Parents’ experiences of sharing neonatal information and decisions: consent, cost and risk
Priscilla Alderson
Joanna Hawthorne PhD Senior Research Associate
Margaret Killen BA RN RHV Research Officer
Social Science and Medicine 62: 1319-1329

Abstract
This paper is about the care of babies with confirmed or potential neurological problems in neonatal intensive care units. Drawing on recent ethnographic research, the paper considers parents’ experiences of sharing information and decisions with neonatal staff, and approaches that support or restrict parents’ involvement. There are growing medico-legal pressures on practitioners to inform parents and involve them in their babies’ care. Data are drawn from observations in four neonatal units in southern England, and interviews with the parents of 80 babies and with 40 senior staff. The paper compares standards set by recent guidance, with parents’ views about their share in decision-making, their first meetings with their babies, ‘minor’ decision-making, the different neonatal units, being a helpless observer and missing opportunities. Parents’ standards for informed decisions are summarised, with their reported views about two-way decision-making, and their practical need to know. Whereas doctors emphasise distancing aspects of the consent process, parents tend to value ‘drawing together’ aspects.

Key words Babies, intensive care ethics, ethnography, informed consent, neurodevelopment

Word count 9019 words
Introduction

This paper is about the care of babies with confirmed or potential neurological problems in neonatal intensive care units (NICU). The paper draws on recent ethnographic research to consider parents’ experiences of sharing information, decisions and care of the babies with neonatal staff, and approaches that support or restrict parents’ involvement. There are growing medico-legal pressures on practitioners to inform parents and involve them in their babies’ care. Recent British Inquiry reports and guidance require practitioners to inform parents in detail, which can involve sharing complex, distressing and uncertain information. ‘The process of consent should apply …to all clinical procedures and examination which involve any form of touching’ (Kennedy 2001:440). Three main groups appear to be promoting this policy:

* medical lawyers and medical and nursing policy makers (GMC 1998; RCPCH 1997, 2000; Alderson and Goodey 1998; BAPM 2000; DH 2001a, 2001b; BMA 2001a, 2001b; Kennedy 2001; Mason and Megone 2001; NMC 2002; NSF 2004);
* parents who have formally complained that their child has suffered, and in some cases died, after inadequate and misleading information was given (Kennedy 2001);
* Trust managers and ethics committees who check that new guidance is observed.

Our research aimed to investigate also the views of two other relevant groups:

* neonatal staff who give information and ask for consent;
* parents who are warned about serious problems that their baby might or might not develop.

Shenoy et al (2003) report the need for ‘drastic changes to incorporate legal and ethical requirements’ in British NICU. The 47 neonatologists who responded to their survey gave varied replies; staff in 95 % of units did not obtain parents’ consent for routine procedures; 77% of units had no guidelines and 73% did not train junior doctors on informed consent; 89% did not obtain consent to initiate treatment when the babies were admitted; consent rates to procedures such as ventilation ranged from 20% to 74%. Shenoy et al. (2003:18) interpret the guidance as requiring that valid parental consent ‘must be obtained’ before starting neonatal tests or treatment, and on ‘every occasion when the doctor wishes to initiate an examination or treatment or any other intervention, except in emergencies or where the law prescribes otherwise’. They say that it is impractical to ask for consent to every routine procedure, but add that in law such consent is required, or else doctors risk legal action by parents and action by their professional body. They also say that written consent is preferable, but is not necessary for all ‘routine and low risk procedures’ such as taking a blood sample.
The advice to request parents’ consent to virtually all neonatal procedures raises questions. Why is this required? Who might benefit? Is this realistic, and what might the effects be? Do most parents want this to happen? The questions are considered in relation to examples from the ‘foretelling futures’ study reported in this paper. This paper compares standards in the recent guidance with parents’ views and experiences of shared decision-making, their first meeting with their baby, making ‘minor’ decisions, the contrasting decision-making contexts in different neonatal units, helpless observers, and missed opportunities. The paper concludes by summarising the parents’ reported views about standards for informed and two-way decision-making, and their concern with ‘drawing together aspects’ of consent in contrast to doctors’ tendency towards the distancing aspects.

Methods
The main background questions asked by the ‘foretelling futures’ research study concerned how fairly recent developments in medicine, nursing and law complicate or illuminate long-standing neonatal dilemmas, how different kinds of knowledge about babies’ neuro-development are selected and applied and shared between neonatal staff and parents, and how new understanding of babies’ own complex responses is influencing neonatal policy and practice. This paper concentrates on a small aspect of the findings from the whole project: the views and experiences of neonatal staff and parents of their practical sharing of knowledge and responsibility for babies.

The researchers (PA, JH, MK) observed parents’, babies’ and practitioners’ experiences and responses in four NICU in southern England over 18 months (Alderson et al. 2004 and see note 1). We put up notices in the units about the ethnographic research, gave information leaflets to staff and parents, and wore badges labelled ‘researcher’. Babies with definite or potential neuro-developmental problems, whose parents gave consent, were selected through purposive sampling for a range of medical conditions and socio-economic and ethnic backgrounds. Semi-structured tape-recorded interviews were held, with their consent, with 40 senior practitioners and with the parents of 80 babies in the units and in their homes; they included the parents of 15 children aged 4-6 who had stayed in the units after birth. All the babies’ mothers, and 16 of the fathers, agreed to take part in interviews. The observation notes and interview transcripts were analysed for references to responses to the researchers’ questions, and for main themes raised by interviewees (Strauss and Corbin 1990). In this highly sensitive area of research, we did not observe formal interviews between doctors and parents. Instead, we relied on their views of what was and what could be said, and our observations of informal contact between staff and parents. In order to convey something of the detailed complexity of the experiences and interactions, this paper
concentrates on reviewing a few of the 80 babies’ cases, while drawing on information given by many of the parents and practitioners.

The researchers enquired about the effects of the new medico-legal information policies in theory and in practice - are parents being informed in detail and being asked to consent to most procedures, and do they want this? Our study is unusual. Firstly, we interviewed most of the parents during their babies' time in the NICU (see also Alderson 1990) instead of only later in retrospect. Secondly, we investigated parents’ views about information and decisions, whereas the neonatal literature is mainly concerned either with parents’ feelings and needs or else with doctors’ decision-making (see, for example, the 250 references in McHaffie, 2001, her research is also unusual in examining parents’ reasoned views).

First meetings and ‘minor’ informed decisions
When babies are admitted to the neonatal unit straight after birth, their first real meeting with their parents is in the NICU. The nurses have two main ways of welcoming and informing parents. One begins by explaining the equipment and clinical care. Some parents appreciate being informed immediately. Iwu’s mother (all the babies’ names have been changed) sounded pleased and reassured: ‘Yes I asked them, when I got there, “What is this for?” “Oh this is the pipe for oxygen, this is for – to help her, for her lungs.” She breathed it in, it went inside her lungs’ (3.5). However, other parents feel too shocked to remember much at first. James’s mother said:

I walked up here [the day after the caesarean] and when I came in the nurse was explaining all the monitors and things and she was very good but while she was talking, first my ears went, and then my eyes went, and I thought I’d pass out. They got me some water and a chair […] It is so hot and so bright and so noisy and it was the first time I had seen my baby. They are really good at telling you what is working, but it’s so much to take in at first, and you’re not up to speed yourself especially after surgery that I hardly saw him on my first visit. My brother felt the same thing, he nearly passed out when he came in. Someone else keeled over the day before. It must be quite a common occurrence (3.4) ([…] means words omitted).

The nurses’ initial explanations implicitly emphasise the baby’s dependence on the equipment and expert staff, and the parents’ need to learn. In contrast, some nurses begin with the parent-baby relationship. Oludayo’s mother had a caesarean at 25 weeks gestation because of severe infection and she needed two days of intensive care herself. A large Nigerian woman, she was shocked when she first saw Oludayo.
I was crying [tearful pause] because she was so tiny and for me I thought I was going to have a big baby, like me […] and full of life, active and all that. Looking at her, she was so helpless and it was like: Is she going to make it? I was in shock. But then […] the nurse there with her was J […] when I came in […] she said, [in urgent excited tone] ‘Talk to her she knows your voice, go on say something,’ and I opened my mouth and I don’t know what I said, you know, and she started moving! […] When I talked, like oh it’s a voice she knows, I was surprised. J was saying, ‘See she knows you’ […]smiling and laughing softly] then and there was the first time I felt a sense of bonding coming on you know, [smiles…] she was looking so helpless and tiny, but then I say something to her and then it was so, she was moving her hands and legs so quickly and right, like trying to recognise you […] ‘Yes go on’, [J] was saying […] ‘this is the one voice she known for a long time, now she can have a sense that she has not been abandoned that you are still here’ (2.4).

When the nurses suggest that parents touch their baby, some parents hang back fearing to become involved with a baby who looks too fragile to survive, although those who overcome their anxiety tend to report feeling very pleased. The staff vary in how much they encourage parents to make early contact (Goldson 1999). In some units, the babies are undressed and tend to stay longer in incubators to conserve their body heat. It is then harder for parents to lift out and hold their baby. Some parents regretted not having early contact.

Yejide’s mother: I couldn’t believe a baby could be that small […] they were telling me different things […] they had terms like, chronic lung disease, and bone disease and that really scared me […] well I kept on coming here, I got used to all the things. At first I couldn’t touch her cos nobody told me I can put my hand in the incubator […] I just sit there and look. Not till I met the other mums and they told me, ‘Oh you can touch your baby’, like that. And for a very long time I wasn’t able to cuddle her […] I see other mums cuddling their baby but nobody told me I can hold my baby, except after a month or so a nurse said, ‘Have you cuddled your baby?’ and I said ‘No’. And she was like, ‘Why?’ […] So she has to bring her out for me, and I cuddled her and that was when I thought, I had a baby. [Before] she is far away from you. But when you cuddle her, you can feel her heart beat and you can feel yours […] she was really saturating [oxygen] well, yes I think it is really good for them. But the nurses say you cannot bring them out as much as possible cos they get tired and they won’t do so well […] because they can’t control their temperature, and they were saying they spend much energy to control that, and I think it’s true, all right […] when you first come here I think they should have told you everything, the rule is that you can
touch your baby, you can change her diaper [...] they should at least show us and educate us and let us know and make us aware (3.8).

Whereas some nurses, as Yejide’s mother described, discourage skin-to-skin cuddling, other nurses and research evidence confirm its benefits (Anderson 1999; Symington and Pinelli 2000, 2004). Policies in many matters, such as feeding or discharge protocols, varied between units. Parents could be unaware of how their choices were opened or closed by the policies of their NICU.

Informed consent tends to be connected to major formal medical decisions, but these relatively seldom arise in the units. Instead, as with talking to the baby, many ‘small minor’ choices and decisions are offered to parents, or not offered, and to the parents these can involve major responsibilities, activities and effects. Repeatedly we found that small matters in the NICU can have large consequences. Guidance that requires that ‘parents give consent to necessary interventions on admission’ to the NICU (Shenoy et al. 2003:19) assume that the staff will adopt the first approach of expert explanations, whereas some parents in our study preferred the second approach of concentrating initially on the baby, and many felt unable to understand enough to begin to consider informed consent to clinical interventions during the first meeting.

Contrasting decision contexts
The next example illustrates how information and predictions can vary and change rapidly, so that decisions may be not only complex but also uncertain. After fetal distress was detected, Rosa’s mother had to wait for 45 minutes until the obstetrician was ready to begin the emergency caesarean section. The obstetrician then:

had the barest bleakest news within a few hours [...] lots went wrong. It is an irony that we get the most incredible care here, in the neonatal unit [unlike] the maternity department […] I felt we needed to know, but he could have packaged it better, it was far too harsh, going through her heart trace saying, ‘This is basically before she’d died’ [...] He implied that we’d have to decide to switch off the life support, but she never needed a ventilator, she always breathed for herself (3.2).

Rosa’s mother, like many parents, found that the neonatologists’ communication varied: one was ‘wonderful but always bleak, they have to be’, another was ‘so sensitive, he did it really well’. Rosa’s parents were warned that she would probably never be able to suck, but a week later the position was transformed.
Specialist Registrar: She has HIE [hypoxic ischaemic encephalopathy after the brain is deprived of oxygen], infarcts, [these can cause serious brain abnormalities] we're worried about her vision, she was fitting badly despite being on high doses of two anticonvulsant drugs […] Rosa was much much more severely affected [than another baby, who] couldn’t feed at all […] whereas Rosa is fully breast feeding. She could go home now […]

Interviewer: Are you surprised?
SpR It is a miracle, yes that's my opinion. No, I have no idea how or why it happened.

A year later, Rosa’s mother said:

It was so horrendous, it will haunt us for the rest of our lives. But everything is absolutely fantastic, there are no signs of all the doctors’ worst prognoses, they are completely revising what they said, and now they say that things now look incredibly good. She’s bang on with all her milestones, her babbling and crawling. We thank God every day for giving us this chance (3.2).

Patrick’s parents were still distressed and angry months after a similar episode, although Patrick was developing very well (2.16), and so were Mary’s parents, months after being misinformed that she might have Down’s syndrome (2.14). Henry’s mother considered that she had been told accurately, but far too abruptly late one night, that Henry probably had Down’s syndrome (3.1). Looking back, these and other parents wanted doctors to stop seeming to treat information-giving itself as an emergency. They wanted doctors to wait a few more hours, to explain how uncertain and complicated the position was, and to take account of the frightening birth complications the parents had just experienced, and the stressful context of admission to the NICU. The parents might be seen as criticising the messenger unfairly for giving an unwanted message. However, they praised some doctors’ sensitive methods and explained clearly how others could improve their methods and timing.

Clinical and parental choices and consent
Oludayo’s and Yejidi’s examples were given in some detail to show that the conventional framing of consent, based on clinical information and choices to permit doctors’ interventions, can ignore choices that are important to parents about the practical ways in which they can actively relate to and care for their baby. These choices partly rely on parents' personal judgement, and practitioners’ permission for parents’ interventions. If they are seen as too minor (whether to touch the baby), parents may not be given explicit
information and the opportunity to choose. This kind of decision is not listed in the guidance, but Yejidi’s mother spoke for many when she said, ‘They should let us know and make us aware’.

To assume that parents know they can touch their child, and also feel free to do so, ignores how anxious parents feel ‘not to do the wrong thing’ to their extremely fragile baby. This anxiety greatly affects parents' involvement in formal decisions and consent. They feel powerless and dependent, their life is ‘on hold’, just when they expect to take on new responsibilities as parents. Some mothers are ill, some parents are homeless, are refugees or speak little English. Many feel very stressed, exhausted and disorientated. When they cannot have their first choice, to go home with the baby, decisions about medical routines can seem secondary.

NICU vary in how far the staff welcome parents and work with them as partners. The more the staff offer time and information and listen to parents, the easier it is for parents to discuss questions and dilemmas on fairly equal terms with the staff. Parents described learning clinical information gradually and incrementally. Looking back over seven weeks, John’s mother ‘couldn’t put a date on it and a time’ when she understood about many processes, but she learned a little ’more each day’ (2.2). Many parents valued being able to read the nursing notes, in one unit the medical notes, as part of their continuing responsible role.

All his notes are there [looks at them…] his charts […] and what drugs they’re using, and what they're for. Sometimes obviously they don’t always say, ‘Ok, let’s go through ABC’, sometimes you have to take the prerogative and be assertive and say, ‘Ok what’s this new drug for?’ And if you look at his chart and see that maybe his temperature was a bit high, you know, if it’s nothing major they probably won’t mention it (2.2).

Although nurses mainly explained details of routine treatments and babies' responses, their detailed updates when parents telephoned or arrived in the NICU enabled parents to be more informed partners in the care giving.

Some [nurses] will say, ‘Oh he’s fine, he’s asleep,’ and they’ll do a whole list of what’s going on with him. And some nurses it’s, ‘Yes he’s ok’. ‘OK?’ And I find I have to push and I have to ask questions. I don’t want to be pushy but I want to know the smallest detail, whether he desated at 79, or he got 100% 6 times in an hour, you know (2.1).
Parents also learn while they spend hours near their child, and if they are encouraged to be present during the medical rounds, overhear and talk with the staff, speak with consultants instead of always having to request this, and if they can feel able to ask seemingly ‘stupid’ or repeated questions. Parents, including those without post-school formal education, learned the complicated language of the tests and treatments as these affected their child. Longer stay parents valued having regular detailed formal reviews. In units that encouraged parents to talk together, many found other parents to be a valued resource for information, support and hope. Other parents’ stories, ‘give you encouragement to say, “Oh we’ll get there eventually”. For you, it may be very new and you feel like you’re all on your own […] but with time you get to know other mums, you see other people’s photographs, you hear their stories’ (2.4).

Over the first weeks, parents come to understand their child’s responses and needs, and to be able to share in informed decision-making. However, by this time, the staff may assume that the parents fully concur with the by now routine intensive care interventions, or the baby has moved beyond these problems into special care. Doctors, and therefore formal medico-legal requests for consent, play little part in special care. Ironically, parents may be asked formally to agree to clinical decisions, such as to intubate or operate on a baby, when they feel there is no choice and they must agree, whereas they may never be asked for their consent to many minor and nursing decisions, such as about breast feeding or the timing of discharge, when they feel more expert and may want to question and negotiate.

**Helpless observers**

Doctors and parents cannot always choose the preferred option. Much neonatal care concerns coping with the aftermath of a perinatal crisis that transforms the baby's future within moments. Rosa’s mother mentioned her 45 minute wait, and Yejide’s mother watched doctors trying for 25 minutes to resuscitate her daughter after heart surgery. Yejide seemed to make a remarkable recovery but a year later she was still being nursed in the children’s ward (3.8). Francis’s African father described his son’s birth:

I asked, ‘Is he all right?’ The midwives said, 'Yes - no - everything is nice,' but the baby was stuck for ten minutes with no oxygen. The baby can’t move or cry. They try doing, try doing, try doing, try doing, try doing, try his breathing, try his breathing, try his breathing, try his breathing. When he is born they bring him up here and put him on a ventilator to see how he goes, then they went on helping him, helping him, helping him. Later they do the MRI scan to see if something is wrong with the brain…After two weeks they say to us, ‘The brain is damaged permanently, there is no way to cure it, Francis can’t walk, Francis can’t breathe on his own’ (3.14).
These parents were fully informed about the events in that they witnessed them, but they were helpless at the time. The parents later carry the gain and joy, and in some cases the risks and costs, including the care of a profoundly disabled child.

**Missed opportunities**

A few parents described decisions with extremely serious consequences, which they felt the doctors should have involved the parents in making, before it was too late. Esmé was one of the 15 follow up children in our study, her parents were interviewed together when she was five years old. Esmé’s mother described four missed opportunities. Firstly, in the 29th week of pregnancy, she developed an infection and leaking liquor, and agreed with the obstetrician that she would return to the hospital at the first sign of labour, when she would be put on an antibiotic drip to protect the baby from acquiring infection during the birth. Later, Esmé’s mother considered that she and her husband were not properly informed about the infection risks to the baby of delaying the birth, so they assumed that the baby would simply benefit by being born later. Secondly, when Esmé’s mother returned to the hospital two weeks later, her husband and her consultant were both abroad, and the doctor on duty refused to accept that she was in labour or to set up the antibiotic drip. About nine hours later, at 3.15 a.m., the staff found her haemorrhaging and Esmé was born very suddenly and taken to the NICU; she developed severe streptococcal infection.

Thirdly, Esmé’s mother said, ‘I think they put her on the ventilator after about an hour because she was struggling too much.’ Five years later, Esmé’s mother still cries at the thought of that early morning when few staff were present: ‘I don’t know what happened in that hour…The rest of her life has been affected 100 per cent.’ Prenatally, Esmé’s mother explained, they had been warned there was a risk of brain damage, but the neonatologist had said: “This won’t happen to you, because you’ve come to us in good time…we won’t let you fall through the safety net” [and] I wiped it absolutely from my head.’ So the fourth delay was that it was not until Esmé was 9 months old that her mother questioned the neonatologist’s rather ‘off-hand’ manner and his list of things that Esmé could not do, and was told that she had cerebral palsy.

I couldn’t believe what he said to me, the fact that he wasn’t going to say anything until I asked him. And to me that is criminal because then I found out that it takes something like 12 weeks to get on any waiting list around here [for therapy and other support...] So he should have told me when he knew, straight away, even if it was only a suspicion [...] and given us a chance to help her from day one [...] it’s just as
painful to hear it on day one, as when she is 9 months old […] and she wasted all that time (3.18).

Parents’ standards for informed consent

Esmé’s parents described standards they wished had been observed, which many other parents we interviewed shared. The standards apply to major, routine and ‘minor’ incidents, such as when to set up an antibiotic drip, but which can have great consequences.

Esmé’s parents wanted decisions to be an informed firm ‘bargain’ between fairly equal partners. Lack of relevant information, and the way the risk equations later changed, made any prior ‘consent’ to delaying the birth invalid. Her mother said:

[We] could have made an informed choice. I would have liked to have known statistically the risks of both choices because [cries…] I knew I was going to have an early birth and there was no going back […] she was going to be very tiny. But they told me they would look after me, and they didn’t. I kept my side of the bargain […] And they had promised (3.18).

Consent as a bargain is a two-way process of listening and sharing information. Esmé’s mother, for example, wanted the obstetrician to stop believing his trace monitor, and instead hear her insistence that she was in labour; she already had two children.

Several parents said they wanted an intermediary or advocate to help them to ask questions and digest answers. Esmé’s mother arrived in labour with her trusted community midwife as her advocate, but the obstetrician sent her away. Henry’s mother, a barrister, said it was too hard in the NICU for her to be ‘proactive’ and ask questions without help. Some parents relied on grandparents as mediators, but when there is a strict rule is that only two adults can visit at a time, this can be difficult.

Esmé’s parents wanted answers to their questions. ‘We’ll probably never know when the brain damage occurred.’ They thought the medical notes had been lost.

They needed clear records to be kept in the medical notes of any agreements so that these could be honoured through the changing staff rotas.

They needed experienced senior staff to be readily available. Better management of Esmé’s birth could have made this more likely.

Timing is very important. They wished the doctors had volunteered information promptly, partly because they felt humiliated, hurt, angry and frustrated that they had been treated as if there were ‘not intelligent people’.
3.18Father: It's treating the parent like an idiot, like a sheep you know, if it doesn't know something is coming it won't think about it […] absolutely completely barking crazy.

3.18Mother: […] They don't tell parents until the parents show concern […]or if there is a chance of not getting the severity level right […] I think that is wrong. Even if they only slightly think there might be a problem, they should be right on it, explaining it and giving you a list of things you can do. [Not knowing what to do] feels terrible.

Their chief concern was to meet Esmé’s needs as far as they could. They are convinced they could have helped her more effectively if they had been better informed. Instead, they felt they carried all the responsibility of caring for a disabled daughter but without the power to be as effective as possible.

Esmé’s father deplored the lack of practical information. ‘We had no idea that we could be doing anything practical. In other words, instead of having a problem that we could perhaps seek to find a solution for, we had this tragedy and the world was black.’

Doctors varied very much in the amounts and kinds of detail they gave. During their interviews, some consultants gave us long replies and introduced new topics, but a few gave brief and seemingly cautious and even dismissive answers. For example:

Int: Do you think information sharing with parents might be improved at all?
3:27: Between parents and staff? Um it’s very hard to think how it could be improved. [pause] Um it might be worse [inaudible] Communication is a two-way thing, what suits some parents might not suit others. Some want to discuss things ad nauseam, some don’t want to discuss them at all, and some are somewhere in the middle.

This answer implies that the doctor can sense what parents want whereas, until they know something of the risks, parents themselves may not know how they want to communicate. Some consultants were deeply interested in talking with parents and trying to phrase ‘bad news’ as positively as they could, such as by starting with all the positive or neutral aspects in the baby’s care and responses before discussing severe problems.

Parents’ responses are also strongly affected by the doctors’ desire or reluctance to inform them. The ‘foretelling futures’ project had an advisory group of practitioners and parents, led by an ethicist. They spent six meetings discussing key themes associated with the research questions and arising from the observations and interviews, such as knowledge and information, love and attachment, predicting the future. A neonatologist summed up all the sessions by saying, ‘Everything comes down to communication’. ‘Communication’ combines
many themes of informing and relating, the message and the medium, sharing knowledge and control, understanding and misunderstanding, the relative status, values and motives of the people concerned.

Esmé’s parents wanted doctors to give them knowledge and some control over events when this was realistic and the parents could give practical help to Esmé. They did not want, as the guidelines advocate, to be asked to consent to every procedure.

She used to cry when they were changing lines. I used to find that very stressful. Some babies had them in their heads when they didn't have any other veins left. She had a lot of scars in her hands as a baby, which I found awful. They used to prick her heels a lot, which I found a bit savage, but these were tests they had to do (3.18).

Miranda’s mother, for example, also saw no point in her permission being asked to urgent, routine and minor procedures, it would be ‘overwhelming…too stressful’ (3.10). It could increase parents’ anxiety and guilt, by giving the illusion that they could and possibly sometimes should say ‘stop’, when they believe that they cannot. Esmé’s mother said, ‘No, there is no choice. You know they have to do that. But I did want to make the serious choice and I don’t think I had the chance.’ Similarly, Miranda’s parents very much wanted to influence the decision about when Miranda could go home but felt they were not listened to. Each procedure may be part of the whole life-sustaining package of treating, monitoring, testing and adjusting, and is therefore not a stand-alone choice. There is not time for doctors to inform parents and check with them about each procedure. Parents who will never have equal knowledge with the clinicians have to trust the staff and leave responsibility to them to a great extent. Attempts to transfer responsibility for numerous routine procedures to parents through the medico-legal device of consent could therefore be both invalid and unkind.

However, to give consent is different from 1) being informed about planned interventions, 2) having the chance to question and discuss whether all the interventions are essential, 3) being told the results of investigations and treatments, and 4) having informed discussion about the meaning of the results. Esmé’s mother did not remember being informed about the brain scans:

I didn’t want them to ask me if they could do brain scans [But…] I would like to know now for sure if she did or did not have a brain scan in that unit. Have they got the results there? […] On the MRI scan that they did later […] it is incredibly obvious to me, the damage. They must have seen the damage [so] why didn’t they say? Why did they let us go away in the belief that we had got through it and come out whole? (3.18)
Many parents said that they ‘took one day at a time’, and a few said that, at least initially, they did not want to hear any bad news. Over time, parents usually wanted to learn as much as possible about their baby’s uncertain future. Consultants varied in their willingness to explain the potential range from mild to severe impairments. Esmé’s mother said that when she learned that Esmé had cerebral palsy, she should have had further support: time to talk then with the doctor and with a counsellor; a telephone number for follow up discussions; written information and leaflets; contact details of related organisations, and a ‘sign of concern’ from the consultant.

Delay could make hard news worse. Joseph’s mother, interviewed when he was 4 years old, gradually found over months that he had cerebral palsy, severe epilepsy, Retts syndrome, and that he had no vision. At each stage she would rethink his life, such as how he could use a wheel chair, only for her new hopes to be dashed by later news; how could he do that if he is blind? (2.17). Esmé’s parents bitterly regretted the months of delay. They had to begin contact with many services at a time when their trust had been shaken, and her father felt the neonatal support had involved ‘woolly inarticulate waffle […] I have no faith in the system’ (3.28).

There was still continuing uncertainty, and no clear prognosis for Esmé when she was 5 years old: ‘you have to guess’. The interviewer asked, ‘Maybe they think if they are uncertain they should not worry the parents?’

3.18Mother: No, that is so wrong. My view is it is better to know: ‘Possibly your child has a problem, and therefore […] we are going to give you physiotherapy from day one’ […]

3.18Father: I suppose that’s true. By the time you’ve realised that your child can’t sit up it’s too late.

3.18M: It’s too late, it’s much too late […] The earlier you can start doing therapy the better.

Int: Is that what the NHS staff say?

3.18M: Well, it is not necessarily their view. Other therapists always say the earlier the better.

NHS staff may question whether earlier preventive treatment is better than later - and possibly corrective - therapy because they are not convinced, or there is not yet evidence from randomised trials, or they want to avoid implying criticism of NHS services, or they want to avoid possibly increasing parents’ guilt and anxiety. Meanwhile many parents grieve over
lost time and opportunities, so that agreed research evidence about optimal times to start therapy for cerebral palsy is urgently needed.

‘Bad news’
Some parents felt that certain doctors could have gauged their information-giving more sensitively according to the needs of parents, and that doctors tended defensively to emphasise bad rather than neutral or good news. These parents wanted doctors to encourage more carefully and personally timed and worded two-way communication on a wider range of issues. The doctors’ bias towards giving ‘positive’ results from tests (when a problem is found), but not always telling parents ‘negative’ results (no identified problem and therefore often good news), could leave parents in great anxiety. For example, Edward’s mother was too sick with worry for a week to dare to ask the results of his MRI scan, which the doctors had known for days were clear. Henry’s mother was told that he had Down’s syndrome, but not until months later that he did not have any of the heart or digestive problems associated with Down’s syndrome. She said she needed that good news in the NICU, ‘they must have known then’.

A doctor’s view
Although this paper is mainly about parents’ views, a neonatologist is quoted whose comments (made in 2002) seemed close to the broad views held by parents when their babies experienced severe problems. The consultant described efforts to increase shared perinatal care, information and decisions with obstetricians, and also the recent pressures to inform parents in much greater detail.

It’s moved quite a lot. The British Association of Perinatal Medicine is currently considering a draft […] a very complex information sheet given to mothers in labour […]or as soon as the babies are admitted, which tells them about every procedure possibly conceivable under the sun that might happen to their child including all the expected complications […] and very suggestively we then ask for their written consent for us to carry out these in some respects likely things. It is extraordinary […] It’s bizarre! It’s gone from things like…your child might have a heel prick that might cause bone infection, we will put a nasal gastric tube to feed your child but it might slip out and it might cause aspiration pneumonia, we will give your child a drip to feed it, but you must remember that the drips might get infected or might slip out and cause a lot of blistering […] this is the knee-jerk reaction of people to Bristol and Alder Hey [Inquiries about malpractice] and this whole thing…around consent…and I have to say the table is so frightening that if I was [the] mother, ‘Do I save my child’s
life or do I send her to this torture chamber that’s going to kill them? It sounds like I
am going to kill my child whatever I do.’

You know it’s so frightening to put that sort of burden on them and I think we are
going to go down to a middle road [to explain all procedures and likely but not
exceptional effects and] document it in the notes [and leave the door] open to the
parents to talk to us, you know, should things go wrong […] Because of the 28
complications people have listed, a child may have one or nothing…But I am not
going to get written consent for every procedure [discusses emergency, life-saving
and routine examples] we have enough to cope with, it’s pathetic […] we should look
to our own training of staff and doctors to reduce risk but to make it non-
confrontational and non-adversarial (2.24).

It is not known how typical this consultant’s pragmatic view is, but it differs from the cautious
views held by the doctors who write current guidelines.

Discussion
This section discusses the questions raised in the introduction. Why is the advice to request
parents’ consent to virtually every neonatal procedure required? Who might benefit? Is this
realistic, and what might the effects be? Do most parents in NICUs want this to happen?
The Bristol Inquiry, chaired by the medical lawyer Kennedy (2001), and the problems about
children’s heart surgery that preceded the Inquiry, gave new impetus to concern about
informed consent that has been increasing over past decades. Consent is a vital protection
again negligence or abuse, and a means of maintaining high standards of care. The value of
the vital elements of consent, developed for medical research and equally applicable to
treatment, has been well proven repeatedly in cases when patients have complained if
doctors failed to meet these standards. The standards involve informing patients/parents
about the nature and purpose of interventions, the potential effects, harms and benefits, and
possible alternative interventions (Helsinki 1964/2000). The standards also involve
respecting voluntary consent as ‘absolutely essential’ ‘free power of choice without the
intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior
form of constrain or coercion’ (Nuremberg 1947).

The parents’ views are not presented in this paper in order to question the importance of
informed and voluntary consent. On the contrary, the interviews repeatedly showed how vital
the consent procedures are, especially if things later go wrong, for example in Esmé’s case.
Greater attention to consent could have helped to prevent problems and to improve the
quality of her care, as well as the partnership between her doctors and parents.
The difficulty arises in deciding to which procedures doctors should request consent. Kennedy was quoted earlier stating: ‘The process of consent should apply …to all clinical procedures and examination which involve any form of touching’ (2001:440). Yet Anglo-American law has always made exceptions to this ‘all’, such as for emergency procedures intended to save life or to prevent lasting injury. Shenoy et al (2003:18) have been quoted above calling for ‘drastic changes’ in order, it is implied by their survey questions, that staff are trained to request parents’ consent to routine procedures, on initiating treatment when the babies are admitted, to ventilation (usually started during a life-saving emergency and stopped as soon as the baby can manage without this essential support), before starting tests or treatment, and on ‘every occasion when the doctor wishes to initiate an examination or treatment or any other intervention, except in emergencies or where the law prescribes otherwise’. Although Shenoy et al. say that it is impractical to ask for consent to every routine procedure, they mention legal and professional penalties for doctors who do not obtain consent. Current guidance appears to be driven by economic concerns to prevent costly litigation, rather than to raise standards of communication and relationships between doctors and parents.

This guidance is not only contradictory, it also ignores the true meaning of consent, which involves a real choice, time to reflect, and the right to refuse, before informed and willing consent can be given – willing in the sense of being committed to what is genuinely believed to be the least harmful decision. Only when these conditions for legally valid consent are met, can responsibility for risk be transferred from practitioner to patient/parent. The consent process involves respecting distance (protection against unwanted touching of patients, protection for doctors against complaints by patients) and also, paradoxically, consent involves a drawing together (shared knowledge, understanding and planning, mutual trust, permission to touch). The consultant quoted earlier highlighted this divergence, and warned against undue official medico-legal influences that over-emphasise defensive distancing and thereby undermine trust, preferring a ‘non-confrontational and non-adversarial’ approach.

The parents’ interviews showed that parents experienced the difference between consent either as an empty distancing formality or else as their genuine involvement in both protecting their baby and also planning with practitioners the best possible care for their baby.

The conditions for valid consent cannot apply to many neonatal interventions that are genuinely emergency, life-sustaining, agreed best practice, or essential elements in packages of care. Parents should be informed appropriately, but guidance that requires consent to all these interventions misunderstands and devalues consent and benefits no one. Consent is appropriate when there is time to make significant choices. There is likely always to be uncertainty about precisely which procedures and choices are ‘significant’.
Doctors and parents have different perspectives and priorities, and the answers partly depend on parents’ later retrospective views following subsequent outcomes that are better or worse than expected. This uncertainty indicates the importance of practitioners being alert to parents’ concerns, willing to discuss choices about seemingly minor or routine matters, and also willing to alert parents to risks and decisions that they may not be aware of.

Doctors’ and parents’ held a range of varied, contingent views, but they tended to emphasise different standards for consent. The neonatologists we observed and interviewed tended to be concerned with the ‘distancing’ aspects described earlier: to give a good service including honest information, to warn and prepare parents for possible problems, to prevent dissatisfaction and potential litigation by parents through keeping records and requesting written consent to procedures, and primarily to use consent as legal permission for medical activities. The parents tended to emphasise the ‘drawing together’ aspects in the content and ethos of the consent process as well as the form: an informed agreement between fairly equal partners; a two-way process of listening and sharing information and decision-making; answers to their questions and practical concerns; appropriate timing, detail and manner when sharing discussions; help from mediators if necessary; clear records to ensure that agreements are honoured; mutual trust and respect.

If their baby developed severe problems, parents wanted to have been warned, although Rosa’s, Patrick’s and Mary’s parents were very distressed to be told about problems that did not develop. The parents’ varying replies on information about risk are trebly complicated to analyse. First, the question will be hypothetical when the problem was predicted or becomes either worse or better than predicted, so that many parents can speak from only one experience. Second, some people’s views change over time, from not wanting to be informed into wanting to have been informed. Which view then counts as the authentic one? Third, everyone’s views are partly contingent. For example, a thoughtful study of parents’ views after neonatal treatment was withdrawn and their baby died found that a high proportion ‘were satisfied with the management of their cases [that were] in tune with most parents’ needs’ (McHaffie 2001: 411). The researcher carefully qualifies her conclusions. However, one layer of complexity is that after a death, people close to the deceased person need to recall and retell the event in ways that bring some comfort (Seale 1998). In that context, parents may need to believe and say genuinely that they are satisfied, because not to be satisfied would magnify their pain in futile and destructive ways. The finality of death can lead people to talk in terms that draw a close. In contrast, most babies in our study survived, and their parents are talking about how the past might affect their hopes and their baby’s future.

The parents’ interviews suggest three main reasons for giving parents information and the chance to discuss consent rather than withholding these. First, the more parents say they
are distressed about being ‘over-informed’ of problems that did not develop, the more distressed the same ones might be if they had been ‘under-informed’

There are not necessarily two groups who either want to be informed or not informed, but parents who react to very difficult experiences. Second, communication is interaction, and only through beginning to inform parents can practitioners learn from them and work out with parents how and when and how far they want to be informed at each session. Third, parents repeatedly linked knowledge to their power to help their child; conversely they were most perturbed if information about how they might give practical help was withheld, even in decisions as seemingly minor as whether they could touch or hold their baby (see Alderson forthcoming for further review of parents’ motives).

This analytical and not statistical study cannot measure the findings or indicate proportions of parents who wish to be informed. The units, the practitioners and the parents all vary. Yet besides individual examples, the research reports structures, processes and concerns that are likely to be widespread. The findings are therefore partly transferable to other neonatal units. The examples are intended to convey something of the complicated emotional and practical risks and costs of neonatal care. The research began from the view that pressures on doctors to inform parents appeared to come mainly from management for medico-legal purposes, rather than from the majority of parents. The findings suggest that parents tend to want to be clearly informed, sometimes after initial inability or unwillingness or preoccupation with other matters, such as the first meeting with their baby. Parents do not necessarily want to be asked to consent, especially to emergency and apparently essential or routine care, but they appreciate practitioners who listen and are receptive to parents’ questions, requests, and cues that they wish to become more involved in decision making. The minority of parents who do not want to be informed are likely to be in a temporary crisis. The timing, manner and content of information giving could be improved in some cases to match the standards of the best practitioners that parents tended to prefer.

Parents have to learn much implicit as well as explicit information besides rules about what they may or may not do. They are unlikely to be aware of how the rules vary between neonatal units, opening or closing their choices, such as to be present at medical rounds or when they can hold their baby. Our observations suggest that the more open the rules and access, the more confident parents and staff tend to be about talking with one another. Parents can then raise questions, vital to them for shared discussion and decision-making about matters that the staff may perceive as too minor to be related to consent. The relatively open or closed quality of the NICU ethos and the relations between staff and parents can be reflected in the open or closed, distancing or sharing quality of the consent process.
Note 1.
This paper is one of a series on information, practical choices and consent in NICU reporting the research project ‘foretelling futures: dilemmas in neonatal neurology’. For details of other papers see http://www.ioe.ac.uk/ssru/projects/neonatalfutures

Acknowledgements
We are grateful to all the families and neonatal practitioners who helped with the research, to the Advisory Group, the four local research ethics committees for their approval, two anonymous reviewers, and the Wellcome Trust Bioethics Programme for funding project no. 066458 ‘Foretelling futures: dilemmas in neonatal neurology, 2002-2004.

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