Patient consultation day report

A consultation with patients to find out about their experiences of patient identification during blood transfusions took place at the National Patient Safety Agency (NPSA) in November 2005.

There were 16 participants. Of these, 14 were people with sickle cell anaemia (or parents of children with the disease), one person had leukaemia and one represented people with leukaemia. All the participants had been recruited via relevant organisations: Sickle Watch, Merton Sickle Cell and Thalassaemia Group, Waltham Forest Sickle Cell Action and Support Group, Makanga Koy Anane Bertrand and Leukaemia Care. In addition, there was a representative from the National Blood Service, a consultant haematologist working with the NPSA, and four NPSA staff members.

This report summarises the key issues that arose in the course of discussions, most of which took place in three small groups. It contains direct quotations from those involved about their experiences.

It should be noted that the number of people who attended the consultation day allowed for a productive discussion, but statistical inferences cannot be drawn from any of the comments made.

Background

Peter Mansell, the NPSA’s Director for Patient Experience and Public Involvement, welcomed the participants and explained that the principal purpose of the day was for them to help the NPSA to learn from their experiences. He began by setting out data on the number of people using the NHS every year: 6.5 million calls are taken by NHS Direct; nearly 17 million people attend A&E; there are 9.5 million GP referrals to outpatient appointments; 206 million GP consultations take place; and 686 million prescriptions are issued (figures from the Chief Executive’s Report to the NHS, 2005). In short, the NHS involves a lot of traffic, so it is not surprising that sometimes things go wrong.

Data on the number of patients injured accidentally suggest that error and harm are systemic in the NHS. The NPSA found that 86,142 patients were subject to patient safety incidents between November 2003 and March 2005, with about one per cent of these incidents leading to severe harm or death. Over the whole of the NHS it has been estimated that a more accurate figure would be 572,000 patient safety incidents and 840 deaths. Most of these incidents are reported by clinicians, although patients can also report incidents. Only a small proportion of incidents involve compensation claims; 5,273 such claims were handled by the NHS Litigation Authority for the year ending March 2005.

The role of the NPSA is to learn from these incidents. It seeks to understand the underlying causes of incidents and how they can be avoided in future, for instance by analysing the environment in which healthcare takes place. The NPSA’s National Reporting Learning System (NRLS) is a database of patient safety incidents which enables clinicians (and sometimes others) to report incidents on an anonymous basis. The NPSA is not concerned with accountability and is not a regulatory body.
Identity checking and blood transfusions

Most of the workshop participants were very experienced in having blood transfusions, having had them on a regular, and sometimes frequent, basis. Some were content that there were good checks concerning their identity:

“When they bring the blood to you, they check it. You get two nurses check the blood, your name and your blood group, your age and when the blood expires or when it was made up, so they check all that to see if you are the right person. They get the labels and they write your name on it and they write your date of birth and the hospital number.”

Others, however, said that their identity was, to their knowledge, never checked:

“I've never actually seen that each bag that they put up is checked with my name and wristband. I suppose it’s all checked by batch. I don’t know.”

A lack of checking was particularly common where patients were well-known to healthcare staff, because of their frequent attendance:

“When I got there, they did not check my name or anything. They know I’m a regular there, I was just in for exchange. So my files were there and they did not ask me my name, my date of birth or anything.”

“Because they know you, it’s ‘hello’ and get on with it.”

Participants were generally less comfortable when this happened, as they felt that their identification details should still be checked, especially as blood to be transfused is so important to get right. It was noted that staff made assumptions about the patient (“they just assume that everything is the same”). Moreover, because staff did not ask questions, it made it more difficult for the patient to ask questions.

Some felt it was difficult to pin down specific aspects of the checking process:

“Sometimes they prepare the name label for the bottle before you come in, sometimes they do it after, sometimes they do it in the process and sometimes you don’t have a clue whether they’ve written your name or not.”

"In the haematology clinic that I go to, they’ve got your notes and stuff – they will ask you for your name and they will ask you for your number, but there is no wristband or anything.”

Participants generally felt that a wristband was important, particularly for children or those who could not speak up for themselves:

“When my son goes in, he always has a wristband. That’s quite good, because if you’re not there – maybe you’ve dashed out to get a cup of tea or something – and because he’s got learning disabilities, he can’t speak for himself.”

Participants stressed that, on those occasions when they were fully aware of what was happening to them, they would like to be more involved in the checking process. Some said that they always checked certain aspects of the blood they were being given, such as expiry date and batch number:

“I am a busy-body. I always ask for a before and after print-out from the blood tests… I have always been vigilant in checking, asking questions, quizzesing the consultants and saying ‘how safe is this blood for my son?’”
It was felt that patients should be encouraged to check these matters, rather than feeling that they were being a nuisance ("sometimes you can be a bit scorned upon for looking"). Staff did not always say anything, but their body language could suggest that the patient or carer was not part of the process.

When patients were in severe pain, however, such involvement was far from their concerns:

“When you go through crisis, you are in pain. You haven’t got time to look at anything, you just want someone to give you pain killers, to get better quickly, so you can go back to your life.”

One participant suggested that there was a need for particular vigilance in the case of people with sickle cell anaemia, as many had names that were difficult for staff to spell or pronounce and this could lead to misunderstandings. Participants felt that staff should ask the patient for their name and check it against what was written down. It was suggested that there was evidence of people getting the wrong treatment because staff misheard a name.

Patient safety incidents

A number of participants recounted poor experiences arising from their own or others’ transfusion. Not all of the experiences necessarily fall under the NPSA’s definition of a patient safety incident, but all were worrying for the patients.

Some of the incidents related specifically to identification. One participant had a missing wristband; the nurses could not identify him or the blood that he needed, despite having his notes, and it took some hours for his identification to be confirmed and for the transfusion to take place.

Another participant found that the hospital number on his wristband was different to the number on the blood. Of the two nurses helping, one knew him, but the other insisted on checking the information (“I felt good, because yes, you do know me, but at the end of the day accidents can happen”).

One woman, visiting a young relative who was having a transfusion, happened to notice that her name was wrong, due to a confusion arising from two patients having similar surnames. On her insistence, the name was checked before the designated blood was given (“if I wasn’t there, it’s quite likely that she would have had that blood”).

One participant related that she had been confused with another inpatient while in hospital, although not for a transfusion, due to having the same surname. A porter had come to take her for an ECG, but when pressed to check the name, he discovered it was the other patient.

Other problems included adverse reactions to drugs. One man developed an allergic reaction to a particular antibiotic (“there were giant spots everywhere on my body – I was screaming”), but despite this being in his notes, he was given the same antibiotic on two further occasions. One woman had a bad reaction to a new painkiller and, although the doctor was reluctant to ascribe these reactions to the injection, it was put in her notes.

Other incidents discussed arose from the transfusion procedure. One participant developed a blood clot in her leg following an infusion into her groin, where the needle had to be left in for three days. The doctor was certain that her pain was due to her disease (“nothing wrong, it’s just you and sickle cell disease”) but, at her insistence, it
was checked via a scan and she did, indeed, have a clot. As a result, she now has to take warfarin for the rest of her life and she needs painful blood tests each week.

Another participant noted that the transfusion given to her son was so delayed that his veins shut down and he had to be rushed to the ICU, despite the fact that she had phoned before bringing him to the hospital. There were no adverse consequences as a result, but she was very upset (“I wasn’t anticipating going into ICU…and time was ticking”).

Other experiences related included that of the son of a participant, who kept going into crisis as a young child. He developed antibodies and was therefore not able to be given blood. The participant felt that it was only her questioning everything that stopped a transfusion from being performed. Eventually, appropriate blood was found from a military blood bank.

Finally, a man who had a very bad sickle cell crisis had gone to the local hospital to have his blood checked, but the hospital did not believe that he was ill and sent him away (“I’d been drinking and they just thought I was being rowdy”). He talked to the key worker at his hostel, who arranged for him to go back to hospital, but he was again told he was not ill.

**Participants’ concerns**

Many participants said that they rarely worried about being given the wrong blood type, at least at the time of the transfusion (“maybe you think about it later”). It was felt there is an inevitable need to trust those who were giving the blood, which made any such thoughts hard to absorb (“your life is in their hands”). One man said he was fairly relaxed about the quality of the blood because he had been a blood donor and he knew how stringent the checks were.

**Infected blood**

Some participants noted that they worried about the possibility of contracting AIDS or other diseases through being given infected blood. Many had heard scare stories of people being given infected blood of one kind or another, and this was a real source of anxiety. Indeed, one man was periodically refused a transfusion for this reason (“it is bad enough as it is and if they were to complicate it by giving you the wrong blood…”).

It was also quite common for those having a transfusion to worry about whose blood it was and what that person was like. One participant noted that a vegetarian colleague worried that she would be given the blood of someone who ate meat.

**The transfusion procedure**

Some were concerned about physical aspects of the procedure. Many spoke of the difficulties of getting needles into their veins (“loads of doctors couldn’t put drips in – one time I had about 18 attempts and I just wanted to hit him”). There was also a fear of infection, as this could make them very ill. Some talked about the after-effects of a transfusion, such as headaches, tiredness and feeling faint. Others spoke of pain during the procedure:

“They might put the catheter in the wrong arm or it slips out and tears you or they use your thumb and some irregular places that are really painful. That’s your main problem – not whether the blood is the right blood.”

“They use this big needle that goes into your heel. There’s a knife where they have to cut a part of your skin for them to put the needle in, so you just think about that.”
However, those in need of regular blood transfusions simply had to go ahead with it:

“We’ve been doing it for so long, you just do it. You just accept it and you just get used to it. You just get it done.”

Not only is the procedure unpleasant, but some found that they had to undergo it more than once because of problems at the hospital, particularly at the cross-matching stage. Sometimes blood was lost (“it’s a favourite for them to say they’ve lost it”); in one case, the wrong name had been put on the bottle, requiring another visit; and in another, blood had become infected during the testing, so it had to be taken again. Another problem was clotting in the blood if it was not sent off quickly enough, again requiring another visit. Participants spoke of their dismay when they had to undergo procedures more than once for these sorts of reasons.

**Nursing and other staff**

Some participants expressed concerns about the nursing and other staff. One had found that they were more tired in the afternoon and therefore liked to schedule her visits for the morning. Some had had experiences of nurses becoming flustered by sickle cell patients, especially when they were in crisis:

“If you are flustered by all of that, then you are in the wrong profession… we end up screaming and effing and blinding and all sorts…”

Several participants were concerned when nurses checked the blood, but not in front of them. There were also various hygiene issues, such as the nurse putting on gloves and then going away for a period. One participant was concerned about a nurse’s apron (“she’ll probably have that apron on for the whole day to protect herself, but does it protect the patient also?”) A number of participants noted that the alcohol rub was often not used, even though it was put in a convenient place.

However, patients said they found it exceedingly difficult to question what nurses were doing, especially where they had tried and did not get a positive response. Some nurses were said to be unwilling to listen to patients, even on simple matters such as which vein to use (“I’ve had so many transfusions, I know which vein is better, but when you tell them it’s like ‘how can you tell me my job?’”). It was much easier when they had nurses who knew them:

“My particular nurse knows everything about me – he is almost like my PDA; he knows where I am meant to be at a specific time, what I am meant to do, what kind of tablets I am meant to take and what the limits are.”

One woman said that she knows the staff dealing with her son, who is now old enough to attend on his own, and she can ring up and learn “in blow-by-blow detail” how he is doing. This gives her confidence that if anything was wrong, the staff would phone her. Another frequent user of his hospital said he was very much encouraged to ask questions (“I was self-administering drugs after the first couple of sessions”).

In one group, there was some discussion of the impact of racism on their NHS experience. One black man said that a black consultant had made the assumption that he was on illegal drugs (“the old misconceptions about us being malingerers, feckless, lazy – it’s still here”). He argued that there should be protocols for dealing with this situation. Others thought the issue was subtle and it was hard to know when it might affect them.

Although some spoke well of their haematologist, some participants had had a disappointing experience:
“Some of them think because they are the doctor, they know more about your body and you don’t know nothing. I have been asking a lot of questions about my illness and about transfusion and one doctor said to me ‘you ask too much questions’. I said, ‘well, if I don’t ask questions how would I know?’ It is your body and you want to know what they are doing.”

Information
A number of participants felt there was a need for more information and support around the process of blood transfusions (“so we can know the basics”), including identity checks. Although some had become experts, simply because of the frequency with which they experienced a transfusion, it had rarely been systematically explained to them. Indeed, it was thought that staff assumed that they knew more than they did. It was not uncommon to go home and then worry about something:

“While they’re putting it up, [they should] talk about it or ask if there’s anything that you’re worried about… It’s probably stating the obvious, like do the checks in front of you and doing it with you as much as you can… it’s all about patient involvement.”

There also tended to be no one they could go to if they had questions afterwards, aside from the clinic nurse, who was unlikely to be able to help. One participant spoke positively of a hospital where there was someone to help people with sickle cell disease (“they basically look after you, like counsellors, to see if you’ve got any problems”).

Interestingly, one participant who had been a patient both on children’s and adult’s wards much preferred the former, as much more was explained to children.

There were mixed views on a general leaflet about the process being provided. Although some said they were unlikely to read them, especially on the day of their transfusion, it would provide something to refer to later on. It was also felt that it would mean that staff time would be saved, as patients would bother them less often with questions. One participant spoke of the question-and-answer leaflets his leukaemia charity provided to patients, which he thought were helpful.

Proposed NPSA solutions
Participants were asked to consider a set of initiatives (the NPSA’s Right patient, right blood project) to improve the bedside patient checking process, as outlined by Bridget James, Patient Safety Manager at the NPSA. She informed the group that the NPSA has a target of reducing the incidence of ABO incompatible transfusions by 50 per cent over three to five years.

Bar codes
IT technology (bar codes) is used to check patient and blood details. A bar code reader generates a set of labels with a bar code, which go onto the sample, wristband, form and bag. This system is currently in use in a couple of trusts in the UK.

Participants’ response to this idea was mixed. Some welcomed the idea of using technology to ensure safety during blood transfusions (“human error gets taken out of that”), especially if it did not make nurses’ jobs more difficult. The fact that the bar code is unique to each individual gave participants confidence in the system:

“You are the only one who would have that code, instead of a second person, so you would know exactly, because everything would be on it.”

However, many were worried about the potential for something to go wrong when high-tech solutions were introduced. It was not unknown for bar codes to indicate the wrong
product (“the computer can read the tin of beans as a bag of crisps”). In the case of blood, it is difficult to tell one from another:

“You won’t be able to tell if it is this type of blood or that type of blood, so you have to rely on that bar code, so you don’t know if it is true or factual or not.”

There was also concern that computers could go down or become infected by a virus and give out incorrect information (“it will say everything is fine, when everything is not fine”).

There was also a fear that nurses would become reliant on the bar coding system (“they will come to rely on it as gospel”), whatever the initial intention, and become more lax in checking procedures that follow. Indeed, if systems did not match, it might be explained by staff as being because of a faulty machine:

“A nurse in a hurry will bar code things and they won’t double check, because it’s bar code technology, it is infallible technology, it has got to be right, move on to the next patient.”

It was suggested that only specialised nurses should handle such technology and it would also be important that they were well trained. Agency nurses were a particular source of concern. There would be a need for careful systems of double-checking. One participant felt it was essential that the procedure take place at his bedside, so he could see it. One man questioned how many barcoding machines could be on a ward and therefore whether this might delay transfusions. A few also raised the issue of cost.

Some participants thought the process might seem dehumanising, reducing people to a number. Some also felt that it would feel a bit odd to have a machine waved over them (“like being in Tesco’s”). Others, however, did not seem unduly worried about this aspect (“we’re all digits anyway, national insurance number, hospital number…”).

In several groups, NPSA staff explained that the potential for human error would be reduced by the use of a bar code, compared to a nurse reading a hospital number, and it would simplify the current system of checks. There would be an alarm system if the bar code for the blood and that identifying the patient were not the same. Moreover, the machine would store information on which nurse undertook the procedure or check, which might make nurses more vigilant. It was also stressed that bar code systems were meant to supplement existing identification systems, not replace them altogether.

**Labelling system**

A labelling system for blood transfusions involves a series of labels, all printed with the same unique identifying number, being used on the patient’s wristband, blood and so forth, providing an additional check between any blood and the patient. When blood goes to the laboratory, the labels would go with it so that those in the laboratory could put the same labels on the blood for the ward. The label numbers would be shorter than the hospital number.

There was generally greater enthusiasm for this idea amongst the group (“I think it’s beautiful in its simplicity”) because the numbered labels were more immediately visible to the eye and did not depend on any kind of technology:

“There’s no error coming in. It’s going to have a sticky label right from the onset right through to when it comes back with the same label.”

But some participants were still concerned about the potential for human error and noted that bar codes would have more information on them. The hundreds of labels being dealt with in the laboratory could get mixed up; it would be important for there to be a
form that went with the blood. Moreover, tired nurses could still get confused by similar looking numbers:

“People might not take the time to read it properly. Human beings are fallible and we all make mistakes… You could be tired and you may not read it properly or you have forgotten your glasses.”

It would be better, it was suggested, if the numbers were not sequential.

Photo identification

Photo identification involves the use of a card with a photo, together with other the unique identifiers – name, age, date of birth, hospital number, gender – which patients carry around with them and bring to the hospital each time they go for a transfusion. The card would not carry information about blood group, but only the same information that would be on a wristband. If someone did not have their card with them, a wristband would serve as a default mechanism.

Participants generally welcomed this idea as it was seen to provide all the information needed by hospital staff in one clear place. Checking ID would become straightforward with a card:

“Manual checking would make me feel a lot better, simply because you have to come down to a more human level: I have got your picture here, I know this is you.”

One participant thought that the card should be labelled in bold ‘Transfusion ID’, so everyone knows what it is for; no one in that group had any objection to this idea. Another thought that it should have the logo of the Blood Transfusion Service. A few participants thought that a bar code could be added to the ID card, giving additional safety. It was suggested that the card should be kept in a patient’s file in hospital, so that people would not need to remember to bring it, for instance in an emergency.

One participant already had a haematology card with his date of birth and blood type on the back; he liked having the card because it stopped staff asking repetitive questions (“you can just give them the card and they don’t have to keep asking you the same questions”). He had no difficulty with the addition of a photo.

Few participants had reservations about having their photo on a card, as this was no different from a passport or a driving licence (“we have photographs all the time”). Indeed, several suggested that a photo should also be on patients’ notes. The parent whose son lost his wristband explained that a lot of time had been lost before he had a transfusion because it was difficult to confirm who he was (“if he’d had a photograph on his file, somebody could have opened up the notes”). NPSA staff explained that there were complex issues of consent, however, if photos were retained.

Some people were known to be reluctant to have their photograph taken, however, sometimes on the grounds that they were not photogenic or that they had some disfigurement. People’s appearance might also change, such as a patient having chemotherapy and losing their hair. Some participants welcomed the suggestion that the ID photo could be changed if people felt they had physically changed, although it was also noted that a person could look particularly drawn at times and therefore less recognisable.

Participants thought that they were less likely to lose a card than a wristband, at least whilst in hospital, as the latter had a tendency to slip off the wrist or be removed by a nurse when undertaking some procedures. Some participants were concerned about the loss of the card when out and about, however, particularly for children and young
people. There was some concern that the loss of a card would mean the loss of treatment.

A few did feel that there would be some reluctance to carrying such a card, due to a concern with privacy and confidentiality; some did not want others to know about their condition:

“ar son is very private about his sickle cell disease and he would not carry that. He would not wear it as a chain, no way.”

Finally, there was some concern that in an emergency, patients would not remember to take their card with them:

“When you’re ill, you don’t even think to pack, really. You just want to get to the hospital, get your medicine and get it over and done with. I’ve been in situations where I can’t even walk down the stairs, let alone think about carrying an ID card.”

NPSA staff noted that other procedures would come into play in an emergency; the photocard was intended for patients having regular blood transfusions that are undertaken as an outpatient or day case.

**Patient leaflet**

A draft version of a patient information leaflet was shown to the group. A number of participants commented on physical aspects of the leaflet. The most common suggestion was that the writing needed to be larger so it can be easily read, as well as in a bold font. In particular, the grey writing on a white background was not easy to read (“it should be dark and sharp”). Several participants said that they liked the colour (“nice and bright, lovely, a nice colour”). When asked whether it should be in bullet points or paragraphs, there were no strong views. One participant thought that the pictures could show more diversity, including children and different ethnic groups. It was suggested that a ‘tri-fold’ leaflet might work better, as this has a full A4 page. A bigger font could then be used.

With respect to the text, the leaflet was generally felt to read well, in clear English. Some participants thought there was a need for more information, for instance on why it was important to have the right blood; although mentioned, this should be given more prominence. Others thought that information to empower patients would be valuable, such as is provided on the back of the leaflet. One participant said the inside front page, which talked about wristbands, could be clearer. In one group, NPSA staff asked whether patients would be frightened of information about the risk of being given the wrong blood. Participants did not see this as a problem.

Participants welcomed the leaflet’s invitation to patients to challenge staff. It was difficult to do so, for instance on hand washing, but having it written in a leaflet gave them permission (“our photo is there, now we can ask these questions”). Having a card also made it easier for people to ask staff whether they had checked the card.

Although some patients probably would not read the leaflet, some participants said they read everything given to them (“you want to read everything you can get your hands on”). Staff tended to be too busy to give patients much time, so a leaflet was helpful. One group discussed when would be the best time for patients to be given such a leaflet. It was suggested that it should be given at the consultation when patients learned that they would need a transfusion (“once you’ve got a diagnosis and you’re going to be going regularly”).

One group expressed concerns about ensuring that similar information was available to people who were unable to read, either because they had not learned or were visually
impaired. It was suggested that the NPSA might wish to speak to people at the RNIB about how best to handle this. There are also people with other kinds of colour disorders, for instance an inability to see red or green in certain contexts. A telephone number that people could ring to get the same information might be useful, or an audiotape with the same information on. In addition, staff should be careful to talk patients through the leaflet as needed.

In one group, there was a discussion about the fact that the sample ID shown on the leaflet indicated ‘patient – not staff’, whereas a member of staff could also be a patient. If the issue was not to confuse staff and patient cards, it need only say ‘patient ID’ as staff would leave their staff ID at home. In another group, it was suggested that the cards might be a different colour for staff and patients, so as to avoid any such confusion.

It was also noted that the photo ID and the bar coding system were not alternatives; one of the pictures in the leaflet showed an ID card with a bar code. Several participants felt that the safest system would involve a combination of solutions, such as a photo ID and a label. A key issue, however, was not to compromise confidentiality.

**Other suggestions**

In one group, a few participants suggested alternatives not covered in the NPSA’s presentation. Some liked the idea of some kind of biometric marker, such as a fingerprint or a retina scan ("iris recognition is being used by banks now, so why can’t it be used by hospitals?") as it is seen as being unique to each individual. Some questioned whether patients would readily submit to this and others thought it was probably too expensive.

Another proposal was for a partnership with the MedicAlert organisation, as this was seen as expert in this area.

Another suggestion combined the photo identification (ID) and the labelling system, so that all blood was labelled with a photo of the patient concerned, perhaps as well as a label identifying his or her condition ("even a monkey would be able to look at the picture on the blood and look at the picture of this guy lying in the bed and say ‘does it look like this bloke?'").

Another idea was an implanted chip, such as those used for dogs ("you wouldn’t lose it, you just need to brush the thing across it and it would read all that information"). Some thought, however, that this would be seen as dehumanising people ("you’re chip number 445, you are just a load of data").

Some participants took the idea of a photo ID card further than initially planned by the NPSA, suggesting in effect that there should be a computerised ‘smart card’, with much more information, such as blood type, diagnosis, allergies and so forth, that could work in any area of the country, using the bar code. They were not worried about carrying this information around if it would help to save their life. It would be easy to carry in a wallet with other cards ("It’s like my debit card, I carry it every day"). If there was a photo on the card, identity could be checked at the same time. Moreover, if key information were also provided, readable by the human eye, the card would work even if a machine broke down. It was suggested that if having a card was a condition of treatment, people would have it on them all the time.
Concluding remarks

At the end of the discussions, Peter Mansell thanked the participants for sharing their experiences and explained that a report would be prepared from the meeting, undertaken by an independent team. This will then be used by the NPSA in discussions with others, such as clinicians. Having the voices of patients is very important to complement statistics because it provides a sense of the human element involved.