



Ipsos
Social Research Institute

Development Report:

2015 Maternity Care Survey

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1. INTRODUCTION

The NSW Patient Survey Program (the Survey Program) is a suite of surveys that collects information on the experiences of patients receiving care in public hospitals and other public healthcare facilities across New South Wales (NSW). The purpose of the Survey Program, which commenced in 2007, is to report on patients' experiences and perceptions of care in NSW public hospitals and public healthcare facilities so that:

- Hospital performance is readily available to the general public; and
- Health services and policy makers can identify strengths and opportunities for improvement, to assist them to provide safe, quality care.

The following principles underpin the Survey Program:

- Participation is voluntary
- Confidentiality of patients' personal information is assured
- Questionnaires are informed by evidence
- Information collected is reliable, comparable and relevant
- Reporting methods are open and transparent
- Information reported is impartial, easily understood and useful.

The Bureau of Health Information (BHI) currently manages the Survey Program. BHI was established by the NSW Government to independently report on the performance of the public health system in NSW, including the healthcare experiences of patients. In 2012, Ipsos Social Research Institute (Ipsos SRI) was contracted by NSW Health to develop and administer a new suite of surveys for the Survey Program.

The redevelopment was designed to ensure that the content of the surveys and any new surveys are specifically tailored to the NSW healthcare environment (the surveys used from 2007-2011 were originally developed by NRC Picker for use in the United States). Where relevant, the surveys include a set of core, common questions. These core questions have been tested in the Adult Admitted Patient Survey, the first of the suite to be developed, on behalf of the National Health Information Standards and Statistics Committee's Patient Experience Information Development Working Group (PEIDWG).

A program of research informed the development of the Maternity Care Survey (MCS). The aims and objectives of the research were to ensure that the MCS adequately captures and provides feedback on the aspects of care that:

- Are relevant to the current policy context
- Are important to NSW patients
- Will be useful to NSW health services and policy makers.

This report describes the research process undertaken to develop the MCS. The first chapters of this report summarise the information collated at each stage of the developmental process, resulting in a list of potential question areas. The final chapter documents how these potential question areas were prioritised and translated into the final questionnaire.

The results of the survey will be fed back to the NSW Government and public healthcare facilities to inform service improvement, and released to the public.

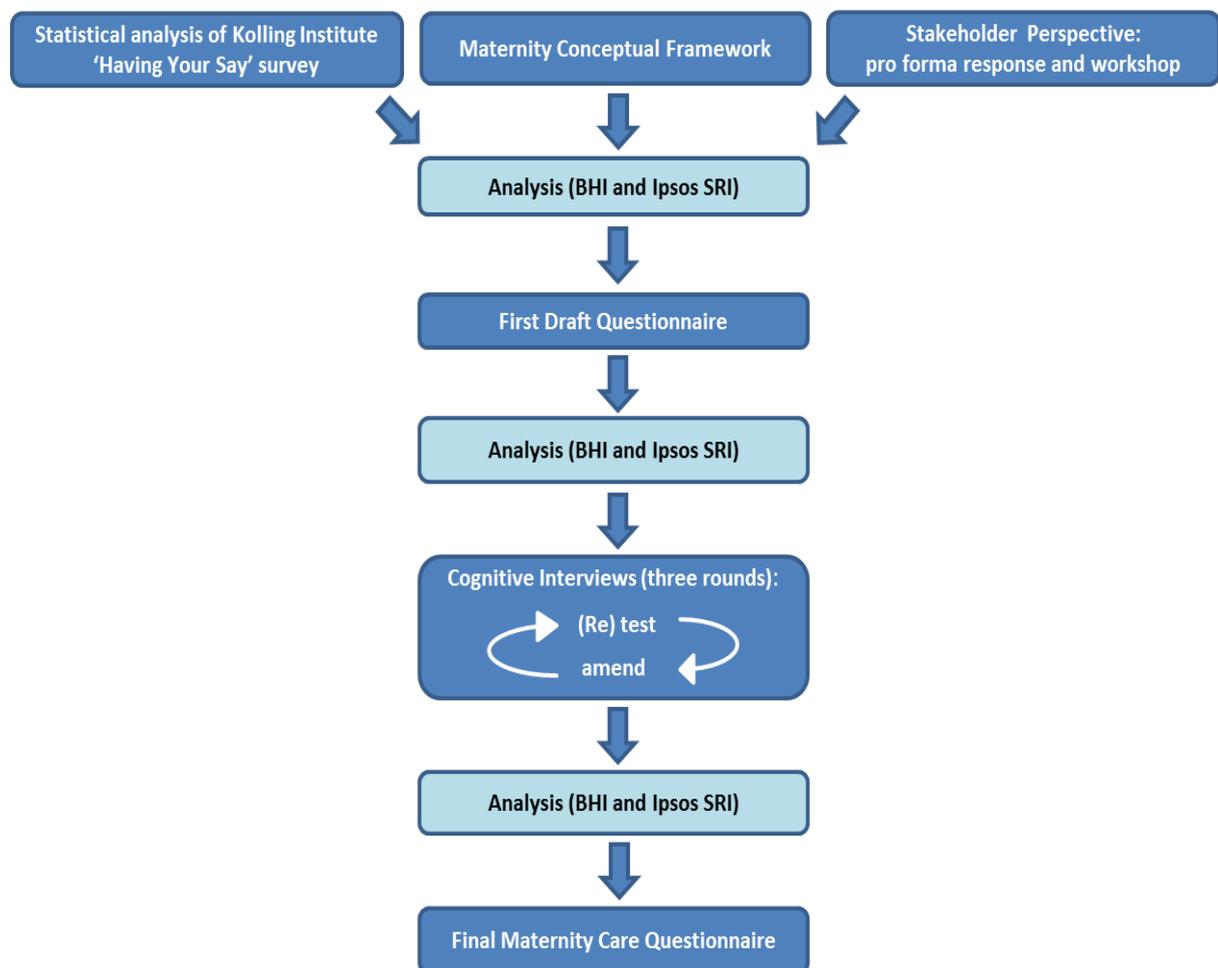
2. METHODOLOGY

The development process comprised:

1. Statistical analysis of the Kolling Institute 'Having your say' survey
2. A maternity conceptual framework
3. Stakeholder engagement
4. Three rounds of cognitive testing
5. Extensive discussion between the development teams at BHI and Ipsos Social Research Institute (Ipsos SRI).

The following diagram illustrates the questionnaire development process (Figure 1).

Figure 1: Questionnaire development process



Analysis of the 'Having Your Say' maternity questionnaire from the Kolling Institute

Prior to developing a bespoke survey tool, BHI conducted an analysis on an existing maternity survey - the "Having Your Say" Maternity questionnaire, designed and administered by the Kolling Institute - in order to support and inform the development of the new NSW Maternity Survey.

The data was analysed to help understand:

- Response rates and evidence of response bias
- Quality of individual survey items, based on three measures
 - Response dispersion, particularly ceiling or floor effects; that is, whether responses to an item were concentrated at one end of the response range – either overly positive (ceiling) or overly negative (floor)
 - Data completeness – items with high levels of missing data (>4%) could indicate that questions and/or response options were not clear, not relevant, or difficult to answer
 - Highly correlated items ($r > 0.7$), which could indicate duplication (i.e. measuring the same construct) or survey design issues (e.g. consecutive items not being treated as independent, resulting in coalescing of responses)
- Data accuracy, which was assessed by comparing three data items (maternal age, mode of birth and neonatal outcome) that were replicated in the survey and available in ObstetriX. This comparison provided an indicator of external validity and how well women were responding to the survey questions.

Maternity conceptual framework

A conceptual framework was developed to provide context and to broadly inform the content of the MCS. The aims of the framework were as follows:

- 1) Identify and compare the core domains of treatment and care for maternity patients;
- 3) Briefly describe and compare the format, content and questionnaire-related methodological issues associated with other jurisdictions' maternity instruments.

Stakeholder engagement

In September 2014, 25 stakeholders were sent a pro forma inviting them to submit the content they thought was suitable for inclusion in the questionnaire (see Appendix C). The stakeholder list was compiled by BHI and is included in Appendix C.

The pro forma contained the following fields: aspect of care or question topic; reason for interest in this area; whether the question applied to a sub-set of patients; how the data would be used;

and suggested question phrasing. The contact email was sent by BHI and is appended (Appendix D). The pro forma was out in the field for a total of three weeks (a reminder was sent out to all those on the stakeholder list who hadn't replied halfway through the consultation period). It was completed by 11 contributors, including representatives from:

- Clinical Excellence Commission
- Kolling Institute, University of Sydney
- NSW Maternal and Newborn Advisory Group
- Faculty of Health, University of Technology, Sydney
- Central Coast LHD
- Illawarra Shoalhaven LHD
- Mid North Coast LHD
- Northern NSW LHD
- Southern NSW LHD
- Western NSW LHD

This exercise was followed up in November 2014 with a workshop in which the key stakeholders - the Kolling Institute and NSW Kids and Families - were invited to further refine the content for the questionnaire along with BHI and Ipsos SRI. BHI analysed the pro forma responses and feedback from the workshop. Relevance to patients and information on how the data would be used were both taken into account during the subsequent prioritisation process and questionnaire design.

The question areas indicated by the stakeholder consultation and workshop were eventually collated with those identified from the other developmental phases of the research to create a comprehensive list of potential question areas for the MCS, which took into account the perspective of both patients, partners/carers of patients and stakeholders.

References to stakeholders within this report refer to ideas and comments put forward by one or more of the consulted stakeholders, but are not necessarily the views of all, or a majority, of stakeholders.

Cognitive interviews

Three rounds of cognitive interviews were conducted with new mothers in order to investigate how they interpreted and responded to the first two drafts of the questionnaire. This was performed to: ensure questionnaire validity (i.e. that questions were understood, consistently interpreted and measured what they were intended to measure); ensure that patients were able to follow the questionnaire routing instructions; ensure that they understood the cover letter; and as a final opportunity to confirm that individual questions were relevant to patients and that no crucial question areas were missing (from the respondent's perspective).

Questions identified as problematic in these interviews were redrafted and presented to mothers in the next round of the cognitive interviews, or removed altogether. The third and final round of

cognitive interviews was conducted primarily to test the layout of the printed questionnaire and other materials to be sent with the questionnaire (i.e. accompanying letter and language information sheet).

The interviews were conducted among a wide range of new mothers from across the greater Sydney area. Quotas were set to ensure representation of a range of participants in terms of background (including culturally and linguistically diverse mothers), type of birth (vaginal or caesarean section) and whether it was a first or subsequent birth.

A total of 15 cognitive interviews were conducted. The first round took place between 3-6 February; the second round between 16-17 February; and the third round between 19-23 March 2015. The profile of participants in each round can be found in Appendix C.

Each interview was audio recorded and cover notes were prepared by Ipsos SRI consultants to facilitate analysis. The discussion guides used in the cognitive interviews can be found in Appendix D.

Analysis sessions involving Ipsos SRI and BHI

Throughout the development process, BHI and Ipsos SRI teams were in regular contact. This involved ad-hoc discussions, as well as a series of meetings held at the key stages of the development, including:

- Completion of the stakeholder consultation
- Each round of cognitive testing
- Each substantial redraft of the questionnaire.

At each meeting, questionnaire inclusions and exclusions were discussed, with decisions made in light of the results of the development components, BHI's expert knowledge of the NSW healthcare system, data analysis and reporting needs and Ipsos SRI's research expertise. Further, upon the drafting of the penultimate version of the questionnaire, it was presented to BHI's Strategic Advisory Committee (SAC) for final review. Feedback from the SAC was subsequently incorporated into the final version of the questionnaire.

3. FINDINGS

3.1 Analysis of the 'Having Your Say' maternity questionnaire from the Kolling Institute^I

Response dispersion

Evidence of ceiling effects, but not floor effects, was found for some items, including a set of questions about different aspects of antenatal care that were grouped together in a grid (i.e. organisation of appointments, information and explanations provided, time to ask questions, treated with kindness and understanding, and involvement in decision making). Similar items were repeated in the birth and postnatal sections of the survey, with similar patterns of responses. Two other questions showed high levels of positive responses across all maternity units (i.e. 'skin-to-skin contact with baby' and 'contacted or visited at home by a midwife').

Data completeness

Rates of missing responses for all items in the survey were less than or equal to 1%.

Highly correlated items

Two items about infant feeding (i.e. 'given active support and encouragement' and 'given practical help') were highly correlated.

Data accuracy

Comparison of three data items (i.e. maternal age, mode of birth and neonatal outcome) collected in the survey and in the ObstetriX database demonstrated high concordance.

3.2 Maternity conceptual framework

In previously published maternity surveys, an effort has been made to recognise and cover the entire pregnancy and birth experience, from the first antenatal appointment, to follow-up care after discharge following birth. Following an evaluation of these question themes, they were grouped together as follows:

Your baby

This theme includes a range of questions relating to information about the baby, and where the baby was born:

^I More detailed results of this analysis are available in the published journal article <http://www.phrp.com.au/issues/january-2016-volume-26-issue-1/testing-a-health-research-instrument-to-develop-a-statewide-survey-on-maternity-care/>

- Type of birth (single/multiple)
- Sex of baby
- Weight of baby
- Date of birth
- Length of gestation
- Whether a public or private patient
- Hospital in which mother gave birth
- Reasons for choosing to give birth in the facility

Interestingly, the Kolling Institute and Queensland surveys used different approaches to multiple births. Kolling Institute's 'Having Your Say' questionnaire asked the mother to complete the questionnaire for the first baby born, but the Queensland survey program offers mothers who had multiples a different form in which they can answer questions for each baby.

Antenatal Care

This section, sometimes referred to as 'Your Pregnancy' includes a breadth of questions about the provision of antenatal care as listed below. In two of the questionnaires used in the Australian setting, questions about the health and wellbeing of the mother were asked. The Kolling Institute's 'Having Your Say' questionnaire used a published, validated scale to assess stressors that the mother experienced in the 12 months prior to the birth. This theme included the following question areas:

- When antenatal care was first provided
- Who co-ordinated and provided antenatal care
- When the booking-in appointment took place
- Whether there was timely access to mothers' medical history
- The quality of the antenatal care provided
- The physical and mental health and wellbeing of the mother
- Healthy weight gain during pregnancy
- Advice about the risks of alcohol and smoking during pregnancy
- Advice on stopping smoking during pregnancy
- Stressors experienced by the mother in the 12 months prior to the birth
- Birth plans of where and how the mother wanted the birth to occur

Labour and birth

This theme covers the range of experiences during labour and birth, both in terms of the nature of the birth, and the interaction with staff:

- Pain management
- Whether mothers had enough say in their pain relief
- Whether mothers were able to move around during labour

- Whether birthing companion was involved as much as they wanted to be
- Whether mothers were offered a water birth
- (Where applicable) the reasons for having a caesarean section
- The kind of birth the mother had (vaginal/caesarean)
- Whether there was skin-to-skin contact between the mother and the baby immediately after birth
- Difference between expectations of birth and the actual experience
- Quality of communication between staff and the mother during labour
- Trust and confidence in staff
- Transfers between facilities

In the section representing this theme in the 'Having Your Say' questionnaire, respondents are asked early on whether their baby was live born, stillborn or live born but died later. The instructions ask the respondent to answer 'not applicable' where appropriate if their baby was stillborn. In the Queensland survey, mothers who experienced a stillbirth are excluded from the sample.

Postnatal care

Both in-hospital and out of hospital postnatal care are covered in this theme:

- Whether, shortly after the birth, health professionals explained how the birth had gone
- Length of stay in hospital
- Appropriateness of length of stay in hospital
- Cleanliness of wards and rooms
- Whether mothers were bothered by lack of security, lack of privacy or noise problems
- Whether mothers received support for breastfeeding/feeding the baby, and whether their feeding decisions were respected by health professionals
- Whether the mother was informed about, and visited at home by, the Child and Family Community Nurse
- Whether the Community Nurse asked how the mother was feeling emotionally
- The mother and baby's health after birth

Overall care experience

This section covers aspects relating to mothers' overall assessment of the experience:

- Continuity of care between different stages of pregnancy and birth, and between different health professionals
- Whether there was good communication, sufficient time to ask questions and the mother felt listened to by health professionals
- Whether the mother would recommend the facility to family and friends
- Overall rating of care

Demographics

This theme covers questions about the demographics of the mother. In the Kolling Institute's questionnaire, the mother was also asked to report their current health status and the current health status of their baby.

3.3 Stakeholder engagement

Fifty-eight stakeholders were invited to submit content they wanted to see included in a questionnaire sampling women who have given birth in a NSW public hospital or birth centre. Eleven stakeholders participated, submitting 56 additional topics or questions for inclusion. Additionally, a copy of the Queensland Mothers and Babies Centre Maternity Survey were sent by two stakeholders, who requested that BHI consider using the questionnaire content from this survey.

The pro forma was out in the field for a total of three weeks (a reminder was sent out to all those on the stakeholder list who hadn't replied halfway through the consultation period). Clear themes emerged from the feedback, as well as conversations with stakeholders prompted by the request. In addition, the Kolling Institute and NSW Kids and Families contributed to a workshop to further refine the content for the questionnaire along with BHI and Ipsos SRI.

Specific questions were put forward by these stakeholders; these can be found in Appendix F. The themes that emerged from this exercise were as follows:

Models of care

There was clear interest from multiple stakeholders in understanding mothers' knowledge of, and experience of, different models of care. Specifically, stakeholders were interested in:

- What the mother knows about the different models of care available
- Whether the mother chose their model of care
- Whether the mother knew which model of care they received
- Whether the mother's experience reflected their expectations of the model of care
- Any feedback the mother had about their model of care
- Factors influencing mothers who changed their model of care during their pregnancy

Antenatal Care

There was interest in understanding mothers' experience of the different aspects of antenatal care received.

- The reasons for choosing the hospital that the mother attended to give birth
- Time taken to travel to antenatal check-ups
- The physical and mental health and wellbeing of the mother
- Healthy weight gain during pregnancy

Labour and birth

Further themes that were identified by stakeholders were specific to labour and birth and the experiences of the mother during this period. Areas of interest included:

- Continuity of care during labour and birth
- Whether the mother could identify or name the midwife that took care of them during each stage of their pregnancy and birth
- Whether mothers were introduced to the health professionals caring for her during labour and birth
- Whether consent/informed consent was given by the mother when doctors or midwives performed checks or procedures on the mother during pregnancy and labour
- Whether the birth plan was followed during labour and birth
- Whether mothers were able to move around during labour
- Whether mothers were given sufficient privacy in labour
- Whether there was sufficient privacy during birth
- Whether decisions made by the mother were respected during labour and birth
- Options for pain relief offered at the facility (including water immersion)
- Whether mothers had enough say in their pain relief
- Whether birthing companion was involved as much as they wanted to be
- Whether mothers received assistance when needed
- If the midwife or obstetrician checked the baby's heart beat regularly during labour (to identify if the baby was in distress)
- (Where applicable) the reasons for having a caesarean section

Care in hospital

As well as asking about the mother's model of care, several of the stakeholders requested that the questionnaire cover specific aspects of the care received, with more of a focus on the in-hospital experience. They highlighted the following areas of interest:

- Whether, shortly after the birth, health professionals explained how the birth had gone
- Whether mothers received assistance when needed

- Whether there was good communication, sufficient time to ask questions and the mother felt listened to by health professionals
- Whether health professionals were kind and caring to mothers
- Cleanliness of wards and rooms
- Rating of hospital food, and whether it was appropriate and met mothers' dietary needs
- Whether a midwife in hospital taught/helped the mother with breastfeeding and mothercraft skills (a number of suggestions related to breastfeeding support, and taking care of both self and baby after the birth)
- Whether the mother was included in discussions about their ongoing maternity care after birth
- Whether the hospital visiting hours were sufficient in allowing partners/family to support the mother throughout their stay
- Whether mothers were bothered by lack of security, lack of privacy or noise problems
- Whether the mother needed, and received, an interpreter
- Whether the mother experienced any complications, and if so, the impact

Discharge Pathways

A number of stakeholders made mention of the discharge process and expressed the need for care providers to understand the helpfulness/effectiveness of the information and support provided during the discharge from hospital. Primarily, the stakeholders wanted the questionnaire to ask about:

- Whether the opportunity to debrief about the birthing experience was given to the mother prior to discharge
- Whether the mother was happy with the discharge processes
- Appropriateness of length of stay in hospital
- Whether information provided to the mother was sufficient and appropriate
- Whether the mother had worries about her health, or the baby's health, after leaving hospital
- Whether the mother was informed about, and visited by, the Child and Family Community Nurse
- Whether there was a handover between the midwife and the Child and Family Community Nurse
- Whether the Community Nurse asked how the mother was feeling emotionally
- Whether the mother felt supported once she had returned home

It should be mentioned that a number of stakeholders made recommendations to use questions/themes that are used in questionnaires that are currently in the field or have been previously used in Australia. However, the overall themes covered by these questionnaires were already used to develop the conceptual framework for the survey. There was also interest in understanding whether mothers' had any long-standing conditions.

Finally, stakeholders were asked about the most important current policies and quality standards they thought were relevant to the survey (taking into account the suitability of the survey as a vehicle for assessment of these). A number of actions under policies and guidelines were raised as potential areas that could be included in the questionnaire. These included:

- From the 'Antenatal Card' Guideline from NSW Health (2005):
 - Provision of an antenatal card for antenatal appointments
 - Health care providers updating the card at each antenatal check-up

- From NSW Health's 'Guidelines for the Management of Substance Use During Pregnancy Birth and the Postnatal Period' (at the time pending, later published in 2014):
 - The offer of assistance in smoking cessation during pregnancy
 - Information provision to the mother about the risks of smoking and drinking alcohol during pregnancy

- From the 'Towards Normal Birth' (2010) policy directive for NSW Health:
 - Continuity of care (e.g. if the mother already knew the staff who cared for them during labour)
 - The offer of a bath/water immersion for pain relief during labour
 - skin-to-skin contact between the mother and her baby very soon after the birth

- From the 'Breastfeeding in NSW: Promotion, Protection and Support' (2011) policy directive for NSW Health:
 - Support for mothers in their choice of feeding method
 - Support for mothers in breastfeeding their babies

- From the NSW Health policy directive 'Maternity - Safer Sleeping Practices for Babies in NSW Public Health Organisations' (2012):
 - Education for mothers about safe sleeping for their babies

4. QUESTIONNAIRE DEVELOPMENT

This section summarises how the various stages of the development process were brought together - the analysis of the Kolling Institute's maternity survey, the maternity conceptual framework, stakeholder consultation and cognitive interviews.

This process involved:

- Applying parameters/rules to guide the questionnaire development
- Creating a list of potential question areas for inclusion in the questionnaire
- Consideration of other implications arising from each stage of the development
- Extensive consultation between BHI and Ipsos
- Three rounds of cognitive testing.

Development of rules/design parameters for the questionnaire design

The design of the MCS built on the rules and design parameters established in the development of the Adult Admitted Patient Survey (AAPS) and the Emergency Department Patient Survey (EDPS). The same planned approach – of consultation with service-users and stakeholders, and review of 'best practice' patient surveys – was adopted. 'Tried and tested' questions as a design starting point, were also used where appropriate, many resulting from the (published) analysis of the 'Having Your Say' survey^{II}. Similarly, the design was a process of extensive discussion between BHI and Ipsos, and finalised through cognitive testing.

These common rules and design parameters included: that the primary focus should be the respondents' experience of care and factual rather than judgemental assessment; inclusion of an overall rating question; use of balanced rating scales; avoidance of double-barrelled questions (wherever possible); avoidance of leading or biased question wording; using a limited suite of question formats and response options for ease of completion; using plain English throughout; and providing 'don't know' and 'not applicable' options only where essential.

Potential question areas

The potential question areas indicated by each stage of the development process were brought together to create a comprehensive list of possible topics. This included a range of issues relating to:

- Nature of the birth (vaginal or caesarean, and whether live or stillborn)
- Knowledge and choice of model of care

^{II} <http://www.phrp.com.au/issues/january-2016-volume-26-issue-1/testing-a-health-research-instrument-to-develop-a-statewide-survey-on-maternity-care/>

- When antenatal care was first provided, and by whom
- Quality of communications with health professionals
- Trust and confidence in health professionals
- Continuity of care between health professionals
- Whether mother's views were respected
- Reasons for having a caesarean
- Information and options for pain relief
- Support in breastfeeding and caring for baby
- Privacy
- Support by health professionals once mother has returned home
- Overall ratings of care (antenatal, during labour and birth, and postnatal)
- Patient suggestions for improvements
- Demographics and health status information (including questions required for standardisation purposes)
- Data linkage permission.

The full list of potential question areas can be found in Appendix E.

This comprehensive list, drawn from all developmental stages, was used as the basis of the initial questionnaire design, and then refined through consultation and testing.

Cognitive testing

An essential part of the development process was the undertaking of cognitive testing to ensure the validity of the questionnaire. The aim of this is to ensure that participants were able to understand and answer the questions and that they were consistently interpreted in the way intended. This stage of development was particularly valuable given the large variety in patient experiences and pathways that it highlighted.

The cognitive interviews were conducted in three rounds. The first two rounds provided an opportunity to assess whether the instrument successfully captured the full range of maternity experiences. This was an iterative process with the findings from the first round informing the subsequent draft, and being tested in the second round. This was then graphically designed and then the layout of the printed questionnaire and other materials to be sent with the questionnaire was tested in the final round.

A summary of the edits made as a result of the cognitive testing and subsequent discussion between BHI and Ipsos SRI, follows below:

- A number of questions were amended to more clearly establish the pathway of care for pregnant women, i.e. when they first presented for antenatal care (Q1) and who provided most of this care (Q2)

- Questions were designed to measure the duration of antenatal appointments (Q5) and the amount of time spent waiting (Q6)
- Numerous questions were amended to refer to health professionals, rather than doctors, midwives or health visitors to capture a broader range of models of care (Q8-Q10, Q17-Q18, Q59, Q66)
- Questions were introduced to establish recall and use of a personal antenatal card (e.g. the Yellow Card), (Q12 & Q13)
- Questions relating to the provision of information around alcohol consumption and smoking were simplified (Q14-Q16)
- The question about weight gain during pregnancy was rephrased to have a more positive tone (Q17)
- Questions were added to ask about the provision of pain relief information (Q21), and whether or not labour was induced (Q27)
- Additional phrases were added to core questions used in other NSW Patient Survey questionnaires, to clarify the period of care referred to:
 - 'During your labour and birth' was added to Q35, Q38, Q41, Q43, Q46
 - 'In the birth room or theatre' was added to Q44
 - 'After the birth' was added to Q47- Q58
 - 'Before leaving hospital' was added to Q73
 - 'After your baby was born' was added to Q75
- A question was added to ask about access to food out of hours (Q65)
- A question was included to establish whether mothers received conflicting advice from health professionals about feeding their baby (Q67)
- The sections in the survey were designed in alternating colours to assist respondents to distinguish between the stages of the maternity journey that the questionnaire was asking about.

Appendix F details the development process for every individual question in the final questionnaire, including the primary reason for inclusion, the source question (where applicable) and changes made to the question during the development process (as a result of cognitive testing and discussion between BHI and Ipsos SRI).

Appendix G outlines which questions in the final questionnaire are relevant to the National Safety and Quality Service Standards and the Australian Charter of Healthcare Rights.

The final questionnaire is included in Appendix H.