National Maternity Experience Survey

International Review of Maternity Care Experience Surveys

About the National Care Experience Programme

The National Care Experience Programme seeks to improve the quality of health and social care services in Ireland by asking people about their experiences of care and acting on their feedback. The National Care Experience Programme is a joint initiative by the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health.

The National Care Experience Programme includes the National Inpatient Experience Survey — an annual survey providing patients with the opportunity to describe their experiences of public acute hospital care in Ireland. The purpose of this survey is to learn from patients' feedback to find out what is working well in our hospitals, and what needs improvement. "The HSE responds to the results of the National Inpatient Experience Programme by developing quality improvement plans at the national, hospital and hospital group levels. In addition, the results of the inpatient survey inform national policy and HIQA's healthcare monitoring programme.

The National Maternity Experience Survey offers women the opportunity to share their experiences of Ireland's maternity services. The aim of the survey is to learn from the experiences of women to improve the safety and quality of the care that they and their baby receive. The first National Maternity Experience Survey will be carried out in early 2020.

A National Care Experience Programme competency centre is currently under development in order to provide support, guidance, information and leadership on the appropriate collection and use of care experience data for all engagement programmes in the health and social care services.

The National Care Experience Programme will expand to include three further surveys of health or social care services by 2021: these are a survey of the care of women who have been bereaved by stillbirth and neonatal death, older person's care and end of life care.

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1. Introduction

Person-centred care has been a key domain of quality in healthcare for well over a decade.[1] The basic premise of focusing care around the person using the health and social care service and responding to their needs and preferences is well-established as a component of high quality healthcare.[2]

Measuring person-centred care involves the collection of feedback on the experiences of people who use health and social care services. This feedback is a key indicator in identifying where expectations in health and social care are being met and where they are falling short. Patient experience, or the experience of those who use health and social care services, is now recognised as one of the three pillars of quality in healthcare, alongside clinical effectiveness and patient safety.[3] Evidence has shown that the three pillars of quality should be looked at as a group and not in isolation.[4]

In recent years, health and social care experience surveys, which capture the experiences of those who use these services, have been implemented at a national level in several countries. Significant benefits have been gained for all stakeholders from capturing this experience, including service providers, people who use the services, the public and national policy developers and regulators. Care experience surveys or other methodologies can lead to informed choice for people who use services, enhanced recovery for patients, improved productivity and efficiency for healthcare providers, and lower staff turnover and absenteeism.[5,6] They provide a means by which patients and people who use services can be engaged, active and informed in their own care.

For healthcare providers, the data collected by care experience surveys helps to identify areas for improvement, provide assurance in the care being provided, and benchmark care experience both nationally and internationally. As care experience surveys are tools which inform healthcare management of the quality and safety of care provided, they drive accountability across the healthcare system. Furthermore, they provide policy developers with definitive data to inform policy development and implementation. They also inform the development of national care standards in addition to monitoring and regulation programmes for care services.

In Ireland, national health policy highlights the importance of engaging with people who use health and social care services and capturing their care experiences to inform quality improvements in healthcare. The Department of Health's Statement of Strategy 2016-2019 commits to the creation of a more responsive, integrated and people-centred health and social care service.[7] It plans for the implementation of national strategies, which are underpinned by the engagement of people that use health and social care services, for example the *National Maternity Strategy 2016-2026* [8] and the *National Cancer Strategy 2016-2026*.[9] Similarly, Sláintecare, the ten-year, cross-political party strategy for healthcare and health policy in Ireland, advocates that "the voices of current service users and citizens must therefore be at the heart of healthcare reform, and success will be judged in terms of patient experience and outcomes and the overall health of our population". Sláintecare explicitly sets out the development and expansion of systems to capture patient experience.[10]

In Ireland, the inaugural National Inpatient Experience Survey[a] was successfully conducted in May 2017, when over 13,000 patients, representing a 51% response rate, chose to share their experiences of care in Ireland's public acute hospitals.[11] The findings helped to inform national and hospital-level quality improvements across the acute inpatient hospital sector.

At the national level, the Health Service Executive (HSE) established an Oversight Group to review the findings of the National Inpatient Experience Survey and to develop a systematic plan for improving patient experience across acute hospitals. This led to the establishment of the National Healthcare Communication Programme and the launch of the National Food, Nutrition and Hydration Policy for Adult Patients in Acute Hospitals. At local level, every hospital designed a quality improvement plan to address the findings.[12]

A commitment was subsequently made by HIQA, the HSE and the Department of Health to establish the National Care Experience Programme (NCEP), tasked with running the National Inpatient Experience Survey and expanding the programme to cover other areas of health and social care. This expansion led to requests for care experience surveys across a range of other areas, in particular maternity care.

In recent years, several reports and reviews have highlighted service deficits and failings in Irish maternity services. The *National Maternity Strategy 2016-2026* was developed as a consequence, with the aim of providing a framework for a new and better maternity service in Ireland. Simultaneously, the *National Standards for Safer Better Maternity Services*[13] were developed to support the implementation of this strategy.

10.1 Aims and Objectives

The aim of this international review is to identify and analyse international experience and best practice with regard to the model and methodology employed to deliver a national maternity experience survey. There is currently no nationally-standardised, comparable data on maternity care experience being

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[a] The National Inpatient Experience Survey was previously known as the National Patient Experience Survey.

collected within Ireland.

This report therefore identifies how international organisations and agencies collect and use national maternity care experience data. Through identifying international best practice, this review is a step towards informing the National Care Experience Programme on the most advantageous approach to implement a national maternity survey in Ireland.

10.2 Methodology

A systematic review of maternity experience surveys was undertaken in 2018 by the National University of Ireland, Galway (NUIG).[b] Five international maternity surveys were selected from this review for the current report for further investigation of their governance, operational and reporting processes. The selection of these surveys, and the affiliated national agencies responsible for them, was based on factors identified in the systematic review, including access to key personnel and availability of technical documentation.

The national maternity experience surveys reviewed in this report are operated in the following countries:

- Australia (New South Wales)
- England
- Norway
- Scotland
- USA (California)

Findings for this review were compiled from national documentation from each country and detailed discussions with key relevant personnel with responsibility for management of national maternity experience surveys within each country. Appendix A lists the personnel who were consulted within each organisation.

The review focuses on the methodology used in each jurisdiction, specifically:

- requirements from an operational perspective, specifically the model, methodology, resources, governance structures, information governance, administration and development of survey model

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[b] The National Care Experience Programme is in collaboration with the National University of Ireland, Galway (NUIG) for development of a validated, tested survey instrument for evaluation of women's experiences of their maternity care in Ireland. The instrument will be implemented by the National Care Experience Programme as the National Maternity Experience Survey.

- administrative requirements, that is communications and distribution
- outputs, that is what is reported, what happens with the results and how they are followed up bythe service provider, quality improvement agency and regulator.

The survey questions are not considered in the current document as these have been addressed in a separate development process.

2. Summary of Findings

A summary of the findings for National Maternity Experience Surveys is set out below. The main themes are:

2.1 Objective

The overall objective of conducting a maternity care experience survey within each of the countries reviewed was to listen to the voices of women as a recognised, essential tool to inform and improve the quality of maternity care provided.

2.2 Governance arrangements

Governance arrangements vary between countries, but the majority of the national surveys reviewed are governed within existing national engagement programmes. The national policy maker is involved in the governance arrangements of most programmes and some have adopted a partnership approach of governance, which includes the healthcare regulator, the healthcare delivery service and the policy maker. All surveys reviewed have a team in place to agree on the development and delivery of the survey.

2.3 Resources

Four of the five international surveys reviewed conducted maternity care surveys as a constituent part of a wider engagement programme. A team of two to four staff members is typically required to manage the maternity care survey; often these staff are part of the wider care experience programme and are assigned to the maternity survey as required. Much of the knowledge, systems and tools used in maternity care surveys have benefited from the expertise gained and the resources developed from previous surveys of other healthcare sectors.

Subcontractors are employed in four of the five surveys to administer the survey in terms of collating the contact list, posting the survey and co-ordinating responses and reminder letters.

2.4 Legislative requirements for data protection

The legislative requirements around data protection are a significant consideration for care experience surveys in light of the large amount of personal data required to conduct these surveys. All of the jurisdictions examined have a legal remit to collect personal data and share the data with a third party if the purpose is service evaluation and improvement. To maintain anonymity, survey participants are assigned a unique identification number.

2.5 Ethical approval requirements

Surveys either did not require ethical approval or were deemed low risk if they sought it. Maternity experience surveys are a tool used in service evaluation and are thus regarded as an essential exercise in healthcare delivery and service improvement.

2.6 Communication

The importance of promoting the survey to women in order to increase response rates was highlighted. Some of the jurisdictions reviewed expressed interest in augmenting their current promotional and communication campaigns.

2.7 The survey

- Eligibility criteria

The eligibility criteria vary across the reviewed maternity experience surveys, with some having less than two exclusion criteria and others having an extensive list. However, women who have been bereaved by stillbirth, neonatal death and infant death is a common exclusion criterion across all five surveys. This is largely based on two reasons; firstly, that general national maternity experience surveys are not designed to capture meaningful data on these experiences and secondly, that the surveys are a potential cause of distress to women who have been bereaved by the loss of their baby.

All the reviewed surveys employ stringent checks to ensure that questionnaires are not mistakenly sent to deceased women, women who have had a stillbirth or neonatal death in the index pregnancy, or women whose baby has died in the period between birth and receipt of the questionnaire. In some cases, these checks are undertaken right up until the day of contacting prospective participants.

Separate surveys or other types of care experience methodologies are employed to evaluate the care experiences of women who have been bereaved by stillbirth and neonatal death. These are not undertaken by any of the agencies responsible for the five reviewed surveys, but rather by other national organisations, charities or academic institutions.

- Sampling

Selection of the survey sample varies amongst the surveys reviewed, with most utilising the country’s available birth registers, either at national level or the level of the healthcare region.

- Question pool

An international library of validated questions is not available for maternity experience surveys as is the case for surveys of acute inpatient care. Most maternity surveys have developed, tested and piloted their own questions or adopted some of those used in other maternity surveys.

The inclusion of questions requiring written, free-text comments is regarded as highly beneficial as these provide a rich source of data for quality improvement and for research purposes.

- Translation

Surveys are generally not translated into languages other than the second language spoken in the jurisdiction (for example Spanish in the Californian survey, and English in the Norwegian survey). However, most surveys offer a telephone translational service in order to encourage participation by women who do not speak the main language. Utilisation of this service is generally not high.

2.8 Survey methodology

- Mode of contact

All of the reviewed surveys use the postal system to contact survey participants. Women are generally contacted between two and six months post-partum, most commonly between two-and-a-half and four months. This is based on capturing care experience in the post-natal period, facilitating checks for women and babies who have died, and obtaining the views of women following a period of time to allow for reflection on their experience.

- Mode of response

All but one of the reviewed surveys utilise an online mode of response, and the exception is currently exploring options for an online response facility.

Amongst care experience programmes, the maternity cohort is considered by survey providers to be the most amenable to an online response mode due to its demographic of young women who are technically savvy. Thus, a number of the surveys reviewed have tested or are currently testing a system whereby the survey can only be completed online. In these cases, the paper questionnaire is included in reminder posts so as not to exclude those who would prefer to complete the survey in hard copy.

The online mode of response has the advantage of being the most cost-efficient and time-efficient method. It also future proofs the survey.

Reminder letters and packs sent out to non-responders significantly increase the response rate. All jurisdictions use approved survey contractors to distribute the survey packs to participants.

- Response rate

The response rates of the most recent maternity surveys undertaken in the countries reviewed range from 35% to 55%. Four of the five surveys had a response rate within the range of 35% to 41%; the fifth, with a response rate of 55%, offered a financial incentive to participants to complete the survey.

Most of the maternity surveys reviewed have experienced some decline in response rate since their first maternity survey; this is largely attributed to survey fatigue due to the proliferation of requests to complete surveys.

- Frequency

In contrast to surveys of acute inpatient care, maternity care surveys are not generally conducted on an annual basis but rather every two-three years for most jurisdictions, or alternatively, when funding becomes available.

2.9 Outputs

The survey results are analysed and reported in each of the countries examined. The results are published in a national report and are distilled into more detail at a local level. Three of the five surveys reviewed publish hospital-level results and three of the five provide an interactive online portal to facilitate the public in viewing hospital-specific or region-specific results.

2.10 Impact

The requirement to act on specific findings of maternity experience surveys varies amongst countries, with some legally required to incorporate care experience feedback into local and national quality improvement plans and others not so. In general, the impact of international maternity care experience surveys is not readily reported.

Nevertheless, the benefits of maternity care surveys are regarded as significant for all those involved, that is women, service providers, the regulator and the policy developer.

Methodologies

for

National Maternity Experience Surveys

3. Australia (New South Wales)

The following is a review of the New South Wales (NSW) Maternity Care Survey.

The information below was obtained from a telephone conference and follow-up communication with the Bureau of Health Information (BHI), and from the NSW Maternity Care Survey technical reports.[14,15]

3.1 Background

In 2017, there were 96,591 births registered in NSW from a population of 7,861,674.[16]

The NSW Patient Survey Programme began surveying patients in NSW public hospitals in 2007. To date, the programme has conducted two state-wide maternity care surveys — in 2015 and 2017. It plans to conduct the maternity survey again in 2019 and include a census of Aboriginal mothers.

In addition to the maternity care survey, it conducts the following surveys:

- Adult Admitted Patient Survey
- Emergency Department Patient Survey
- Admitted Children and Young Patients Survey
- Outpatient Survey
- Outpatient Cancer Clinics Survey
- Small and Rural Hospitals Survey
- Maternity Care Survey
- Small Hospital Emergency Care Survey
- BreastScreen NSW Client Experience Survey

Recently, the NSW Patient Survey Programme has initiated an Integrated Care Survey which contains Patient Reported Experience Measures (PREMs), Patient Reported Outcome Measures (PROMs), the Patient Activation Measure (PAM), and demographic information.

3.2 Objective

The objective of the NSW Patient Survey Program is to measure and report on patients' experiences of care in public hospitals in NSW on behalf of the Ministry of Health and the local health districts (LHDs). The results are used as a source of performance measurement for individual hospitals, LHDs and the state.

The Programme provides independent reports to government, clinicians and the community on the performance of the NSW public sector health system. Performance measures include activity, access, effectiveness, efficiency, outcomes and safety and quality measures.

3.3 Governance Arrangements

The NSW Patient Survey Programme is managed by the NSW Bureau of Health Information (BHI). The BHI was established by the NSW Government to deliver timely, accurate and comparable information on the performance of the NSW public healthcare system. The BHI is a board-governed statutory health corporation that produces independent reports and information about the performance of the healthcare system in NSW. It works closely with the Ministry of Health and other pillar organisations including the NSW Agency for Clinical Innovation, NSW Clinical Excellence Commission, Health Education and Training Institute, and Cancer Institute of NSW to support the health system to deliver on NSW Government and NSW Health priorities.

3.4 Commitment

The NSW Patient Survey Programme is a collaboration between BHI; the survey contractor, Ipsos; and the NSW Ministry of Health's Systems Information and Analytics Division (SIA). Each organisation has specific organisational responsibilities in the operation of surveys. A team of two from BHI conducts the Maternity Care Survey, working with teams from Ipsos and SIA.

3.5 Data Protection

The NSW Patient Survey Programme gives significant consideration to protecting personal data used in the operation of its surveys.

The *Health Record and Information Privacy Act, 2002* and the *NSW Health Privacy Manual for Health Information* allow the NSW Ministry of Health to release limited information to BHI for the express purpose of conducting patient experience surveys. The privacy act allows use or disclosure of information without the consent of the person when there is a directly-related secondary purpose that is within the reasonable expectations of the person. The Secretary of NSW Health has authorised the Ministry of Health and local health districts to provide information to BHI to allow it to undertake the survey programme.

Using patient information supplied by the NSW Ministry of Health, Ipsos mails surveys to people who have recently received healthcare services in NSW. The Ministry of Health randomly selects the patients who are sent the survey questionnaire.

Upon completion of a survey questionnaire, the respondent either posts a paper-based questionnaire or submits an online response to Ipsos. When paper forms are returned, Ipsos scans in the answers electronically and manually enters free-text fields. Once all data are collated into a single dataset, names and addresses are removed. Also, all text-entry fields are checked for potential identifiers (for example, names of patients or of hospital staff, telephone numbers, and so on) and any that are found are replaced with 'XXX'.

Ipsos uses a secure NSW Ministry of Health system to transfer the data from its servers to BHI's secure servers, all of which are password protected with limited staff access. At no stage does BHI, which analyses the data, have access to the names and contact details of respondents. This ensures that respondent answers remain confidential and identifying data can never be publicly released.

3.6 Ethical Approval

As patient experience is a constituent part of surveillance and service evaluation, ethical approval is not required to undertake the NSW Maternity Care Survey.

3.7 The Survey

3.7.1 The Sample

Admitted patient data pass through two phases of screening to create a sampling frame of patient eligibility for participation in the NSW Maternity Care Survey. Phase one screening is conducted by BHI to create an interim sampling frame.

Women are eligible to be sampled if they are 18 years and older and if they give birth at a hospital where there were 100 or more births per month in the previous twelve months.

Exclusions include the following:

- hospitals where there were fewer than 100 births in the previous 12 months
- patients who died during their hospital admission
- patients receiving acute and post-acute care services
- patients who are not receiving either acute or rehabilitation care in hospital
- patients who were admitted to a psychiatric unit during the hospital stay
- patients with a personal history of self-harm or who have intentionally self-harmed
- patients with a family history of mental or behavioural disorders and patients who have expressed suicidal ideation

- patients with maltreatment syndromes in any diagnosis field, including neglect or abandonment, physical abuse, sexual abuse, psychological abuse and other maltreatment syndromes
- patients who experienced a stillbirth
- patients who experienced pregnancy with an abortive outcome
- patients admitted for a termination of pregnancy procedure
- patients admitted for same-day haemodialysis
- same-day patients who stayed for less than three hours
- same-day patients transferred to another hospital
- patients recorded as receiving contraceptive management in any diagnosis field, including general counselling and advice on contraception, surveillance of contraceptive drugs, surveillance of contraceptive device and other contraceptive management and contraceptive management.

BHI provides the interim sampling frame to SIA, who add patient name and address information. Data then undergo a second phase of screening. This review results in exclusions for administrative/logistical reasons, or where death has been recorded after discharge, but before the final sampling frame is prepared.

Patients meeting the following exclusion criteria are removed in this phase:

- invalid address (including those with addresses listed as hotels, motels, nursing homes, community services and jails)
- invalid name (including twin, baby of)
- invalid date of birth
- on the ‘do not contact’ list
- sampled in the previous six months for any BHI patient survey currently underway
- recorded as deceased according to the NSW Birth Deaths and Marriages Registry and or Agency Performance and Data Collection, prior to the sample being provided to Ipsos.

The data following these exclusions are defined by BHI as the final sampling frame. Thereafter, a stratified sample design is applied, with each hospital defined as a stratum. Simple random sampling without replacement is applied within each stratum to create a final sample of patients to be posted a survey.

The NSW maternity survey differs from the other surveys in this review by conducting a rolling monthly sampling strategy from January to December in the survey year, rather than employing discreet sampling months or periods.

3.7.2 Distribution and Collection

The survey is distributed via post as part of a survey pack. The pack contains a questionnaire, a Freepost envelope and a multilanguage interpreter service helpsheet.

In the case where there is no initial response, a reminder letter is sent two weeks later. A third and final mailing, consists of a full questionnaire pack, is sent five weeks after the initial mailing.

The survey is retrospective. Mothers are invited to participate 2.5 months from the end of the month of discharge from hospital. This time period facilitates collection of data on postnatal care, the removal of women meeting exclusion criteria and also collection of the 'settled views' of hospital users. With the increasing use of real-time data collection in NSW, the need for considered, post-discharge review has become important. The settled view of maternity users is regarded to be approximately three months post-birth. (BHI, pers comm)

Participants can participate in the survey online, via the paper questionnaire or by phone completion. This survey has the highest rates of online completion of all BHI surveys; in the 2017 maternity survey, approximately 52% of respondents completed their survey online, compared to 19% for the adult admitted patient survey and 30% for the emergency department survey. The costs of online submission are a small fraction of those involved in hard-copy submission as data (questions and freetext comments) are directly entered by the patient.

The approximate time period for receipt of returns is nine to ten weeks. Previous experience has demonstrated that if this period is reduced, a disproportionately high percentage of non-english speakers and minority ethnic groups do not respond.

Translated questionnaires are not provided, although a telephone translation service in more than 130 languages is provided.

3.7.3 Communication and Publicity

In terms of promotion of the survey, posters are displayed in public health areas. It is not known, however, if they reach the target audience of maternity service users. The NSW Patient Experience Program aims to augment its current public awareness campaigns.

Prospective participants are informed about the survey by means of the participant information leaflet, which is included in every survey pack.

3.7.4 Response Rate

The overall response rate was 35% for the 2017 survey and 36% for the 2015 survey.

3.7.5 Analytical Methodologies

Survey data are analysed per calendar year, that is January to December, using the statistical software package SAS. Responses are weighted to optimise the degree to which results from respondents are representative of the experiences and outcomes of the overall patient population. At the LHD and NSW level, sample weights also ensure that the different sampling proportions used at the hospital level are accounted for so that LHD and NSW-level results are not unduly influenced by small hospitals that have larger sampling proportions.

3.7.6 Outputs

A comprehensive results report, Patient Perspectives, is published online and in hard copy. Other output formats include a snapshot report, supplementary data tables, a summary tool in Tableau (an online software tool which facilitates visualization of data), hospital profiles, notification briefs and media briefs, all of which are published online. The BHI deploys Healthcare Observer, an online interactive data portal, to facilitate the public to explore and download information about the performance of the NSW healthcare system. Results can be displayed at the level of the state, hospital and LHD.

The BHI provides hospitals with access to their own specific data using Tableau.

3.7.7 Impact

There is no requirement for LHDs and hospitals to utilise patient feedback and act on the specific findings. The BHI meets with senior health policy makers for example the chief obstetrician, on foot of the Maternity Care Survey. The reports provide valuable insight into where there are opportunities to improve and help healthcare professionals and policy makers deliver quality care.

3.8 Key Recommendations and Lessons Learned from the Australian NSW survey

- The Australian NSW survey excludes participation by women who have been bereaved by stillbirth or neonatal death, firstly due to project risk as a result of the risk of distress and harm to participants and the requirement for resources to manage the risk, and secondly, due to questionnaire design, as inclusion of bereaved women will necessitate both extra response options and skips of whole sections.

- Cognitively test and pilot the questionnaire with women service users.
- Surveying of minority groups is essential to ensure representativeness of the care experience. In order to achieve responses from minority groups, it may be necessary to oversample this cohort or it may be necessary to undertake qualitative interviews and focus groups to capture their views. It is also necessary to promote the survey to these communities.
- Women wish to relay their maternity care experience. At 101 questions, the length of the questionnaire is not a significant deterrent (35% response rate). Whilst the questionnaire contains a large number of questions, the majority of women complete all of them.
- It is best not to state how long it may take to complete the questionnaire; the time varies greatly from one woman to the next and the distraction of newborn babies means that women may complete the questionnaire in more than one session.
- Free-text questions are useful for providing a rich source of data; women often relay much detail when responding to these.
- The response rate is an indication of bias and can be corrected by weighting the data.

4. England

The information below was obtained from a telephone conference and follow-up communication with the Care Quality Commission and from the 2017 and 2018 Maternity Survey Quality and Methodology reports.[17,18]

4.1 Background

There were 646,794 live births in England in 2017[19] from a population of 55,619,400.[20]

England's Maternity Survey is conducted as part of the National Health Service (NHS) National Patient Survey Programme (NPSP). The maternity survey is a long-running, nationwide survey assessing women's experiences of their maternity care within each NHS Trust. The survey has been undertaken in the years 2007, 2010, 2013, 2015, 2017 and 2018.

The NPSP undertakes the following other surveys:

- Children and Young People's Patient Experience Survey
- Adult Inpatient Survey
- Community Mental Health Survey
- Urgent and Emergency Care Survey.

4.2 Objective

The maternity survey provides NHS Trusts with information on patient experience during antenatal care, labour and birth, and postnatal care, to facilitate targeted quality improvement. The Care Quality Commission (CQC) uses the data in their regulation, monitoring and inspection of acute NHS trusts in England, while NHS England and the Department of Health use the results in measuring performance against a range of indicators and objectives.

4.3 Governance Arrangements

The NPSP is managed through a coordinated approach between:

- The Department of Health and Social Care
- The Care Quality Commission
- NHS England.

The Department of Health and Social Care established the survey programme and partially funds the CQC to coordinate the surveys. The partnership contracts the

Picker Institute Europe to develop the survey questionnaires, materials, and methodology for implementing the national surveys. The Picker Institute develops surveys and toolkits to assist organisations with quantitative research to understand the views and experiences of their patients, service users and staff in order to facilitate quality improvement.

The CQC meets the Insight Team of the Department of Health and Social Care, NHS England and Citizen Voice on a regular basis. The purpose of these meetings is to discuss the progress of each national survey and the strategic direction and delivery of the programme.

4.4 Commitment

A team of two to three CQC staff members work on the survey, whilst also being spread across other patient experience surveys in the programme. The Picker Institute usually requires three to four staff members per survey to develop guidelines, develop and manage the website, manage communication with service providers and subcontractors and analyse the results. Either the individual trust or an approved survey contractor is responsible for conducting the sampling for the surveys. The Picker Institute is also one of the approved mailing sub-contractors for some Trusts.

4.5 Data Protection

Under Section 251 of the National Health Services Act 2006, patient identifiable information is temporarily allowed to be transferred to a third party for the purpose of research if an application to do so is approved by the Health Research Authority Confidentiality Advisory Group. England has established thorough guidelines to ensure that personal data used in the surveys remains secure and confidential.

Trusts are required to comply with the following legislation:

- Data Protection Act 2018
- NHS Code of Practice on Confidentiality
- Caldicott principles
- The EU General Data Protection Regulation.

Trusts sign declarations of compliance to ensure that all precautions are taken to protect personal data. In order for sampling to be conducted by a trust, the designated person responsible for supervising access to personal information (Caldicott Guardian) must co-sign the trust's declaration of compliance. If any trust's Caldicott Guardian does not authorise the declaration of compliance, then sampling must be undertaken by an approved survey contractor.

Approved survey contractors also work with trusts to anonymise personal data before the information is sent to the CQC or third party contractor working with the CQC. To be approved to undertake a national survey on behalf of a trust, potential survey contractors must submit their procedures and policies to be reviewed by the Health Research Authority Confidentiality Advisory Group as part of the recommendation for support granted under Section 251 of the NHS Act 2006. This ensures that the survey contractor has measures in place to protect the security and confidentiality of data during all stages of the survey.

Accountability to the Health Research Authority Confidential Advisory Group ensures that personal data remains confidential for the entire survey process. Throughout the survey process, any breach of the Data Protection Act is elevated by the CQC and reported to the Health Research Authority Confidentiality Advisory Group.

Trusts are required under the Data Protection Act 2018 to inform patients about the use of their personal data. The CQC is legally required by the confidentiality rule to provide the public with the information necessary to make an informed decision to opt out of participating in the national survey. This is done through pre-survey publicity, including informational leaflets, brochures, and posters.

4.6 Ethical Approval

Ethical approval for the maternity survey is not required on the basis that the survey is a constituent part of service evaluation, which is a legal remit of NHS Trusts. Nevertheless, approval is sought from the Health Research Authority Research Ethics Committee for assurance of the survey methodology and consequent alleviation of any concerns of trusts.

4.7 The Survey

4.71. The Sample

England's maternity survey sample is selected by the trusts. All trusts that provide maternity services and have a sufficient number of births are eligible to take part in the maternity survey.

Women who give birth between 1 and 28 February (and the month of January if a trust does not have a minimum of 300 eligible births in February) are invited to take part in the survey, with the following exceptions:

- women aged under 16 on the date on which their baby was delivered
- women whose baby died during or since delivery

- any women who had a stillbirth, including if it occurred during a multiple delivery
- women who were in hospital, or whose baby was in hospital, at the time the sample was drawn from the trusts' records
- women who had a concealed pregnancy (where it was possible to identify from trust records)
- women whose baby was taken into care (foster care or adopted), where this was known by the rust
- women who gave birth in a maternity unit managed by another provider
- women who gave birth in a private maternity unit or wing
- women known to have requested that their details should not be used for any purpose other than their clinical care (those that have opted out solely through the national data opt-out service, however, are presently eligible)
- women without a UK postal address.

Trusts are required to compile their sample according to strict eligibility criteria, as set out in the CQC's Survey Co-ordination Centre's sampling instructions.[21]

4.7.2 Distribution and Collection

As with most surveys in the NHS Patient Survey Programme, the maternity survey uses a postal methodology. The sole option for completion of the survey by respondents is via paper and return by post.

Following sample selection, an approved survey contractor distributes the survey pack in the case of most trusts. A small number of trusts (four in the 2018 survey) post the packs themselves. Some approved contractors in turn employ sub-contractors to carry out the distribution of the survey packs. The packs consist of:

- a covering letter
- a questionnaire
- a multi-language sheet
- a Freepost return envelope.

A reminder letter is posted to survey participants two to three weeks after the initial survey pack. A second and final survey pack is posted to participants an additional two to three weeks after the first reminder letter in an attempt to further increase the response rate.

The survey pack is sent to participants two to six months after birth. This allows for the six-week postnatal period to have concluded, which is important as a number of questions in the questionnaire relate to postnatal care. Additionally, the checks undertaken to ensure that deceased mothers or mothers of deceased babies are not contacted take time to process in the interim period between birth and the posting of the pack.

A pilot study, in which respondents complete the maternity survey online, is being undertaken in 2019. On the basis that the maternity cohort is predominantly young, familiar with online tools, participants may find it more convenient to complete the survey online rather than by paper. Positive online response rates from another survey within the NPSP highlighted that the online response rate is bolstered by omitting the paper questionnaire from the initial survey pack and directing prospective participants to the link to the online survey. The paper questionnaire is subsequently included with the follow-up reminder letter in order to encourage those who have not completed it online.

Targeted sampling of minority groups is not undertaken. Generally, ethnic profiles across trusts are very diverse which facilitates sampling of minority groups. In order to ensure that members of ethnic minority groups respond to the survey, a multi-language document is included in the first and third mailings of the survey pack. The document contains instructions in the 20 most common non-English languages on how to complete the survey, that is by phoning a free helpline to speak with an interpreter. There is, however, low utilisation of this service.

Trusts are permitted an 18-week period from the time the survey is sent to collect responses. This is a programme-wide timeline and not specific to the maternity survey.

4.7.3 Communication and Publicity

Posters in hospitals, social media and local media are used to inform women of the survey.

A cover letter is included in the survey pack with information on why the survey is being conducted and the importance of patient feedback. A website is provided for survey guidance, timetables, forms and national tables.

4.7.4 Response Rate

Response rates for the 2017 and 2018 surveys were both 37%, constituting responses from 17,600 women from 129 different trusts in 2018 and 18,426 women from 130 Trusts in 2017. Response rates have dropped since the maternity survey was first launched; from 59% in 2007 to 37% in 2018. This is consistent with other surveys in the NPSP and with industry-wide trends in social and market research.

4.7.5 Analytical Methodologies

All survey responses are analysed by the Picker Institute Europe at both trust level and national level. Hospital-level analysis is not undertaken as sample numbers in some hospitals are not sufficient. Both the CQC and Picker Institute Europe use SPSS for analysis. Weights are applied to data to give trusts equal influence over England's national averages. This is done because some trusts have higher response rates than others. For the trust-level analysis, weights are applied to individual responses to counteract under- or over-representation of patient groups.

4.7.6 Outputs

The CQC generates a national report and local trust benchmark reports. Each participating trust (up to 130) receives a labour and birth benchmark report. Additionally, each trust that submits attribution data and has sufficient respondent numbers, receives an antenatal and postnatal benchmark report. The CQC also publishes an outliers report which identifies trusts where women's experiences are better, or worse, than expected, when compared with the results across trusts.

Additonally, the CQC publishes the survey data for each participating NHS trust on the Trust's profile page. The data is presented in an accessible format, alongside their inspection results, to enable the public to examine how services are performing. The search tool is available from the CQC website: http://www.cqc.org.uk/. All reports and supplementary data tables are also published on the CQC website.

4.7.7 Impact

The survey results are used to inform the work of the trusts, the CQC, NHS England, the Department of Health and patient groups and the general public.

- Trusts

The trusts use the results to identify and make necessary changes to improve the experiences of people who use their services.

- CQC

The CQC uses the results from the survey in the regulation, monitoring and inspection of acute trusts in England. Survey data is used in the CQC Insight system, which provides inspectors with an assessment of risk in areas of care within an NHS Trust that need to be followed up. The survey data is also included in the data packs produced for inspections. Results form a key source of evidence to support the judgements and ratings published for trusts.

- NHS England

NHS Improvement uses the results to inform quality and governance activities as part of its Oversight Model for NHS Trusts. The NHS Maternity Transformation Programme has recently developed a set of National Maternity Indicators, which will feature as part of an upcoming maternity data viewer to help maternity providers identify unwarranted variation. Results of select questions from the maternity survey are reported to the Maternity Transformation Programme Board.

- Department of Health and Social Care

The UK government's strategy sets out a commitment to measure progress on improving people's experiences through the NHS Outcomes Framework, which includes results from the maternity survey. The framework sets out the outcomes and corresponding indicators that the Department of Health uses to hold NHS England to account for improvements in health outcomes. National results for six survey questions contribute to framework indicator 4.5: 'women's experiences of maternity services'.

4.8 Key Recommendations and Lessons Learned from the English survey

- Trusts are legally obliged to evaluate their care experiences and thus to provide patient data to the CQC for evaluation of care.
- Rigorous data protection measures are in place to protect the personal data which is transferred from trusts for the operation of the survey.
- Stringent checks should be undertaken to ensure that mothers of babies who have died, including stillbirths, and mothers who have died, are not contacted to participate, even if these checks lead to a longer time interval between birth and the distribution of the survey.
- It is envisaged that the maternity survey is the survey most likely to generate a positive online response rate due to the nature of the cohort.
- The initial contact letter should direct prospective participants to the online link to the questionnaire and not include a paper version; this has been shown to successfully improve the online response rate as effectively a choice is not provided. One of the first or second reminders should contain the paper questionnaire as a way of ensuring a response from those who prefer to complete by paper.
- The questionnaire is focused on the standard model of birth. However, it is important to capture all models of birth as there are now a multitude of choices around where and with whom women give birth. Women may have different care experiences depending on their model of birth.

- The questionnaire is focused primarily on labour and delivery. The CQC wishes to capture the care experience along the full pathway of maternity care from antenatal to postnatal care. However, the maternity system is set up such that trusts do not generally provide antenatal and postnatal care; rather this care is provided by organisations external to the trusts. This presents operational challenges in the collection of data on antenatal and postnatal care.

5. Norway

The information below was obtained from a telephone conference and follow-up communication with the Norwegian Institute of Public Health and from Sjetne *et al.* (2015).[22]

5.1 Background

In 2018, there was a total of 55,120 births in Norway,[23] from a population of 5,328,212.[24]

In Norway, the responsibility to conduct surveys of people who use health services is assigned to the Norwegian Institute of Public Health (NIPH), a public organisation that operates under the Norwegian Ministry of Health. The NIPH supports decision-makers in health and welfare services by providing knowledge to help ensure high-quality and equitable services.

The NIPH has developed a variety of data-collection tools and surveys for a range of target groups. Data are collected through centralised and standardised routines, and can be aggregated on different organisational levels for comparisons and benchmarking. To date, the NIPH has conducted three maternity care surveys - in 2012, 2017 and 2018.

5.2 Objective

The explicit purpose of Norwegian care experience surveys in general is fourfold: social legitimacy and control, business control, professional quality improvement, and to inform choices made by patients.

Strengthening the role of patients has been a policy priority since the turn of the millennium, manifested in a comprehensive Patients' Rights Act. The objective of this Act is 'to help ensure that all citizens have equal access to good quality health care by granting patients' rights in their relations with the health service'.

In 2009, the Ministry of Health and Care Services issued a white paper entitled '*A happy event. About a comprehensive pregnancy, birth and postnatal care*', in which the Ministry commissioned a national user survey of women who had recently given birth, and their partners. On foot of same, the first national maternity survey was conducted in 2012.

5.3 Governance Arrangements

The maternity care survey is organised and financed as a constituent part of the national patient experience programme at the NIPH.

5.4 Commitment

As maternity care surveys are part of the national programme for patient experience surveys, they have availed of the same infrastructure and resources (administrative, research) as other national surveys. However, the maternity survey was the first survey conducted with an online mode of response only.

Technological innovations and solutions have evolved considerably since the first NIPH patient experience survey. The maternity survey avails of in-house software first developed for these surveys. The University of Oslo provides data storage solutions to the NIPH.

5.5 Data Protection

Hospitals in Norway are obliged by law to have systems in place for the collection of user experiences as a means to achieve user involvement for quality improvement in healthcare. Therefore, there is dispensation from data protection for patient feedback and experience programmes. To date, there have not been any data protection issues with any of the Norwegian care surveys, including the maternity survey.

5.6 Ethical Approval

Ethical approval for the development of the questionnaire and data collection methods was originally obtained from the Regional Committee for Medical and Health Research Ethics for the first survey. In subsequent surveys, the NIPH has operated under a data sharing agreement with each hospital trust. As hospitals are legally required to incorporate patient feedback as a measure of quality, there have not been any ethical issues in conducting maternity experience surveys.

5.7 The Survey

5.7.1 The Sample

Women who give birth during the survey period in a Norwegian hospital and who are 18 years old (16 years old in the 2012 survey) or older are included in the sample. Any birth in which either the woman or child has died is excluded.

The sampling frame is compiled from the Norwegian Medical Birth Registry. Women are sampled randomly from hospitals with more than 400 births and sampled consecutively from hospitals with fewer than 400 births. Information on deaths from the National Registry (the national population register) is used in order to remove deceased women and babies from the sampling frame.

Targeted sampling of minority groups is not undertaken.

5.7.2 Distribution and Collection

Potential respondents are first contacted by post about 17 weeks after birth. They are sent a letter with information on the survey and an invitation to participate online, including a specific username and password. Two reminders are subsequently sent to non-respondents. In the 2012 survey, both reminders included a printed version of the questionnaire whilst in the 2017 and 2018 surveys, paper questionnaires were not provided during any part of the distribution process.

Informed consent is considered expressed when the participants have received the posted information and submitted their responses. Participants have a period of three to four months in which they could respond to the survey. Names and addresses are subsequently deleted when all of the mailings are completed.

5.7.3 Communication and Publicity

The invitation to participate in the survey is supplemented by an information leaflet. The leaflet provides general information on the survey, such as why women have been asked to participate and the importance of their feedback for quality improvement in maternity services. Instructions on how to respond to the survey are also included. The survey is publicised by poster displays in hospitals.

5.7.4 Response Rate

In 2012, among 8,760 eligible women in the sample, 4,904 returned completed questionnaires, yielding a response rate of 57%. The response rates in 2017 and 2018 were 45% and 41% respectively. In 2017, a simple log-in code was provided to access the online survey, whilst in 2018, women were required to use their public service access code in order to respond. The latter proved to be a more complicated process for women and may have negatively impacted the response rate. Furthermore, the complete omission of the paper questionnaire in the 2017 and 2018 surveys also impacted the response rates, with evidence that the loss of response was attributable to women of lower education levels in particular.[25]

5.7.5 Analytical Methodologies

The data are analysed using the SPSS and R statistical packages. Responses are weighted to adjust for non-response bias and are additionally adjusted for case-mix differences amongst hospital maternity populations.

5.7.6 Outputs

Hospital-level data is provided in PDF format. Patient Reported Experience Measures (PREM) scores based on survey data are published as a quality indicator of hospital performance by the Norwegian Directorate for e-health (under the Ministry of Health). Data is also made available for research studies.

5.7.7 Impact

Hospitals are not required to implement specific quality improvements initiatives; however, the funding model in Norway is such that hospital funding is allocated based on hospital performances in a number of domains, one of which is patient experience. Actions from patient experience are incorporated into strategic plans with other key performance indicators.

5.8 Key Recommendations and Lessons Learned from Norway

- Women are invited to participate at 17 weeks after birth. Concerns about recall bias are assuaged by studies which have indicated that information about major life events, such as pregnancy and childbirth, are more easily retrieved compared to information about fluctuating phenomena [c] and that maternal recall at four months post-partum of important events that occurred during labour and delivery is excellent.[d]
- There were 145 questions in the 2012 survey, and fewer in subsequent surveys. This was largely to do with the requirement in 2017 and 2018 to focus on care in the hospital around labour and delivery rather than on antenatal and postnatal care covered by public health clinics.
- Translation of questionnaires in order to reach minority groups and to achieve representativeness is complicated and offers a number of challenges. It may be problematic, for example, to choose which languages the survey should be translated into and it is difficult to find perfect translation techniques. Generally, response rates are low from translated questionnaires. For example, in one Norwegian survey, a patient experience questionnaire in one hospital was translated into Albanian, Arabic, Bosnian, English, French, Kurdish-Badini, Kurdish-sorani, Polish, Russian, Somali, Spanish, German and Vietnamese: less than one per cent of the subsequent survey returns was in a language other than Norwegian.
- The benefits of conducting a national maternity experience survey online include reduced cost, a streamlined and automated process, as well as less staff and administration resources than are required for paper-based surveys. However, loss of representativeness is a possible consequence.

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[c] Stull DE, Leidy NK, Parasuraman B, Chassany O. Optimal recall periods for patient-reported outcomes: challenges and potential solutions. Curr Med Res Opin. 2009;25(4):929–42.

[d] Bat-Erdene U, Metcalfe A, McDonald SW, Tough SC. Validation of Canadian mothers' recall of events in labour and delivery with electronic health records. BMC Pregnancy Childbirth. 2013;13 Suppl 1:S3.

- Survey fatique is a general trend observed in Norway.

6. Scotland

The information below was obtained from personal communication with the Scottish Care Experience Survey Programme and from Maternity Care Survey Technical Reports.[26,27]

6.1 Background

In 2017, there were 52,861 births registered in Scotland[28], from a population of 5,424,800.[29]

The Scottish Care Experience Survey Programme has conducted three national Maternity Care Surveys — in 2013, 2015 and 2018. In addition to the Maternity Care Survey, the Programme conducts the following national care experience surveys:

- Inpatient Experience Survey
- Health and Care Experience Survey
- Scottish Cancer Patient Experience Survey.

6.2 Objective

The Scottish Maternity Care Survey provides comprehensive information on women's experiences of maternity care in Scotland. The survey programme as a whole is conducted to provide a basis for measuring the quality of healthcare as experienced by patients. The programme supports the three quality ambitions of the Healthcare Quality Strategy for NHS Scotland, namely safe, effective, and person-centred care.

The surveys aim to provide National Health Service (NHS) hospitals and Boards with feedback on their patients' experiences where possible. This data is used for local improvement, providing feedback on the experiences of patients relative to previous surveys. Nationally, the results are used to identify variations between NHS Boards, highlight areas of best practice as well as areas for improvement, explore the variations in the experiences of different groups of patients and inform a range of national policies.

6.3. Governance Arrangements

The Scottish Care Experience Survey Programme is managed and conducted by the Scottish Government. The Maternity Care Survey does not have a dedicated steering group; however, key stakeholders are regularly updated on the survey's progress and feedback is sought where appropriate (for example, when reviewing the questionnaire content, et cetera.)

6.4 Commitment

The Scottish Care Experience Survey Programme is managed by a team of three analysts within the Scottish Government. The Scottish Government work in partnership with Information Services Division, part of NHS Scotland, who complete the sampling and analysis for three of the four surveys in the programme (all excluding the Maternity Care Survey). An approved survey contractor is appointed to manage the administration of each survey.

6.5 Data Protection

Personal data is required in order to conduct a national maternity care survey. Approval has been provided by the Public Benefit and Privacy Panel (PBPP) for Health[30] to use Birth Registration Records to identify a survey sample and approach individuals via an approved survey contractor. The PBPP monitors information governance and data protection and ensures that the data is being used appropriately in the survey.

A privacy impact assessment of the survey was undertaken as part of the survey preparation and was included in the application to the PBPP.

Scotland is also required to uphold the principles outlined within the General Data Protection Regulation (GDPR) and the Data Protection Act 2018. All staff working on the survey must adhere to the Information Sharing Toolkit Scotland[31] and all data must be transferred between organisations securely. For the 2018 survey, a privacy notice was published, which describes how the personal data collected through the survey is used.[32]

6.6 Ethical Approval

As patient experience surveys are a constituent part of service evaluation, the South East Scotland Research and Ethics Centre advised that the Scottish Care Experience Survey Programme does not require NHS ethical review. However, an internal Scottish Government Ethical Assessment was completed ahead of the survey and a copy of this assessment was included as part of the PBPP application for the survey.

6.7 The Survey

6.7.1 The Sample

The women who are eligible to participate in the surveys are those who have given birth between 1 February and 31 March of the survey year, aged 16 or over (17 or over for the 2018 survey), and who are normally resident in Scotland. Women were excluded from the surveys if either the mother or baby had died. Eligible women are identified using birth records from the National Records of Scotland (NRS) Birth Registrations. All births in Scotland must be registered within 21 days of the birth.

The NRS generates the sampling frame. The sample is stratified by the hospital where women gave birth, with a separate stratum for non-hospital births. The survey is based on a disproportionate stratified sample design with random sampling within strata.

NRS subsequently securely provides the survey contractors with the names and addresses of the sampled mothers to enable them to post the survey packs. To minimise the risk of questionnaires being sent to deceased women, or women whose baby has died, both women and babies details are linked to NRS's database of registered deaths and the survey contractor is notified of any individuals who should be removed from the sample. This check is undertaken on the morning of each mail-out to ensure that the most up-to-date information is used. Having access to daily death information greatly reduces the possibility of questionnaires being sent to the addresses of deceased women or babies, thus reducing potential distress.

Targeted sampling of minority groups is not undertaken as the samples by hospital are considered to be representative of the Scottish population.

6.7.2 Distribution and Collection

The survey is distributed to women approximately three months post birth. It is distributed via post as part of a survey pack and individuals may respond by post, online or by telephone. A language line is also available in a wide range of languages.

Scotland uses an approved survey contractor to distribute survey packs. Table 1 outlines the contents of the initial survey pack by year. In the 2018 survey, of 2,049 respondents, just over half responded by post and just under half completed the survey online. There was only one telephone completion. In previous surveys, over 90 per cent of responses were by post. This change in response mode is due to a change in the postal methodology in the 2018 survey — the initial survey pack only provided details on how to complete the survey online or via the helpline, and no longer included a paper questionnaire. This resulted in a notable increase in the number of online responses, to almost equal postal completions.

Table 1: Documents included in initial maternity survey pack by year

2013 and 2015 Surveys	**2018 Survey**
Introductory cover letter, including details of online and phone completion options	Introductory cover letter, providing details of online and phone completion options. Participants were advised that a paper questionnaire would be provided in a few weeks if no response was received.
Paper questionnaire	X
Language sheet	X
Information leaflet	Information leaflet, including details of language line
Freepost envelope to return survey	X

A reminder letter is posted around three weeks after the initial pack is sent. After an additional three weeks, a second and final reminder letter is sent along with an additional survey pack.

Completed surveys are returned to the approved survey contractor to be anonymised and subsequently transferred to Scottish government analysts for data analysis. Each completed questionnaire is linked to a unique ID number to maintain anonymity. The survey contractor is required to ensure survey responses are always held separately from individuals' personally identifiable information, such as name and address.

The approximate time period for receipt of returns is around three months. The response rate is monitored throughout to ensure reminder letters are sent at the best time to maximize responses where possible.

6.7.3 Communication and Publicity

An information leaflet is provided to women in the survey pack along with a cover letter. The cover letter provides instructions on how to complete the survey and answers some FAQs, particularly around why the participants were selected to complete the survey and information regarding data protection. The information leaflet explains the arrangements for reporting the survey results and includes directions for accessing the survey in other formats, such as the language line. Participants are advised that the survey is voluntary and to call the survey helpline if they do not wish to be contacted again.

The Scottish Government have also tried to raise awareness of the survey by asking GP practices, pharmacies and hospitals to display promotional posters for the survey. However, the Government wishes to further increase the publicity around the surveys in an effort to increase the response rate and intend to undertake a more comprehensive promotional campaign for future surveys.

6.7.4 Response Rate

In 2018, a total of 5,064 surveys were sent out and 2,049 were returned completed, giving an overall response rate of 40%. In 2015, the response rate was 41% and in 2013 it was 48%.

6.7.5 Analytical Methodologies

The data analysis and reporting is conducted by Scottish Government. The survey data collected by the approved survey contractor are securely transferred to Scottish Government via secure File Transfer Protocol. Data are analysed using the statistical software package SAS.

Survey results are weighted in order to increase the representativeness of the Scottish population. Weights are applied to all survey responses (excluding demographic questions) based on the number of eligible mothers who gave birth in each hospital. This means that the per cent contribution of each hospital to the NHS Board and Scotland results is proportional to the number of eligible mothers that gave birth there. Weighting the results in this way provides results that are more representative of the population (at Scotland, NHS Board or hospital level) than would be the case if all hospitals (large and small) are given equal weighting in the calculation of aggregate results.

6.7.6 Outputs

The Scottish Government publishes a national report on the survey results, as well as more detailed, local-level results at NHS Board and Hospital level. The local level results are available via an interactive dashboard, using Tableau, which can be accessed by the public. Infographics and supplementary tables are also made available. All outputs can be accessed via the website.

Respondents’ free-text comments are reviewed and any personal information suppressed by the approved survey contractor. The comments are then shared with the relevant NHS Board for quality-improvement purposes.

6.7.7 Impact

The maternity survey is designed to support improvement activities, both at local level and national level. The results provide a benchmark for improvement in maternity services and are used to support and monitor a review of maternity services in Scotland.

6.8 Key Recommendations and Lessons Learned from Scotland

- Resources are saved as a result of adopting a centralised approach, operating in conjunction with other patient experience surveys.
- Install contingency time into the survey process, especially the pilot survey.
- Future-proof the survey as much as possible by encouraging online responses.
- Omitting a paper version of the survey from the initial survey pack did not make a sizeable difference to the response rate, that is, 41% for the 2015 survey when a paper survey was included and 40% for the 2018 survey when a paper survey was excluded. The omission of the paper survey lead to an increase in online responses from 8% in the 2015 survey to 49% in the 2018 survey.
- Having checks in place to ensure that questionnaires are not sent to deceased mothers or mothers of deceased babies is extremely important and must be done right up to the day that the questionnaire is sent out.
- Consider analysis which examines differences in care experience between different socio-economic groups, for example by age or by deprivation group.

7. USA (California)

The information below was obtained from personal communication with the National Partnership for Women and Families and from the Listening to Mothers in California Survey Methodology document.[33] This section describes the process for the most recent state-level survey. The prior national surveys had somewhat different methodologies, which are described in their respective full survey reports, available at www.nationalpartnership.org/listeningtomothers.

7.1 Background

In 2017, there were 471,658[34] births registered in California from a population of 39,557, 045.[35]

In the USA, the National Partnership for Women and Families operates the maternity care surveys. National Listening to Mothers surveys have been carried out since 2002 to better understand experiences and perspectives of childbearing women. Listening to Mothers in California is the sixth and first state-level Listening to Mothers survey.

7.2 Objective

The objective of the Listening to Mothers surveys is to better understand experiences and perspectives of childbearing women. The surveys cover the time from before pregnancy through the postpartum and infant periods, and shed light on women's attitudes, beliefs, preferences and knowledge on a broad range of topics, as well as on their maternity care experiences and family and employment life. Survey results also reveal gaps between women's actual experiences and experiences they should have in light of their preferences, and highlight best maternity care practice and women’s legal rights. Survey results thus point to opportunities for improvement and inform policy, practice, education and research.

7.3. Governance Arrangements

The National Partnership for Women and Families governs and operates the Listening to Mothers surveys. The National Partnership is a nonprofit, nonpartisan advocacy group dedicated to promoting access to quality healthcare, reproductive health and rights, fairness in the workplace and policies that help women and men meet the dual demands of work and family. The Listening to Mothers in California survey is funded by the California Health Care Foundation and the Yellow Chair Foundation.

7.4 Commitment

For the Listening to Mothers in California survey, investigators at the National

Partnership for Women and Families and the Boston University School of Public Health collaborated with investigators at the University of California San Francisco (UCSF) Center on Social Disparities in Health as well as Quantum Market Research Inc., a survey research firm.

7.5 Data Protection

Personal data is required in order to conduct the maternity care survey. For the Listening to Mothers in California survey, the California Department of Public Health (CDPH) Vital Statistics Advisory Committee approved access to birth certificate data for sampling, for contacting sampled women, for weighting the data, and for conducting analyses. The CDPH Health Information and Research Section provided the requested items.

In operation of the survey, Quantum Market Research Inc. provided survey data without respondents' personal information to investigators at UCSF for processing. Data were cleaned, formatted and merged with birth certificate data for the sampled women using a unique ID. The National Partnership for Women and Families only received de-identified data.

7.6 Ethical Approval

The Committee for the Projection of Human Subjects of California's Office of Statewide Health Planning and Development was the Institutional Review Board for Listening to Mothers in California. The committee designated the project as low risk to human subjects, and approved it and subsequent protocol amendments. The UCSF Institutional Review Board also approved the project.

7.7 The Survey

7.7.1 The Sample

For Listening to Mothers in California, women were sampled based on their birth certificate data. Women were eligible for sampling if they were 18 years or older; with a residential address in California; who gave birth in a California hospital to a singleton baby between 1 September 2016 and 15 December 2016; whose babies were living with them at the time of the first survey contact; who were not incarcerated, mentally incapable of taking the survey, or in a rehabilitation facility; who were living in the United States at the time of the first survey mailing; and who could complete the survey in English or Spanish.

The following situations indicating ineligibility for the survey were detectible from the birth certificates, and these birth certificates were removed prior to sampling:

- mothers younger than 18 years old

- women with birth certificates indicating that the infant had died
- women who were not residents of California at the time of birth, according to residential address on birth certificate
- women whose births occurred out of hospital (primarily home births or births in freestanding birth centers)
- women who had a twin, triplet, or higher-order birth.

The rationale for these exclusions was based on ethical concerns around surveying minors or women whose babies were deceased or in foster care, the ability to reach and survey sampled women, the exclusion of distinctive populations with too few survey participants to produce meaningful results (multiples, out-of-hospital births), the logistical challenges of questionnaire development and programming for these special cases, and a lack of resources for extending to other languages.

Determination of eligibility occurred at two separate points — prior to sampling (eliminating birth certificates of known ineligible participants) and at the beginning of the questionnaire during a brief eligibility screen. A random sample was drawn from the pool of eligible births to women defined by the following groups: black women with vaginal births after previous cesarean (VBACs), all other women with VBACs, women in Northern California who had a midwife as a birth attendant, women in Northern California who did not have a midwife, women in Southern California who had a midwife, and women in Southern California who did not have a midwife. Black women, women who had a midwife as their birth attendant, and women who had a VBAC were oversampled to increase the confidence in any conclusions about these relatively small groups in data analysis and reporting.

In order to ensure the sample was representative of the Spanish-speaking community of the Californian population, estimated to be 29% of the population aged 5 years and older in 2009–2013[36], the outreach materials and survey questionnaire were available in Spanish and English.

7.7.2 Distribution and Collection

Participants were recruited using up to four online invitation and reminder mailings. Paper surveys were not distributed. Invitational mailings were sent during the initial field weeks to email addresses obtained from birth certificates, with two follow-up reminder mailings to non-respondents. The mailings included an invitational letter with the required elements of informed consent and information about how to access the survey, including a unique access code.

Respondents could complete the questionnaire in English or Spanish, either online using any device, or on the phone with an interviewer. They could work through the questionnaire in one or more sessions and switch between modes and devices. Most women who responded to the mailings chose to participate online, rather than with an interviewer. As online responses to mailings tapered off, interviewers attempted to contact both non-respondents and those who had partially completed the survey online using information from birth certificates and other supplementary sources, such as the Genetic Disease Screening Program, the MIS/DSS Warehouse (the state medical assistance database) and various online search engines.

The process of contacting sampled women may also have included many phone calls, emails and text messages to the extent that these methods of contact were available. To encourage non-respondents to participate over time and in recognition of the scarcity of women's discretionary time as a result of caring for their baby and any other children, returning to paid work, and other responsibilities, the value of thank-you gift cards offered over the course of the field period increased from $15 to $30 to $50 to –(via a fourth and final mailing)– $75.

The field period ranged from 22 February 2017 to 15 August 2017. Women participated from two to 11 months after giving birth.

A total of 2,539 women completed the survey — 34% on their own with a device, 28% by phone with an interviewer and 39% using a variety of methods, generally by starting on a device and finishing with an interviewer. About 4 in 5 (81%) elected to use the English version and 1 in 5 (19%) chose the Spanish version.

7.7.3 Communication and Publicity

Prospective participants received comprehensive information on the survey. The initial invitation pack included a cover letter detailing general information and elements of informed consent. It also included cards providing information on how to access the survey online on any device using the unique code provided. The card also indicated how to reach a telephone interviewer and learn more about the project.

7.7.4 Response Rate

The survey response rate was 55%, calculated using the response rate calculation of the American Association of Public Opinion Research.[37]

7.7.5 Analytical Methodologies

Survey results were weighted using the final 2016 California birth certificate file (Birth Statistical Master File) in order to increase their representativeness of the California population. Sampling weights were created to account for the stratified sample design, oversampling of specific groups, non-response among the women who were sampled, and non-coverage of women who could not be sampled because their births were not in the sampling frame (births from September 2016 to 15 December 2016). Although the survey data were weighted to the entire birthing population, minus these few exclusions, the survey was only administered in English and Spanish and results may not be applicable to women who speak other languages.

7.7.6 Outputs

Findings from Listening to Mothers in California are published in a variety of formats, including a snapshot of data highlights, a full survey report and interactive digital version of the full survey report. The following topic-specific outputs have also been made available:

- an infographic on the over-medicalisation of childbirth
- fact sheets on care team and place of birth; caesarean births; and maternal mental health
- issue briefs on the experiences of Asian and Pacific Islander, Black and Latina mothers
- videos featuring stories from childbearing women and providers
- webinar materials.

Survey reporting products are available at both www.nationalpartnership.org/LTMCA and www.chcf.org/listening-to-mothers-CA. Several journal manuscripts of secondary analyses on focused topics, as well as a qualitative analysis of open-ended responses, are in process.

Hospital-level responses are not reported: women answered the questionnaire on the condition that their data would not be fed back to their hospital. National/State-level responses are reported and are available from an online public repository.

7.7.7 Impact

In terms of impact, there is no requirement for the State of California nor individual hospitals to utilise feedback and act on the specific findings from Listening to Mothers in California*.* The findings provide valuable insight into opportunities for improvement and can help healthcare professionals and policy makers deliver safe, quality care. They are also used by researchers, media outlets and lawyers (for class action suits) and specific groups use the data for advocacy purposes.

7.8 Key Recommendations and Lessons Learned from the USA *Listening to Mothers in California* survey

- Ensure that the governance of the survey is in order.

- Undertake oversampling if there are specific areas of interest, for example Vaginal Birth after Caesarean Section (VBAC) and midwifery-led birth.
- Operate a data holdback policy to facilitate deeper dives of the data before it is made available in data repositories.
- Repeat the survey to assess trends.
- Evaluate and revise questions over time.
- Encourage follow-up surveys.

8. Conclusion

8.1 Findings

The findings of this review are set out in Section 2, Summary of Findings.

8.2 Next Steps

The National Care Experience Programme will roll out Ireland's first national care experience survey of maternity care, the National Maternity Experience Survey, in October 2019. The methodology outlined in this paper will be adapted for Ireland's purposes.

9. Appendix 1: Organisations and participants that contributed to this review

The National Care Experience Programme would like to thank the below organisations and participants for providing their time and knowledge to inform this international review.

Table 1: Conference call organisations and participants

Date of Conference Call	Organisation	Type of Organisation	Title
4 December 2018	Bureau of Health Information, New South Wales, Australia	Board-governed, statutory health organisation	Director, Patient Surveys
10 December 2018	Care Quality Commission, UK	Regulator of health and social care services	Survey Manager
4 December 2018	Scottish Government, UK	Government	Survey Manager
28 November 2018	Institute of Public Health, Norway	Government agency	Senior Researcher
7 December 2018	National Partnership for Women and Families, USA	Nonprofit advocacy group	Director, Childbirth Connection Programmes

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