Patient Information Forum

Maternity Decisions Induction Survey

Executive Summary

This survey was a collaborative project between the Patient Information Forum and Norgine Pharmaceuticals Ltd, which includes funding from Norgine.

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Introduction

The Maternity Decisions Survey was led by PIF and developed by a collaborative group which included women who had recently given birth or were pregnant.

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PIF would like to thank Norgine UK for providing partial funding to support the survey, Lisa Ramsey at NHS England for her advice, Dr Alex Freeman at the Winton Centre for Risk Communication for providing PIF with expert advice on risk communication.

In this report we use the terms 'woman' and 'women', based on the gender identity chosen by people who responded to the survey. More than 99% of respondents selected 'woman'. The findings and recommendations also apply to people who do not identify as women but are pregnant or have given birth.

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A message from the Chair

The results in this report make for a sober read. In the 21st century we fail women at their most vulnerable, when they are trying to make decisions which may affect the long-term wellbeing of their unborn child.

At a time when rates of induction are rising in the UK, women ranked fear of induction as their second biggest birth concern. 50% said they did not have the information needed to make an informed choice. Many were left feeling completely disempowered and unheard.

The women who completed the survey were very clear about the need to have better quality, evidence-based, data-led information to help them have a supportive conversation. This is an issue which can and must be addressed immediately, so that women can participate equally and make informed choices about their care.

Sue Farrington – Chair, PIF

Executive summary

Decision making and maternity care

Women are entitled to clear information on the risks and benefits of different options in order to make informed decisions about the birth of their babies.

This legal principle of shared decision making was set by Montgomery V Lanarkshire[1] (see box). The ruling gives patients a right to be advised of material risks and alternative treatment options.

Rates of induction are rising. One in three pregnancies is induced in Great Britain, according to most recent data. [2,3,4]

Earlier this year PIF members raised concerns about availability of information to support decision-making on induction of labour.

Induction Survey

PIF responded by collaborating on a survey with maternity charities including Tommy's, Bliss and Birthrights. In August 2021, the survey was shared on social media channels including Twitter, Facebook and Instagram. In less than a fortnight, 2,325 women who had given birth in the last three years responded.

The results are sobering and echo the findings of earlier small studies.[5,6] Our findings show there is much to do to put personalised care and shared decision making into practice in maternity care.

For example, fewer than 20% of survey respondents were provided with any risk benefit data to help them make an informed decision about induction of labour.

Montgomery v. Lanarkshire Health Board

Doctors must ensure patients are aware of any "material risks" involved in a proposed treatment, and of reasonable alternatives after the 2015 Montgomery Judgement.

The case was brought by Nadine Montgomery. Her son Sam's traumatic birth resulted in cerebral palsy. Nadine is diabetic and small in stature. Women with diabetes are more likely to have large babies.

Nadine argued she should have been advised on the 9-10% risk of shoulder dystocia when she asked about the risks of vaginal birth, so she could make an informed decision about whether a vaginal or caesarean birth was right for her.

The case marked a major change in the law and is the basis of shared decision making and informed consent.

Better Births

Better Births[7] published by NHSE in 2016 set a vision for maternity services across England to become safer, more personalised, kinder, professional and more family friendly; where every woman has access to information to enable her to make decisions about her care.

The Ockendon Review[8] published in December 2020 concluded all women should have ready access to accurate information to enable their informed choice in birth: "Women must be enabled to participate equally in all decision making processes and to make informed choices about their care."

The report also listed this essential action: "Maternity services must ensure that women and their families are listened to with their voices heard."

Women's Voices Unheard

Too many of the women who responded to our survey felt their concerns and wishes were dismissed. A minority felt bullied and coerced into decisions.

In November 2021, NICE published new guidelines on induction of labour[9]. The recommendations may increase the number of women who undergo induction.

Importantly, NICE made a series of recommendations on information which echo many of the concerns and demands for better information made by survey respondents. NICE also made a series of recommendations for further research to provide the evidence women need for decision making.

Guidelines to Change

The challenge now is to make sure these new NICE guidelines and the recommendations of earlier reviews are implemented. All women must receive personalised information to allow them to make informed decisions about how their baby is born.

Too many of the women who responded to our survey felt their concerns and wishes were dismissed. A minority felt bullied and coerced into decisions.

What Women Want

Women described the information they need to support decision making in free text responses to the survey. They want more information on the risks and benefits of induction, their right to choose and make decisions. They want to know more about the process, methods and timelines of induction, to have information earlier and to make more realistic birth plans.

This report provides an executive summary of the survey findings, an identification of women's top 5 information needs from the thematic analysis of free text comments and recommendations for change.

The full survey results, including comments made by women, are also provided. In selecting the comments for inclusion we have tried to include a range of experience.

We recognise there is a potential bias in the survey and women with a poor experience may be more likely to respond. We have amplified the voices of women who had a more positive experience so those insights can be used to improve both the information experience of pregnant women and the supportive conversations they have with healthcare professionals.

Key Survey Findings

Women and babies

2,325 people responded to the survey. All gave birth in the past three years or were currently pregnant. There were 6,300+ detailed free text comments. 84% of babies were born between 38-42 weeks. 87% were born on hospital labour ward.

Information sources and timing

Information sources were ranked as trustworthy in the following order:
1 NHS, 2 search online, 3 friends and families, 4 health charities, 5 healthcare professionals.

More than 50% of respondents received verbal information only from healthcare professionals. 40% only received information after 38 weeks.

Enough information?

- 50% of women felt they had received enough information on induction
- 40% felt the information provided was not detailed enough.
- 65% did not have enough risk benefit information to make an informed decision.
- 18% were provided with a number or statistics to help them decide.
- 32% felt they had a supportive conversation with a doctor or midwife.
- 25% felt the information they received prepared them for induction.
- 52% felt they had the birth that met their and their baby's needs.

Induction of labour

- 73% of the sample had some form of induction (excluding sweeps). An additional 4% of women reported having a sweep followed by vaginal birth. If sweeps are included as a method of induction this brings the total experiencing some form of induction to 77%.
- 1,756 women responded to the question on method of induction. They had collectively experienced 3,241 induction attempts, demonstrating the 'cascade of intervention methods' mentioned by respondents when initial induction attempts failed.
- Women ranked fear of induction as their second biggest birth concern.
- Fear that something might happen to their baby was their number one concern.
- Women perceived three times as many concerns relating to induction than benefits.

Other findings

- Rates of induction were higher in first time mothers.
- Those with pre-existing health conditions and pregnancy-related conditions had a marginally better information experience than women without health conditions.
- Women also reported a marginally better information experience since the start of the pandemic.

What pregnant women want – top 5 information needs

We asked women how to make information on induction better. Here are the top five suggestions from an analysis of 1,200 comments.

1 Numbers, numbers, numbers

Women want statistics on risks, benefits and alternatives to induction and what would happen if they waited for birth to start naturally for pregnancy beyond 42 weeks and the impact of factors including:

- Babies small and large on growth scans
- Mother's age
- Health conditions
- Pregnancy related conditions

They also wanted data on side effects of induction for mother and baby and success rates of induction.

Less scary language around risks, for example the risk of stillbirth at late term could be framed as 'x in 1000' instead of 'doubling of the risk since 40 weeks'.

With my second baby there was an induction team who were amazing and gave me lots of information. With my first birth this wasn't available and I felt completely uninformed and unprepared.

2 Information on choices

Women want to know they have a choice about induction and the right to informed consent. The word 'told' featured as one of the most common words in this section, used in the context 'I was told I was being induced'. More than 70 comments included stronger language including 'coerced', 'harassed' and 'bullied' .

Doctors need to choose their language very carefully. I felt I was being bullied into having an induction.

3 Supportive conversations

Birth plans do not always go to plan. When that happens women want support to understand their options.

The first consultant would not give me any evidence-based information. The second consultant I saw gave me the information I needed and the support to make a decision.

4 The process and timeline of induction

Women want information on the timeline of induction, the cascade of intervention and other impacts including use of birthing pool, pain relief, birthing position, food, monitoring and time spent in hospital. They also want to know that sometimes induction doesn't work.

It would have been helpful to know what happens when certain methods of induction fail. I had no idea it would take three attempts to induce my labour over several days. I would have opted for a C-section and probably will if I have another baby.

Induction was not discussed in my midwife appointments. It came as a surprise when a doctor I had never met before, advised it was required.

Far too much emphasis on birth centres /home birth and avoiding effective pain relief. Should give an honest picture of reality and offer all options as true informed choice including induction.

5 Realistic birth plans made sooner

There is a need for better birth planning, with options for methods of induction, realistic 'what if' scenarios and decision trees. Women wanted this information earlier in pregnancy and to hear positive stories of induction.

Birth plans often go sideways. Full plans should be done with a midwife to cover all eventuality and those assisting with birth should respect these plans and follow them.

Case study: A complicated situation for women

I was told my amniotic fluid was low and it could put the baby in danger; cause things like cerebral palsy or even death so the safest thing to do was induce labour.

I had read about induction and about my 'rights' so part of me was aware that I could technically refuse the induction and hope to go into labour naturally. The problem is: I think you have to put trust into your medical providers because the whole ordeal is terrifying and, if you can't trust the decisions they are making then you're putting your fears and desire to have a natural birth ahead of their training and experience.

I thought to myself that, if I say 'no' and something happens to my baby, I'll never forgive myself and even if the birth doesn't happen the way I had wanted it to, the birth is still very likely to result in a healthy baby.

In terms of information I was provided, it was explained to me what induction was, the different forms it can take, the plan they had for me, and the risks. What I wasn't given was information on realistically what would happen if I decided to wait, things like the percentage of births where induction was recommended and refused and what the result was or what the plan would be if I said 'no' and how the baby would be monitored.

Maybe they could have told me how quickly things could get dangerous if I waited, or stats comparing the negative consequences of induction versus the stats of waiting and monitoring the situation.

Recommendations

1 Support for Trusts and Local Maternity Systems to embed and make personalised care and support planning guidance[10] a reality

- Train maternity teams in how to have decision conversations (e.g. implementing House of Care model). The Personalised Care Institute's free e-learning module on personalised maternity care[11] is a good place to start. Birthrights also provide training.
- Enable healthcare professionals with health literate information products to provide pregnant women with comprehensive information covering all birth planning and induction topics.
- Establish a key HCP to act as a personalised care planner throughout a woman's pregnancy. Enable informed decision making by prompting women to ask questions to identify individual health and emotional concerns relating to different methods of induction and what happens if it fails.

2 Improve risk/benefit communication

Women want data on risks and benefits of different options. NICE has identified priorities for research to help build the evidence base. Where there is data available it should be communicated in line with NICE guidelines[12] and best practice principles. This will help people feel confident in making decisions about their baby's birth.

PIF top tips on risk communication

Numbers not words

- Use a statistic such as 1 in 100 people alongside words like rare or common.
- Use expected frequencies, for example, 10 in 100, rather than 10%.
- Give comparisons 'out of' the same number (1 in 100 compared with 2 in 100, not 1 in 100 compared with 1 in 50).

Absolute risk rather than relative risk

Using relative risk can be misleading. The absolute risk of an event increases from 1 in 100 to 2 in 100, but the relative risk of the event doubles.

Illustrating risk

Use visuals to improve users' understanding of risk and statistics. Using a mix of numerical and visual formats to communicate risk is helpful. Visual displays help give an overall pattern. Actual numbers are better for giving detail.

Perceptions of risk

Use positive and negative framing, i.e. '3 out of 100 people experienced this side effect, but 97 out of 100 did not'.

Explain uncertainty

Be honest with women about what we know and don't know.

Making sense of risk and benefits guide for the public – available on the PIF TICK website.

3 Embed women's right to choose through the use of consistent national decision support tools

The NHS is the most trusted source of information for pregnant women. The NHS website's maternity pages saw a huge increase in traffic throughout the pandemic. The development of a new national decision support tool, iDecide, is underway. The web-based tool will provide women with information so they become familiar with the decisions they might face during the birth of their child. It will be supported by two-page decision aids. These are to be piloted in 2022 and will cover the following areas:

- Augmentation of labour
- Assisted vaginal birth (forceps/ventouse)
- Unplanned caesarean birth.

PIF welcomes the iDecide approach and recommends:

- Its development is accelerated and expanded to include induction of labour
- It is supported by a marketing and implementation plan aimed at pregnant women and healthcare professionals.
- It is provided in accessible and alternative language formats to help counter the health inequalities experienced by women from minority ethnic communities.
- Allows for increasing personalisation of content as it develops.

Healthcare professionals should be trained to use the tool and to have supportive conversations with pregnant women and their partners.

iDecide is a digital framework under development by NHSE in partnerships with other organisations and service user representatives. It is designed to be used by healthcare professionals and women/individuals and their partners during childbirth. It aims to support a woman to make an informed decision about next steps during labour. Development of the tool started in response to the Montgomery judgement.

iDecide stands for:

I Identify urgency.

D Details of the current situation.

E Exchange objective and subjective information (history, organisational context, woman's perspective, healthcare professionals' experience).

C Choices available (evidence-based information will be on the tool – generic at first but in time individualised).

I I (the woman) confirm my understanding and seek any further clarification needed.

D Decision is made (by woman) and recorded on the tool.

E Evaluation takes place a few days/weeks later using a recorded experience measure.

4 Maternity services should signpost women to other trusted sources of information and support. Search online was second only to information on the NHS website as the most popular source of maternity information.

Trusted sources of information are available from a range of maternity charities and medical organisations. Bliss, Tommy's and the Strep B Support Group provide health information. Tommy's concise and clear leaflet (see right) on reduced foetal movement is one of the charity's most popular resources.

Organisations like Diabetes UK provide specific support for women with long term conditions who are pregnant. Birthrights advises women about their legal rights in childbirth.

Bliss and Tommy's are both members of the PIF TICK scheme, PIF's trust mark for health information.

Trusted Information Creator

When the public sees the PIF TICK they can be confident the information is evidence-based, written in plain language and produced by trained staff.

The PIF TICK aims to help patients and the public identify trusted information from misinformation and disinformation.

5 Trusts should work through Maternity Voices Partnerships and respond to women's local information needs

Better information is needed at local level to meet women's needs. The impact of good quality information and support about induction is clear from survey respondents. Women who had received supporting information in good time felt better prepared, less fearful about induction and less out of control. In comments, women argued information should be provided earlier so they understood the processes and could include realistic options in birth plans.

Existing examples of good practice

→ **Epsom and St Helier Maternity Voices Partnership** carried out a survey of 114 women who had been induced at the hospital. The survey looked at the expectations of women in relation to induction of labour, the information given to enable them to make an informed choice and the experience of undergoing induction. The responses have been used to revise the Trust's information on induction.

→ **Isle of Wight Hospital's Trust** leaflet on balloon induction was identified by members of the stakeholder group as an example of good practice. Concise and written in plain language it provided women and their partners with an essential guide to the process and possible risks and benefits.

→ **Brighton and Sussex University Hospitals NHS Trust** has a dedicated web page on induction of labour. It explains when induction might be considered, the different methods of induction, alternatives and signposts to other sources of information including NICE guidelines.

→ **Mid Yorks** provides easy-to-access information on induction on its website. It includes personal accounts of induction from women who have been induced at the hospital: midyorks.nhs.uk/maternity

I was not provided much information, and when I did my own research (using NHS material) none of the material properly explained the implications of induction/the process /the steps (why each step is taken).

Case study: 'Post-dates' clinic improves patient experience

Queen Elizabeth Hospital, King's Lynn, ran a dedicated clinic for post-dates women and birth people. The service was provided at 40 and 41 week appointments. The initial aim was to reduce post-dates inductions of labour by 3-5%. Hour long appointments could include an antenatal check, a membrane sweep, acupressure to three pressure points and an aromatherapy treatment.

Discussions were based around the woman's needs on early labour care, pain relief, birth expectations, the induction process and optimal fetal positioning. Any worries or fears surrounding the labour or induction process were discussed.

An audit was conducted the year before the introduction of the service and the year that the service was introduced. The results showed a significant impact on reducing post-dates induction of labour by 27.6%

Women who would have been eligible to use the service but did not, provided a 'control group'. This allowed an initial comparison of outcomes of women who did and who did not use the service.

For women who used the post-dates service and did go on to have an induction of labour, there was a significant reduction in Caesarean section rates compared to those who did not use the service (14.8% vs. 29.1%). Further service evaluation and research is needed to confirm these findings.

Qualitative feedback demonstrated an improved experience for women giving birth in the area. www.all4maternity.com/complementary-therapies-postdates-service

6 Change NHS Birth plan template to include options for induction of labour
The NHS birth plan template excludes options for induction of labour. Including induction in the template would allow women to consider induction options in their planning. Not doing so was described as 'ableist' by one respondent, given the number of women who are induced and who are unable to go ahead with planned midwifery unit or home births.

7 Produce information in plain language and use jargon busters for medical terms
The need to use plain language and 'words I understand' was raised by respondents specifically in relation to medical terms like 'Bishop's Score'.

PIF recommends writing health information with a reading age of between 9-11 to match the skill level of the population.

It is very important that plain language is used in decision making conversations, given the number of women who received verbal information only. Avoiding medical terms and using consultation techniques like Teach Back can support this.

Statistic from the PIF Health Literacy Matters infographic

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Join us

PIF is the independent UK membership body for people working in health information and support. We operate the PIF TICK, the UK-wide quality mark for health information.

We have more than 1,000 members in 300 cross-sector organisations. These include national charities, the NHS, commercial, government, freelance and academic sectors. We use the insight and support of our membership to lobby governments in support of our vision.

Our vision

Everyone has access to personalised health information and support to enable them to make informed decisions about their health, wellbeing and care.

Our Partners

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