on for another couple of hours, you know.*

Finally, a patient who could not sleep was not offered help:

*I walked the wards all night every night and I was never offered a sleeping tablet.*

## Adult in-patients

### 3.3.6 Facilities

Patients commented on some of the facilities available (or not) in the hospital.

#### Telephones

*There were no telephone points, you could not eh, get hold of a telephone in the ward, I think it would probably have been, eh, as much a comfort for my family and friends as it would have been for me, em, and I, I did, I did actually miss not having that opportunity.*

#### TV and music

*I think there should be the opportunity to watch television, and probably, it would be helpful for many people to have a wider selection of programmes than just the five terrestrial channels, em, with the digital TV, and cable TV, it's probably not that difficult em, apart from financially, eh, I think, em some sort of audio entertainment, radio, eh, a sort of remote music selection facility, something like that, that's something I would have liked.*

#### Washing and showering facilities

*But there was big shower units. But not a lock. And then when I was able to get up and have a shave, there was just a wee, wee miniature hand-basin. And that was it, you know: you had very great difficulty having a wash and a shave on your own, and that was... that was in the, all the wards that I was in, the three.*

*The bath in the ward I was in, you had to climb up a flight of stairs to get into the bath – they were like the old library steps you had to climb up to get into the bath, and I was quite weak so I couldn't climb the stairs.*

#### Call buttons/buzzers

*It can't take a week to fix buzzers, but it seemed to. Same with the payphone, that didn't work. Somebody checked it out and that was the end of it. You need something, you need to be able to contact people.*

*For me, when I was in Ward Six, I was in a side-ward, the buzzers didn't work – all the time I was there they didn't work.*

#### Windows

*Well, I think it, it em... if I can see out the window, eh, I can see the outside world, and be reasonably comfortable that I'm going to return there sometime! Em, but if that is removed, then that's one avenue of sort of mental stimulus which is cut off, and you're just left with, you can do nothing but imagine, em, what it's, what it's like outside, whether it's raining etc, and if you have to imagine, then you might imagine things to be somewhat blacker than they are, you might imagine it to be raining all the time.*

### 3.3.7 Cleanliness and hygiene

The issue of poor cleanliness and hygiene was raised by a number of patients

*I made a special request to get a sheet which didn't have holes in it, and the standard of the, the sheets and the blankets was, was pretty awful, actually.*

*At no time did anybody offer me a bowl to wash myself in bed; I was never offered a bed-pan; so I stayed mucky until I was able to move.*

*and that poor lady was wandering about regularly with stained nightclothes and everything on; they couldn't ever keep her clean. I mean, the lady wasn't capable of keeping herself clean, but they couldn't do it for her, and I thought it was so disgusting.*

## Adult in-patients

*The girl did wash my hair for me, but she said she'd never work in a British hospital again, or at least in the Royal anyway, because it was filthy. In the last ward I was in there was a wash-hand basin next to me – the toilet happened to be blocked about an hour before, and just before I was due to be discharged, stuff came gurgling out of this bit – 'Thank you, I won't have any tea.' And that really was – I felt the place should be cleaned out.*

*I've never been in such a filthy place in my life.*

### 3.3.8 Privacy

In general, patients appeared to accept the fact that their privacy would necessarily be compromised by being in hospital.

*First thing you must do when you go into hospital is to forget all ideas about privacy. Any – any ideas about being, you know, any privacy is just out the window. You're all just the same: you're all just patients: you're all sitting or lying in bed and you share things – you share ideas; you talk to – Privacy is something you can't expect.*

*Well you've never really got much privacy in hospital, really.*

*Although some found this to be very difficult to deal with.*

*I really did find there was no privacy. They're asking you questions; it's like – you know, either you whisper or – y'know, you whisper then they ask you again, 'What was that?' So you have to make yourself very clear, and obviously other people are tuning in – not out of choice, 'cos you've got nothing else to do: you're fed up reading the magazines, you're fed up looking at the other person's face, facial features, so what do you do?.*

*Yes, I found that: I mean, there were times – you were just either feeling off-colour or you were worried about things and you just wanted a bit of private time; or you were in pain and you just wanted to shut the rest of the world of. And there was no way of doing it. There was nowhere to go to be alone for five minutes: nowhere to go, unless you walked the corridors, and when you're in pain, you can't walk corridors. So yes, the privacy aspect was – One of my little moves, I was actually moved into the side-ward, which was lovely. The place was an oven, but it was mine. And I loved that, and that lasted for about two days and then they moved me again, which is a big shame, I didn't want to go.*

Lack of privacy was of particular concern to them when using the shower or toilet.

*The showers, there was only one shower for the whole ward, you know, there they had no curtain, you know, you had no privacy whatsoever to take a shower.*

*Yes, the showers where I was, none of them had locks, and like the ones you were in, there was constantly people walking about and the nurses were chasing them about and they'd just got up and do whatever they want, so I was too scared, 'cos they didn't have a lock; I didn't really want to sort of go in.*

*The only facilities that I would care about are the toilets, which lacked privacy.*

Patients found it frustrating that they could not pull the curtains around their bed for some privacy:

*Yeah, 'cos if, if you got up and closed the curtains, they'd be around two seconds later to open them up again. And I don't understand why, because sometimes you just need a little bit of space.*



## Adult in-patients

### 3.3.9 Food

Food was described at best as “adequate” and at worst as “about as disgusting as you could get”.

*I really had no appetite in hospital, but what we got I felt was... adequate. It's not – I wouldn't call it cordon bleu, but I found the food adequate.*

*Very poor choice. It was terrible.*

*Well, to be honest, I... I had a double dose of my anaesthetic: that results in an upset stomach. It all just – you know, you get a nausea all the time for days and days and days; you just – horrible nausea. And it's the result of the anaesthetic. It puts you off – but I tried to eat and I just, it just wasn't any good.*

*Hospital food is just about as disgusting as you could get. So I was like, 'I want something tasty, I want something tasty.' I phoned my husband; I said: 'Bring me anything! Something spicy – just one potato with spices in it, just bring me that: I'm gasping for some good food.'*

*Yes, yes, but I'm sure they could put a bit more into it; I'm sorry, even, even catering for that many people – I used to be a chef for two hundred and fifty students, and I could cater for anybody. It's just a case of size – I mean, there are as many chefs and as many saucepans as there are people to feed, and they could do better than they do.*

*You were limited, like yourself, you were limited to what you could actually have, so you got a choice of nothing and it was rubbish.*

Of great concern to one patient was being offered an out of date drink:

*Well, I actually got, I got supplied with em, out of date fruit juice about three days in a row, that sort of thing, and having had salmonella poisoning in the past, I don't eat anything that's out of date, apart from anything else, in a hospital, it's the very last thing you would expect the, if it's past its use by date, em, so I did, I did em, I did complain about that.*

Some patients valued being offered freshly cooked food from a ward kitchen (not from the central kitchen).

*I think some of the stuff was fine. We also had a ward auxiliary that would have made anything for anybody after your operation, because she said to me, 'If there's something you don't like they'll make you anything – make you scrambled egg, whatever.' And that was fine.*

*Yes, people were offered certain things: if there was something they really fancied eating.*

*Yes, toast or cereal – you just really couldn't eat what came up from the kitchen.*

*I think there's always a small kind of kitchen attached to the ward, because in the mornings, obviously people worked down in the ward ?? were making toast and things like that.*

One patient was assisted by her family:

*My family got wise to it, used to bring me food in to me.*

## Adult in-patients

One patient was concerned that no one noticed, or took time ask why he had not eaten anything:

*Well, I just couldn't eat very much. But it was unappetising inasmuch as – I just – well, you know, I took two or three mouthfuls and that was. What I found strange: nobody asked me why I'm not eating. Nobody said 'Oh, you haven't eaten anything,' and I say, that's what was happening – I was sort of taking a couple of mouthfuls and saying – no, I couldn't touch it. Nobody said: 'Why?' The obvious thing, if they had asked I would have told them, 'I can't, because of the dreadful nausea.' Now, there are remedies for that, but nobody asked. I was silly – I should have said so.*

## 4. Paediatrics

### 4.1 Treatment

#### 4.1.1 Admission and fears

Most of the admissions were not planned. A lot of the children expressed fear and anxiety when they arrived at hospital:

*Scary because I didn't know what was happening.*

*Don't know, just scared because my granddad had went into hospital and he had to get... things happened to him.*

*And I was scared of the operation because I'd never had one before.....I thought I wasn't going to wake up or something.*

*I was watching this thing on the TV and I saw it and I thought that could happen to me.*

*Well, it was just the thought of going up there and just getting put to sleep and you didn't know what was happening.*

*I was just scared in case it...of what it was. Scared of what it would turn out to be.*

*I was afraid I was going to wake up in the middle of the operation.*

#### 4.1.2 Continuity of care

It was felt that if a sick child had their parents with them in hospital a lot of the time then they didn't get as much care or attention from staff that they should have. The nurses gave medical attention to the child but tended to stay clear if the parents were there:

*Your child's there to be looked after and given the same care.....They should all be given the same care, regardless.*

But they also understood that if they were there to look after their own kids then it meant that the nurses could concentrate on those children who do not have parents there for them:

*And I think that's what they want, parents to stay, so that you're a one-to-one. If your kid's needing the toilet, then it's up to you .*

One respondent had an experience where a student doctor hadn't checked with the consultant before discharging a small child. The child actually shouldn't have been discharged at that point:

*They've never read their notes properly....I was a wee bit annoyed about that.*

### 4.1.3 Information

In terms of information about the nature of the injury or diagnosis, for some of the parents it was all explained quite well. The parents felt they were always informed as to what was going to happen and how their child would be after any kind of procedure. None of them felt there was a lack of this type of information when it came to the operations, tests and procedures.

Some of the parents suggested that they probably received more information than they required. Both parents and children had experiences of being told the same thing over and over again:

*I think because some people maybe are in shock at the beginning, they can't take it in. So I suppose they feel they have to keep sort of going over it to make sure that you really do understand.*

*They asked me my name and address five times...I had to answer it about four times, five times or something.*

*The same doctor kept on asking me if my address was the right one. And I kept saying 'aye' and he'd come back and do it again.....Ended up being bored.*

What wasn't appreciated was the way that the same information would come from different sources, which could make it confusing:

*I'm glad he told me the whole lot. No, I had to know, but the thing is, I wish one doctor alone had told me, because I thought that was it. The first doctor came down. I was really shocked when the second one came down and went over it again.*

*Different doctors telling you different things as well...they would discuss it in different terms so I thought he had two things wrong with him, and nobody once said to me that it was the same thing, so we wondered what was going on.*

Parents wanted to know what was happening to their child and most of them were not afraid to ask if they needed to know anything. It was suggested that sometimes they did have to "sneak" a look at the medical notes while the staff weren't around. One of the young patients also said that she wasn't afraid to ask questions:

*I wanted to know everything that they were going to do...I was wanting to know every time I was going to get my medicine.*

All the children knew what was going on during their stay in hospital. The younger age group described the doctors as "nice" and "helpful" because they told them what would and wouldn't hurt. One patient was told that putting a cannula in her hand would "sting a little bit" but suggested that it might have been better if they'd said that it was really going to hurt:

*Because then I would be prepared for it.*

## Paediatric

During a scan the patient thought it was good that she was kept informed by the nurse of how long each scan would take and that she could have a conversation with them while she was having the scan:

*There was this kind of microphone up there and up on the wall, and you could see them....the first one was like ten seconds, but then they would say, Now this one's going to be nine minutes, OK. So this is going to be a long time.*

Some of the children had their operation fully explained to them as soon as they were admitted. One patient had two surgeons explain to her everything that would happen during the operation:

*They were just saying that they were going to put me with loads of green sheets over me so all the bits that they could see was the bit they were operating on, and I had to take my earrings out because in case there was infection or something.*

Their explanation helped because her biggest fear was in having to take off her clothes:

*It was just, 'Oh no! I'm going to be lying there with no clothes on, and there's going to be those two doctors there and you know.*

*Because I didn't want to take me pants off because I was too embarrassed, but that was what I was really scared of, but when he told me that I didn't have to do it, that was OK.*

*But before I went for my operation there was like a book, and it said my operation and it had the photos and everything. And it says it takes you down in a bed and it's got wheels and stuff, and it had photos of the room that you were getting your operation in and loads of stuff like that, so that was good because then I knew what I was going to look like.*

*The nurses have it and they showed it to everybody who's going to get an operation.*

*I knew that my mum could like see me afterwards, but I didn't know she was allowed to come down with me, so that was good.*

*Yes, the books were a really good idea because it calms you down and you wouldn't know what was happening because you were reading.*

Some of the children who were going to have operations were told about scars, some weren't:

*They said they were going to give me one, maybe two, but I didn't know I was going to get four.*

*They went through it and they showed me what they were going to do....they showed me a picture of an appendicitis scar.*

However, not all of the children thought it was better to know what was going to happen to them:

*Well, they didn't exactly tell me in the ambulance because they probably didn't know, but em...it's like Christmas really, you don't know what you're going to get, and then it's a surprise. But I think it was best....it's better if you don't really know.*

## Paediatric

### 4.1.4 Giving blood

One of the younger children had a hatred of needles and one of the worst things about hospital was having blood taken:

*Well, the blood people. You know how they use these ?? needles, that's the heavier?? needles. I thought they were going to kill me....I mean the size of the needle, it was like that, like that...big.*

Another described his experience of needles:

*I had about fifteen holes. Well, at first they were just trying in my arm and they couldn't get any blood. So they tried both arms and they tried on my hip. They only got blood out of my hip, and when I came in to the operate...the operating theatre I realised I had more on my foot, on my feet...they tried to get blood out of my feet.*

*On my ward, when they were trying to take blood, they couldn't find a tourniquet so they got one of the nurses to hold my arm really tight.*

### 4.1.5 Emotional support

Emotional support was an important issue for parents of children in hospital. All the parents agreed that anxiety levels are “pretty high” when you have a child in hospital and it can cause a lot of stress. A lot of the parents needed help from other family members/relatives, especially those who had other children to take care of:

*Because you're going through so much stress, you've got to get relief, and you know you have to have relatives that come in and relieve us.*

Parents who had other children at home sometimes felt “torn” between looking after them and staying at the hospital with the sick child. It was even more stressful for those who did not have family available to take care of the home life. Some support from staff would have been appreciated:

*Some kind of support. If someone could take your children during the day and there's somebody there to help out, like maybe crèche workers.*

*If you were in a distressed state, obviously at that time, well, they do not offer you any support.*

Apart from the cancer ward, parents with children in other wards of the hospital found that they didn't get much emotional support from the staff. All the respondents agreed that they got more support from other parents:

*I find you get a lot of support, more support from other parents. They help you more. You go for a cup of tea and they'll sit with your child.*

*I think it's very important, you need to get a break, you need to get away from the ward.*

But the parents never discussed this with the hospital staff. They tended to deal with it themselves which meant it was stressful and exhausting.

The experience in the cancer ward was very different to this:

## Paediatric

*I think because most of the children in the wards have got cancer, there is a lot more support, em, on that ward, and there's a higher, probable, staff-patient ratio on that ward, em, because they're dealing with such traumatic circumstances.....they obviously need more staff to deal with that.*

*There's so many people to talk to and they take you away and discuss things and, eh, go over things over and over again. They give you booklets and various things as well as hearing it you can read it as well if you don't take it in. So I couldn't...their support is excellent.*

There was a lot of support from the cancer ward/staff, the family had a social worker and a health visitor assigned to help them out with anything they needed. There has also been a monthly parents support group set up, run by a clinical specialist and a social worker

The children agreed that it was good that their mums were with them all the time:

*She was making me feel safe and because I wouldn't like to go down there on my own because then I'd have no one to talk to.*

And how important their families were:

*I didn't like it because em...your mum or your dad can't always be there.*

### 4.1.6 Discharge

Group members had different experiences of the discharge process. Where one thought the discharge procedure was very good because she left with all the information she needed, another had a horrendous experience of her new-born baby being wrongly discharged by a “young paediatrician” and consequently the baby ending up in intensive care the next morning. Feelings of anxiety were reported:

*I was a bit anxious but then, probably because of the severity of his illness,...even though they told you all what to do and gave you lists of what to do, you were still very anxious because it was the first time you'd ever been in that situation.*

What would have alleviated this anxiety, it was suggested, would be for the hospital to call, just once a week, to check on progress of the patient. Although they were given a number to contact the clinical specialist they felt awkward and didn't want to phone them:

*I think it's 'cos you're a mum and you're supposed to know what to do with your child. You're like, you don't want to be a nuisance.*

It was felt it may be better if everyone was given written information on discharge to make sure that everybody got the same information and all of the information:

*If the nurses had like a list of things that the parents should be told, before you go home, and they were ticked or signed or something to make sure that parents were told everything they should have been told then they wouldn't have got missed.*

## Paediatric

The children were all glad to be discharged:

*I felt happy that I was home, but I felt sad in case I had the pain again, and I had no tablets, so they gave me tablets to go home with.*

*It was brilliant, because when I'm sick it usually lasts for about three days, and because I was feeling better I could go home.*

### 4.1.7 Pain management

One member of the parents' group only found out by chance exactly what type of pain control was being administered to the child:

*They decided to give him painkillers..... I asked what they were, some sort of paracetamol, and of course the next day it somehow turned out it was morphine. So I was thinking maybe they should have told me that and maybe explained to me....I think maybe if it was explained to me that that was quite a normal thing to do even for the young ones, then that maybe would have been useful.*

*Maybe they explain when they sort of- they didn't tell me it was morphine in conversation.*

Because the parents were there with their child most of the time it was easy for them to keep watch and decide whether their child was receiving enough pain medicine. Sometimes they had to decide whether more medicine was needed and actually ask the staff to administer whatever they thought was needed even though this could be quite difficult for some people:

*You've got to keep saying, you know, can we have some more...you've got to kind of tell them how they're doing and that you feel maybe they should be getting more or whatever.*

It was suggested that more communication is needed between parents and staff with regards to the amount of pain medicine given to patients:

*We felt we had to keep a close eye on what he was due and when he was due it and when he could get more, and you would occasionally sort of go off and say is he not due this, sort of keep on at them all the time.*

When asked about pain medicine, one of the younger patients said that she was given paracetamol but it didn't really work at all. Another patient was given "little pink tablets" which were more effective than the paracetamol:

*The paracetamols....they gave me paracetamols as well. They were working but only for a short time. So...they weren't very good, but the pink ones were good.*

*Sometimes I had to ask for them, but usually they just came down and I had them...I think the longest time, I had to wait for about seven minutes or something.....I wasn't in that much pain, I was just sore.*



## 4.2 Staff

Most of the parents thought the staff were “great”. The doctors and nurses kept them informed, and were supportive and “genuinely care about the children”.

### 4.2.1 Doctors

All of the parents found it easy to talk to the doctors at the hospital, especially the younger ones, who were described as “more down to earth” and not as pompous as the older generation of doctors sometimes appeared to be. Younger doctors were “on the same wavelength” and had time for the parents:

*And it's more informal now. It's more informal...and they tend to do things sort of for the child's welfare rather than anybody else.*

Whereas some of the older doctors tended to be too clinical in their approach and could make patients feel a bit inferior:

*The younger ones tend to laugh and joke and talk to the children.*

Surgeons and consultants gave the parents options and choices whenever there were decisions to be made. The communication between surgeons and parents was important:

*The surgeons are really good. They tend to involve you I think a lot, and whether it's true or psychology or whatever they tend to let you think that you're still in control when you're making the decisions and everything's cool, .....the surgeons..and the consultants – I feel make you feel very much – you have a choice, it's your child and you're the boss and remember you're mum and you're important.*

*One of the nuttiest anaesthetists.*

*I thought they were nice, because not many doctors would come down and see how you were.*

### 4.2.2 Nurses

One parent likened nurses to teachers because she felt intimidated by them. She was in a situation where she had no control and so was not in the best frame of mind. Others found it difficult to speak up, but when they did the nurses were generally quite helpful:

*To begin with you feel as if you're being really a pest. Sort of, you know, they'll hate me now.....so you really have to stick up for yourself and speak out.*

*I was terrified.....Bothering them, 'cos they just seemed to be rushing about all the time...I've learnt my lesson now, three years down the line, but at the time I just – I think I was a bit bothered by everything and my situation, a new-born baby and everything when I was in the first time. Naive, I was terrified to say anything, I just-I dunno.*

## Paediatric

All of the children got on well with the nurses:

*They always came in and asked me if I wanted like bits of games....and make me happy and all that.*

*They were just friendly.*

*They would make jokes and everything.*

*You didn't feel like nervous about talking to them.*

*There was a really nice nurse. She helped me a lot....Just her personality and that stuff.*

One of the older girls didn't like the fact that she would only ever see the nurses when she was being given her medicine. Although she thought all the nurses were nice, an auxiliary nurse was the "nicest of them all" because she made an effort to make her laugh and get out of bed:

*She was just funny and she wasn't like...she was just shouting and she was really funny. Because all the other ones, they were just really serious...but she was nice.*

*I think the nurses should come in and talk to you sometimes. I know there's loads of people, but they could still come in and talk to you.*

One issue that did arise from the parents however, was the fact that the nurses didn't seem to differentiate between day and night:

*They still walk the same, they still close the doors the same, everything is done exactly the way they would during the day.....sometimes you catch them discussing patients. Could be your child.*

The parents didn't think that this was the way for nurses to behave and suggested that nurses should be more discreet and confidential. They should also be aware that there are anxious parents trying to get some rest, often under stress and needing peace and quiet:

*Maybe try and walk a bit quieter, wear softer shoes, and not bang the doors during the day and try and keep things a bit quieter. Maybe they feel it's because, you know, the children sleep through anything, but they forget that there's parents there and they're under a lot of stress.*

The young patients also found it hard to sleep because the night staff were quite noisy:

*Sometimes the night staff were talking quite loud, and I couldn't get to sleep then.*

*It was annoying but you couldn't tell them to be quiet because they were there for you, so it was OK, but annoying as well.*

## 4.3 Hospital environment

### 4.3.1 Wards

All parents had stayed overnight at the hospital but had found it difficult to sleep because it was such a stressful time and also because of the noise on the ward. They were often woken at shift changeover or disturbed by the night staff. It was worse on the wards at night because they could not settle, and not everybody switched their light out or television off at the same time:

*I find it quite bad living on the ward...sometimes it's unbearable.....I found it very annoying that people were still listening to the TV right next to my child's head...the nurses didn't seem to do much about it.*

All of the children were in wards either with or right next door to the babies and, as a result, had trouble getting to sleep because of the babies crying:

*Em...it was OK, but in the night they kind of like cried and you couldn't get to sleep.*

*I didn't get to sleep till three o'clock in the morning.*

*But I didn't get to sleep until about twelve o'clock, because that's when like...because of all the babies crying and everything.*

*None of the children seemed to mind being in a mixed ward. One of the patients said that having her own room off the ward was the best thing about her hospital stay because it meant she had her own space and it was really peaceful.*

*There was two beds in it and it was really big, and there was a TV and video in there, and it couldn't come away, so I had it all the time. And there was a toilet and a shower.....There was a cabinet you could put all your stuff in...that was much better.*

### 4.3.2 Playroom

None of the young patients said they were bored with the books and computer games that were provided, especially the Nintendo's and Sega's. It was suggested that the little battery "game boys" were really good, and that patients should be allowed to play with them before an operation because it would take their mind off it.

All of the children enjoyed requesting songs on the hospital radio, and the competitions that were organised by the nurses:

*And the nurses would come round and do these competitions, and you'd have to make this model. And I wanted to make this Statue of Liberty thing, and Titanic thing.....me and a wee lad across the ward from me, a friend, me and him won a Titanic CD...And if you liked, you could take your own model home.*

Parents agreed that the playroom had everything to keep the children from getting bored, but the only criticism was that there was no system of sharing, especially with the computers.

## Paediatric

This issue was also raised by the children:

*All the boys got them first and then they wouldn't stop playing them till ten o'clock at night...he didn't know I wanted to play them because I couldn't really shout.*

*I think they should get like more like things for the older children because it was mostly like toys and...but they could get like video games or computer stuff.....they had two Nintendos, but that was to go round loads of people, so you could only get on it for a while.*

*Well, there was three on one, but somebody stole the other ones.*

It would have been preferable for nurses or play leaders to make sure that each child had some access to the computer games:

### 4.3.3 Furniture

Some younger children said that the beds were alright, but not like their beds at home, whereas others said their hospital bed was more comfortable than their own at home:

*When I was at the hospital and I first went in the covers were absolutely freezing, and when I first go into my bed at my house, at home, and I go under the covers and they're nice and warm.*

*Aye, the bed was comfortable. It was just a metal bed like that.....Much more comfortable.*

Some of the parents said that the chairs on the wards were uncomfortable, especially if they had to sleep or sit in them for hours at a time. They suggested that the hospital should have more comfortable chairs:

*The chairs are useless.*

### 4.3.4 Food

When asked about the food given to their children parents described it as “terrible”, “unappetising”, always the same food and not much variety. It was overcooked so the nutrition had been cooked out of it, and a lot of the time the parents had to provide their own food for themselves and the children:

*I found more or less I was making up his food for him and quite a lot of other parents were doing the same. It was quite a strain on some of them.*

Parents spent a lot of money on food and juice/drinks while their child was in hospital. It was mentioned that the only decent thing supplied was the cereal because it was fresh in the morning.

Most of the children weren't too impressed by the food either:

*At first I wasn't too impressed. Like there was these boiled potatoes....Horrible.*

*They weren't very nice at all.....My mum used to go to the shops and buy me stuff when I left my dinner.....They (potatoes) were just like pieces of water.*

## Paediatric

*It's all dry.*

*It was nice the food. I didn't think it was going to be nice, because all my friends were saying it was horrible, but it was nice.*

The boys suggested that the food should be changed to pizza and chips, McDonalds and tomato soup.

### 4.3.5 Worst thing about being in hospital

*Waiting around, because like waiting for the doctors to come, because they had to go round every single ward, and they had to go round every single person.....and so they come to you a bit late.*

*I'd be in bed and the doctors would come in and stand at the side of my bed and every time I woke up they gave me a fright. I couldn't handle it.*

*Your mum and dad can't always be there and sometimes you're just lying there and you've got nothing to do.*

*Maybe the worst thing was that the nurses didn't come in and talk to you very much, because they just don't. They only come in when you had...to give you your medicine.*

*Every morning at home I usually have a shower as soon as I get up.....there were quite a few people who had sinks at the side of the beds, but I sometimes asked for a wash and I didn't get it until eleven o'clock....I wasn't quite happy about this.*

*I think you didn't have much privacy, well...like if you put something in your locker or something.*

*You weren't allowed to lock the door or anything so anybody could just walk in.*

*And the nurses had to actually give me a wash and get me into the bath which is quite embarrassing, and then they left me to have a bath but they didn't lock the door.*

### 4.3.6 Best thing about being in hospital

*Getting out again.*

The play leaders:

*They just were really nice to talk to and they would sit and chat to you.*

*I think the best thing was getting my own room and having my own space.*

At Easter when the rugby players came into the hospital dressed up as bees:

*Because it was a change, because I didn't think they done that in the hospital. I thought it was just so quiet, so it was good*



# Maternity

## 5. Maternity

### 5.1 Treatment

#### 5.1.1 Information

The women using maternity services found that the information they had received before admission *was* useful. There were pre-admission visits to the hospital and delivery rooms. Although the visit was a “little disconcerting” because of the “alien environment”, it was helpful because by the time they were admitted it “felt more familiar”, comfortable and it “wasn’t such a shock”.

Once admitted, before delivery, they were really surprised that they were given so much information about what could happen. It was suggested that there was a “great emphasis on patient choice”. Although it was good to have this information in advance it was also said that perhaps there was **too much** information and choice which was “almost dismaying”. Written information came in the form of an information pack, a book and leaflets. These were very helpful, written in simple terms and covered a lot of ground. However, it was suggested that a lot of information was given at a time when they were not really mentally prepared for it all. This could have been improved by giving information in stages rather than all at once, i.e. they would have liked the opportunity to ask questions at different stages of the pregnancy.

One issue regarding the delivery itself was the point at which the labour was too far advanced for the women to be able to request any further pain control. Up to that stage there was plenty of choice of pain control on offer if wanted, but it was also suggested that sometimes they were presented with too many options at a time when they needed more direct advice:

*There’s almost too many options given to you. One point where I think I just wanted someone to make a decision for me.....And at that point in time I really, you know, I think I needed not a range of options, I really needed advice.*

Sometimes there seemed to be too much information, too many competing pieces of advice:

*I would have preferred it if maybe one person was advising me and then I would’ve had a good system, a sort of care plan as it were, to try and get the breast feeding established....instead of trying one thing to see if it worked over a number of things.. therefore it was a constant dimension of suggestions.*

Another issue of concern was the way in which test results were reported. The hospital advised patients that they would not be informed if their test results were negative, but this subsequently caused a lot of anxiety. This system was said to be “terrible” and “awful”:

*The timing was vague.....you can’t help but think you’re the one that they have missed off the list or the letter didn’t come.*

*It just seems these are very, very important tests, you know, and it’s like why do they do it like that...even if it’s just a postcard with an X on or something.....to know that the test’s been done and you know that you’ve received the result.*

# Maternity

## 5.1.2 Co-ordination and continuity of care

A prominent issue that arose from the discussion was that there was no continuity of care. The women had not met their midwife before being admitted in labour, but said they would have preferred to have had the same person in charge of their care all the way through:

*You sort of hope that somebody who starts with you will finish with you*

*It was a little disconcerting...I know what it's like if somebody starts with you know a case or a patient or whatever and then hands it over to someone else, ...you're just starting to get to know the person...to whose care you've been placed and then to have someone else.*

They would have preferred to see the same midwife all the way through their pregnancy, before the birth, during the delivery and aftercare. They would have preferred the choice of having DOMINO, where pregnant women are looked after by the same midwife all the way through:

*There was no continuity. I would have liked to have someone that I knew and that I got to know, you know the confidence thing comes into it, especially for first time mums.*

One woman said she felt more comfortable and more in control when there were only a couple of staff in the delivery room, rather than having lots of doctors and nurses around.

## 5.1.3 Discharge

The women felt that they went home at the right time. However, one said that she felt “cut loose and let go” on being discharged and that it was “absolutely terrifying”:

*Having changed from one life to another almost overnight....I worked right up daily until the end of my pregnancy....and then all of a sudden I was at home with a small child....it was easy to feel isolated and cut adrift from everything else.*

There was a view that the hospital could have provided more information in terms of networking, giving advice or getting mothers from the antenatal classes together. The health visitors should inform new mothers about community resources:

*I really feel it's the role of the health visitor, because she should be sort of telling you about things that are going on in the area...I think it's a lot better if you're attached to a clinic...that clinic will run a lot of things for mothers.*

Fears were expressed relating to returning home after the birth. There were concerns about a fear of the unknown, of caring for a new baby and doing the wrong thing. For example, there had only been one bathing lesson before the birth and a first time mum found it hard to bath her baby once back at home:

*I didn't bath her for ages when I got her home – I mean, for the first week I couldn't bring myself to do it.*



# Maternity

## 5.1.4 Involvement of partners

Their partners were present at the birth and made to feel welcome and involved:

*They really were spoken to and made to feel very welcome.*

Partners were involved from the beginning at the antenatal classes, where they were told about the option to cut the cord at the birth. A particularly important issue for the women was the time directly after the birth when they had time alone with their partner and baby. Staff left them alone for a short while (10 – 20 minutes) in the delivery room. This moment of privacy was much appreciated:

*It's very special, a special time...you're numb and you're so upside down, looking back it was just very special.*

*It is a special time just the three of you but they know that, they know that you're just best left alone.*

## 5.1.5 Physical comfort

The toilets were a long way down the corridor. For one woman, it felt like an “excursion” whenever she had to go to the toilet, which didn't make her feel any better when she was uncomfortable after the birth. There was also the problem of getting someone to look after her baby while she went to use the facilities. This meant that she felt reluctant to use the facilities because she just wanted to relax. The toilets and shower facilities themselves were “very institutionalised”, the shower block was compared to a school gym's. Because it was such a long trip to use the facilities it also made her feel like she was “leaving the party” when she left her partner and baby.

Mothers felt awkward asking staff to look after their new baby while they went to use the facilities. They felt that they had nothing life threatening and they were perfectly healthy so they didn't want to “bother” the staff and take up their time “unnecessarily”. They would rather wait for their partner to arrive before going to the toilets and showers.

## 5.1.6 Postnatal treatment

Mothers were brought toast and tea straight after the delivery, which they thought was “marvellous”.

The treatment was:

*Very hands-off at that stage, it was sort of like well you've got the baby so we'll put you upstairs and get you're stitches done...it seems to be sort of medical procedure at that point, well that's how it felt.*

Another issue raised was that after the birth, the opportunity to sit down with the midwife and talk about what had just happened and why certain things happened, was really important. It was an opportunity to ask questions and thank the midwife:

## Maternity

*For days afterwards, and even now, there are things I would very much like to have talked to the midwife about after the event.....certainly my experience was, she just came out of the picture and just faded away completely, and , unless she'd come onto the ward I would never have seen her again...you feel like it's slightly unfinished and it would have been nice to just sort of close the chapter, to have had that almost debrief.*

### 5.1.7 Fear of complaining

One woman felt that there was no real clear system for complaints about staff. There was no one she felt she could complain to about the “dippy” midwife.

# Maternity

## 5.2 Staff

The women didn't really mind **student midwives and doctors** being present at the birth. They accepted that medical staff have to do their training:

*But this student doctor with me – you know again they asked, 'Would I mind if a student doctor was there?' she wasn't actually doing the delivery, she was doing her obs and gynie part of her course and that didn't bother me, didn't bother me at all.*

The **nursery nurses** were most helpful and most practical in their hands-on approach:

*I found those who were nursery nurses were most helpful, were most practical in their approach, sort of hands on.*

The midwives exuded confidence, were very matter of fact and were calm and clear. The midwives who were in charge of their care at the birth had the right attitude:

*The midwife was firm with me and I think that was exactly what was required.....she was very clear, very firm about it and it was just what was needed at that point in time.*

One mother commented that she felt that her need to see a doctor was trivial compared to other patients:

*I think from my point of view my mother was a nurse and my brother's a doctor and I hear how busy they are and I don't know you feel I certainly felt as if it was nothing that I had was life affecting em you know I was perfectly healthy em what I'd done was a perfectly natural thing so yes I almost felt there must be other people who needed their attention an awful lot more than I did and that taking their time was taking their time unnecessarily for what I perceived to be minor or trivial things in comparison.*



## 5.3 Environment

### 5.3.1 Wards

Very different experiences of the hospital environment were described. The wards where the mothers stayed after delivery were very different. While one was presented with a choice of single room or ward:

*I had a single room to myself which is beautifully furnished and again wallpaper on the walls, matching wooden rocking crib for the baby, everything matches, curtains, duvet covers and a table which you could sit at and have you meals.*

Another described her ward as:

*Pretty grim....I mean it's just so unappealing, so unattractive. ....In terms of the condition, the paintwork, the colours, the fact that the baby lies in a sort of goldfish bowl bed...there's very little in the way of privacy and I looked out onto a wall, a brick wall of the facing building.*

The state of the ward had an effect on the feelings of the women. While one said she did not want to go home because she felt “like the queen”, another, who stayed in a ward where the paintwork was peeling off and the colours were drab, said that it didn't do anything to lift her spirits:

*At a time when you're feeling very vulnerable, it wouldn't be difficult to find it quite depressing at that point.*

### 5.3.2 Food

The food was described as “appalling”. One woman reported being hungry all the time and having to wait a long time between early supper and breakfast. The food would be served even if mothers were breast feeding, and therefore the food would be left to go cold while they fed their children.



## **7.2 Appendix 2 – Focus group topic guide**

# Paediatric Questionnaire Development

## Focus Groups 12-19 yr olds

### Introduction

- Here to find out what children and young adults think about being in hospital.
- Good and bad experiences – what was really good? What could be improved?
- Running lots of similar groups with children and young adults – aim to eventually help to improve hospital stays for children/YAs

### Focus Group protocol

- General chat; no right or wrong answers etc.
- Talk about experiences but only to extent that you are comfortable
- Last just over an hour – lots to get through, topic guide etc.
- Tape recorded – to help analysis. Will be confidential, no names etc. Ask permission to turn on tape recorder

### Warm-up

- Introductions:
  - Name; age; when in hospital, how long for and why.
  - How many times have you been in hospital in the past year?

### Perceptions of hospital

I want to talk about what you think of hospitals first of all.

#### FLIPCHART - WORD ASSOCIATION GAME

- Hospital, nurses, doctors, operation
- What did you imagine hospital to be like before you went there?  
*PROMPT (if needed): Doctors in white coats; smell of disinfectant etc.)*
- Have you seen any **TV hospital programmes**? Did this affect your view of hospitals?
- Have you ever **visited** anyone in hospital before? Who? Was that what you thought it would be like for you?

### Going into hospital

- Was it planned (e.g. operation) or did you go in as an emergency?

#### If emergency:

- How did you get to hospital?
  - If ambulance, who called it, how quickly did it get there?
- What happened when you got to the Emergency dept?
  - Were you waiting? How long for? What did you do while you waited?
- Who came with you to hospital?
- Who did you see (doctor, nurse etc.)?
- Did they **explain** what was wrong clearly to you? To your mum/dad/guardian?
- Was there **anything particularly good** about the Emergency Dept?
- What could have been **done better** in the Emergency Department?



If **planned**:

- **Before you went into hospital** how were you feeling?
  - Had you been in hospital before? The same hospital?
  - Were you/your parents given information about the hospital?
  - Were you/your parents given info about your operation / tests etc.?
  - Did you go and visit the hospital / meet the staff? If no, would you have liked to have done this? If yes, was it helpful?

## Staying in hospital

### YOUR WARD/ROOM

- How many wards did you stay in? (If more than one, how did you feel about that?)
- How many other people? Children's ward? Share with adults? Same sex / mixed wards? How did you feel about this? Did you want to be with adults / children?

Tell me about the ward(s) or room you stayed in.

- What did the ward **look like**? How was it **decorated**? Was it **clean**?
- What **things to do** were there on your ward? TV at bedside (PROBE for type, whether new type with phone, internet etc.)
- Was there a **hospital school**? Did you go there at all? Would you have liked to?
- Did you have a **routine** on the ward? (e.g. mealtimes, rules etc.) Was it strict? What about **visiting hours**?
- What was the **food** like? What would you have liked?
- Were you **disturbed by noise** on the ward at all? Was this at night or during the day? Did you mind?
- Was it **easy to sleep** at night? If not, why not?
- What were the **other patients** on the ward like? Did you make friends on the ward?

[FLIPCHART]

If you could 'design' your own ward to stay in in hospital, what would it be like? Be as imaginative as you like.

PROMPT: *Decorations? Things to do (games, TV etc.)? Clean/tidy? Routine? Food? Noisy/quiet? Other patients? Doctors/nurses?*

### MISSING HOME

- Did your **mum/dad stay in hospital** overnight with you at all?
- If yes, did they have the right facilities for them (e.g. bed, food etc.)
- If they did not stay, did you want them to?
- Were you **homesick** at all? Did you talk to a nurse/other staff about this? Did they comfort you?

SCENARIO:

- If you had, for example a bad dream at night, what would you have done? Was there someone you could talk to?

[FLIPCHART]

## Doctors

- What makes a good doctor? What should they be like? (WRITE ON FLIPCHART)
- Were the doctors that treated you like this? What was the same? What was different?

ADDITIONAL PROMPTS:

- Did they explain things clearly? (to you, parents)
- Did they answer your questions / your parents' questions?
- Did they tell your mum/dad more than they told you? How did you feel about that?
- If you were worried or scared, did they help/comfort you?
- Did you think they knew a lot about your illness/condition?
- Differences between senior/junior doctors / students

## Nurses

- What makes a good nurse? What should they be like? (WRITE ON FLIPCHART)
- Were the nurses that looked after you like this? What was the same? What was different?

ADDITIONAL PROMPTS:

- Did they explain things clearly? (to you, parents)
- Did they answer your questions / your parents' questions?
- Did they tell your mum/dad more than they told you? How did you feel about that?
- If you were worried or scared, did they help/comfort you?
- Did you think they knew a lot about your illness/condition?
- Differences between junior/senior staff

## Other staff

- Were there any other hospital workers who you remember as being good/bad?  
*PROMPT: Therapists; Porters; receptionists; kitchen staff etc.*
- What was good/bad about them? What did they do?

## Tests & Treatment

- When a doctor/nurse **examined you**, was this in private? Did you feel comfortable? Were your parents present? Did you want them to be?
- When a doctor/nurse was **talking to you about your illness or treatment** was this in private? Did you feel comfortable? Were your parents present? Did you want them to be?
- Did you have any **tests** in hospital (e.g. x-rays, blood tests etc.)?
- Did they explain **why** you needed the tests (to you / your parents)?
- Did they explain **what would happen** during the tests?

- Did you have to **wait for the results**? How long?
- Did they **explain the results** of the tests clearly?
- Did you need any **special care** while you were in hospital – e.g. help eating meals, going to toilet etc.? Did you get this help? Did you have to ask for it?
- Did you have **any other special needs** when you were in hospital – e.g. special diet; religious needs etc. Were these needs met?

## Pain

- How much of the time were you in **pain** when you were in hospital?
- Did the doctors /nurses give you medicine to help the pain go away when you wanted them to? Did you have to ask for this?

## Leaving Hospital

- Did you know how long you were going to be in hospital?
- How did you feel about **going home**?  
*PROMPT: Ready for it; too soon; excited; nervous*
- Before you left, were you/your parents given enough information about how to look after yourself at home?  
*PROMPT: What to do if a problem; how to take medicines etc.*
- Were you told when you could **return to school**/college/work?
- Were you told when you could **start doing other hobbies**?
- Were you **visited at home** by a hospital doctor/nurse? Or by your doctor/nurse?

## CARD SORT EXERCISE

We are now going to do an exercise. I am going to give you pile of cards with things people have said are important to them when going into hospital. I want you to sort them into 2 groups – Most important and Least important, of what matters most to you when you are in hospital.

Then pick out 3 most important.

SEE ATTACHED SHEET FOR STATEMENTS

## General

- Did you always **understand what was happening** to you in hospital?
- Were things **explained clearly** to you or your parents or both?
- Would you have liked them to **tell you more** about what was happening or were you happy for your parents to be told?
- Did you feel that you were **treated differently to the adults**? Did you want to be treated differently?
- Did you feel that you were **treated/looked after well** in hospital?
- Is there anything that would have made your hospital stay better?
- Is there anything that you thought was really good about your stay in hospital?
- If you had to go into hospital again, how would you feel?



### **7.3 Appendix 3 – Card sort exercise**

**PAEDIATRIC QUESTIONNAIRE DEVELOPMENT (12-19yr olds)**

**CARD SORT EXERCISE – FINAL LIST**

	<b>Most Important</b>	<b>TOP 3 MOST IMPORTANT</b>
<b>A clean ward and clean toilets</b>		
<b>A nicely decorated ward</b>		
<b>Being able to talk to staff about my illness in private</b>		
<b>Being examined or treated in private</b>		
<b>Being given enough information about my illness</b>		
<b>Being given medicine when I am in pain</b>		
<b>Being treated differently to adults</b>		
<b>Being treated like an adult</b>		
<b>Doctors / nurses who I trust and can talk to if I am worried or scared</b>		
<b>Doctors / nurses who know a lot about my illness</b>		
<b>Having my own room on the ward</b>		
<b>Having my special needs (e.g. Diet) looked after</b>		
<b>Having things to do on my ward (e.g. Games, TV etc.)</b>		
<b>Hospital food that I like</b>		
<b>My mum or dad being able to stay with me in hospital</b>		
<b>Not being kept awake by noise at night</b>		
<b>Not being on a children's ward</b>		
<b>Not being on a mixed ward (e.g. Girls/boys together)</b>		
<b>Not being on a ward with adults</b>		
<b>Visiting the hospital and meeting the staff before going into hospital</b>		

## **7.4 Appendix 4 – Parent or guardian questionnaire**



# YOUNG PATIENT QUESTIONNAIRE

## Inpatient or Day Case

### Parent or Guardian

#### What is the survey about?

This survey is about your child's most recent stay at one of the National Health Service hospitals named in the letter enclosed with this questionnaire.

#### Who should complete the questionnaire?

The questions should be answered by a parent or guardian of the child named on the front of the envelope, with the help of that child if possible.

#### Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please **do not** write your name or address anywhere on the questionnaire.

#### Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

### **Your participation in this survey is voluntary.**

If you choose not to take part in this survey it will not affect the care you receive from the NHS in any way. If you do not wish to take part, or you do not want to answer some of the questions, you do not have to give us a reason.

Your answers will be treated **in confidence.**





Please remember, this questionnaire is about your child's **most recent** stay at the hospital named in the accompanying letter.

## ADMISSION TO HOSPITAL

1. Was your child's hospital admission planned in advance or an emergency?

- 1  Emergency/dialled 999/immediately referred by GP or NHS direct → **Go to 2**
- 2  Waiting list or planned in advance → **Go to 5**
- 3  Something else → **Go to 2**

### Emergency or immediately referred

2. When you arrived at hospital where did you and your child go first?

- 1  Straight to a ward → **Go to 10**
- 2  Accident and Emergency Department → **Go to 3**

3. Following arrival at the hospital, how long did you wait before your child was admitted to a bed on a ward?

- 1  Less than 1 hour
- 2  At least 1 hour but less than 2 hours
- 3  At least 2 hours but less than 4 hours
- 4  At least 4 hours but less than 8 hours
- 5  8 hours or longer
- 6  Can't remember
- 7  We did not have to wait

4. How organised was the **care** your child received in Accident & Emergency (or the Medical Admissions Unit)?

- 1  Not at all organised
- 2  Fairly organised
- 3  Very organised

→ **Now please go to Question 10 on next page**

### Waiting list or planned admission

5. How do you feel about the length of time your child was on the waiting list before admission to hospital?

- 1  She/he was admitted as soon as I thought was necessary
- 2  She/he should have been admitted a bit sooner
- 3  She/he should have been admitted a lot sooner

6. Were you given a choice of admission date?

- 1  Yes
- 2  No
- 3  Don't know/ Can't remember

7. Was your child's admission date changed by the hospital?

- 1  No
- 2  Yes, once
- 3  Yes, 2 or 3 times
- 4  Yes, 4 times or more

8. Before your child was admitted, were you invited to visit the hospital and meet the staff?

- 1  Yes, and we did visit → **Go to 9**
- 2  Yes, but we did not visit → **Go to 10**
- 3  No, and we would have liked to have visited → **Go to 10**
- 4  No, but we did not want to visit → **Go to 10**

9. Did visiting the hospital and meeting the staff help your child when he/she was actually admitted?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

### All types of admission

10. Did you feel that your child had to wait a long time to get to a bed on a ward?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

### THE HOSPITAL AND WARD

11. For **most** of your child's stay in hospital, what type of ward were they on?

- 1  A children's ward
- 2  An adult ward
- 3  An adolescent or teenager ward
- 4  Other

12. What type of ward would you **prefer** your child to stay on?

- 1  A children's ward
- 2  An adult ward
- 3  An adolescent or teenager ward
- 4  Other

13. In your opinion, how clean was the hospital room or ward that your child was in?

- 1  Very clean
- 2  Fairly clean
- 3  Not very clean
- 4  Not at all clean

14. How clean were the toilets and bathrooms that your child used in hospital?

- 1  Very clean
- 2  Fairly clean
- 3  Not very clean
- 4  Not at all clean
- 5  She/he did not use a toilet or bathroom

15. In your opinion, did the ward look nicely decorated?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

16. Were there enough toys and/or entertainment facilities on the ward?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  My child was not able to use these facilities
- 5  My child did not need/want to use these facilities

17. How would you rate the toys and/or entertainment facilities on the ward?

- 1  Very good
- 2  Good
- 3  Fair
- 4  Poor
- 5  My child was not able to use these facilities
- 6  My child did not need/want to use these facilities

18. Was your child ever bored during his/her stay in hospital?

- 1  Yes, most or all of the time
- 2  Some of the time
- 3  Hardly ever or not at all

19. How would you rate the hospital food your child was given?

- 1  Very good
- 2  Good
- 3  Fair
- 4  Poor
- 5  She/he did not have any hospital food

20. Did you feel that the hospital ward was a safe and secure place?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

21. Was your child ever bothered by noise from other patients?

- 1  Yes
- 2  No

22. Was your child ever bothered by noise from hospital staff?

- 1  Yes
- 2  No

23. Did your child stay overnight in hospital?

- 1  Yes → Go to 24
- 2  No → Go to 28

24. Did your child have a chance to see a play leader during her or his hospital stay?

- 1  Yes
- 2  No
- 3  He or she did not need/want to see a play leader
- 4  I did not know there was a play leader

25. Was your child given help with his/her education while in hospital?

- 1  Yes
- 2  No, but it was needed
- 3  He or she did not need help with education

26. Did you think the visiting hours were...?

- 1  Not strict enough
- 2  About right
- 3  Too strict
- 4  I did not know the visiting hours

27. Did you feel friends or other relatives were welcome to visit your child?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

## DOCTORS

28. Did doctors give **you (the parent or guardian)** information about your child's care and treatment in a way that you could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

29. Did doctors give **your child** information about his or her care and treatment in a way that he/she could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  It was not necessary

30. If you had any worries or fears about your child's condition or treatment, did a doctor discuss them with you?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not have worries or fears

31. Did you have confidence and trust in the doctors treating your child?

- 1  Yes, always  
2  Yes, sometimes  
3  No

32. Did doctors talk in front of you as if you were not there?

- 1  Yes, often  
2  Yes, sometimes  
3  No

33. In your opinion, did the doctor(s) who treated your child know enough about her/his condition or treatment?

- 1  All the doctors knew enough  
2  Most of the doctors knew enough  
3  Only some of the doctors knew enough  
4  None of the doctors knew enough  
5  Can't say

## NURSES

34. Did nurses give **you (the parent or guardian)** information about your child's care and treatment in a way that you could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

35. Did nurses give **your child** information about his or her care and treatment in a way that he/she could understand?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary

36. If you had any worries or fears about your child's condition or treatment, did a nurse discuss them with you?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not have worries or fears

37. Did you have confidence and trust in the nurses treating your child?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

38. While your child was in hospital, did nurses give her or him emotional support and comfort when she/he needed it?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary

39. Did nurses talk in front of you as if you were not there?

- 1  Yes, often
- 2  Yes, sometimes
- 3  No

40. In your opinion, were there enough nurses on duty to care for your child in hospital?

- 1  There were always or nearly always enough nurses
- 2  There were sometimes enough nurses
- 3  There were rarely or never enough nurses

41. In your opinion, did the nurses who treated your child know enough about their condition or treatment?

- 1  All of the nurses knew enough
- 2  Most of the nurses knew enough
- 3  Only some of the nurses knew enough
- 4  None of the nurses knew enough
- 5  Can't say

## YOUR CHILD'S CARE AND TREATMENT

42. Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to you during your child's hospital stay?

- 1  Yes, often
- 2  Yes, sometimes
- 3  No

43. Were **you** (as a parent or guardian) involved as much as you wanted to be in decisions about your child's care and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

44. Was **your child** involved as much as he/she wanted to be in decisions about his/her care and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  He/she was not able to be involved

45. How much did you participate in your child's care, such as feeding or bathing?

- 1  Not enough
- 2  The right amount
- 3  Too much
- 4  It was not necessary

46. Were you and your child given enough privacy when discussing your child's condition or treatment?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

47. Was your child given enough privacy when she/he was being examined or treated?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

48. When your child needed help from staff in using the bathroom or toilet, did he/she get it in time?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  He/she did not need help from staff

49. When your child needed help from staff in eating meals, did he/she get it at the time it was needed?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  He/she did not need help from staff

50. How many minutes after you or your child used the call button did it usually take before he/she got the help they needed?

- 1  0 minutes/right away
- 2  1-2 minutes
- 3  3-5 minutes
- 4  More than 5 minutes
- 5  I/we never got help when I used the call button
- 6  I/we never used the call button

## PAIN

51. Was your child ever in any pain?

- 1  Yes → Go to 52
- 2  No → Go to 54

52. During your child's stay in hospital, how much of the time was your child in pain?

- 1  All or most of the time
- 2  Some of the time
- 3  Occasionally

53. Do you think the hospital staff did everything they could to help control your child's pain?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

## OPERATIONS AND PROCEDURES

54. During his or her stay in hospital, did your child have an operation?

- 1  Yes → Go to 55  
2  No → Go to 62

55. Before the operation, did the surgeon explain to **you (the parent or guardian)** what would be done during the operation?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I did not want an explanation

56. Before the operation, did the surgeon explain to **your child** what would be done during the operation?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  My child was not able to understand

57. Before the operation, did the surgeon explain the risks and benefits of the surgery to you **(the parent or guardian)** in a way you could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I did not want an explanation

58. Before the operation, did the surgeon or any of the other doctors answer your questions about the surgery in a way you could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I did not have any questions

59. Before the operation, did a doctor or nurse discuss your child's worries or fears about the surgery or operation with **your child**?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  My child did not have any worries or fears  
6  It was not necessary

60. Before the operation, did a doctor or nurse explain accurately how your child would feel after surgery?

- 1  Yes, completely  
2  Yes, to some extent  
3  No

61. After the operation, did the surgeon or any of the other doctors explain how the operation had gone in a way you could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No

## LEAVING HOSPITAL

62. Do you feel your child was discharged too early, at the right time, or too late?

- 1  Too early
- 2  At the right time
- 3  Too late

63. On the day you left hospital, was your child's discharge delayed for any reason?

- 1  Yes → Go to 64
- 2  No → Go to 66

64. What was the **main** reason for the delay? (Tick **ONE** only)

- 1  He/she had to wait for **medicines**
- 2  He/she had to wait to **see the doctor**
- 3  He/she had to wait for an **ambulance**
- 4  Something else

65. How long was the delay?

- 1  Up to 1 hour
- 2  Longer than 1 hour but no longer than 2 hours
- 3  Longer than 2 hours but no longer than 4 hours
- 4  Longer than 4 hours

66. Did a member of staff explain the **purpose** of the medicines your child was given to take at home in a way you could understand?

- 1  Yes, completely → Go to 67
- 2  Yes, to some extent → Go to 67
- 3  No → Go to 67
- 4  I/we did not need an explanation → Go to 67
- 5  My child was not given any medicines → Go to 69

67. Did a member of staff tell you about medication **side effects** to watch for when you went home?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not need/want an explanation

68. Were you given enough information about **how to use** the medicine(s) (e.g. when to take it, how long you should take it for or whether it should be taken with food)?

- 1  Yes, enough information
- 2  Some, but not enough
- 3  No information at all, and I wanted some
- 4  I did not need/want any information

69. Did a member of staff tell you about what danger signals you should watch for after your child went home?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary
- 5  Don't know/Can't remember

70. Did someone tell you when your child could carry on his or her usual activities, such as playing sport or returning to school?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary



71. Did hospital staff tell you what to do or who to contact if you were worried about your child's condition or treatment after he/she left hospital?

- 1  Yes  
2  No  
3  Don't know/Can't remember

72. Did hospital staff arrange the services your child would need after leaving hospital? (e.g. district nurse, social worker, occupational therapist)

- 1  Yes  
2  No but these services were needed  
3  It was not necessary

### OVERALL

73. Did you feel that you and your child were treated with respect and dignity while she/he was in the hospital?

- 1  Yes, always  
2  Yes, sometimes  
3  No

74. How would you rate how well the doctors and nurses worked together?

- 1  Excellent  
2  Very good  
3  Good  
4  Fair  
5  Poor

75. Overall, how would you rate the care your child received?

- 1  Excellent  
2  Very good  
3  Good  
4  Fair  
5  Poor

### ABOUT YOUR CHILD

76. Is **your child** male or female?

- 1  Male  
2  Female

77. What is **your child's** year of birth?

(Please write in) e.g. 

1	9	9	7
---	---	---	---

--	--	--	--

78. Do you consider your child to be disabled?

- 1  Yes  
2  No

79. How many times **including this admission** has your child been admitted to hospital in the past six months?

- 1  Once  
2  Two or three times  
3  Four times or more

80. Up to **this point** in the questionnaire, who was the **main** person or people that filled it in?

- 1  The **young person** who was a patient in the hospital  
2  The parent or **guardian** of the patient  
3  Both patient and parent/guardian together  
4  Someone else

81. To which of these ethnic groups would you say your **child** belongs? (**Tick ONE only**)

**a. WHITE**

- 1  British  
2  Irish  
3  Any other White background  
(Please write in box)

**b. MIXED**

- 4  White and Black Caribbean  
5  White and Black African  
6  White and Asian  
7  Any other Mixed background  
(Please write in box)

**c. ASIAN OR ASIAN BRITISH**

- 8  Indian  
9  Pakistani  
10  Bangladeshi  
11  Any other Asian background  
(Please write in box)

**d. BLACK OR BLACK BRITISH**

- 12  Caribbean  
13  African  
14  Any other Black background  
(Please write in box)

**e. CHINESE OR OTHER ETHNIC GROUP**

- 15  Chinese  
16  Any other ethnic group  
(Please write in box)

## PARENTS AND CARERS

This section should be completed by a parent or guardian if they accompanied the child or young person to hospital.

82. Were you able to buy cooked meals for yourself on the hospital premises?

- 1  Yes, as often as I wanted  
2  Yes, but not as often as I wanted  
3  No

83. Did you have access to tea and coffee making facilities while you were on the ward?

- 1  Yes  
2  No, but I would have liked them  
3  No, but I did not mind

84. Did you ever want to stay overnight with your child?

- 1  Yes → **Go to 85**  
2  No → **Go to 88**

85. Were you given the chance to stay overnight when you wanted to?

- 1  Yes, always → **Go to 86**  
2  Yes, sometimes → **Go to 86**  
3  No → **Go to 88**

86. How would you rate the facilities for parents or guardians staying overnight?

- 1  Excellent  
2  Very good  
3  Good  
4  Fair  
5  Poor

87. Were you offered a bed near your child?

- 1  Yes  
2  No, but I would have liked it  
3  No, but I did not mind

88. Were you ever bothered by noise from **other patients**?

- 1  Yes  
2  No

89. Were you ever bothered by noise from **hospital staff**?

- 1  Yes  
2  No

### **OTHER COMMENTS**

If there is anything else you would like to tell us about your child's stay in hospital, please do so here.

Was there anything particularly good about your child's hospital care?

Was there anything that could be improved?

Any other comments?

**THANK YOU VERY MUCH FOR YOUR HELP**

**Please check that you answered all the questions that apply to you.**

**Please post this questionnaire back in the FREEPOST envelope provided.**

**No stamp is needed.**

## 7.5 Appendix 5 – Young Patient Questionnaire



# YOUNG PATIENT QUESTIONNAIRE

## Inpatient or Day Case

### What is the survey about?

This survey is about your most recent stay at one of the National Health Service hospitals named in the letter enclosed with this questionnaire.

### Who should complete the questionnaire?

The questions should be answered by the young patient with the help of the parent or guardian if necessary. The questions should be answered from the young patient's point of view.

### Completing the questionnaire

For each question please tick clearly inside one box using a black or blue pen.

Sometimes you will find the box you have ticked has an instruction to go to another question. By following the instructions carefully you will miss out questions that do not apply to you.

Do not worry if you make a mistake; simply cross out the mistake and put a tick in the correct box.

Please **do not** write your name or address anywhere on the questionnaire.

### Questions or help?

If you have any queries about the questionnaire, please call the helpline number given in the letter enclosed with this questionnaire.

## Your participation in this survey is voluntary.

If you choose not to take part in this survey it will not affect the care you receive from the NHS in any way. If you do not wish to take part, or you do not want to answer some of the questions, you do not have to give us a reason.

Your answers will be treated **in confidence**.

Please remember, this questionnaire is about your **most recent** stay at the hospital named in the accompanying letter.

## ADMISSION TO HOSPITAL

1. Was your hospital admission planned in advance or an emergency?

- 1  Emergency/dialled 999/immediately referred by GP or NHS direct → **Go to 2**
- 2  Waiting list or planned in advance → **Go to 5**
- 3  Something else → **Go to 2**

## Emergency or immediately referred

2. When you arrived at hospital where did you go first?

- 1  Straight to the ward → **Go to 10**
- 2  Accident and Emergency Department → **Go to 3**

3. Following arrival at the hospital, how long did you wait before you were admitted to a bed on a ward?

- 1  Less than 1 hour
- 2  At least 1 hour but less than 2 hours
- 3  At least 2 hours but less than 4 hours
- 4  At least 4 hours but less than 8 hours
- 5  8 hours or longer
- 6  Can't remember
- 7  We did not have to wait

4. How organised was the **care** you received in Accident & Emergency (or the Medical Admissions Unit)?

- 1  Not at all organised
- 2  Fairly organised
- 3  Very organised

→ **Now please go to Question 10 on next page**

## Waiting list or planned admission

5. How do you feel about the length of time you were on the waiting list before admission to hospital?

- 1  I was admitted as soon as I thought was necessary
- 2  I should have been admitted a bit sooner
- 3  I should have been admitted a lot sooner

6. Were you given a choice of admission date?

- 1  Yes
- 2  No
- 3  Don't know/ Can't remember

7. Was your admission date changed by the hospital?

- 1  No
- 2  Yes, once
- 3  Yes, 2 or 3 times
- 4  Yes, 4 times or more

8. Before you were admitted, were you invited to visit the hospital and meet the staff?

- 1  Yes, and we did visit → Go to 9  
2  Yes, but we did not visit → Go to 10  
3  No, and we would have liked to have visited → Go to 10  
4  No, but we did not want to visit → Go to 10

9. Did visiting the hospital and meeting the staff help you when you were actually admitted?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

### All types of admission

10. Did you feel that you had to wait a long time to get to a bed on a ward?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

### THE HOSPITAL AND WARD

11. For **most** of your stay in hospital, what type of ward were you on?

- 1  A children's ward  
2  An adult ward  
3  An adolescent or teenager ward  
4  Other

12. What type of ward would you **prefer** to stay on?

- 1  A children's ward  
2  An adult ward  
3  An adolescent or teenager ward  
4  Other

13. In your opinion, how clean was the hospital room or ward that you were in?

- 1  Very clean  
2  Fairly clean  
3  Not very clean  
4  Not at all clean

14. How clean were the toilets and bathrooms that you used in hospital?

- 1  Very clean  
2  Fairly clean  
3  Not very clean  
4  Not at all clean  
5  I did not use a toilet or bathroom

15. In your opinion did the ward look nicely decorated?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

16. Were there enough toys and/or entertainment facilities on the ward?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  I was not able to use these facilities  
5  I did not need/want to use these facilities

17. How would you rate the toys and/or entertainment facilities on the ward?

- 1  Very good
- 2  Good
- 3  Fair
- 4  Poor
- 5  I was not able to use these facilities
- 6  I did not need/want to use these facilities

18. Were you ever bored during your stay in hospital?

- 1  Yes, most or all of the time
- 2  Some of the time
- 3  Hardly ever or not at all

19. How would you rate the hospital food you were given?

- 1  Very good
- 2  Good
- 3  Fair
- 4  Poor
- 5  I did not have any hospital food

20. Did you feel that the hospital ward was a safe and secure place?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

21. Were you ever bothered by noise from **other patients**?

- 1  Yes
- 2  No

22. Were you ever bothered by noise from **hospital staff**?

- 1  Yes
- 2  No

23. Did you stay overnight in hospital?

- 1  Yes → **Go to 24**
- 2  No → **Go to 28**

24. Did you have a chance to see a play leader during your hospital stay?

- 1  Yes
- 2  No
- 3  I did not need/want to see a play leader
- 4  I did not know that there was a play leader

25. Were you given help with your education while in hospital?

- 1  Yes
- 2  No, but it was needed
- 3  I did not need help with education

26. Did you think the visiting hours were...?

- 1  Not strict enough
- 2  About right
- 3  Too strict
- 4  I did not know the visiting hours



27. Did you feel friends or other relatives were welcome to visit you?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

## DOCTORS

28. Did doctors give **your parent or guardian** information about your care and treatment in a way that they could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

29. Did doctors give **you (the patient)** information about your care and treatment in a way that you could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No  
4  It was not necessary

30. If you had any worries or fears about your condition or treatment, did a doctor discuss them with you?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  I did not have worries or fears

31. Did you have confidence and trust in the doctors treating you?

- 1  Yes, always  
2  Yes, sometimes  
3  No

32. Did doctors talk in front of you as if you were not there?

- 1  Yes, often  
2  Yes, sometimes  
3  No

33. In your opinion, did the doctor(s) who treated you know enough about your condition or treatment?

- 1  All the doctors knew enough  
2  Most of the doctors knew enough  
3  Only some of the doctors knew enough  
4  None of the doctors knew enough  
5  Can't say

## NURSES

34. Did nurses give **your parent or guardian** information about your care and treatment in a way that they could understand?

- 1  Yes, definitely  
2  Yes, to some extent  
3  No

35. Did nurses give **you (the patient)** information about your care and treatment in a way that you could understand?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary

36. If you had any worries or fears about your condition or treatment, did a nurse discuss them with you?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not have worries or fears

37. Did you have confidence and trust in the nurses treating you?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

38. While you were in hospital, did nurses give you emotional support and comfort when you needed it?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary

39. Did nurses talk in front of you as if you were not there?

- 1  Yes, often
- 2  Yes, sometimes
- 3  No

40. In your opinion, were there enough nurses on duty to care for you in hospital?

- 1  There were always or nearly always enough nurses
- 2  There were sometimes enough nurses
- 3  There were rarely or never enough nurses

41. In your opinion, did the nurses who treated you know enough about your condition or treatment?

- 1  All of the nurses knew enough
- 2  Most of the nurses knew enough
- 3  Only some of the nurses knew enough
- 4  None of the nurses knew enough
- 5  Can't say

## YOUR CARE AND TREATMENT

42. Sometimes in a hospital, a member of staff will say one thing and another will say something quite different. Did this happen to **you** during your hospital stay?

- 1  Yes, often
- 2  Yes, sometimes
- 3  No

43. Was your **parent or guardian** involved as much as they wanted to be in decisions about your care and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

44. Were **you (the patient)** involved as much as you wanted to be in decisions about your care and treatment?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No
- 4  I was not able to be involved

45. How much did your parent or guardian participate in your care, such as feeding or bathing?

- 1  Not enough
- 2  The right amount
- 3  Too much
- 4  It was not necessary

46. Were you given enough privacy when discussing your condition or treatment?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

47. Were you given enough privacy when you were being examined or treated?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No

48. When you needed help from staff in using the bathroom or toilet, did you get it in time?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  I did not need help from the staff

49. When you needed help from staff in eating meals, did you get it at the time it was needed?

- 1  Yes, always
- 2  Yes, sometimes
- 3  No
- 4  I did not need help from the staff

50. How many minutes after you used the call button did it usually take before you got the help you needed?

- 1  0 minutes/right away
- 2  1-2 minutes
- 3  3-5 minutes
- 4  More than 5 minutes
- 5  I/we never got help when I used the call button
- 6  I/we never used the call button

## PAIN

51. Were you ever in any pain?

- 1  Yes → Go to 52
- 2  No → Go to 54

52. During your stay in hospital, how much of the time were you in pain?

- 1  All or most of the time
- 2  Some of the time
- 3  Occasionally

53. Do you think the hospital staff did everything they could to help control your pain?

- 1  Yes, definitely
- 2  Yes, to some extent
- 3  No

## OPERATIONS AND PROCEDURES

54. During your stay in hospital, did you have an operation?

- 1  Yes → Go to 55  
2  No → Go to 62

55. Before the operation, did the surgeon explain to **your parent or guardian** what would be done during the operation?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  My parent/guardian did not want an explanation

56. Before the operation, did the surgeon explain to **you (the patient)** what would be done during the operation?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I was not able to understand

57. Before the operation, did the surgeon explain the risks and benefits of the surgery to **your parent or guardian** in a way they could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  My parent/guardian did not want an explanation

58. Before the operation, did the surgeon or any of the other doctors answer your questions about the surgery in a way you could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I did not have any questions

59. Before the operation, did a doctor or nurse discuss your worries or fears about the surgery or operation with **you (the patient)**?

- 1  Yes, completely  
2  Yes, to some extent  
3  No  
4  It was explained by someone else  
5  I did not have any worries or fears  
6  It was not necessary

60. Before the operation, did a doctor or nurse explain accurately how you would feel after surgery?

- 1  Yes, completely  
2  Yes, to some extent  
3  No

61. After the operation, did the surgeon or any of the other doctors explain how the operation had gone in a way you could understand?

- 1  Yes, completely  
2  Yes, to some extent  
3  No

## LEAVING HOSPITAL

62. Do you feel you were discharged too early, at the right time, or too late?

- 1  Too early
- 2  At the right time
- 3  Too late

63. On the day you left hospital, was your discharge delayed for any reason?

- 1  Yes → Go to 64
- 2  No → Go to 66

64. What was the **main** reason for the delay? (Tick **ONE** only)

- 1  I had to wait for **medicines**
- 2  I had to wait to **see the doctor**
- 3  I had to wait for an **ambulance**
- 4  Something else

65. How long was the delay?

- 1  Up to 1 hour
- 2  Longer than 1 hour but no longer than 2 hours
- 3  Longer than 2 hours but no longer than 4 hours
- 4  Longer than 4 hours

66. Did a member of staff explain the **purpose** of the medicines you were given to take at home in a way you could understand?

- 1  Yes, completely → Go to 67
- 2  Yes, to some extent → Go to 67
- 3  No → Go to 67
- 4  I/we did not need an explanation → Go to 67
- 5  I was not given any medicines → Go to 69

67. Did a member of staff tell you about medication **side effects** to watch for when you went home?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  I did not need/want an explanation

68. Were you given enough information about **how to use** the medicine(s) (e.g. when to take it, how long you should take it for or whether it should be taken with food)?

- 1  Yes, enough information
- 2  Some, but not enough
- 3  No information at all, and I wanted some
- 4  I did not need/want any information

69. Did a member of staff tell you about what danger signals you should watch for after you went home?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary
- 5  Don't know/Can't remember

70. Did someone tell you when you could carry on your usual activities, such as playing sport or returning to school/work?

- 1  Yes, completely
- 2  Yes, to some extent
- 3  No
- 4  It was not necessary

71. Did hospital staff tell you who to contact if you were worried about your condition or treatment after you left hospital?

- 1  Yes  
2  No  
3  Don't know/Can't remember

72. Did hospital staff arrange the services you would need after leaving hospital? (e.g. district nurse, social worker, occupational therapist)

- 1  Yes  
2  No but these services were needed  
3  It was not necessary

### OVERALL

73. Did you feel that you were treated with respect and dignity while you were in the hospital?

- 1  Yes, always  
2  Yes, sometimes  
3  No

74. How would you rate how well the doctors and nurses worked together?

- 1  Excellent  
2  Very good  
3  Good  
4  Fair  
5  Poor

75. Overall, how would you rate the care you received?

- 1  Excellent  
2  Very good  
3  Good  
4  Fair  
5  Poor

## ABOUT YOU (THE PATIENT)

76. Are you male or female?

- 1  Male  
2  Female

77. What is your year of birth?

(Please write in) e.g. 

1	9	9	7
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78. Do you consider yourself to be disabled?

- 1  Yes  
2  No

79. How many times **including this admission** have you been admitted to hospital in the past six months?

- 1  Once  
2  Two or three times  
3  Four times or more

80. Up to **this point** in the questionnaire, who was the **main** person or people that filled it in?

- 1  The **young person** who was a patient in the hospital  
2  The parent or **guardian** of the patient  
3  Both patient and parent/guardian together  
4  Someone else

81. To which of these ethnic groups would you say **you** belong? (Tick **ONE** only)

**a. WHITE**

- 1  British
- 2  Irish
- 3  Any other White background  
(Please write in box)

**b. MIXED**

- 4  White and Black Caribbean
- 5  White and Black African
- 6  White and Asian
- 7  Any other Mixed background  
(Please write in box)

**c. ASIAN OR ASIAN BRITISH**

- 8  Indian
- 9  Pakistani
- 10  Bangladeshi
- 11  Any other Asian background  
(Please write in box)

**d. BLACK OR BLACK BRITISH**

- 12  Caribbean
- 13  African
- 14  Any other Black background  
(Please write in box)

**e. CHINESE OR OTHER ETHNIC GROUP**

- 15  Chinese
- 16  Any other ethnic group  
(Please write in box)

## PARENTS AND CARERS

This section should be completed by a parent or guardian if they accompanied the child or young person to hospital.

82. Were you able to buy cooked meals for yourself on the hospital premises?

- 1  Yes, as often as I wanted
- 2  Yes, but not as often as I wanted
- 3  No

83. Did you have access to tea and coffee making facilities while you were on the ward?

- 1  Yes
- 2  No, but I would have liked them
- 3  No, but I did not mind

84. Did you ever want to stay overnight with your child?

- 1  Yes → **Go to 85**
- 2  No → **Go to 88**

85. Were you given the chance to stay overnight when you wanted to?

- 1  Yes, always → **Go to 86**
- 2  Yes, sometimes → **Go to 86**
- 3  No → **Go to 88**

86. How would you rate the facilities for parents or guardians staying overnight?

- 1  Excellent
- 2  Very good
- 3  Good
- 4  Fair
- 5  Poor

87. Were you offered a bed near your child?

- 1  Yes
- 2  No, but I would have liked it
- 3  No, but I did not mind

88. Were you ever bothered by noise from **other patients**?

- 1  Yes
- 2  No

89. Were you ever bothered by noise from **hospital staff**?

- 1  Yes
- 2  No

### OTHER COMMENTS

If there is anything else you would like to tell us about your stay in hospital, please do so here.

Was there anything particularly good about your hospital care?

Was there anything that could be improved?

Any other comments?

**THANK YOU VERY MUCH FOR YOUR HELP**

**Please check that you answered all the questions that apply to you.**

**Please post this questionnaire back in the FREEPOST envelope provided.**

**No stamp is needed.**