



Report of a survey on
Availability of Information and
Consent

The Association for Improvements in the
Maternity Services in Ireland (AIMS Ireland)

March 2008

Introduction

AIMS Ireland is a voluntary organisation that was formed in early 2007 by mothers dissatisfied with the maternity care system and ready to campaign for changes. The organisation's goal is to highlight and support normal birth and mother-friendly birth practices in Ireland. It is a consumer led, campaign pressure group operating with a self-regulating committee elect and a body of members consisting of parents, consumers, health care professionals, and support group representatives throughout Ireland. AIMS Ireland was set up with the support of The Association for Improvements in the Maternity Services UK. AIMS UK has been at the forefront of improving maternity services the past 40 years.

In autumn of 2007 AIMS Ireland ran an electronic survey on the topic of "Availability of Information and Consent". It was available through the AIMS Ireland website (www.aimsireland.com) and it was open to any one who wished to fill it in. Respondents who completed the survey were anonymous. It was voluntarily completed by 161 women.

Results

Quantitative data

Opportunities to discuss choices and information needs

More than half of respondents (61%) said that in pregnancy (outside of antenatal classes), they had no opportunity to discuss choices and information regarding hospital policies, routine procedures and common procedures, tests or treatments which you may need to make a decision about during your pregnancy, labour or birth. Of the 39% who responded that they did have opportunities, over half (53.1%) had to be the one to initiate the discussion to gain access to information.

Availability of information

96.3% of the respondents said they would like to see information booklets readily available in all maternity units, health centres, GP surgeries outlining maternity related procedures, tests, treatments and benefits/risks.

Qualitative data – Availability of Information

Many women also included comments on the issue of availability of information. These quotes illustrate women's serious concerns about the limited availability of information to them.

Information was seen to be based on hospital policy, rather than objective evidence-based sources. Women who tried to challenge this were put in a difficult and unfair position, for example:

Information given is usually hospital based policies only, rather than a full benefit/risks/alternatives etc analysis. My experience was that this information was presented in a very biased way and that even if you refused and had the evidence to justify your position you were still made to feel that you were in some way putting your baby at risk and were made to feel difficult or

unreasonable. It takes a very strong person to be able to stand your ground in these circumstances especially for a first timer (P4).

They also perceived that information was used as a source of pressure on them:

I feel that every woman needs to have access to all information. I was very informed but it was due to research done by myself. However when you are in the hospital there is a subtle pressure put on you saying you want your baby to be safe (P17).

This information was also felt to be very negative and undermining of women's abilities:

There is too much focus on what could go wrong with labour and birth and so starting from a negative position instead of building the expectant mother's confidence that things have as much chance of going well and what she can do to maximise this. This is particularly prevalent in hospital ante-natal classes which seem to overly focus on the pain of labour, need for interventions, etc instead of providing positive examples. Also, you are not made to feel that your body is capable of a successful and natural birth and so there is less trust and confidence going into labour. (P41)

Women stated the need for written information and that many women have to research and pay for information themselves:

There is a definite need for information leaflets to be handed out free of charge to pregnant women.. EARLY ON in pregnancy and not just towards the last trimester. It can take the whole pregnancy for you to decide what you want and don't want and to prepare for any "bad" things that may happen. There was no such information provided to me, all I was told was provided with the help of a website and a book which I bought and paid for myself (P12)

The importance of using the appropriate format for information was also stressed:

Booklets will not help, unless they are for the medical team. Doctors and midwives need to treat pregnant and labouring women with respect and inform them of their choices, not ignore them (P8).

This quote highlights that the provision of full information is a fundamental need for women and its lack is demeaning to women, as another woman agreed:

Doctors and midwives seem discuss procedures as if patient isn't there and would not give a lot of information when asked what was happening (P11).

This was related by some women to the pressures in the maternity services and the lack of responsive and trained staff, for example one woman commented that,

[the] Irish maternity service is very hospital driven and us not at all geared towards the mother, it is focused on coping with the huge amount of births and limited, poorly trained staff. Many of the staff are out of date, pressurised, have been trained in techniques which are out dated and do not have the communication skills and or the ability to deal with patients who stand up for themselves and who are well informed (P16).

Many women also made reference to feelings of vulnerability in regards to addressing issues to their care providers, illustrated by these very moving and alarming quotes:

I think I felt like I would have been a nuisance to push any concerns/questions on medical staff. That is a terrible way to be (P18)

You are in a supremely vulnerable position in labour and birth. It's barely informed consent even if it is explained fully, and that is not happening. I never felt, even when tokenly offered a choice, that there was in fact any choice open to me as it was clearly a case that they knew best and were informing me of their chosen course of action, not genuinely asking me a question that I could debate or refuse. (P1)

I feel there was a real lack of humanity towards me during the birth of my son. Very medicalised and inhuman treatment. Has left strong negative feelings about the birth (P26)

Consent

In this survey, 75.6% of respondents stated that they felt that consent is an issue of concern in the Irish maternity system. Further questions on the survey have unfortunately illustrated how key an issue consent is:

Full consent given for all medical procedures, tests, and treatments	% who responded "Yes, my consent was fully sought and given"
In pregnancy	48.4
During labour	38.4
During the baby's birth	33.3
After birth	41.5

More than half of respondents (57.6%) were not given the option to refuse a procedure, test or treatment. Regarding **informed refusal**, 23% responded that they were given information and choice for all procedures.

Qualitative data- Consent

Many women also included comments about consent. AIMS I found that the instances of procedures specified by women to be of greatest concern were in relation to invasive procedures such as ARM, Episiotomy, the use of Oxytocin, and Membrane Sweeps.

Other areas of concern were assisted delivery, internal fetal scalp monitoring and the management of the third stage of labour.

AIMS Ireland found that the comments concerning consent could be divided into 3 sub-groups; although in many instances they are intertwined.

- *Implied Consent*, where consent was often implied but not sought by care providers. Example: “We are just going to break your waters now”
- *Coercion*, where consent was sought but women were given no choice or information to refuse and sometimes felt pressurized to give consent. Coercion is often used when a medical professional sites ‘hospital policy’ or accuses the mother of putting her baby at risk when asking about her choices or information on refusing a procedure.
- And finally, *Complete Disregard of Consent*, where there was a complete disregard to the fact that consent needs to be sought and obtained. The women were given no information or choice in the decision process and procedures were carried out specifically against mother’s wishes or without even informing the women of what was happening.

Examples of Implied Consent – Comments from Women:

It seems to me that frequently staff don't even perceive that there is a consent issue. Things are 'routine' and therefore not discussed (P3).

Everything was a given, not a choice: we are going to do x now, we are going to do x, y now, is that okay? (Sometimes not even the latter.) On my first I had every intervention except a section: Prostin gel, oxytocin, antibiotics, ARM, scalp monitoring, scalp blood tests (2), Paracetamol for fever, episiotomy, failed ventouse, forceps, etc. (P3)

Forceps without informed consent, I.e. we are just going to give you a little hand..... (P4)

The one factor which left me feeling horrible after the birth of my daughter was the feeling of helplessness, that the doctors are doing what they want with your body and you seem to have no choice in the matter - especially on your first child as you do not know what to expect. Now I know my own choices I will not let them talk me into anything again or let them do things without questioning them!(P38)

Episiotomy 'I'm going to make a little cut, ok?' (similar for checking if waters were fully broken) (P8)

All procedures were done with verbal consent only and because I was a nurse and had some understanding did I feel I was allowed make any decisions I feel if I had

not already been somewhat informed they would have done what they thought was best without discussion. (P17)

Episiotomy during the birth of my son, I asked what the midwife was doing and she told me while in the process of doing it. I point blank refused syntometrine for 3rd stage, I was given no info on reusing but had researched it myself, midwife wasn't totally happy but respected my wishes (P23)

episiotomy was performed without my consent, I was told they were doing it just before they produced the forceps. again I wasn't asked about this either, they told me it was happening as they were doing it (P31)

Membrane sweep, thought doc was doing an internal, he told me after what he had done! (P32)

I was given intravenous antibiotics and accelerants without much choice or explanation. (P48)

My waters were broken without much being said to me and I think I had an episiotomy without a word to me - ended up with 3rd degree tears anyway (P49)

I got a few membrane sweeps done without my consent. The doc explained what she was doing when it was being done (P56)

Membrane sweep with my 2nd child, dr [doctor] just did it; oxytocin drip with my 1st child - dr put it on after telling me that it was needed; episiotomy cut with my 1st child - dr announced, that I am going to be cut; use of vacuum wit my first child - no one asked and was very briefly explained why the procedure was needed (P61)

membrane sweep - was told I had to get an internal. Many internals during labour were not consented to. My waters were broken while amidst a contraction and I was unable to refuse. I was given the injection to deliver the placenta - I didn't know this wasn't normal until reading it here. (P62)

Examples of Coercion – Comments from Women:

I refused to have my waters broken when first brought to the labour ward. I was basically told they would allow me a few hours to see if I progressed but then they would break my waters. The same with oxytocin. I felt pressured at every turn. If they had been honest with me about the effects of oxytocin I would have refused point blank. I was also not aware until it was happening that a forceps was required no permission was sought (P16).

Forced pushing (requested mother directed pushing but was over ruled - no medical indication, in fact second stage only took 15 mins (1st birth) but I ended

up with a 2nd degree tear which I feel could possibly have been avoided had I not been bullied into pushing so forcefully). Birthing position - on bed (P9)

I have no firm memory at any point of what you refer to as 'consent being sought'. That says a lot to me. I decided to inform myself by reading a lot. On my one birth so far I arrived at the hospital 7cm dilated after staying at home as long as possible to achieve a drug free birth. But tiredness was a major problem for me 8 hours later during active labour. I felt fully supported in a drug free birth at the hospital but once I caved I ended up with every procedure going. I did not feel that 'consent' was something that was specifically asked for. Looking back 'intervention' in the form of the epidural was the point where my control in the situation firmly went, I agreed to everything then. My waters were broke, episiotomy, kiwi suction etc. I was told about hospital policy on pushing after pushing for an hour. I wish this information had been presented in more detail prior to the event. (P11)

For two days running at 9a.m. was given gel to induce but didn't work and on second day at 4:30 p.m. was just told that they were going to break my waters - not asked but told. (P13)

Injection to deliver placenta, and vit [Vitamin] K injection to my baby. All quoted as being "routine" when questioned by myself or my partner. (P22)

Waters broken "accidentally" during second labour during very rough internal exam. During first labour they presumed I wanted an epidural and pushed me to have one, I did not. (P52)

Scalp monitor; oxytocin in 3rd stage; stirrups (I had SPD); I gave very seriously pressured consent for an episiotomy (P47)

I was pressurised to have an epidural with my 1 child, eventually said yes but much to my relief it was too late (P61)

In some instances I was given the option to refuse, in others, I was not, I was told it was "hospital policy" and I had to agree. E.g., having continuous fetal monitoring in labour (P64)

Baby was given blood sugar test soon after birth - I had no choice in this and was also pressurised into giving my baby a bottle which he did not need. (P67)

Foetal clip (sorry don't know the correct term for this), I was given a choice but very pressurised into doing it. When I said 'No' they came back 20 minutes later when my husband had left to ask again, and basically told me I was harming my child if I said no again. My feelings regarding accelerating the contractions (syntocinon drip) were ignored - I didn't feel it was necessary at the early stage it was suggested but I was pressurised into letting it be put in place. (P71)

Membrane sweep @ 41wk 4days - I explained that I didn't want an induction unless absolutely necessary. I was told an internal sometimes gets things moving as my trousers were pulled down!!! Very embarrassing & felt very vulnerable. During labour were TOLD I needed- Antibiotic drip; Syntocinon; Episiotomy. In each case I rather pathetically asked if I HAD to have the procedure/drug and was just told yes. Because we hadn't done any research we didn't feel informed enough to argue with them. (P73)

first birth I was told that my waters were been broken even though I had consented to an internal at that time. 4th birth I was made to feel that I was making reckless choices when I refused fetal electrode monitoring. I had birth plans but I was still made to feel that it was a way out thing to do , up to ten midwives and students came in to my labour room to read them and ask questions. I was never asked if they could read my plans they just opened up my chart and took a look???? (P74)

Examples of Complete Disregard for Consent – Comments from Women:

I had an ARM done without consent and against my wishes - I said I did not want it and it was done anyhow.. my baby and I were never in any distress or at risk (P1)

Injection to deliver placenta.....vit k for baby – none with consent
formula given to baby on day 2in nursery even though I am breastfeeding (P4)

Waters were broken during what I had been told was an examination to see if I was dilating. The first I knew about having an episiotomy was seeing the junior doctor coming towards me with a scissors. My baby was delivered by ventouse, something which was necessary for her survival but I was not informed of what was happening at any stage, it was all spoken about in code or hushed voices. I assume as I was a young mother (22) they thought I didn't have the right to know what was happening (P7).

Membrane sweep during pre-labour. Administration of oxytocin during labour. No consent asked for or given. (P10)

Episiotomy was performed without my consent (P14).

I was given an internal in early labour by a midwife, which was fine, but then a registrar came to check me and was about to perform a sweep when I ASKED WHAT SHE WAS DOING and stopped her! She assumed I would want one without even telling me what a sweep was. I was asked on numerous occasions whether I wanted ARM (although labour was progressing normally) to "speed things up". As I was a DOMINO gal, I had discussed everything with my MWs [midwives] and knew what I wanted so was able to resist all these persuasive

attempts. Even though my birth plan was there and the hospital MWs read it, they still kept offering me pain relief (OK this is not so bad!) and ARM (although this was expressly refused in my plan) (P18).

When the doctor arrived into the room he told me I might have to have an episiotomy. He didn't ask me if that was ok. It was only after my daughter was born and he was stitching me up that I realised he had carried out an episiotomy. (P23)

Waters broken "accidentally" when checking cervix when in labour. (P22)

I was given Pethidine and I don't remember asking for it at all and combined with the sleeping tablet I had been given I was very out of it and that's the only reason I can think of to explain why I was out of it for so long. (P24)

I was given a episiotomy resulting in a 3rd degree tear. I was never informed this was happening, they doctor just went ahead with it. (P30)

Internal examinations were carried out as if I was not a part of them.
3. Had an episiotomy, didn't know I was given that until afterwards (P32).

Had a very rough vaginal exam during a contraction asked midwife to stop please she proceeded, I cried she forced my legs open and continued (P43).

Waters broken at 3cm after 10mins in labour - no consent asked for or given (P49)

After the birth I was put on antibiotics without my knowledge, thought they were painkillers, as a result developed bad case of thrush (P50)

I was given an episiotomy and a forceps was used. I would not have objected to either of these but was actually never asked. (P53)

Membrane sweep done without consent - found out by reading notes.
Episiotomy done - told afterwards, baby placed in incubator - no reason given, extra observers at birth, rectal exam - found out by reading notes - this left me feeling raped. no shower facilities for 3 days, suppository used without consent (combined with broken tailbone). Totally inadequate pain relief in hospital and for weeks after (P55).

I was also given medication without even knowing what it was.... (P56)

All the women on the evening of my first child were given Pethidine on the orders of the ward sister so that they could have a bit piece. (P59)

I failed to progress after 2 rounds of induction. A doctor who I thought was just checking dilation did a membrane sweep without telling me she was going to. It was the most painful, traumatic thing to happen to me during pregnancy. (P68)

Episiotomy happened without my consent - I even asked while it was being done why no one asked me, the person it was been performed on whether I was happy with it or not. Vacuum delivery was not discussed with either myself or my partner either, it just happened. I had been told that my child would be given to me straight after delivery, and that my husband would cut the cord, neither happened. Our baby was whisked away immediately for the routine checks to occur (P71)

All the procedures were hospital policy which I was not aware of, I was never once informed of what was happening never mind given a choice. This angers me so much now, when only afterwards I realised I had my waters broken, labour accelerated, episiotomy etc. I didn't want any of these things but wasn't even told they where been performed. (P72)

Conclusions: The unavailability of unbiased information and a serious regard for consent within maternity care settings in Ireland are shockingly highlighted within this survey. Women's choice appear to be backed up by information obtained by themselves and the majority of women surveyed were not happy with the current levels of information available to them by their care providers. AIMS I can also conclude that issues surrounding consent are a major issue in the Irish Maternity System. Women's accounts regarding consent appear to suggest that consent is not always sought or obtained where needed in Irish Maternity Units and that care providers are not always clear when consent is and should be obtained. There appear to be very few instances when informed consent and refusal was apparent.

Recommendations: AIMS I would recommend that the issue of consent and availability of information become areas of importance with Irish maternity units. "Hospital Policy" should not over-ride or give illusion of consent and individual choice for admission/refusal of procedures, tests and treatments. Consent policies should be re-visited and printed material become available for every woman booking into maternity units.