The development of a survey instrument to evaluate women's experiences of their maternity care in Ireland

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PhD by publication

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Table of Contents

Declaration

I, Claire Beecher, certify that this work is submitted to fulfil the requirement of the degree of Doctor of Philosophy, at the National University of Ireland Galway. I have not obtained a degree in the National University of Ireland Galway, or elsewhere, on the basis of the work detailed in this thesis. I am the author of this thesis and the principal author of the five included papers. Contributions by others are included under 'Contributions to research'.

Signature:  Date: 05 June 2020

Abstract

Introduction

The value of survey instruments in measuring the quality of maternity care from the perspective of service users is well recognised. Many countries, including, for example, the UK, USA and Australia use large scale national and regional surveys to explore women's experiences of their maternity care with the results informing national maternity policy and practice. Prior to the commencement of this project, there was no such survey used within the Irish maternity services.

The aim of the work presented in this thesis is to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. In line with the recommendations of the Irish National Maternity Strategy, the purpose of this instrument is to identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high-quality care.

Methods

This thesis includes five papers. The first paper (Chapter 2), a discussion paper on concept development methodology, was developed in response to the challenges faced in attempting to develop the concept of 'women's experiences of their maternity care'. This paper presents a review of concept development in nursing and midwifery and explores methodological considerations in concept development specific to nursing and midwifery. Paper one informed the concept development strategy and method used in paper two. Paper two (Chapter 3) presents an analysis of 'women's experiences of their maternity care' using the principle-based concept analysis method by Penrod and Hupcey (2005). Following the development of the concept, the remainder of the study was completed using an adapted two-phase exploratory sequential mixed methods design as reported in papers three, four and five. A protocol for a systematic review of self-report instruments used internationally to measure women's experiences of their maternity care was developed and has been presented as paper three (Chapter 4). A systematic review was then completed in line with the protocol, the findings of which are presented in paper four (Chapter 5). The purpose of the review was to identify self-report survey instruments available internationally to measure women's experiences of their maternity care, evaluate the methodological quality of each survey instrument and evaluate the criteria for good measurement properties using quality criteria and to categorise items included within each identified instrument.

Paper five (Chapter 6) reports the identification and prioritisation of items for inclusion in the survey instrument. This consisted of the systematic review (Chapters 4 & 5), focus groups and one to one interviews, and a gap analysis. An exhaustive item pool was then developed based on items identified. Items were prioritised for inclusion in the final item bank through a Delphi study and consensus review.

Results

Paper one presents an overview of the methodological considerations of commonly used concept development strategies and methods within nursing and midwifery. The methodological considerations discussed provides guidance in determining the most appropriate strategy and method of concept development. Paper one informed the choice of the principle-based concept analysis method by Penrod & Hupcey as being the most suitable conceptual development framework for the analysis of women's experiences of their maternity care. Using the principle-based method of concept analysis, the concept was analysed under the epistemological, pragmatic, linguistic and logical principles. The outcome of the concept analysis is a theoretical definition that highlights the subjective nature of the concept, its dependency upon a woman's individual needs, expectations and circumstances and the influence of the organisation and delivery of maternity care.

Citations were identified (n=4,905) from database searches as part of the systematic review. Additional records were obtained via reference checking and by expert suggestion. Following stepped screening, 40 papers related to 20 instruments are included in the review. Findings indicate that published evidence of the methodological and psychometric quality of self-report survey instruments to measure women's experiences of their maternity care is lacking.

Focus group and one to one interviews were completed with 82 participants from key stakeholder groups, i.e., women as service users as the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, General Practitioners, policymakers and funders. These interviews enabled exploring aspects of care that stakeholders consider to be of most importance for inclusion within this survey instrument and identify any further potential outcomes of importance to each stakeholder group not identified in the concept analysis & systematic review. A hybrid approach to the analysis of the data arising from the interviews was adopted. The analysis was guided first by an inductive approach (Braun and Clarke's recursive thematic analysis approach) and

subsequently influenced by a deductive approach (framework approach) (see Chapter 6).

The gap analysis mapped the suite of international items against the findings of the focus group and one to one interviews in addition to Irish policy documents, i.e., (i) National Maternity Strategy (Creating a Better Future Together) (ii) HIQA National Standards for Safer Better Maternity Services and (iii) the background document supporting the development of National Standards for Safer Better Maternity Services. The purpose of the gap analysis was to identify items for inclusion within the survey instrument that had not been identified within the suite of items arising from the systematic review.

An item pool for inclusion in the pilot survey was drawn up. It included items identified in the international analysis, as per the results of the focus group and one to one interviews and gap analysis. Various formats were also determined at this stage; for example, the selection of the number of scale points to be used.

Refinement of the item pool was completed via an online two-round Delphi study with key stakeholder groups, i.e., women as service users as the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, General Practitioners, policymakers and funders. Twenty-two participants completed round one of the Delphi study and 127 participants completed round two of the Delphi study.

Following the Delphi study, all items judged suitable for inclusion in the survey instrument were reviewed by experts in the areas of survey development and maternity care in Ireland. The purpose of additional reviews was to assess for areas not included, inclusion of irrelevant areas and to identify if a relevant part of the construct may have been missed.

Integration of the use of the survey instrument within the Irish maternity services;

The National Care Experience Programme (NCEP) is a partnership between the health service regulator (Health Information and Quality Authority (HIQA)), the national healthcare provider (Health Service Executive (HSE)) and the national policymaker (Department of Health). It was launched in Ireland in 2019 to evaluate service users' experiences across the public acute healthcare services with the results informing care improvement actions nationally. A formal agreement was reached in 2018 with HIQA, who oversees the programme, that the bank of items developed within the project reported here will be the basis for the National Maternity Experience Survey (NMES). The NMES was launched nationally on February 4th 2020.

Conclusion

A bank of 95 items have been prioritised and grouped within eight sections; care during your pregnancy, care during your labour and birth, care in hospital after the birth of your baby, specialised care for your baby, feeding your baby, care at home after the birth of your baby, overall care and you and your household. As per the National Inpatient Experience Survey development process, HIQA will now use this bank as the basis for the survey with the remainder of the questions acting as a reserve list for possible inclusion in future iterations of the survey.

Contributions to research

This thesis consists of five paper, four of which have been accepted for publication by peer reviewed journals and one paper that has been submitted for review.

The first paper published is presented in Chapter 2. This is a concept development methodology paper. I led on this discussion paper. All relevant literature was searched and interpreted by me. The content and synopsis of concept development literature was reviewed for accuracy by Maura Dowling (MD) and Declan Devane (DD). I drafted the manuscript and it was approved by the authors MD, DD, Mark White (MW) and Richard Greene (RG). I led on the reviewer's feedback and it was approved by MD and DD.

The second paper published is presented in Chapter 3. This paper presents the analysis of the concept of 'women's experiences of their maternity care' using the principle-based method of concept analysis by Penrod and Hupcey (2005). I led on this concept development. The concept development strategy for use was chosen by me and approved by MD. Literature searching was completed by me following consultation with DD and a National University of Ireland, Galway (NUI Galway) research librarian in relation to the search strategy. Results of the data searches were managed in Endnote X7 by me. Title and abstract screening were completed by MD and myself. Full text screening was completed by me. Development of a spreadsheet specifically to facilitate the analysis of this concept was completed by me. Analysis and interpretation was completed independently by me and confirmed by MD. I drafted the manuscript and it was approved by the authors MD, DD, MW and RG. I led on the reviewer's feedback and it was approved by MD and DD.

The third paper published is presented in Chapter 4. This paper presents a protocol for a systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care. I led on the development of this protocol in line with the Preferred Reporting Items for Systematic Reviews and Meta- Analysis Protocols (PRISMA- P) statement. The review protocol was submitted by me to the International Prospective Register of Systematic Reviews (PROSPERO) on 14/08/2018 (No. CRD42018105325). The search strategy was developed iteratively by DD and myself. The search strategy was tested in three databases and revised by me. Methods of data screening, inclusion and exclusion criteria and the data extraction process were determined by DD and myself. Methods by which to complete critical appraisal of included data were devised by DD, Michelle Beattie (MB) and myself. A data extraction form was developed by me following

advice from MB and approved by DD to standardise the collection of information related to the items included within each survey instrument and included within the publication. I drafted the manuscript and it was approved by the authors RG, Laura O'Dwyer (LO'D), Ethel Ryan (ER), MW, MB and DD. I led on the reviewer's feedback and it was approved by DD.

The fourth paper is presented in Chapter 5 and presents a systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care. I led on this review. The conduct and design of the review followed an adaptation of the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidance for completing systematic reviews of patient-reported outcome measures. Searching of citation databases was completed in line with the protocol (Chapter 4) by me. I searched the reference lists of retrieved literature was searched and contacted international experts in the area of maternity care survey development were contacted and asked to suggest studies for inclusion. All citations were managed by me in Endnote X7. All citations were exported to Covidence by me and screened at title and abstract, and then by full text by DD and myself. A data extraction form based on an excel spread sheet supplied by COSMIN to assist with the organisation of data extraction was modified and piloted by me to extract data from included instruments. Prior to submission, an updated literature search was completed by me to identify any newly published data related to the instruments arising from the 2018 search. A stepped approach was employed by DD and myself to facilitate evaluation of the methodological and psychometric quality of included instruments. Analysis and interpretation were completed by me. I drafted the manuscript and it was approved by the authors RG, LO'D, ER, MW, MB and DD. I led on the reviewer's feedback and it was approved by DD.

The fifth paper is presented in Chapter 6. This paper has been submitted to Women and birth journal and describes multiple processes that were adopted as part of two-phase exploratory sequential mixed methods study design. I led on this study. The design of the study was conceived by DD and myself with input from LOD. The application for ethical approval to complete the focus groups and one to one interviews to the NUI Galway Research Ethics Committee was prepared by me and approved by DD. Amendments to the application were requested by me with DD's support. Recruitment letters, Participant Information Leaflets, consent forms and interview schedules were developed by me and approved by DD. Recruitment for the interviews was completed by the National Care Experience Programme (NCEP). Analysis of the data arising from the interviews was completed independently by me

in NVIVO and confirmed by MD. The gap analysis was completed by me and Elaine Finucane (EF). The write up of item pool was led by me and supported by DD. The application for ethical approval to complete the Delphi study and consensus review to the NUI Galway Research Ethics Committee was prepared by me and approved by DD. Amendments to the data collection methods were requested by me with DD's support. Recruitment letters, Participant Information Leaflets, consent forms and interview schedules for the Delphi study and consensus review were developed by me and approved by DD. Recruitment for the Delphi study was completed by the NCEP assisted by DD and myself. The Delphi study was input into Crowdsignal, and hosted by, the NCEP. Analysis of all data arising from the Delphi study was completed by DD and myself. Recruitment for the consensus reviews was completed by the NCEP with assistance from DD and myself. Analysis of all feedback arising from the reviews was incorporated into the item pool by me and confirmed by DD. I drafted the manuscript and it was approved by the authors Conor Foley (CF), Linda Drummond (LD), RG, LO'D, ER, MW, MB and DD. I will attend to reviewer requests for amendments as needed, with the support of DD.

List of Publications from the Thesis

Published papers

1. BEECHER, C., DEVANE, D., WHITE, M., GREENE, R. & DOWLING, M. 2019. Concept development in Nursing and Midwifery: An overview of methodological approaches. *Int Journal of Nursing Practice*, 25, 1, doi: 10.1111/ijn.12702.
2. BEECHER, C., DEVANE, D., WHITE, M., GREENE, R. & DOWLING, M. 2019. Women's experiences of their maternity care: A principle- based concept analysis. *Women and Birth*. doi: 10.1016/j.wombi.2019.11.001.
3. BEECHER, C., GREENE, R., O'DWYER, L., RYAN, E., WHITE, M., BEATTIE, M. & DEVANE, D. 2020. Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments. *Systematic Reviews*, 9, 4, doi: 10.1186/s13643-019-1261-8.
4. BEECHER, C., GREENE, R., O'DWYER, L., RYAN, E., WHITE, M., BEATTIE, M. & DEVANE, D. Measuring women's experiences of maternity care: a systematic review of self-report survey instruments. *Women and Birth, (accepted for publication May 2020, awaiting publication details)*

Submitted paper

1. BEECHER, C., DRUMMOND, L., FOLEY, C., WHITE, M., GREENE, R., RYAN, E., O'DWYER, L., DOWLING, M., DEVANE, D. Development of a survey instrument to evaluate women's experiences of their maternity care. *Submitted to Women and Birth.*

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Thank you to both of my co- supervisors- Professor Richard Greene and Professor Laura O'Dwyer for the time and expertise that they afforded to me throughout this project.

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I would like to thank each of my co- authors on the included papers. Thank you to Dr. Maura Dowling in particular, who has co- authored on three of the five papers included in this project and has been extremely generous with her time and knowledge.

I would like to thank my three Graduate Research Committee members; Professor Dympna Casey, Dr. Hazel Killeen and Dr. Maura Dowling for their guidance at our annual meetings.

Thank you to Dr. Yvette Millar for giving her time generously to me and discussing in detail the operational aspects of Having A Baby in Queensland. Her guidance on various aspects of this project was very much appreciated.

I would like to thank each of the participants that took part in any stage of this project. I am so grateful to all participants for taking the time to share their views.

Thank you to the Health Information and Quality Authority (HIQA) for their support of this project, in particular their assistance with recruitment of participants for the focus groups, one to one interviews and the Delphi study.

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Thank you to my friends and my extended family- who are a constant support to me, for always being there to listen, but more importantly for the regular distractions from this work, which helped to keep me sane.

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List of Tables

List of Figures

List of Abbreviations

AUC; Area Under the Curve

CINAHL; Cumulative Index of Nursing and Allied Health Literature

COSMIN; COnsensus- based Standards for the selection of health Measurement Instruments

CQC: Care Quality Commission

CTT; Classical Test Theory

DIF; Differential item functioning

EMBASE; Excerpta Medica dataBASE

HIQA: Health Information and Quality Authority

HSE: Health Service Executive

HSE: Health Service Executive

ICC; Interclass Correlation Coefficient

IRT; Item Response Theory

LoA; Limits of Agreement

MEDLINE; MEDLINE is the online counterpart to MEDLARS MEDical Literature Analysis and Retrieval System)

MIC; Minimal Important Change

NCEP: National Care Experience Programme

NI: Northern Ireland

NMES: National Maternity Experience Survey

NPEU: National Perinatal Epidemiology Unit

PRISMA- P; Preferred Reporting Items for Systematic Reviews and Meta-Analyses-Protocols

PRISMA; Preferred Reporting Items for Systematic Reviews and Meta-Analyses

PREM; Patient Reported Experience Measure

PROM; Patient Reported Outcome Measure

PROSPERO; International Prospective Register of Systematic Reviews

SDC; Smallest Detectable Change

WHO: World Health Organization

Chapter 1: Introduction

1.1 Introduction

This chapter introduces the thesis and provides background information necessary to understand the context in which the work is positioned. It outlines the importance of, and need for, the development of a survey instrument to evaluate women's experiences of their maternity care in Ireland. The chapter also presents the study aims and outlines the thesis structure.

1.1.1 Evaluation of maternity care experiences

Traditionally, the quality of healthcare received has been determined primarily by health outcomes such as mortality and morbidity. An additional aspect of performance, the way that service users experience their care, has gained prominence in recent decades both as an independent marker of performance, and as a critical means of evaluating the quality of care received (Larson et al., 2019, Ahmed et al., 2014). In the broader healthcare context, *patient* experiences of care have been identified as a means of evaluating the degree to which the care provided is person-centred (Anhang Price et al., 2014). Person-centred care, and evaluating patient experiences specifically, are an essential aspect of quality of care, as they are associated positively with safety and clinical effectiveness and linked intrinsically to the protection of human rights (Doyle et al., 2013, Larson et al., 2019).

Given the importance of evaluating *patient* experiences, there is a growing body of work on the development of the concept of patient experiences (Wolf et al., 2014). There are, however, distinct differences between the care provided within maternity and general healthcare services (National Partnership For Women & Families, 2015) and this work is not transferrable to the interpretation of the concept of women's experiences of their maternity care. In contrast to the body of work in developing the concept of *patient experiences*, minimal work has been completed to date that contributes to an agreed definition of the concept of *'women's experiences of their maternity care'*. This may be attributable to the complex trajectory of maternity care, with care generally being provided by multiple professionals, across numerous time points at different locations, with tasks often executed interchangeably (Scheerhagen et al., 2015).

The memories that arise from women's experiences of being pregnant, giving birth and the early postpartum period can stay with them for their lifetime (Redshaw et al., 2019). A

woman's experiences of maternity care can have long- and short-term effects on the woman herself, her baby and the wider family. A positive experience of maternity care, for example, can contribute to women's positive feelings of self- worth (Redshaw et al., 2014), facilitate a woman's comfort and confidence with maternity services (Pangas et al., 2019) and improve attendance at maternity care services (Carolan and Cassar, 2010). Conversely, negative experiences of maternity care contribute to feelings of vulnerability, fear, stress, and low self-confidence (McLeish and Redshaw, 2019, Aktas and Aydin, 2019, Ronnerhag et al., 2018). Furthermore, negative maternity experiences can lead to postnatal mental health disorders, as well as influencing decision making around any future pregnancies and possibly impacting on a woman's future reproduction in general (Redshaw et al., 2019). Given the impact of both positive and negative maternity experiences, the evaluation of the maternity care that women receive is essential for the optimisation of maternity services.

As experiences of care are abstract, and therefore not observable directly, there is a growing focus on how they are evaluated. As a reflection of the complexity of healthcare, a multitude of methods to evaluate experiences of care exist, including qualitative, quantitative and mixed-method approaches. Data collection methods such as one to one interviews and focus group interviews offer the opportunity to collect data that provide an in-depth understanding of the care that has been received but the summation and interpretation of such data can be challenging (LaVela and Gallan, 2014). Conversely, structured survey instruments, as the most common quantitative method of collecting data, can be implemented with relatively large samples allowing for a greater comparison, albeit without the depth and richness of qualitative methods (Beattie et al., 2015). The use of a mixed-methods approach that incorporates the use of both qualitative and quantitative methodology offers the benefit of providing a greater comprehension of the care experience and the triangulation of data. Although resource-intensive, it offers an insight into contradictions between the quantitative results and qualitative findings (LaVela and Gallan, 2014). While it is clear that survey instruments do not provide the same richness and depth that might be provided through interviews, the benefit of such instruments in collecting substantial amounts of data from a large number of respondents efficiently has led to their use in many large-scale initiatives to evaluate women's experiences of their care. The use of such large scale surveys has facilitated the identification of areas of care requiring practice and or policy change. In the UK, for example, the NHS Trusts that provide maternity care regularly employ the use of the large scale Care Quality Commission (CQC) self- report survey instruments to assess the care that is provided (Survey Coordination Centre, 2019). Prior to

the completion of the work presented in this thesis, there was no such survey used within the Irish maternity services.

1.1.2 Comparable evaluations of healthcare

Contemporary evaluations of *experiences* of care, as a marker of care quality, contrast with a historical focus on *satisfaction* with care. The overlap between the two concepts in the literature is apparent with the terms often used interchangeably (Berkowitz, 2016, Ahmed et al., 2014). Despite both concepts being identifiable as person-centered measures (Larson et al., 2019), there are marked differences in underlying approaches (Beattie et al., 2015). Asking a service user to report either their experience or satisfaction with the care that they have received inherently introduces a level of subjectivity; however, it is how survey items are framed when attempting to evaluate either of the concepts that determine the degree of subjectivity elicited (Larson et al., 2019). Evaluation of satisfaction with care seeks to identify service user's subjective interpretation of their level of contentment with the care they received, in contrast to the evaluation of experiences of care that instead ask for a direct report of the care that was received (Graham and Woods, 2013). It is argued that as satisfaction with care consists of some level of happiness, it can be influenced easily by factors other than the care received (Manary et al., 2013). The evaluation of satisfaction with care is also identified as having limited utility in the improvement of quality of care as an identification of dissatisfaction with care establishes that there is a deficit in care but provides little information on what caused the dissatisfaction, or how the issue should be addressed (Graham and Woods, 2013).

Similarly, there is considerable interest in the evaluation of patient reported health outcomes. These outcomes focus on the service user's subjective reports of the effects and performance of treatments that they have received, and data are collected by using questionnaires or surveys known as Patient Reported Outcome Measures (PROMs) (Jenkinson and Fitzpatrick, 2013). Comparisons are often drawn between PROMs and Patient Reported Experience Measures (PREMs). Although comparable in ways, the underlying principles of both differ significantly (Kingsley and Patel, 2017). PREMs focus on the evaluation of the process of care specific to a particular healthcare need or disease (e.g. COPD) and may be used to complement more generic survey's that evaluate experiences of healthcare (Walker et al, 2017). Alternatively, PROMs assess the effect of health interventions on physical and emotional functioning and quality of life and can be classified as either generic or disease specific. Findings arising from the use of PROMs are attributable

to the intervention or treatment received by service users with potential uses for PROMs including outcomes in research, service user informed decision making, clinical decision making, and cost-utility studies (Jenkinson and Fitzpatrick, 2013, Padula and McQueen, 2019).

The focus of this thesis is on the development of a survey instrument to evaluate experiences of care. Due to the minimal work that has taken place on the definition of the concept of 'women's experiences of their maternity care' to date and the consistent comparisons that are drawn between the evaluation of experiences of care and other concepts such as satisfaction with care, an essential preliminary step of the project was to analyse the concept. A theoretical definition[1] of the concept was developed under the guidance of Penrod and Hupcey (2005) principle-based concept analysis method (Beecher et al., 2019). Using this method of analysis, the theoretical integration of the concept of 'women's experiences of their maternity care' with related concepts, such as satisfaction, was explored. The theoretical definition provided a basis for the remainder of the project and, as is critical in the development of survey instruments that evaluate experiences of care, it contributed to the understanding of how care quality is experienced (Holt, 2018).

1.1.3 Evaluation of women's experiences of their maternity care in the Irish context

The National Maternity Strategy- Creating a Better Future Together 2016-2026 (Department of Health, 2016) was launched in Ireland in 2016 by the Department of Health. The Strategy mapped the future of the maternity care services to safeguard the provision of safe, nationally consistent, high-quality woman centered care to the women of Ireland and their families. The Strategy focused on the provision of choice to women who avail of maternity care within Ireland through three care pathways, i.e., Supported Care, Assisted Care and Specialised Care.

The Strategy, which is Ireland's first National Maternity Strategy, identified four drivers for change of the maternity services. These are; population needs, international trends, public consultation and reports on Irish maternity services.

[1] "Women's experiences of their maternity care' is a complex concept referring to women's interpretation of their care encounters within the maternity services. It is subjective in nature and evolves throughout the course of pregnancy, childbirth and the postpartum period. It is dependent upon a woman's individual needs and expectations, shaped by their personal circumstances and influenced by how their care is organised and delivered".

1.1.3.1 Population needs

Maternity services in Ireland are complex and advancements in the provision of women-centered maternity care, for example, the introduction of midwifery-led units, are often protracted as the medicalisation of maternity care dominates (Devane et al., 2007, Hunter et al., 2017). The demographics of women who give birth in Ireland are continuously evolving (Corbett et al., 2020). To provide a framework for the provision of maternity services in Ireland, trends in the Irish population and their needs were evaluated to inform the Strategy. These trends included maternal age, the identification of the distribution of the population of childbearing age, birth rates, mode of birth, the incidence of high-risk pregnancies, the rates of pregnancy loss, perinatal mortality rate, maternal mortality ratio and the rates of termination of pregnancies of Irish women. At the time of the publication of the report, termination of pregnancy remained unconstitutional[2] and therefore, the rates of Irish women seeking termination of pregnancy in the U.K. was evaluated.

1.1.3.2 International trends

An analysis of the international trends in the provision of maternity services was undertaken to inform the development of the Strategy and focused on seven jurisdictions, each of which had produced a plan for the delivery of maternity services. Although maternity care services vary significantly internationally, a commonality that emerged was a woman-centered approach to the provision of care that takes into account the experiences, and wishes, of women.

1.1.3.3 Public consultation

The priorities of women who access maternity services are crucial for informing the design and provision of those services (Downe et al., 2018). The development of the Strategy was informed by a public consultation in the form of an online questionnaire and two focus groups with most participants being identified as service users. This consultation focused on what was working well within the maternity services, what was not working well, and what could be improved. The National Maternity Strategy report presents several service user quotes that highlight what had been working well within the maternity services, for example;

[2] In December 2018 the Health (Regulation of Termination of Pregnancy) Act 2018 was signed into law by President Michael D. Higgins. This defines the circumstances and processes within which abortion may be performed legally in Ireland.

> *"There are many aspects of our current maternity service working well and this is due to the dedicated, caring and knowledgeable healthcare workers providing excellent care to women and their families"*

> *"The introduction of midwifery led care is a step in the right direction giving women more choice and allowing them to be involved in the planning of woman centered care and giving feedback to those delivering and planning each woman's individual care"*

The report also presents service user quotes that identify areas in need of improvement, for example;

> *"It's disheartening to see that the range of ante and postnatal care and birthing options that are available in major urban areas (Dublin) are not available in smaller hospital catchment areas. As someone who lives rurally I would love to be able to avail of home based antenatal and postnatal care"*

> *"I didn't have a say in how I wished my birth would go, I felt like I was a number and didn't matter. I felt the consultants team members were dismissive of my feelings regarding their choices for me and felt like I was a puppet with no voice; going through a first pregnancy is scary enough without being made feel like I had no control or say with anything that was to be done to my body. Communication needs to be improved greatly; a woman should be made feel part of the process not just an instrument in it!"*

1.1.3.4 Reports on Irish maternity services

The greatest driver of the development of the Strategy was the publication of several reports and reviews in the year's previous highlighting service deficits and failings within the maternity services. These reports included the Health Information and Quality Authority (HIQA) report into the safety, quality and standards of services provided to patients at the Regional Hospital, Portlaoise (Health information and Quality Authority, 2015), the HSE Midland Regional Hospital, Portlaoise Perinatal Deaths (2006-date). Report to the Minister for Health Dr James Reilly TD From Dr Tony Holohan Chief Medical Officer (Department of Health, 2014) and the 2015 reviews of Governance of Maternity Services in Cavan General Hospital and South Tipperary General Hospital (Flory, 2015a, Flory, 2015b).

The commitment to the development of the Strategy arose from the recommendation of the HIQA report titled *'Investigation into the safety, quality and standards of services provided by the Health Service Executive to patients, including pregnant women, at risk of clinical deterioration, including those provided in University Hospital Galway, and as reflected in the care and treatment provided to Savita Halappanavar'* (Health Information and Quality Authority, 2013). The report recommended that a strategy be developed to implement models for the delivery of a maternity service that, based on best available evidence, provides women with choice and access to appropriate care and support. The National Maternity Strategy provides the framework for this service.

Priority two of the Strategy recommends that women have access to safe, high quality, nationally consistent, woman-centered care. The development of a formal structure to evaluate women's experiences of their maternity care, as a means of informing quality improvement actions, was identified as a critical component of delivering this priority.

The National Standards for Safer Better Maternity Services (Health Information and Quality Authority, 2016), published by HIQA to support the implementation of the National Maternity Strategy, informed a policy decision to develop and implement a survey instrument to evaluate women's experiences of their maternity care in the Republic of Ireland specifically and gives impetus for this study.

The National Care Experience Programme (NCEP) is a partnership between the health service regulator (HIQA), the national healthcare provider (Health Service Executive (HSE)) and the national policymaker (Department of Health) launched in Ireland in 2019 to evaluate service users' experiences annually across the acute public healthcare services. Results inform care improvement actions nationally. Following numerous meetings and extensive discussions with key personnel within HIQA, who will oversee the National survey, it was agreed that the survey instrument being developed, as presented within this thesis, would become the National Maternity Experience Survey (NMES). It was decided *a priori* with the NCEP that the NMES would cover the full pathway of maternity care from a woman's first antenatal contact, through labour and birth, to the care provided in the community up to three months postpartum. Given the scope of the survey instrument, it was also decided *a priori* that women who have been bereaved by pregnancy and infant loss would not be asked to complete the final NMES when launched nationally. In line with international practice, the NCEP plans to develop a survey instrument specific to the needs of these women. The NMES was launched nationally in February 2020.

1.1.4 Development of survey instruments used to evaluate women's experiences of their maternity care

The implementation of an instrument such as the NMES, from which the arising results will influence the direction of limited resources, must be of sound methodological quality. The methodological quality of such an instrument impacts directly on the credibility of the findings (Mokkink et al., 2018). The emerging focus on the evaluation of experiences of healthcare in recent decades has led to a parallel growth in the development of survey instruments specifically for the evaluation of such experiences. This has resulted in a dramatic increase in the volume of available instruments in recent decades (Terwee et al., 2007).

Despite availability, and although various aspects of instruments that are used internationally to evaluate women's experiences of their maternity care have informed the development process of the NMES, no existing instrument in its entirety was applicable to the Irish context, primarily because of the complex differing nature of the maternity services currently provided to women in Ireland. To provide meaningful and psychometrically robust results relevant to and actionable in the context of the Irish maternity services, it was crucial that the development process incorporated the perspectives of key stakeholder groups. Redshaw et al. (2019) identify two key stakeholder groups, the service users of the maternity services, and the organisation implementing the survey and interpreting the arising results into quality improvement actions. The methods used to develop the NMES incorporated the views of these two groups, as well as other stakeholder groups, including midwives, obstetricians, public health nurses, general practitioners, neonatologists, neonatal nurses, anaesthesiologists, policymakers and funders.

As the number of instruments measuring women's experiences of their maternity care has grown, it is evident that the quality of such instruments varies, despite many being used widely. In the UK, for example, the large-scale surveys implemented by the CQC, although providing an important overview of the maternity care that has been provided to women and the change in this care over time, there is (perhaps counter intuitively) a lack of evidence that the inferences made from these evaluations are valid (Redshaw et al., 2019). Content validity has been defined as the degree to which the content of a survey instrument reflects the construct being measured, specifically, how adequately the content of a survey instrument reflects women's experiences of their maternity care (Mokkink et al., 2010). The content validity of such instruments is critical as a lack of content validity impacts all other

measurement properties directly, such as internal consistency and structural validity (Terwee et al., 2018). If the items included within an instrument lack relevance, then the evaluation of any other measurement properties is futile (Prinsen et al., 2018). Furthermore, the use of validated instruments addresses the issue of an introduction of subjectivity in reporting experiences of care (Larson et al., 2019).

1.2 Study aim

The aim of this study is:

- Develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. In line with the recommendations of the Irish National Maternity Strategy, the purpose of implementing this instrument is to identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high-quality care.

1.3 Outline of thesis

This thesis comprises seven chapters. The chapters include four published peer-reviewed papers (Chapters 2, 3, 4 and 5) and one has been submitted to a peer-reviewed journal (Chapters 6). As the structure of the PhD is thesis by publication, the references for each individual paper are presented at the end of the respective chapters. Due to the independent nature of the papers for publication, there is an unavoidable element of repetition.

Chapter 1 introduces the thesis and presents background information on the development of a survey instrument to evaluate women's experiences of their maternity care.

Chapter 2 presents a discussion paper on the methodological approaches to concept development as relevant to the nursing and midwifery domain.

Chapter 3 presents an analysis of the concept 'women's experiences of their maternity care' using the principle-based concept analysis method.

Chapter 4 presents a protocol for a systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care and **Chapter 5** presents the completed systematic review.

Chapter 6 describes all additional studies that were completed in the development of the item bank, namely, focus groups and one to one interviews with key stakeholder groups, a

gap analysis, development an initial item pool, a two-round Delphi study and a consensus review.

Chapter 7 presents an overall discussion of the thesis and the individual findings of each aspect of the work that has been undertaken. Overall strengths and limitations and implications for practice and further research are identified.

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Chapter 2: Concept development in Nursing and Midwifery: An overview of methodological approaches.

2.1 Introduction

This chapter presents paper 1. Paper 1 provides an overview of the methodological considerations of commonly used concept development strategies and methods (Norris 1982, Walker & Avant 2018, Rodgers 2000 and Penrod and Hupcey 2005) within nursing and midwifery. This paper was written in response to the challenges faced in attempting to develop the concept of 'women's experiences of their maternity care' (Chapter 3). The clarification of the intended use of various concept development strategies and explication of the fundamental methodological principles of four commonly used concept development methods will provide guidance to nurse and midwife researchers in their choice of concept development methodology.

2.2 Paper 1

Concept development in Nursing and Midwifery: an overview of methodological approaches

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Chapter 2: Concept development in Nursing and Midwifery: An overview of methodological approaches.

2.3 Abstract

Background Over the past four decades, there has been a growing focus on the resolution of conceptual problems through the process of concept development. As the focus on this area has grown, so too has the number of debates in the literature on methodological aspects of concept development.

Aim To provide an overview of the essential methodological considerations of concept development.

Design Discussion paper. An overview is presented of the methodological considerations of commonly used concept development strategies and methods (Norris 1982, Walker & Avant 2018, Rodgers 2000 and Penrod and Hupcey 2005) within nursing and midwifery.

Data Sources Literature dating from the inception of concept development in nursing and midwifery.

Implications for Nursing and Midwifery The robust development of concepts is a vital component in advancing the knowledge base of nursing and midwifery theory and practice. However, the complexity of the concept development literature may serve to exacerbate the challenges of developing a given concept, in particular for the novice researcher.

Conclusion The methodological considerations discussed provides guidance in determining the most appropriate strategy and method of concept development.

Key words Concept analysis, concept clarification, concept development, method, midwifery, nursing, strategies.

Chapter 2: Concept development in Nursing and Midwifery: An overview of methodological approaches.

2.4 Introduction

The value of concept development in advancing the unique knowledge base of nursing and midwifery theory and practice has been widely acknowledged (Baldwin, 2008; Duncan, Cloutier, & Bailey, 2007; Penrod & Hupcey, 2005; Rodgers, 2000a, 2011). Concept development is also critical to the credibility of research without which "subsequent research may be based on false assumptions, false premises, and hypotheses that have no relevance in the real world" (Norris, 1982, p. 11).

Over the past four decades considerable attention has focused on the resolution of conceptual problems through the process of concept development (Beckwith, Dickinson, & Kendall, 2008; Meleis, 2007; Rodgers, 2011; Walker & Avant, 2018), with the first concept development method specific to a nursing and midwifery domain pioneered by Norris in 1982, followed shortly after by Walker and Avant in 1983.

The growing focus on this topic has led to a proliferation of debate in relation to all aspects of concept development, much of which centres around the philosophical perspectives of leading metatheorists. For example, debates abound on the interpretation of the term 'concept' (Penrod & Hupcey, 2005; Rodgers, 1989, 2000b; Walker & Avant, 2018), the nature of the relationship between concepts and theory (Bergdahl & Bertero, 2016; Morse, 1995; Paley, 1996; Risjord, 2010; Rodgers, 2000b) and the optimum strategies and methods to be used to effectively facilitate the development of concepts (Beckwith et al., 2008; Meleis, 2007; Penrod & Hupcey, 2005; Weaver & Mitcham, 2008).

Complexity of the concept development methodology literature exacerbates the challenges of developing concepts and for the novice researcher the translation and utilisation of this literature is often problematic. Despite these challenges, the knowledge base of nursing and midwifery continues to expand rapidly through research, therefore it is important that concept development methodology is not only understood but also utilised to ensure practice is informed by high quality evidence. The practice implications of concept development are evident for instance, by the recent development of the concept of 'women's experiences of their maternity care' by the authors of this paper. The outcome of this development has highlighted aspects of the concept that were not initially evident, which has informed the ongoing development of a survey instrument to measure women's experiences of the maternity care within the Republic of Ireland specifically; the results of which will be used to influence national policy and practice.

In response to an evident gap in the literature and supported by relevant literature and theory, an overview is provided here for the novice researcher, or those new to concept development, on the essential methodological considerations of concept development. When searching for and reviewing the supporting literature, no restrictions on year of publication were applied.

2.5 Discussion

2.5.1 Methodological considerations

2.5.1.1 Concept development strategies;

The first step required by researchers when developing a concept is to choose a strategy that is most appropriate to the concept being developed. Concept development literature in the nursing and midwifery domain is replete with interchangeable terms relating to the strategies of concept development (Duncan et al., 2007; Fawcett, 2012; Meleis, 2007). For example, the terms concept analysis, concept clarification and concept exploration are widely used to describe concept development strategies within the nursing and midwifery domain (Duncan et al., 2007; Fawcett, 2012; Meleis, 2007; Walker & Avant, 2018). Each are vital for the progression of knowledge development in nursing and midwifery, however, the fundamental difference between each can be found in their intended use, as described in table 2.1 (Meleis, 2007). It is clear from these descriptions that choosing a concept development strategy wholly depends on the concept being developed and the conceptual problem that requires resolving. Researchers must therefore attempt to gain an insight into current understandings of the concept, through an examination of the literature, before deciding on an appropriate strategy.

Table 2.1. Concept development strategies;

Strategy name	*Description*
Concept analysis	Concept analysis, considered to be the most familiar of concept development terms (Rodgers, 2000b), is a means of further developing a concept that has previously been defined, clarified and utilised in nursing and midwifery literature (Meleis, 2007). Concept analysis methods include the work of Wilson (1963), (Walker & Avant, 2018), Rodgers (2000a) and Penrod and Hupcey (2005).
Concept clarification	Concept clarification is used for the refinement of existing concepts that have been accepted into the nursing and midwifery domain without a “clear, shared

	and conscious agreement on the properties or the meaning attributed to the concept" (Meleis, 2007, p. 167). A common concept clarification method used in the Nursing and Midwifery literature is by Norris (1982).
Concept exploration	Concept exploration may be employed by researchers who aim to raise and answer questions on ambiguous concepts whose relationship to the nursing and midwifery setting may be at the preliminary stages (Meleis, 2007). For example, concept exploration may be used for the development of newly identified concepts, concepts that have been uncritically adopted from other healthcare settings, or concepts so familiar to a discipline that their application and relevance to the development of practice is unknown or undervalued. The exploration of many concepts is influenced by the work of Morse et al (Morse, 2000; Morse, Hupcey, et al., 1996).

2.5.1.2 Concept development methods;

Once an appropriate strategy has been decided, researchers must then turn their focus to the methods recommended. The methods of concept development are frameworks that have been formulated to provide a structured approach to adequately implement the chosen concept development strategy. Rodgers (2000b, p. 31) states that "the selection of methods must be based on sound philosophical rationale and appropriateness for the purpose of the study". However, little guidance is available on the process of identifying the appropriateness of these methods, which means that ultimately the onus is on each individual researcher to decide on their choice of method (Rodgers, 2000b). It is apparent that many published concept development endeavours have not considered the fundamental methodological principles of the methods of concept development and instead state that the rationale in choosing a given method is based principally on ease of use or popularity, which ultimately throws into doubt the rigour of the concept development and the 'usefulness' of results (Rodgers, 2000b).

Over the past four decades as the focus on the area of concept development in nursing and midwifery has grown, so too has the number of concept development methods (Meleis, 2007; Walker & Avant, 2018). Four of the most commonly used concept development methods, as evident in contemporary publications, are presented here in relation to their fundamental methodological principles. Explication of the methods by Walker and Avant (2018), Rodgers (2000a), Penrod and Hupcey (2005) and Norris (1982) serve as a guide to aid researchers' decision making in choosing the most appropriate method to develop a given concept. Although it is evident that there has been little evolvement of each of these

methods from the time of their conception, some have used adaptations through a hybrid approach of such methods, for example Lewis (2018) used a combination of the methods by Penrod and Hupcey (2005) and Walker and Avant (2011) to analyse the concept of 'Fluency in Nursing Education and Simulation'. Moreover, it is important to highlight that there are other additional methods of concept development also used (albeit less commonly) within the nursing and midwifery domain, but not presented within this overview, namely, Chinn and Kramer (1995), Morse, Mitcham, Hupcey, and Tason (1996), Parse (1997) and Schwartz-Barcott and Kim (2000).

Table 2.2 provides additional information on each of the four methods by Walker and Avant (2018), Rodgers (2000a), Penrod and Hupcey (2005) and Norris (1982) including their individual philosophical perspectives and examples of use in contemporary literature. The philosophical underpinnings, data collection processes and the utilisation of collected data of each individual method should be compared against the complexity of the concept being developed, to facilitate the choice of the most appropriate method of development.

2.5.1.3. Philosophical rationale;

The philosophical underpinnings of concept development have a fundamental influence on the design of concept development methodologies, the interpretation of subsequent findings and the application of any results (Rodgers, 2000b). Furthermore, a "strong and defensible philosophical rationale for decisions made by researchers is ultimately the primary ingredient in efforts to promote conceptual progress in nursing" (Rodgers (2000b, p. 34).

A wealth of literature is available on the philosophical underpinnings of concept development which is brimming with the diverse viewpoints of philosophers and metatheorists (Frege, 1970; Kant, 1965; Locke, 1975; Penrod & Hupcey, 2005; Rodgers, 2000b; Ryle, 1971; Walker & Avant, 2018; Wittgenstein, 1968). Moreover, there is an ever-growing body of secondary literature from those who then attempt to interpret these viewpoints (Beckwith et al., 2008; Duncan et al., 2007; Duncan, Cloutier, & Bailey, 2009; Risjord, 2009, 2010).

Table 2.2. Additional information on discussed methods;

	Concept analysis: (Walker & Avant, 2018)	*Concept analysis: (Rodgers, 2000a)*	*Concept analysis: Penrod and Hupcey (2005)*	*Concept clarification: Norris (1982)*
Philosophical underpinnings (Beckwith et al., 2008; Duncan et al., 2007; Rodgers, 2011)	Reductionist, realist, positivist	Relativist	Reductionist, realist	Reductionist, realist, positivist
No. of steps	8	6	3	5
Basic outline of steps	1. Selection of concept 2. Determine aim of analysis 3. Identify all uses of concept 4. Determine defining attributes 5. Construct a model case 6. Construct additional cases (such as borderline, related, contrary, and invented) 7. Identify antecedents and consequences 8. Define empirical referents	1. Identify the concept and associated expressions (such as surrogate terms). 2. Select an appropriate data collection realm. 3. Collect data. 4. Analyse data. 5. Identify an exemplar of the concept. 6. Identify implication's and propose hypotheses.	1. Identification of a concept and collection of literature. 2. Assess literature in accordance with the criteria supported by the epistemological, pragmatic, linguistic and logical principles. 3. Integration of the assessments into a singular theoretical description of the concept.	1. Observe & describe the concept. 2. Categorise the observations. 3. Write an operational definition. 4. Create a model. 5. Formulate hypotheses.

Examples of use	1. 'A concept analysis of proactive behaviour in midwifery' (Mestdagh, Van Rompaey, Beeckman, Bogaerts, & Timmermans, 2016); 2. 'Integrity in nursing students: A concept analysis' (Devine & Chin, 2017); 3. 'Integrity in nursing students: A concept analysis' (Devine & Chin, 2018).	1. 'A concept analysis of professional commitment in nursing' (Garcia-Moyano et al., 2017); 2. 'A Concept Analysis of Self-Management of Cancer Pain' (Yamanaka, 2018); 3. 'Personhood: An evolutionary concept analysis for nursing ethics, theory, practice, and research' (Sofronas, Wright, & Carnevale, 2018).	1. 'Postpartum sexual health: a principle-based concept analysis' (O'Malley et al., 2015); 2. 'Concept analysis: Wrong-site surgery' (Watson, 2015); 3. 'A Concept Analysis of Resistiveness to Care' (Spigelmyer, Hupcey, & Kitko, 2018).	1. 'Adverse childhood experiences: towards a clear conceptual meaning' (Kalmakis & Chandler, 2014); 2. 'Full Nursing Potential: A Concept Clarification' (Aroke, 2014); 3. 'Goals of care: a concept clarification' (Stanek, 2017).

An in-depth discussion on the philosophical debates that flood the concept development literature is beyond the scope of this article, however where relevant the philosophical underpinnings of the four concept development methods will be referred to. These references merely serve to highlight the influence that philosophy has upon concept development methodology and to reiterate to researchers that these philosophical underpinnings are owed early consideration in their concept development journey in respect of the concept being developed. Table 2.3 provides descriptions of several philosophical terms used throughout the concept development literature.

2.5.1.4 Origin of many concept development methods in nursing and midwifery;

When discussing methodological considerations of concept development in the nursing and midwifery domain it is imperative to acknowledge the work of Wilson (1963). As identified by Beckwith et al. (2008) all four concept development methods discussed here have been strongly influenced by the work of Wilson, as have the methods by Morse, Mitcham, et al. (1996), Schwartz- Barcott and Kim (2000) and Chinn and Kramer (1995). Wilson, an educationalist, originally formulated his method of concept analysis to facilitate his students successfully complete their school entrance exam. He constructed an 11-step tool, grounded in relativism (see Table 2.3), that acknowledged the importance of applying context to concepts, which would then allow his students to identify the essential features of a concept through a focus on actual and possible use of words.

Table 2.3. Descriptions of philosophical terms;

Philosophical term;	*Description*
Positivism	The view that genuine scientific knowledge can only be achieved through the unbiased, rigorous ordering of confirmable observation (McKenna, Pajnkihar, & Murphy, 2014). As such, "the ontological position of positivism is one of realism" (Scotland, 2012, p. 10, p.10)
Realism	The view that the world exists as an ontologically independent reality (Polgar & Thomas, 2013; Risjord, 2010).
Logical positivism	Developed by members of the Vienna Circle the logical positivism paradigm, in comparison to positivism, places an even greater emphasis on the importance of confirmable observation and scientific verification with logical

	positivists believing that for a statement to be meaningful it must be verifiable (McKenna et al., 2014; Risjord, 2010).
Interpretivism	Interpretivism, formed as an opposing view to the philosophy of positivism in the late 19th and early 20th centuries, is the view that reality is based on meanings and understanding (Schwandt, 2000) and consequently, "the ontological position of interpretivism is relativism" (Scotland, 2012, p. 11, p.11).
Relativism	The belief that reality is subjective and varies based on the beliefs of each individual or culture (Guba & Lincoln, 1994).
Reductionism	"The process of reducing complex phenomena to simpler, more fundamental elements" (Polgar & Thomas, 2013, p. 13, p. 13).
Causality	"The theory that one action or outcome can be identified as a consequence of another "(Beckwith et al., 2008, p. 1835).
Casuistry	The theory that one action or outcome sets precedence for other similar cases. It has been stated that if the lowest standards of nursing and midwifery are practiced then "the use of precedents based on case studies from this arena to make judgements in other analogous cases could drive down standards overall" (Beckwith et al., 2008, p. 1835).

Wilson's 11 steps, which are not mutually exclusive, are identified below;

1. **Isolating questions of concept;** Wilson describes three sets of questions which are related to the facts, values and meanings of a concept (Meleis, 2007).
2. **Finding right answers;** In reply to the isolated questions, as above.
3. **Model cases;** simply, this is the process of presenting an example of the concept which identifies its typical and atypical features.
4. **Contrary cases;** Cases which serve as an example of the exact opposite of the concept and its related properties. In identifying what is not the concept, an indication is made to the features that are essential to the concept.
5. **Related cases;** Cases which bear some similarities to the proposed concept- these cases can offer an insight into the concept's network of associations.
6. **Borderline cases;** These cases contain most, but not all of the defining attributes of the concept. These cases offer the author the opportunity to clarify what constitutes as the concept, and what does not.

7. **Invented cases;** This step may not be essential if a sufficient number of models have been identified through steps 3- 6 to elucidate the concept**.** Invented cases are those that are developed based on ideas that are outside the author's own experiences and are a magnification of the major features of the concept.
8. **Social context;** This is the identification of who may use the concept, why it may be used and how (Meleis, 2007).
9. **Underlying anxiety;** This is the determination of any 'feelings' that may be associated with a concept, for example uncovering any related stigma, debates or controversy.
10. **Practical results;** A description of the practical use of a concept and its application to practice.
11. **Results in language;** Simply put, this is describing the results of the previous 10 steps and the attachment of a descriptive 'label' to the concept.

Although Wilson's work is the basis for many of the commonly used concept development methods today, it is criticised heavily throughout contemporary literature as being focused on the enablement of critical thinking, rather than providing a solid base for the scientific examination of concepts (Beckwith et al., 2008; Hupcey & Penrod, 2005; Risjord, 2009). Furthermore, Beckwith et al. (2008, p. 1839) claim that Wilson's method, which was not created with the intent that it be modified for use in a realm such as nursing and midwifery, fails to provide sufficient depth that is required for the development of complex concepts within this domain, and that adaptations of his framework have been carried out in an "unjustified and ad hoc way". As each of the four concept development methods discussed here have originated from the work of Wilson (1963) it is unsurprising that all four methods share several key steps with regards to the collection, and subsequent utilisation, of data.

2.5.2 Data collection

Each of the four methods begin by describing the processes for data collection. Norris (1982) pioneering concept clarification method, grounded in positivism (see table 2.3), suggests that data be collected by a combination of observing a concept through fieldwork and a systematic literature review. The suggested use of fieldwork as a means of observing a concept may be attributed to this method's development in 1982 at a time when the volume of literature available was significantly less than what it is in the present day. In response to the volume of literature now available to researchers, the data collection aspect of Norris'

method is often completed through a systematic review alone. This is evident particularly in more recent work on developing abstract concepts for nursing and midwifery (Aroke, 2014; Kalmakis & Chandler, 2014; Levine & Lowe, 2014). This is despite Norris placing particular focus on the fieldwork aspect of data collection, and in doing so failing to provide any specific guidelines in respect of completing the literature review. This contrasts with the concept analysis method by Penrod and Hupcey (2005) which was created over 20 years later and provides researchers with significant guidance on the selection and sampling of data that is to be used in the development of concepts. For example, Penrod and Hupcey (2005) highlight that the selection of disciplinary literatures is one of the most important preliminary decisions in a concept development endeavour. Researchers are advised that the "selection of disciplinary literatures should be based on the potential for contribution to the understanding of the concept, not a rote listing of inter- related disciplines" (Penrod & Hupcey, 2005, p. 407). For clarity, Penrod and Hupcey (2005) provide the example of the development of the concept of trust. To effectively develop the concept of trust, the authors (Hupcey, Penrod, Morse, & Mitcham, 2001) included literature from the disciplines of sociology, medicine, psychology and business with each of these disciplines contributing to a unique perspective and a deep understanding of the concept. The guidelines on the selection of disciplinary literatures set out by Penrod and Hupcey (2005) are similar to those provided within Rodgers (2000a) evolutionary concept analysis method, labelled so due to the basis of this method centring on the belief that concepts evolve in a cycle of significance, use and application. Rodgers (2000a), who shared a relativist viewpoint with Wilson (see table 2.3), also highlighted the importance of choosing literature across diverse disciplines. However, guidelines on the sources of literature from within these chosen disciplines are an aspect of data collection in which the methods differ.

The methods of concept analysis proposed by both Rodgers (2000a) and Walker and Avant (2018) endorse a broad review of the available literature including dictionaries, thesauri and popular press, in addition to scientific data. Conversely, Penrod and Hupcey (2005) state that only scientific literature should be included in the analysis as a means of producing an evidence based theoretical definition of a concept that has not been "intuitively or creatively derived" (Penrod & Hupcey, 2005, p.408.). Further differences between the methods proposed by Penrod and Hupcey (2005) and Rodgers (2000a) are evident in their data sampling guidelines. Penrod and Hupcey (2005) describe the importance of using a conceptually driven sampling approach which focuses on the adequacy and appropriateness of the sample to the concept of interest, whereas Rodgers (2000a) suggests a conflicting

approach. Rodgers' data sampling guidelines, which were originally published in the 1980's and as per Norris (1982) may be reflective of the volume of literature available to researchers at that time, specify that the data be sorted by discipline and by year before a computer generated, stratified systematic sampling technique is applied and a final cohort of material for analysis is produced. Penrod and Hupcey (2005) have criticised this technique of delimiting the sample, as random selection may lead to the omission of the most relevant pieces of literature. Furthermore, Beckwith et al. (2008) suggest that Rodgers' aim of acknowledging the evolving state of concepts is precluded by this selection procedure as the randomised stratification does not allow for assurance for the inclusion of all literature that may allow the identification of the evolving state of the concept over time.

2.5.3 Utilisation of collected data

There are similarities across all four methods in regard to the utilisation of the collected data, which is unsurprising given each of the methods are based upon the work of Wilson. Similarities include Walker and Avant (2018) stipulation that the defining attributes of a concept must be identified, as do (Rodgers, 2000a) and Penrod and Hupcey (2005) under their 'analyse data' and 'Integration of the assessments into a singular theoretical description' steps respectively. However, the methods by both Walker and Avant (2018) and Rodgers (2000a) have been subject to criticism for their failure to provide an adequate description of the criteria for identifying these attributes (Paley, 1996). Ultimately, this has resulted in many authors refraining from justifying their choice of defining attributes of a concept, which has been referred to as a principle weakness of published concept analyses (Hupcey & Penrod, 2005; Paley, 1996).

Furthermore, (Walker & Avant, 2018) instruct the researcher to identify the antecedents (predecessors) and consequences (result, or effect) of a concept, which is also included in the method by Rodgers (2000a), again within the 'analyse data' step. Similarly, Norris (1982) instructs the researcher to categorise the observations and descriptions of the concept by establishing patterns, categories and hierarchy through the identification of the causes and effects of a concept. Although Meleis (2007) has suggested that concept clarification does not require the development of antecedents or consequences, which are important in understanding the social context in which the concept is used (Walker & Avant, 2005), identifying possible causes and effects of a concept are essentially similar to identifying antecedents and consequences. Moreover, the final step of the method by Penrod and Hupcey (2005) is the integration of the data assessments into a singular theoretical

description of the concept. Although the use of antecedents and consequences is not specifically mentioned by Penrod and Hupcey (2005) in the development of this description, it is evident in the literature that they are identified and reported in the description of conceptual components, which in turn inform the description (O'Malley, Higgins, & Smith, 2015; Smith, Devane, & Murphy- Lawless, 2012).

The use of model or associated cases as integral steps in the interpretation of a concept is an additional commonality evident across the works of Norris (1982) and Walker and Avant (2018) and would appear to directly mirror the work of Wilson (1963). It has however been argued that the use of model cases that transcend context by identifiably realist methods (see table 2.3), such as those presented by Norris (1982) and Walker and Avant (2018), are in contrast to the relativist perspective of Wilson, who had originally used model cases to describe contextual bound examples (Duncan et al., 2007).

There has been particular criticism focused on the heavy reliance by Walker and Avant (2018) on the use of model and associated cases. Risjord (2009) suggests that the use of such a volume of cases by Walker and Avant may serve to illustrate, rather than provide evidence of, a concept. Furthermore, Rodgers (1989) states that the reductionism (see Table 2.3) of a concept through the use of borderline, contrary, illegitimate and invented cases lends itself to isolation of the apparent essence of a concept, rather than providing a focus on the vast number of interrelationships it may hold. It is important at this point to acknowledge that within Rodgers (2000a) method, the identification of an exemplar of a concept is indicated with comparisons evident in the literature between the use of this exemplar, and the use of model cases. These comparisons have prompted Rodgers (2000a, p. 96) to explicitly state that "this exemplar does not constitute a model case or prototype of the concept. Instead, it serves to provide a practical example of how the concept might appear in 'real life' for purposes of clarity". Nonetheless, comparisons and criticisms remain based on the boundaries the identification of an exemplar would impose on a concept (Beckwith et al., 2008; Duncan et al., 2007).

Beckwith et al. (2008, p. 1834) also criticise the reliance on cases, or reconstructions, in the approaches proposed by Wilson (1963), Norris (1982) and (Walker & Avant, 2018). They state that the use of cases raises concerns based on the hypothesis that "truths are revealed as a result of a causal explanation of the effects of a social action within the 'pure case' and the distance and difference between it and other cases". This hypothesis is based on the philosophical theories of casuistry and causality (table 2.3).

2.6. Conclusion

Over the past four decades, concept development has been a vital component in advancing the unique knowledge base of nursing and midwifery theory and practice. However, it is apparent that since the publication of Norris' first concept development method specific to the nursing and midwifery domain in 1982 there has been a proliferation of literature that debates almost every aspect of developing concepts, much of which can be attributed to the diverse philosophical viewpoints of leading meta-theorists. Ultimately, the complexity of this literature exacerbates the challenges of effective concept development, in particular for the novice researcher. Further exacerbating this challenge is the dearth of knowledge evolvement in concept development within nursing and midwifery. It is evident from the literature that there has been relatively little evolvement of the seminal methods of concept development since their inception. This highlights a need for review and possible advancement of the existing methods to ensure compatibility with the complexity of current concepts within this domain.

In addition, we acknowledge the assertation by Fawcett (2012, p. 285) that the first step in undertaking a concept analysis is to choose a conceptual model that provides "the frame of reference or context" for the analysis and data collected should be focused within the context of the chosen model. This suggestion has the potential to inform further development of current conceptual models in nursing. For instance, Neuman's systems theory (Neuman & Fawcett, 2011) would provide a frame of reference for a concept analysis of alarm fatigue, a contemporary concept of importance in critical care nursing.

In conclusion, we have provided guidance here on the methodological considerations of concept development by identifying the importance of choosing the most appropriate strategy and method based on the concept that is being developed and the conceptual problem that needs to be resolved. The paper therefore builds on the critique by Risjord (2009) of concept development where he highlights the gaps between data and results evident in many concept analyses. We provide further clarification on the approaches to data collection in concept development and how the explosion of nursing and midwifery knowledge has influenced trends in data collection. Clarification has also been provided on the intended use of various concept development strategies that have, in the past, been used interchangeably under the umbrella term of concept development.

Finally, four of the most commonly used methods of concept development methods by Walker and Avant (2018), Rodgers (2000a), Penrod and Hupcey (2005) and Norris (1982)

have been discussed in regard to their basic fundamental methodological principle, with additional information provided in the supporting tables. It is hoped that this attempt to explicate the fundamental methodological principles of each method will assist the decision making of novice researchers and provide a basis on which to build their knowledge of concept development.

2.7 Declarations

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2.7.2 Authorship Statement

I confirm that all authors meet the criteria for authorship, have approved the final article and that all those entitled to authorship are listed as authors.

2.7.3 Conflict of Interest Statement

I confirm that there are no potential conflicts of interest arising from the authors of this manuscript.

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2.8 Summary of key points

Paper 1 was written in response to the challenges faced when embarking on the development of the concept of 'women's experiences of their maternity care'. Challenges centred around the complexity of the concept development methodology literature attributed to the diverse philosophical viewpoints of leading meta-theorists and exacerbated by the dearth of knowledge evolvement in concept development within the nursing and midwifery domain.

This paper informs the choice of concept development strategy and method for use in the development of the concept of 'women's experiences of their maternity care' and informs the novice researcher or those new to concept development of the essential methodological considerations of concept development.

Guidance has been provided in this paper on the methodological considerations of concept development by identifying the importance of choosing the most appropriate strategy and method based on the concept that is being developed and the conceptual maturity of the concept that needs to be analysed.

Following this guidance, a lengthy analysis of the strategies of concept exploration, delineation, clarification was carried out whilst simultaneously assessing the level of advancement of the concept of 'women's experiences of their maternity care' in the literature to gain an insight into the current understanding of the concept. From this assessment, it became apparent that the strategies of concept clarification and concept analysis would be most appropriate to the development of this concept. Based on this decision the concept development methods by Norris (1982), Walker & Avant (2018), Rodgers (2000) and Penrod & Hupcey (2005) were analysed in depth to assess their appropriateness for the development of the concept of 'women's experiences of their maternity care'.

The concept being developed is specific to a particular population- the population of women who encounter maternity care during the perinatal period. The impact of context on this concept is especially important as the overarching concept of 'experiences' differs across specific populations.

Considering the relevance of context to this concept, each method was considered in regards to their stance on the philosophical schools of thought of 'entity' and 'dispositional'. It

became clear that the methods by Norris (1982) and Walker & Avant (2018), who subscribe to the 'entity' viewpoint which regards concepts as mental or physical 'things' that can be defined irrespective of its context of use, could not provide sufficient focus on the developmental needs of the given concept. This is because the concept of 'women's experiences of their maternity care' is an abstract concept that is linked inherently to its context of use which lends itself to the dispositional viewpoint, as shared by Rodgers (2000) and Penrod & Hupcey (2005).

Furthermore, in contrast to the more rigid description of concepts achieved using the methods by Norris and Walker & Avant, Rodgers and Penrod & Hupcey provide methods that aim to develop a concept based on its *current* state in the literature, which acknowledges the continuous evolution of concepts that is especially fitting in the midwifery domain, considering the continuous organic growth of this area.

These comparisons initially indicated that the concept analysis methods by either Rodgers or Penrod & Hupcey would be most appropriate for use. On further inspection the method by Rodgers did not in fact 'fit' with the concept as well as originally thought. This is based on the use by Rodgers of an 'exemplar' which may ultimately serve to isolate the essence, and therefore the context, of a concept.

Consequently, the principle based concept analysis method by Penrod & Hupcey (2005) was most focused on the needs of the concept of 'women's experiences of their maternity care'.

Chapter 3: Women's experiences of their maternity care: A principle- based concept analysis.

3.1 Introduction

This chapter presents paper 2. Paper 2 describes the analysis of the concept of 'women's experiences of their maternity care' under the epistemological, pragmatic, linguistic and logical principles as per the principle-based method of concept analysis by Penrod and Hupcey (2005). The outcome of this analysis is a theoretical definition of the concept.

3.2 Paper 2

Women's experiences of their maternity care: a principle- based concept analysis

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3.3 Abstract

Background Despite many countries employing the use of national and large scale regional surveys to explore women's experiences of their maternity care, with the results informing national maternity policy and practice, the concept itself is ambiguous and ill-defined having not been subject of a structured concept development endeavour.

Aim The aim of this review is to report on an in-depth analysis conducted on the concept of 'women's experiences of their maternity care'.

Methods Using the principle-based method of concept analysis by Penrod and Hupcey (2005), the concept of 'women's experiences of their maternity care' was analysed under the epistemological, pragmatic, linguistic and logical principles. The final dataset included 87 items of literature published between 1990 and 2017 retrieved from a systematic search of the MEDLINE, CINAHL, EMBASE and PSYCinfo databases.

Findings The epistemological principle identified that a theoretical definition of the concept is elusive with a variety of implicit meanings. The pragmatic principle supports the utility of the concept in scientific literature, however the lack of a theoretical definition has led to inconsistent use of the concept, as highlighted by the linguistic principle. Furthermore, the logical principle highlighted that as the concept lacks definition blurring is identifiable when theoretically positioned with related concepts.

Conclusion The outcome of this concept analysis is a theoretical definition of a previously undefined concept. This definition highlights the subjective nature of the concept, its dependency upon a woman's individual needs, expectations and circumstances and the influence of the organisation and delivery of maternity care.

Keywords experiences of care, maternity care, midwifery, nursing, concept analysis

3.4 Introduction

A paradox of modern healthcare is that as healthcare knowledge advances, bringing with it considerable benefits, the delivery of healthcare has become increasingly complex and fragmented. Since the 1960s, the growing focus on the measurement, recording, interpretation and analysis of people's experiences of healthcare has been described as an attempt to "address the imbalance of knowledge, skills, and research effort with the aim of making care more patient- centred"[1, p.8]. People's experiences of care are now regarded widely as a fundamental component of healthcare quality assurance and improvement[2]. This is evident within maternity services where the concept of women's experiences of their maternity care dominates discussions on the measurement of maternity care quality.

The value of evaluating the quality of maternity care from the perspective of service users has been recognised by many countries including the United Kingdom[3,4], United States of America[5] and Australia[6], who have employed the use of large scale regional surveys to explore women's experiences of their maternity care with findings informing maternity policy and practice. However, despite the recognition of the significance of women's experiences of their maternity care[7-10], the concept itself is ambiguous.

The ambiguity surrounding the meaning and use of the concept became apparent when preforming preliminary searches of the concept prior to embarking on a research project to develop a self- report survey instrument for use within the republic of Ireland specifically to evaluate women's experiences of their maternity care, namely, the National Maternity Experience Survey; the results of which will be used to influence national maternity policy and practice.

Following careful consideration and comparison of numerous methods of interrogating the literature, and given that "the primary utility of concept analysis is to determine the existing state of the science so that further work may be strategically and appropriately planned"[11], a concept analysis was undertaken to optimise effective application of the concept to theory, practice and research [12-14].

The aim of this paper is to present the findings of a concept analysis of 'women's experiences of their maternity care'.

3.5 Methods

It is argued that in relation to concept analysis "the selection of methods must be based on sound philosophical rationale and appropriateness for the purpose of the study"[15, p.31]. Consequently, the principle-based concept analysis method by Penrod and Hupcey[11] has guided the analysis of this concept. This method provides a robust means to determine the state of the science surrounding the concept at a given point in time. Principle based concept analysis focuses exclusively on the use of empirical literature, rather than interpretations from media, art forms or other representations[11]. Retrieved literature is analysed in accordance with four principles that represent the philosophical perspectives of epistemology, pragmatics, linguistics and logic. The degree to which the criteria of each is met by the concept of 'women's experiences of their maternity care' indicates the level of advancement, and maturity, of the concept. The outcome of the analysis is a theoretical definition of the concept as evident in the empirical literature, described as the "best estimate of probable truth"[11, p.404]. By defining the best estimate of probable truth, gaps are identified and used as a guide to inform future concept advancement research[16].

3.5.1 Data sources

The citation databases MEDLINE, CINAHL, EMBASE and PSYCinfo were searched systematically within the time limit of 1990 to May 2017. Previous research has deemed the inclusion of data from 1990 onwards sufficient to capture the evolving recognition of the importance of women's experiences to the woman and her family[17]. Penrod and Hupcey[11] recommend the inclusion of scientific literature originating from disciples relevant to the concept being analysed. Based on the multidisciplinary nature of maternity care, and as such the potential of literature from these disciples for contributing to the analysis of the concept, literature was sought from within the disciplines of midwifery, obstetrics, nursing, medicine, psychology and sociology. However, the majority of literature retrieved originated from within the midwifery domain.

Keywords and phrases used to guide the search were 'women* experience*', '(women*) N5 (opinion* OR perspective* OR perception* OR attitude* OR perceiv*)','antenatal care', 'prenatal care', 'intrapartum care', 'postnatal care', 'obstetric care', 'maternity care', 'childbirth'. N5 represents the number of words that could appear between keywords/phrase. Truncation, wildcard and proximity functions were used in accordance with the guidelines of each individual database. Boolean logic was used to combine search strings.

Papers were eligible for inclusion if they were primary research, in English, and focused upon either women's experiences of their maternity care or terms that are often used interchangeably with 'experiences' including women's opinions on, perspective on or perception of their maternity care. Papers that focused on women's experiences of their maternity care in general, as opposed to a focus on care received from a specific profession, e.g. midwives were also included. Furthermore, papers that focus on multiple experiences of maternity care, as opposed to just one were included. For example, 'women's experiences of care during labour and birth' would be included, but 'women's experience of care during caesarean section' would not be included. This criterion has been influenced by the work of Kalmakis and Chandler[18] and has been included to maintain the intent of analysing the concept of women's experiences of maternity care as a plural term.

Conversely, papers were excluded if they were deemed as being non- empirical data, if they focused solely on women's satisfaction with their maternity care, rather than their experience of that care or if they focused on a woman's maternity experience, rather than their experiences of their maternity *care* during that period. Finally, papers that addressed childbirth experiences that merit specific consideration, for example stillbirths, were excluded as, while important, these experiences require approaches focused on the particular needs and experiences of women in these groups.

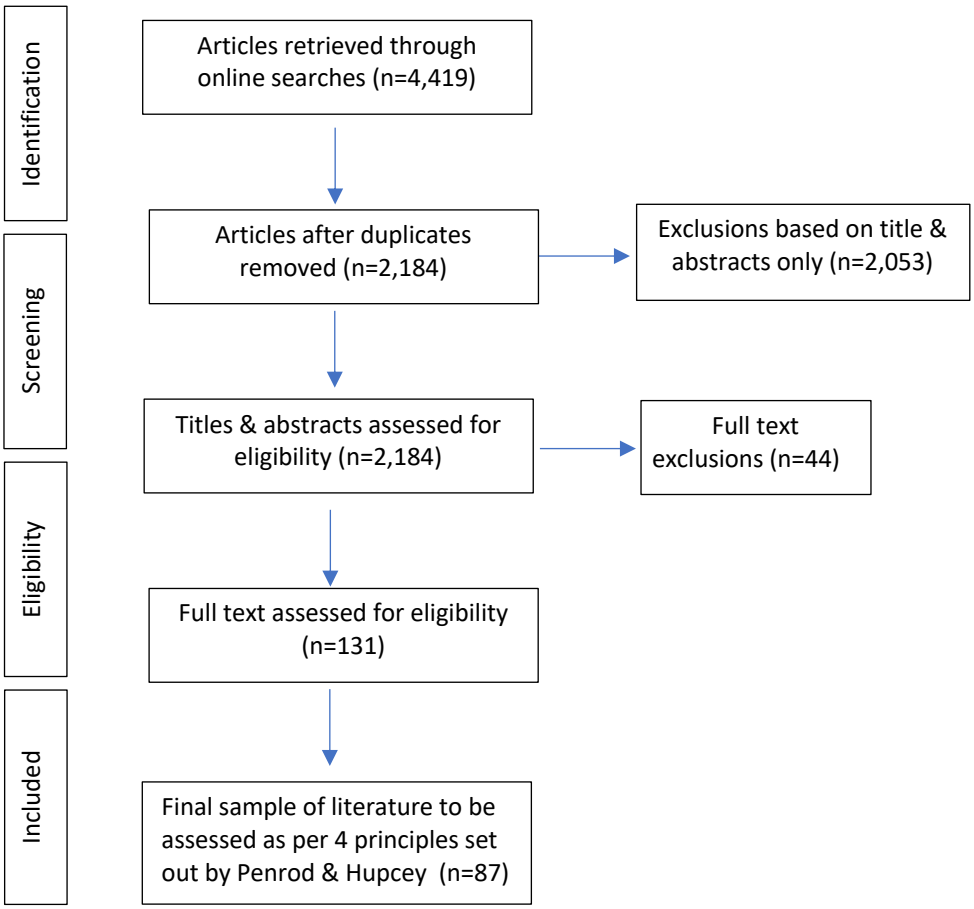
3.6 Findings

Searches yielded 2184 citations after the removal of duplicates. Following title and abstract screening by two authors (CB and MD), 2053 citations were excluded based on the predetermined exclusion and inclusion criteria.

A full text review (CB) of the remaining 131 papers resulted in a further 44 exclusions. These results are documented within the PRISMA flow diagram (figure 3.1)[19].

The final dataset comprised of 87 papers addressing the concept of 'women's experiences of maternity care' (a list of the 87 included literature items is presented in appendix 1). Key aspects of each paper (complete citation, important quotes, etc) were exported to a spreadsheet developed specifically to facilitate the analysis of this concept. The individual analysis of each paper was also added to this file allowing for easy access to, and comparison of, a relatively large dataset.

Figure 3.1. PRISMA flow diagram;



Each paper within the final dataset was analysed (by CB and confirmed by MD) using the epistemological, pragmatic, linguistic and logical principles outlined by Penrod and Hupcey[11]. Please see Table 3.1 for definitions of each of the four guiding principles and a description of their application to the concept. The findings of these four principles are presented in the following section. The conceptual components attributed to the concept, as revealed through this analysis, are then discussed and finally all findings are summated in a theoretical definition.

Table 3.1. Definitions of each of the four guiding principles and a description of their application to the concept;

Principle	*Definition of principle provided by Penrod and Hupcey*	*Description of the application of principle to the concept 'women's experiences of their maternity care'*
Epistemological principle	"Epistemology refers to the nature of knowledge. The related analytic criterion is rooted the rationalists' reliance on reason as a source of knowledge. When applied to concept analysis, the epistemological principle focuses on the discipline's distinction of a concept within the knowledge base"[15 p. 405]	The epistemological maturity of 'women's experiences of their maternity care' guided an examination of how clearly the concept has been defined in the scientific literature and how well it has been differentiated from other concepts.
Pragmatic principle	"Focusing on pragmatics, that is, on the concept's applicability in explaining or describing phenomena encountered within the discipline, the data are analysed from the perspective of usefulness. For a concept to be pragmatically mature, members of the discipline should be able to recognise manifestations of the concept; it should ring true with experience"[15 p.405]	The pragmatic principle was used to describe 'women's experiences of their maternity care' as encountered in the scientific literature and its usefulness to midwifery.
Linguistic principle	"Linguistics refers to human speech and language and, when applied to concept analysis, this principle evaluates the appropriate use of the concept. In this assessment, consistency in use and meaning are considered. There is also a more oblique consideration of context, examining the fit of the concept within context (Penrod 2001b). Concepts	The linguistic principle was used to evaluate whether the consistency of use and meaning of the concept of 'women's experiences of their maternity care' was maintained in the scientific literature.

	should be appropriate to their use in context; however, in this sense, context is a more complicated issue than merely the setting. Concepts may be context-bound (that is, limited to a pre- scribed setting or theoretical use) or stripped of context (stripped of contextual ties, of broader scope, more abstract).”[15p. 406]	
Logical principle	“Derived through the philosophical perspectives of logic, that is, focused on correct and incorrect reasoning, this principle refers to the integration of the concept with related concepts. Focusing on conceptual boundaries, the data are analysed to determine if the concept becomes blurred when positioned theoretically with other concepts”[15p. 406]	The logical maturity of ‘women’s experiences of their maternity care’ was evaluated based on the how well the concept held its boundaries when theoretically integrated with related concepts.

3.6.1 Epistemological principle;

The epistemological principle guided an exploration of how well defined the concept of ‘women’s experiences of their maternity care’ is within the empirical literature and how well differentiated it is from other concepts. Despite the recognition of the significance of the concept, no explicit definition of the concept was evident within the literature retrieved. However, implicit meaning contributes to the identification of the key aspects defining this evidently complex concept.

Penrod and Hupcey[11] have highlighted that concepts within the realm of healthcare may manifest differently at various stages of the health trajectory. This is especially true for the concept analysed here as women’s experiences of their maternity care encapsulates the antenatal, intranatal and postnatal periods during which numerous models of care and services can be encountered with several professions and professionals at various timepoints[20-25]. As such, the concept is multifaceted and diversely manifested throughout each individual woman’s pregnancy and the postpartum period[26-29].

The concept of women's experiences of their maternity care is referred to consistently, and at times interchangeably, throughout the literature with 'women's perceptions of their maternity care'[30-36] and 'women's views of their maternity care'[20,37,38] highlighting the ambiguous nature of the concept[38-40].

Given this ambiguity, it is unsurprising that the majority of the literature retrieved focused on the measurement of women's individual experiences of the maternity care they received[21,37,41-46]. Measuring experiences of care can be accomplished using mixed methods, quantitative or qualitative approaches. The literature retrieved included 44 qualitative, 30 quantitative and 13 multi or mixed method studies.

Penrod and Hupcey[11] have stated that a concept is epistemologically mature when well defined and well differentiated from other concepts. We believe the concept of 'women's experiences of their maternity care' is epistemologically immature with differentiation from similar concepts often unclear.

3.6.2 Pragmatic principle;

The pragmatic principle focused on exploring the applicability of the concept of 'women's experiences of their maternity care' in explaining or describing the phenomenon from the perspective of how it is used[11]. Considering the range, depth and frequency of the application of the concept of 'women's experiences of their maternity care', the utility of the concept appears high.

Throughout the literature, the 'use' of the concept is related to the subjective measurement of women's experiences, perception or views of various aspects of the maternity care that has been delivered to them. The concept has, for example, been measured in terms of organisational factors including access and referral to maternity services[31,47,48], organisation of care (waiting times, hospital food)[49,50], human and physical resources (medicines, water, electricity, staff)[31,51,52], continuity of care[37,53-55], privacy[33,35] and cost of care[24,33].

Interpersonal aspects of the concept that have been measured throughout the literature include cognitive support (information sharing, informed choice, consent)[21,56-58], perception of control[7,21,57], emotional support[44,58,59], being treated with respect and dignity[60-63] and staff having the knowledge and ability to inspire confidence[24,25,42,48,54,64].

Furthermore, the concept has been used to describe the measurement of physical interventions throughout maternity care for example induction and augmentation of

labour[23,44,65], pain management (pharma logical/ non pharma logical)[47], labour interventions (birthing position, episiotomy)[29,44,65] and management of the third stage of labour[23].

There is robust evidence of a high utility of the concept of 'women's experiences of their maternity care' throughout the empirical literature, suggesting that women's experience is influenced by organisational, interprofessional and birth intervention elements. Even in the absence of a precise definition, these elements suggest development in the concept's pragmatic maturity.

3.6.3 Linguistic principle;

The appropriate and consistent use of the concept of 'women's experiences of their maternity care' is explored through the linguistic principle along with the fit of the concept in context[11].

The concept of women's experiences of their maternity care is dependent on the individual woman who is a consumer of the care, and the actual care delivered. This is evident throughout the empirical literature with a wide variation of factors attributed to the interpretation of the concept across the continuum of maternity care.

Women's individual circumstances play a significant role in their experience of their maternity care[66]. It is evident that although women may experience the same maternity care within the same maternity service, their interpretation of this can vary widely [28,54]. This has been attributed to women's diverse needs[33,67], expectations[40,52], socio economic statuses [32,33,37,68,69], whether they reside in an urban versus rural setting[7], level of education[31,70,71], age[65], marital status[60], previous experiences such as abuse[60], previous experiences of maternity care[28,40,70,72] and the risk status of their pregnancy[7].

Linguistic analysis of consistency in meaning has identified that culture makes a significant contribution to the complexity of this concept and the way in which it is interpreted[54,58,70,73,74]. Cultural norms lead to variation in the standard of care provided to women with studies from India, Cambodia and Zambia each reporting the lack of availability of medicines, equipment, water, electricity and skilled staff as normal experiences for women as part of their maternity care experiences [31,71,75]. This is in contrast to the standard of care provided routinely and expected in developed countries[20,22,23,30,49,69].

Inconsistency is also apparent in relation to the timing of data collection across studies. Whilst it has been acknowledged that a woman's reported experience of her maternity care is influenced by when she is asked[35,42,43], an optimal timing has not been recommended

within the retrieved literature. Considering the complex trajectory of maternity care and the various aspects of women's experiences of their care that are evaluated, this absence may be attributed to the inappropriateness of having a single optimum timing for data collection. Consequently, dependant on the aspect of care being evaluated data collection timings varied from antenatally[22,30], prior to discharge postnatally[35,44,54,58,60,64], up to 3 months post-partum[24,41,76], between 3 months and one year postpartum[20,43] and up to two and a half years postpartum[42,56,74].

The implied meaning of the concept of 'women's experiences of their maternity care' within the retrieved literature is inconsistent. The concept is complex and may be interpreted differently depending on numerous factors which ultimately limits generalisability, therefore we are suggesting that it is linguistically underdeveloped.

3.6.4 Logical principle;

The logical principle explores the theoretical integration of the concept of 'women's experiences of their maternity care' with related concepts[11]. Given that the concept has been found to be epistemologically immature, it is unsurprising that at times the boundaries between it and other related concepts appear blurred.

The blurring between, and interchangeable use of the concept with, concepts such as 'women's perceptions of their maternity care'[30-36] and 'women's views of their maternity care'[20,37,38] has been identified previously. It is also evident that the concept is bound tightly with the concepts of 'women's satisfaction with their maternity care'[7,20,40,42,48,76] and 'quality of maternity care'[44,46,56,65,77].

The quality of maternity care can be measured from a number of perspectives including clinical outcomes such as morbidity and mortality, cost and efficiency of the service and service user feedback [44]. The measurement of 'women's experiences of their maternity care' and 'women's satisfaction with their maternity care' are two methods regularly utilised to evaluate service user feedback.

Despite the concepts of both 'women's experiences of their maternity care' and 'women's satisfaction with their maternity care' being considered widely as a marker for quality care[78,79] there are significant differences in the underlying approaches to the measurement of each. The measurement of 'women's satisfaction with their maternity care' has been criticised in the retrieved literature as being limited in its usefulness to understanding and improving quality care[7,27]. This criticism focuses upon a tendency to extract high reported

level of contentment and acquiescence bias that may mask critical issues[22,27,67]. As satisfaction with care has generally been found to be reported as high, regardless of the actual quality of care that was being provided, focus has shifted from the measurement of 'women's satisfaction with their maternity care' to 'women's experiences of their maternity care' as a means to elicit more specific and relevant reports on the quality of maternity care received[27].

It is clear that the concept of 'women's experiences of their maternity care' is closely related to, yet a separate entity from, the concepts of 'women's satisfaction with their maternity care' and 'quality of care'. However, the apparent blurring between the concept being analysed and 'women's perception of their maternity care' and 'women's views of their maternity care' highlights that clear conceptual boundaries between each of these latter concepts do not exist. Consequently, we propose that the concept of 'women's experiences of their maternity care' is judged logically immature.

3.6.5 Summary of principle-based analysis;

The evidence reviewed supports the utility of the concept of 'women's experiences of their maternity care' (pragmatic principle) yet the lack of a precise definition of the concept, and as such the reliance on implied meaning (epistemological principle), had led to inconsistent use of a concept (linguistic principle) that blurs when theoretically positioned with other concepts (logical principle).

3.7 Conceptual components of 'Women's experiences of their maternity care'

Through the analysis of 'women's experiences of their maternity care', conceptual components attributed to the concept are identified. These are categorised as antecedents (preconditions that influence the concept) and consequences (effects of the concept).

3.7.1 Antecedents;

The physical antecedent to women's experiences of maternity care is pregnancy. Once pregnant, a woman accesses and experiences maternity care. There are, however, barriers to this care. These may be practical such as being unaware of why, where and how to access services[40,48,80], difficulty in physically attending the services due to personal circumstances[50,75,81] or being unable to afford to pay for those services [38,75,82]. There may be perceived barriers to care such as fear of experiencing disrespectful or abusive care[29,60] and culturally inappropriate care, for example the unavailability of female staff for women who did not want to be treated by male staff due to their cultural beliefs[59,80].

Affective antecedents to women's experiences of their maternity care are a woman's needs and expectations of their maternity care. Each has a significant effect on a woman's individual interpretation of their experiences of care. Akin to Maslow's hierarchy of needs[83], women's maternity care needs, based on their personal and cultural circumstances, vary widely from basic needs such as food, water, medicines and electricity[31] to self-actualisation needs such as feeling in control of their maternity care and the choices that are to be made as part of that care[7,21,68,77].

Similarly, women's expectations of their maternity care are affected by their personal and cultural circumstances including their previous experience of maternity care[42,81,84], the standard of maternity care provided[35,46] and personal preparation[21].

3.7.2 Consequences;

Consequences of women's experiences of their maternity care are based upon each woman's interpretation of that care. The perception of either negative and positive experiences of maternity care carry the potential to influence a woman's future development as a woman and mother[74]. More specifically, positive experiences of maternity can lead to a woman's increased self-confidence[30,63], improved concordance with and attendance at maternity care services[70] and improved outcomes[43]. Conversely, negative experiences of maternity care can lead to women feeling alone, hurt, afraid, angry and anxious[28,34,42,85,86] which promotes distrust of maternity services affecting future use[21,30,48,50,61].

3.8 Theoretical definition

The concept of 'women's experiences of their maternity care' is ambiguous. Through the integration of theoretical insights from the literature, this concept analysis has revealed a greater understanding of the complex and multi-dimensional nature of, and the interaction between, the concept, its antecedents and subsequent consequences. This understanding has facilitated the development of the following theoretical definition;

'Women's experiences of their maternity care' is a complex concept referring to women's interpretation of their care encounters within the maternity services. It is subjective in nature and evolves throughout the course of pregnancy, childbirth and the postpartum period. It is dependent upon a woman's individual needs and expectations, shaped by their personal circumstances and influenced by how their care is organised and delivered.'

3.9 Discussion

The purpose of the analysis of 'women's experiences of their maternity care' using the principle-based method by Penrod and Hupcey[11] was to reveal the current state of empirical knowledge surrounding this concept in order to facilitate its advancement. Although it is evident that much work has taken place on defining people's experiences of healthcare in general[87,88], these definitions are not applicable directly to the area of maternity care as the spectrum of care varies significantly.

Despite the utility of the concept being high, and the recognition of the importance of women's experiences of their maternity care evident from a recent policy guideline published by the World Health Organization[10],a conceptually derived definition of the concept was absent from the literature and implicit meaning abounds. This affects the epistemological maturity of the concept directly and the differentiation between it and related concepts such as 'women's perception of their maternity care' and 'women's views of their maternity care', emphasising the need for the development of a universally accepted definition.

Through analysis of the concept under the epistemological and pragmatic principles, its multifaceted nature is highlighted with the concept encompassing organisational and interpersonal aspects of care as well as physical interventions throughout the continuum of maternity care. Through an examination of the linguistic principle and the identification of the concept's antecedents and consequences, it is evident that these aspects of care are context dependant with interpretations of the concept reliant on a woman's needs and expectations of care, as influenced by individual circumstances. This clearly accentuates the impact that individualised maternity care has upon each woman's perceived experience of that care.

The frequent measurement of 'women's experience of their maternity care' has been identified throughout this analysis as a means for assessing quality care. Furthermore, within the logical principle the contrast between this measurement (report of actual care) and that of the concept of 'women's satisfaction with their maternity care' (contentment with care) has been highlighted.

3.10 Conclusion

Despite the international focus on the concept of 'women's experiences of their maternity care', as evidenced from the inclusion in this analysis of literature from 25 different

countries, it is apparent that this concept is philosophically immature. This immaturity stems from the lack of a definitive agreed definition of the concept, ultimately hindering its effective utility. Further advancement of the concept of 'women's experiences of their maternity care' has the potential to facilitate greater utility for research application. This concept analysis, and theoretical definition, serve as a foundation for future research, particularly in defining this evidently complex concept.

3.11 Declarations

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3.11.2 Author agreement

- I can confirm that the article being submitted is the original work of the authors submitting;
- I can confirm that this article has not received prior publication and is not under consideration for publication elsewhere;
- I can confirm that all authors have seen and approved the manuscript being submitted;
- I can confirm that the authors abide by the copyright terms and conditions of Elsevier and the Australian College of Midwives.

3.11.3 Conflict of interest

I confirm that there are no potential conflicts of interest arising from the authors (CB, DD, MW, RG & MD) of this manuscript.

3.11.4 Sources of support for research- funding

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3.11.5 Ethical statement

Not required.

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3.12 Summary of key points

To facilitate the development process of a survey instrument to evaluate women's experiences of their maternity care, a clear understanding of the concept of 'women's experiences of their maternity care' was required. Paper 2 developed the concept of 'women's experiences of their maternity care' using a dataset of 87 literature items published between 1990 and 2017 that had been sought from the disciplines of midwifery, obstetrics, nursing, medicine, psychology and sociology. The principle-based method of concept analysis by Penrod and Hupcey (2005) was chosen, and the concept of was analysed under the epistemological, pragmatic, linguistic and logical principles. The findings of this concept analysis provide a foundation for future research on this concept, in addition to informing future work presented within this thesis.

This epistemological maturity of the concept highlights the differentiation between 'women's experiences of their maternity care' and related concepts such as 'women's perception of their maternity care' and 'women's views of their maternity care'. This identification informed the search strategy in the following systematic review (Chapters 4 and 5) and the inclusion of such concepts in order to adequately retrieve all literature related to the concept of 'women's experiences of care'.

Furthermore, analysis under the logical principle highlighted the contrast between the measurement of experiences of care and that of the concept of satisfaction with care. This contrast informed the systematic review (Chapters 4 and 5) where, based on the marked differences between the two concepts, literature that focused on instruments measuring women's level of satisfaction with their care was excluded from inclusion.

Chapter 4: Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments.

4.1 Introduction

This chapter presents paper 3. Paper 3 is the protocol for a systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care. This protocol identifies *a priori* methods for completing the review and proposed methods to guide the evaluation of the methodological and psychometric quality of relevant instruments.

Chapter 4: Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments.

4.2 Paper 3

Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments

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Chapter 4: Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments.

4.3 Abstract

Background The use of survey instruments to measure women's experiences of their maternity care is regarded internationally as an indicator of the quality of care received. To ensure the credibility of the data arising from these instruments the methodological quality of development must be high. This paper reports the protocol for a systematic review of self-report instruments used to measure women's experiences of their maternity care.

Methods Citation databases CINAHL, Ovid MEDLINE and EMBASE will be searched from 2002 to 2018 using keywords including; women, experience, maternity care, questionnaires, surveys, self- report. Citations will be screened by two reviewers, in two rounds, for inclusion as per predetermined inclusion and exclusion criteria. Data extraction forms will be populated with data, extracted from each study, to evaluate the methodological quality of each survey instrument and the criteria for good measurement properties using quality criteria. Data will also be extracted to categorise the items included in each survey instrument. A combination of a structured narrative synthesis and quantitate summaries in tabular format will allow for recommendations to be made on the use, adaptation and development of future survey instruments.

Discussion The value of survey instruments that evaluate women's experiences of their maternity care, as a marker of quality care, has been recognised internationally with many countries employing the use of such instruments to inform policy and practice. The development of these instruments must be methodologically sound and the instrument itself fit for the purpose and context in which it is used. This protocol describes the methods that will be used to complete a systematic review that will serve as a guide for choosing the most appropriate existing instruments to use or adapt so that they are fit for purpose, in addition to informing the development of new instruments.

Systematic review PROSPERO registration CRD42018105325

Keywords midwifery, maternity, measurement, experiences of care, quality care, systematic review protocol, instruments, questionnaires, surveys.

4.4 Background

The measurement of quality healthcare from the service user's perspective is a crucial element in the application of quality assurance and improvement processes (1, 2). Much of the quantitative measurement of the quality of care from the service user's perspective has focused on two aspects i.e., satisfaction and experiences of care. The use of survey instruments to measure satisfaction with healthcare dates back to the 1950s (3). However, the adequacy of satisfaction as a measure of quality has been questioned because it is indirectly related to the quality of care received (4, 5). Satisfaction is also, generally, rated high by service users regardless of the quality of care that has been received, and has been attributed to a reluctance to criticise caregivers, as well as service users valuing what is known, or available, to them (6, 7). Given these limitations, the use of survey instruments that focus on the measurement of experiences of care, as an indicator of quality, has become more prominent. In contrast to satisfaction, experiences of care focus on accounts of the care received. (8, 9). Survey instruments that measure experiences of care minimise the need for respondents to make evaluations on their care and focus on the reporting of what did or did not happen (9).

A reliance on the measurement of experiences of care to inform policy and practice is evident within maternity services (10-12). There are, however, many challenges to measuring women's experiences of their maternity care. Maternity care is complex, encompassing numerous services at various time points, with a wide variety of professions and professionals along a temporal care continuum (13). Furthermore, models of maternity care vary significantly between jurisdictions. The complex nature of maternity care coupled with the variances in services internationally, has led to a proliferation of instruments that each seek to gather data on the quality of various aspects of these services from the perspective of women as service users (4).

Measurement of women's experience of maternity care requires robust instruments. Clinicians, managers, policy makers and researchers must have access to the processes of development and measurement properties of these instruments when using or adapting existing instruments or developing new instruments to ensure that the resulting data, often used to direct policy and practice, is credible (14, 15). The aim of this review is to systematically review and critically appraise self- report survey instruments measuring women's experiences of their maternity care. The results of this review will serve as the basis

of future research on the use, adaptation and development of self- report survey instruments internationally to measure women's experiences of their maternity care. For example, within the republic of Ireland specifically, these results will inform the development of the National Maternity Experience Survey (see: https://yourexperience.ie/maternity/about-the-survey/).

The objectives of the review are to;

1. Identify self- report survey instruments that are available internationally to measure women's experiences of their maternity care;
2. Categorise items included within each survey instrument;
3. Evaluate the methodological quality of each survey instrument;
4. Evaluate the criteria for good measurement properties using quality criteria.

4.5 Methods and design

4.5.1 Design and registration

The review protocol was submitted to the International Prospective Register of Systematic Reviews (PROSPERO) on 14/08/2018 (No. CRD42018105325). The protocol has been developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta- Analysis Protocols (PRISMA- P) statement (16) (appendix 2) and the completed review will be reported in accordance with the PRISMA guidelines (17).

4.5.2 Search strategy

An extensive literature review will be performed and refined using the following citation databases; CINAHL, OVID Medline and Embase. Searching will be limited to literature published from 2002 onwards. This is based on a literature search by Messent (18) who found that up until this point no published maternity survey instruments had been validated.

An example of a complete search to be carried out is included in table 4.1. The search strategy was developed iteratively based on the authors experience (including experienced clinicians and systematic reviewers) and a review of strategies in related reviews. The strategy was then tested in three databases and revised to achieve the best balance between sensitivity and specificity of retrieved citations. The search strategy included in table 4.1 has been formulated for use in the CINAHL database and will be adapted to respective databases.

Table 4.1. Search strategy for CINAHL database;

Search #	*Search string*
1	(women*) N5 (experience* OR perspective* OR perception* OR perceiv* OR view*)
2	(patient*) N5 (experience* OR perspective* OR perception* OR perceiv* OR view*)
3	#1 OR #2
4	(MH "Prepregnancy Care") OR (MH "Prenatal Care") OR (MH "Postnatal Care") OR (MH "Obstetric Care") OR (MH "Perinatal Care") OR (MH "Patient Care") OR (MH "Intrapartum Care")
5	(MH "Childbirth")
6	(MH "Maternal Health Services") OR (MH "Obstetric Service") OR (MH "Maternal-Child Care") OR (MH "Nurse-Midwifery Service") OR (MH "Midwifery Service")
7	"maternity care" OR childbirth OR “maternity services”
8	“antenatal care” OR “prenatal care” OR “intrapartum care” OR “postnatal care” OR “obstetric care”
9	“antenatal services” OR “prenatal services” OR “intrapartum services” OR “postnatal services” OR “obstetric services”
10	#4 OR #5 OR #6 OR #7 OR #8 OR #9
11	(MH "Process Assessment (Health Care)") OR (MH "Health Care Delivery")
12	“health care measurement” OR “maternity care measurement”
13	(MH "Structured Questionnaires") OR (MH "Open-Ended Questionnaires") OR (MH "Questionnaires")
14	(MH "Surveys")
15	(MH "Patient-Reported Outcomes")
16	questionnaire* OR survey* OR measure* OR tool* OR assessment OR validation OR “patient reported” OR evaluat* OR “self-report”
17	#11 OR #12 OR #13 OR #14 OR #15 OR #16
18	#3 AND #10 AND #17

Footnote for Table 4.1: MH represents CINAHL headings. N5 represents the number of words that could appear between keywords/phrase.

4.5.3 Data screening

Once all database searches have been completed, citations will be exported to the reference manager software Endnote X7 and duplicates removed. Remaining citations will then be exported to Covidence (19) and screened by two reviewers for inclusion using predetermined inclusion and exclusion criteria, set out in the following section. The first

round of screening will assess eligibility based on title and abstract. Round two of screening will assess the eligibility of all remining studies based on a full text review. All abstracts and full texts will be sourced as necessary. Disagreements will be resolved through consensus with a third reviewer. Reasons for exclusion decisions at full-text (round 2) will be documented. References of included papers will be analysed for additional literature on the theoretical, empirical and psychometric development of instruments not identified in the original searches.

4.5.4 Inclusion & exclusion criteria

Inclusion criteria;

1. Literature that describes the theoretical or empirical development, or tests the psychometrics, of self- report instruments that measure women's experiences of their maternity care;
2. Literature that focuses on self- report instruments that measure women's experiences of their maternity care from the perspective of women, rather than staff, families or others;
3. English language;
4. Primary research;
5. Literature that focuses on women's perceptions or views on their care are to be included as often these terms are used interchangeably with 'experiences';
6. Literature that focuses on the measurement of women's experiences of their entire maternity care process (from conception up to ten days postpartum), rather than one temporal aspect of care specifically, e.g. antenatal care;
7. Literature that focuses on the measurement of experiences of maternity care as received by women in general, rather than a focus on participants by specific demographics e.g. teenage pregnancy.

Exclusion criteria;

1. Case reports and series, systematic reviews or meta- analysis;
2. Literature that focuses on indirect evidence of measurement properties of an instrument; for example, if an instrument is being used within a randomised controlled trial or alternative study, or if the instrument is being used as part of the validation process of an alternative instrument. This exclusion criterion is based on the recommendation of Terwee, deVet (20) who suggest that not only is the process

of sourcing this literature difficult but it is also a challenge to interpret the evidence provided in terms of validity and responsiveness as no hypothesis about these aspects of the instruments are formulated and tested in such studies;

3. Literature that focuses on instruments that measure women's level of satisfaction with their care, rather than their actual experience of that care, as per the methodological limitations with satisfaction as discussed earlier in this paper;
4. Literature that focuses on care received from a specific profession, e.g. midwives, as opposed to a measurement of women's experiences of their maternity care in general;
5. Literature that focuses on brief versions of full instruments that have been reported elsewhere;
6. Childbirth experiences that merit specific consideration, for example stillbirths. These experiences require more specific approaches based on the needs and experiences of women in these groups.

4.5.5 Data extraction process

A prespecified data extraction form will be designed and populated with data extracted from each study. This form will be piloted on three studies independently by two reviewers and compared to ensure consistency in the interpretation of the data being extracted and modified as required. Based on the expectation that some instruments will be the focus of multiple studies; these studies will be grouped together to reduce data extraction duplication (21). Where the same data has been reported in more than one place, the more comprehensive version will be included.

A stepped approach will be employed to facilitate the extraction of data. Double data extraction will commence with both reviewers independently analysing 10% of the overall number of studies for inclusion in the review. The results of this initial analysis will be compared, and errors resolved through discussion. If significant discrepancies (>10% of all data items extracted per study) are apparent, then double data extraction will continue for a further 10% of studies. The results will again be compared, and errors discussed. If there are still significant discrepancies at this stage of the analysis, double data extraction will continue for all studies for inclusion in the review. If significant discrepancies are not apparent at this stage each reviewer will take 50% of the remaining studies and extract data independently. Disagreements will be resolved through consensus with a third reviewer.

4.5.6 Evaluation of methodological quality and quality of results

The COnsensus- based Standards for the selection of health Measurement Instruments (COSMIN) steering committee have developed a guideline for systematic reviews of patient-reported outcome measures (PROM) (22). This guideline, adapted as necessary to suit this review, will be used to guide the evaluation of the measurement properties of each included study.

Each measurement property will be evaluated via a three-step process; 1. Evaluate the methodological quality of each included study, 2. Evaluate the criteria for good measurement properties using quality criteria and 3. Summarise the evidence.

1. Evaluate the methodological quality of each included study;

This COSMIN Risk of Bias checklist (23, 24) is an adaptation of the original COSMIN checklist (25). The Risk of Bias checklist has been developed specifically for use in systematic reviews of PROMs to assess the risk of bias of studies on measurement properties.

The checklist contains one box on development and nine boxes for measurement properties (content validity, structural validity, internal consistency, cross cultural validity/ measurement invariance, reliability, measurement error, criterion validity, hypothesis testing for construct validity and responsiveness) (23). The COSMIN expert group reached international consensus on the taxonomy, terminology and definitions of these measurement properties; full explanations are available from Mokkink, Terwee (26).

Each box contains between 3 and 35 items and applicable items will be scored for each included study based on a four-point rating scale (i.e. ‘inadequate’, ‘doubtful’, ‘adequate’ or ‘very good’). An overall score for the methodological quality of a given measurement property is determined by the lowest rating that is assigned to the items within a given box (23).

2. Evaluate the criteria for good measurement properties using quality criteria;

The measurement properties of each included instrument will be evaluated using the COSMIN recommended criteria for good measurement properties, as outlined in Table 4.2 (15, 22, 27).

Table 4.2; COSMIN recommended criteria for good measurement properties;

Measurement property	*Rating*	*Criteria*
Structural validity	+	**Classical Test Theory (CTT)** Confirmatory factor analysis: Comparative Fit Index or Tucker Lewis Index or comparable measure > 0.95 OR Root Mean Square Error of Approximation < 0.06 OR Standardised Root Mean Residuals < 0.08 **Item Response Theory (IRT)/Rasch** No violation of unidimensionality: Comparative Fit Index or Tucker Lewis Index or comparable measure > 0.95 OR Root Mean Square Error of Approximation < 0.06 OR Standardised Root Mean Residuals < 0.08 *AND* no violation of local independence: residual correlations among the items after controlling for the dominant factor < 0.20 OR Q3's < 0.37 *AND* no violation of monotonicity: adequate looking graphs OR item scalability > 0.30 *AND* adequate model fit: IRT: $\chi 2 > 0.001$ Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z-standardised values > −2 and < 2
	?	**CTT**: not all information for '+' reported **IRT/Rasch**: model fit not reported
	-	Criteria for '+' not met
Internal consistency	+	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) ≥ 0.70 for each unidimensional scale or subscale
	?	Criteria for "At least low evidence for sufficient structural validity" not met
	-	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) < 0.70 for each unidimensional scale or subscale
Reliability	+	Interclass Correlation Coefficient (ICC) or weighted Kappa ≥ 0.70
	?	ICC or weighted Kappa not reported
	-	ICC or weighted Kappa < 0.70
Measurement error	+	Smallest Detectable Change (SDC) or Limits of Agreement (LoA) < Minimal Important Change (MIC)

	?	MIC not defined
	-	SDC or LoA > MIC
Hypotheses testing for construct validity	+	The result is in accordance with the hypothesis
	?	No hypothesis defined (by the review team)
	-	The result is not in accordance with the hypothesis
Cross-cultural validity\measurement invariance	+	No important differences found between group factors (e.g. age, language) in multiple group factor analysis OR no important differential item functioning (DIF) for group factors (McFadden's R < 0.02)
	?	No multiple group factor analysis OR DIF analysis performed
	-	Important differences between group factors OR DIF was found
Criterion validity	+	Correlation with gold standard ≥ 0.70 OR Area Under the Curve (AUC) ≥ 0.70
	?	Not all information for '+' reported
	-	Correlation with gold standard < 0.70 OR AUC < 0.70
Responsiveness	+	The result is in accordance with the hypothesis OR AUC ≥ 0.70
	?	No hypothesis defined (by the review team)
	-	The result is not in accordance with the hypothesis OR AUC < 0.70

The reported findings for each measurement property will be compared with the predetermined criteria described in Table 4.2, and the adequacy of results of each study will be rated as sufficient (+), intermediate (?) or insufficient (-).

3. Summarising the evidence;

The results retrieved from 1 & 2 above will be evaluated for consistency across studies. If the results are consistent they will be summarised, compared against the criteria for good measurement properties and deemed as (+) sufficient, (-) insufficient, (±) inconsistent, or intermediate (?).As per COSMIN guidance (22), we will explore any inconsistency in results. If an explanation is found, an overall rating of the instrument will be provided for several subgroups. The subgroups of interest include ethnicity, religion, sexual orientation, delivery type, age of participants (e.g. under 18) , type of country (developing vs. developed), setting (public hospital, private clinic, midwife led, etc.), multiple vs. singleton pregnancy, nulliparous vs. multiparous women.

4.5.7 Additional evaluation

As per the stated study objectives, additional evaluations will be made on the items included within each survey instrument. The purpose of categorising items that are included within each instrument is to evaluate what aspects of care are being measured as it has been acknowledged that a limitation of survey instruments, and possibly the reason why there has been a proliferation of such instruments in recent times, is that feedback is provided only on aspects of care that are included specifically [9]. The inclusion of this objective allows for the identification of the most commonly used items within survey instruments that encompass the entire maternity care process and will highlight gaps or inconsistencies across the domains of all instruments. A data extraction form has been developed to standardise the collection of information related to the items included within each survey instrument and to aid analysis (Table 4.3). All relevant information that is available within the included studies will be extracted as direct quotes to populate the data extraction form.

Table 4.3. Data extraction form;

General information	Original author
	Title
	Journal
	Year
	Country of Origin
	Language & available translations
	Background of the jurisdictions healthcare
	Study design
	Study aim
Instrument details/ items included	Outcome measure
	Purpose/ use
	Number of domains
	Number of items
	Structure of domains and items
	List of complete bank of items included*
	Scale design (Type of scale e.g. Likert, no. of points of scale
	Target population- inclusion and exclusion criteria

*Footnote for Table 4.3: *Bank of items included within each survey instrument to be recorded within an additional file under the headings; antenatal, intranatal, postnatal, misc.*

4.5.8 Planned methods of analysis

General information and instrument detail will be summarised in tabular format. The reasons for excluding studies at full text will also be reported in tabular format. The analysis of each retrieved item pool and the use of this in later phases of the project will be published separately.

The methodological quality and results of each instrument will be compared using a structured narrative synthesis. Additionally, an overview of the combined results of measurement properties will be summarised in tabular format as described above under the subheading 'Summarising the evidence'. This combination of analysis will allow for recommendations to be made on the use, adaptation and development of future survey instruments measuring women's experiences of their maternity care.

4.6 Discussion

The value of survey instruments that measure women's experiences of their maternity care has been recognised internationally with many countries employing the use of such instruments to inform policy and practice. In influencing policy and practice, the data arising from these instruments is used to direct limited resources within maternity services. As such, the development of instruments must be methodologically sound and the instrument itself fit for the purpose and context in which it is used to ensure the resulting data is credible. This systematic review will serve as a guide for choosing the most appropriate existing instruments to use or adapt so that they are fit for purpose, in addition to informing the development of new instruments. This review is timely, not only as it fills a gap in the current literature, but also because the use and development of such instruments is increasing internationally.

4.7 Declarations

4.7.1 Acknowledgements

Not applicable.

4.7.2 Authors contributions

I, Claire Beecher as guarantor of the review, confirm that all authors (CB, RG, LO'D, ER, MW, MB & DD) meet the criteria for authorship, have approved the final article and that all those entitled to authorship are listed as authors.

4.7.3 Competing interests

The authors declare that they have no competing interests.

4.7.4 Funding

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4.7.5 Ethical approval and consent to participate

Not applicable.

4.7.6 Consent for publication

Not applicable.

4.7.7 Availability of data and material

Not applicable.

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4.8 Summary of key points

Paper 3 reports the protocol to guide a systematic review of self-report instruments used to measure women's experiences of their maternity care. The protocol has been developed in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA- P) statement and was submitted to the International Prospective Register of Systematic Reviews (PROSPERO) on 14/08/2018 (No. CRD42018105325).

Chapter 5: Measuring women's experiences of maternity care: a systematic review of self-report survey instruments.

5.1 Introduction

This chapter presents paper 4, the systematic review of self-report survey instruments measuring women's experiences of maternity care. The primary purpose of the review was to evaluate the methodological and psychometric quality of included instruments to inform the development of the NMES. The review will also inform future research on the use, adaptation, and development of new self-report survey instruments that measure women's experiences of their maternity care.

5.2 Paper 4

Measuring women's experiences of maternity care: a systematic review of self-report survey instruments.

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BEECHER, C., GREENE, R., O'DWYER, L., RYAN, E., WHITE, M., BEATTIE, M. & DEVANE, D. Measuring women's experiences of maternity care: a systematic review of self-report survey instruments. *Women and Birth (accepted for publication May 2020, awaiting publication details)*

5.3 Abstract

Background Recognition of the measurement of women's experiences of their maternity care as a critical component of care quality evaluation has led to a proliferation of instruments to measure this concept. However, the suboptimal methodological and psychometric quality of these instruments, or the lack of reporting of same, hinders the credibility and efficient use of the arising results, which often serve as an indicator for the direction of limited resources within maternity services.

Aim To review systematically and critically appraise self-report survey instruments measuring women's experiences of their maternity care.

Methods A systematic review was conducted using comprehensive searches of the CINAHL, OVID MEDLINE and EMBASE citation databases. Inclusion and exclusion criteria were applied, and a stepped approach employed to facilitate evaluation of the methodological and psychometric quality of included instruments.

Findings 4,905 records were obtained from database searches. Additional records were obtained via reference checking and by expert suggestion. Following stepped screening, 40 papers related to 20 instruments are included in this review. Findings indicate that evidence of the methodological and psychometric quality have not been reported for many included instruments.

Conclusions Published evidence of the methodological and psychometric quality of self-report survey instruments to evaluate women's experiences of their maternity care is lacking. The conduct and reporting of future development processes of such instruments can be improved.

Systematic review PROSPERO registration CRD42018105325

Keywords Systematic review; midwifery; maternity care; Surveys and Questionnaires; experiences of care; quality care.

5.4 Introduction

In the broader healthcare context, evaluation of consumer experiences of healthcare is important not only for accountability and quality care improvement[1] but also because of the positive association between consumer experiences, safety and clinical effectiveness[2].

The use of survey instruments to evaluate consumer experiences of healthcare, as an indicator of quality of care, have come to prominence in recent decades, having been preceded by the use of instruments that evaluate satisfaction with care[3]. This has been accompanied with a concomitant decline in the use of instruments to evaluate satisfaction with care, which, unlike experiences, focuses on how a person *felt*.[4]

The use of survey instruments to evaluate women's experiences of their maternity care specifically, as an indicator of quality of care, is commonplace internationally with the results of routine national or large-scale instruments used to inform changes in policy and practice. Despite various aspects of women's experiences of their maternity care having been the focus of several research endeavors within Ireland[5-9], a national survey evaluating these experiences has not yet been implemented in Ireland.

In response to the National Standards for Safer Better Maternity Services[10] published to support the implementation of the National Maternity Strategy, a policy decision was taken to develop and implement a self-report National Maternity Experience Survey[11] for use within the Republic of Ireland[12].

Given the public resources used in developing and implementing such large scale national surveys, and the impact that the arising results have on the allocation of limited resources within maternity services, it is important that the results of such surveys be credible[13]. The credibility of results is associated with the methodological and psychometric quality of the instrument used[14].

The purpose of this systematic review is to (a) inform the development of the Irish National Maternity Experience Survey and (b) inform future research on the use, adaptation, and development of new self-report survey instruments that measure women's experiences of their maternity care.

Chapter 5: Measuring women's experiences of maternity care: a systematic review of self-report survey instruments.

The objectives of the review are to:

1. Identify self-report survey instruments available internationally that measure women's experiences of their maternity care.
2. Identify published developmental studies related to each survey instrument;
3. Evaluate the methodological quality of each survey instrument;
4. Evaluate the criteria for good measurement properties using quality criteria;
5. Categorise items included within each survey instrument.

5.5 Methods

5.5.1 Design and registration

The conduct and design of this systematic review follow the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidance for completing systematic reviews of patient-reported outcome measures[15] adapted as necessary to suit this review. A protocol was written a priori[16] and registered in the international prospective register of systematic reviews, accessible at https://www.crd.york.ac.uk/PROSPERO/ (registration number CRD42018105325).

5.5.2 Search strategy

The citation databases CINAHL, OVID Medline and Embase were searched systematically for literature published from 2002 to the time of searching (July 2018). The search strategy consisted of three groups of search terms and Boolean logic was used to combine search strings; 1. women's experience, perspective, perception or views 2. maternity care or services, 3. measurement keywords such as 'questionnaire' or 'surveys'. For the purpose of this review, the authors define maternity care as the care received from conception up to six weeks postpartum. Truncation, wildcard and proximity functions were used in accordance with the guidelines of each individual database.

All resulting literature was exported to Endnote X7[17] and duplicates removed. An additional search was completed in October 2019 for any newly published data related to the instruments arising from the 2018 search to ensure completeness of reporting.

5.5.3 Data screening

A 13- step screening form developed based on predetermined inclusion and exclusion criteria (appendix 3) was applied to all literature that resulted from the database searches.

Literature was eligible for inclusion if it was primary research, in English, that described the theoretical or empirical development, or tested the psychometrics, of self-report survey instruments measuring 'women's experiences of their maternity care'. Literature was also included if it focused on concepts that are often used interchangeably with 'women's experiences of their maternity care' including women's perceptions or views on their care. Literature that focused on instruments that measure women's experiences of their maternity care from the perspective of women, rather than staff, families or others was included. Literature that focused on the measurement of women's experiences of their entire maternity care process (from conception up to ten days postpartum), rather than one temporal aspect of care specifically was also included. Furthermore, literature that focused on the measurement of experiences of maternity care as received by women in general, rather than a focus on participants by specific demographics e.g. teenage pregnancy was included.

Conversely, literature was excluded if it was a case report or series, systematic review, meta-analysis or if it was a brief version of a full instrument reported elsewhere. Literature that focused on indirect evidence of measurement properties of an instrument was excluded; for example, if an instrument was being used within a randomised controlled trial or alternative study, or if the instrument is being used as part of the validation process of an alternative instrument. Literature that focused on instruments that measure women's level of satisfaction with their care, in addition to literature that focused on care received from a specific profession, e.g., midwives, as opposed to a measurement of women's experiences of their maternity care in general, were also excluded. Finally, literature that addressed childbirth experiences that merit specific consideration, for example stillbirths, were excluded. These experiences require more specific approaches based on the needs and experiences of women in these groups.

Data were screened by title and abstract, followed by full-text screening using Covidence software[18]. All screening was completed by two reviewers independently (CB & DD) and disagreements resolved through face to face discussion. Following the screening process, the references of retained papers for inclusion were reviewed for additional literature on the theoretical, empirical and psychometric development of instruments not identified in the original searches. In addition, international experts in the area of maternity care survey development were contacted and asked to suggest studies for inclusion.

5.5.4 Data extraction process

A data extraction workbook, based on an excel spread sheet supplied by COSMIN to assist with the organisation of data extraction[19], was modified and used as part of a stepped approach to extract data from each included study[16]. The majority of instruments included were included in multiple studies so related literature was grouped to minimise data extraction duplication.

5.5.5 Evaluation of methodological quality, and quality of results

Each included instrument was evaluated in its entirety despite several instruments identifying that they had embedded pre-existing scales that evaluate one temporal aspect of care e.g. experiences of care received during labour and birth, within their instruments.

1. Evaluation of the methodological quality of each study on measurement properties;

The evaluation of the methodological quality of each study on measurement properties was guided by the COSMIN Risk of Bias Checklist[14]. The COSMIN Risk of Bias checklist is an adaptation of the original COSMIN checklist[20,21] developed specifically for use in systematic reviews of Patient Reported Outcome Measures (PROMs) to assess the risk of bias of studies on measurement properties. COSMIN authors were contacted prior to commencing this review and it was determined that the updated checklist was most appropriate for use. The checklist contains 10 separate checklists referred to as 'boxes'. One box evaluates PROM development and nine evaluate measurement properties, with each box containing between 3 and 35 items. Applicable items are scored for each included study based on a four-point rating scale (i.e. 'inadequate', 'doubtful', 'adequate' or 'very good'). An overall score for the methodological quality of a given measurement property is determined by the 'lowest score counts' i.e. the lowest rating that is assigned to the items within a given box[14].

This checklist was developed specifically for use in systematic reviews of PROMs. It was necessary therefore to adapt it in places to ensure applicability to this review. The modified Risk of Bias checklist[14], as described below, is presented in appendix 4. Details on the consensus reached by the COSMIN expert group on the taxonomy, terminology, and definitions of the following measurement properties can be found elsewhere[22].

1. Instrument development

Box one relates to instrument development; part A relates to the quality of research studies performed to identify items for inclusion in a new instrument and part B relates to the quality of research studies performed to evaluate comprehensiveness and comprehensibility of the instrument. COSMIN offer clear guidance on the difference between interpreting whether a study relates to the development (box 1) or the assessment of content validity (box 2) of an instrument[23]. The guidelines state that a development study is considered to be any study completed in the development of an instrument, *prior* to it being finalised, including cognitive interviews and pilot testing. Studies completed *after* the final form of the instrument (existing instrument) was established are considered content validity studies.

2. Content validity

Box two relates to the risk of bias in studies of content validity that assess the relevance, comprehensiveness or comprehensibility of an existing instrument.

It is essential to complete the checklist in the order it has been presented. Completion of the content validity box as the first of the measurement properties is significant given the effect a lack of content validity has on all remaining measurement properties[24]. For example, in an instrument that is not deemed to be valid, items that lack relevance may impact negatively on internal consistency and structural validity[24]. Given the influence of content validity on the remaining properties, COSMIN authors have recommended that if there is high-quality evidence that the content validity of an instrument is insufficient then the remaining measurement properties of that instrument should not be evaluated[15].

Internal structure (3. structural validity, 4. internal consistency, 5. cross cultural validity)

The internal structure of each survey instrument is evaluated based on structural validity (box 3), internal consistency (box 4), cross cultural validity (box 5). The evaluation of internal structure is only relevant for instruments that are based on a reflective model, as opposed to a formative model, as items in a scale or subscale of a reflective model are, collectively, assumed to be a manifestation of one underlying construct and therefore highly correlated and interchangeable[15].

COSMIN advises that if it is not reported whether or not an instrument is based on either a reflective or formative model, reviewers must make a decision on which model the instrument is likely to be based on[15]. However, as identified by COSMIN it is not always possible for a decision to be made on whether an instrument has been developed based on a formative, reflective or mixed (reflective *and* formative items within a scale) model and in such instances, it is advised that reviewers consider the instrument as being based on a reflective model and as such complete the relevant boxes based on the quality of analysis performed and reported[25].

Box 5 relates to the assessment of the risk of bias in studies on an instrument that has been translated or instruments that have been adapted culturally, therefore, this box was only completed in relevant instruments and not applicable (N/A) was documented in relation to all other instruments.

6, & 7. Reliability and measurement error

Box 6 relates to the assessment of the risk of bias in studies on the reliability (box 6) and measurement error (box 7) of an instrument.

8, 9 & 10. Criterion validity, hypothesis testing for construct validity and responsiveness

Boxes 8, 9 and 10 focus on the risk of bias in studies on criterion validity, hypothesis testing for construct validity and responsiveness. Based on COSMIN guidance, authors must consider if there is a 'gold standard' or well- defined high-quality comparator instrument available for measuring the construct of interest in the population of interest to assess the risk of bias in studies of these measurement properties. As there is neither a 'gold standard' nor a well- defined high-quality comparator instrument for measuring women's experiences of their maternity care, it is not possible to formulate or specify a hypothesis for use in evaluating these three measurement properties and therefore these three boxes were excluded from evaluation.

2. *Evaluation of the result of each study on measurement properties against criteria for good measurement properties;*

The results of each study on measurement properties of each included instrument were evaluated using an adaptation of the COSMIN recommended criteria for good measurement properties[15,26,27]. The reported results for each measurement property were compared with

these criteria, and the adequacy of results of each study rated as sufficient (+), intermediate (?) or insufficient (-).

As per the modification of the Risk of Bias checklist, only measurement properties related to the internal structure and cross cultural validity were evaluated as relevant and the measurement properties of hypothesis testing for construct validity, criterion validity and responsiveness were not evaluated. See appendix 5 for the adapted criteria[15,26,27].

3. Summarising the evidence;

The results from 1 and 2 above were evaluated for consistency across studies and, if results for a given instrument were consistent, the evidence was summarised.

Summarising the evidence of the content validity of each instrument consisted of two steps; 1. the results of each study on instrument development and content validity were evaluated against the 10 COSMIN criteria for good content validity and a rating assigned by reviewers on the content of the instrument itself and 2. The results of all available studies were summarised in order to determine whether *overall* the evidence indicates if the relevance, comprehensiveness, comprehensibility and overall content validity of an instrument was sufficient (+), insufficient (-), inconsistent (±) or indeterminate (?)[24].

Summarising the evidence of the remaining measurement properties also consisted of two steps; 1. the results of each study were quantitatively summarised and 2. the summarised result per measurement property, per survey instrument, were rated again against the COSMIN recommended criteria for good measurement properties, as described above, to determine an *overall* rating for the remaining measurement properties of each instrument.

As per COSMIN guidance[15], any inconsistency in results were to be explored and if an explanation found, an overall rating of the instrument provided for several subgroups with consistent results. The subgroups of interest included ethnicity, religion, sexual orientation, birth type, age of participants (e.g. under 18), type of country (developing vs. developed), setting (public hospital, private clinic, midwife led, etc.), multiple vs. singleton pregnancy, nulliparous vs. multiparous women.

5.5.6 Additional evaluation

As this systematic review is one phase of a project to develop and implement the National Maternity Experience Survey in the Republic of Ireland, the final item pools of the included survey instruments were documented at the data extraction stage to aid later stages of the

project. For any studies that have not made the full item pool available to the public, the author or owner of the instrument was contacted, and a copy requested. In some cases, no replies have been received to date. A list of the final item pools of the included survey instruments has been presented in appendix 6.

5.6 Results

5.6.1 Data screening

Results of the search strategy and additional methods of data retrieval are reported within a modified PRISMA flow diagram[28] presented in figure 5.1.

7,640 citations were identified from the search strategy. These were exported to the reference manager software Endnote X7[17] and duplicates removed. Remaining citations (n= 4,905) were exported to Covidence[18] and screened by two reviewers (CB & DD) for inclusion using the predetermined inclusion and exclusion criteria. Following title and abstract screening, 85 full-text papers were uploaded and screened for eligibility. Disagreements at the end of both rounds were resolved through discussion. Reasons for exclusion at full-text (round 2) are reported in figure 5.1. Following the full-text screening, 17 papers/reports were retained. Reference lists for each included paper/report were reviewed for additional literature on the theoretical, empirical and psychometric development of instruments not identified in the original searches resulting in 38 additional literature items for inclusion. Five international experts in the area of maternity care survey development were contacted who suggested an additional four papers for inclusion. Based on the 2018 searching, 59 records were included for analysis. Following the 2019 review of data and updated search, 28 literature items were removed and replaced with 9 updated literature items. Reasons for exclusion following the 2019 search are reported in figure 5.1. In total, 40 papers/reports relating to 20 instruments remained and were included in analysis.

5.6.2 Characteristics of included instruments

The instruments originated from various countries within the developed world. The majority of instruments were from the United Kingdom and Australia. Additional instruments originated from the USA, Japan, the Netherlands, Norway, and New Zealand. Characteristics of each of the 20 included instruments have been provided in table 5.1.

The number of items included within each instrument varied widely from 17[29] to 211[55-57] . Given that maternity care exists along a temporal continuum of care, it is unsurprising that

the majority of included instruments comprised items evaluating various dimensions of the construct (e.g. continuity of care, information provision) grouped within, or associated with, temporal headings (e.g. antenatal care, postnatal care).

Figure 5.1. Modified PRISMA flow diagram;

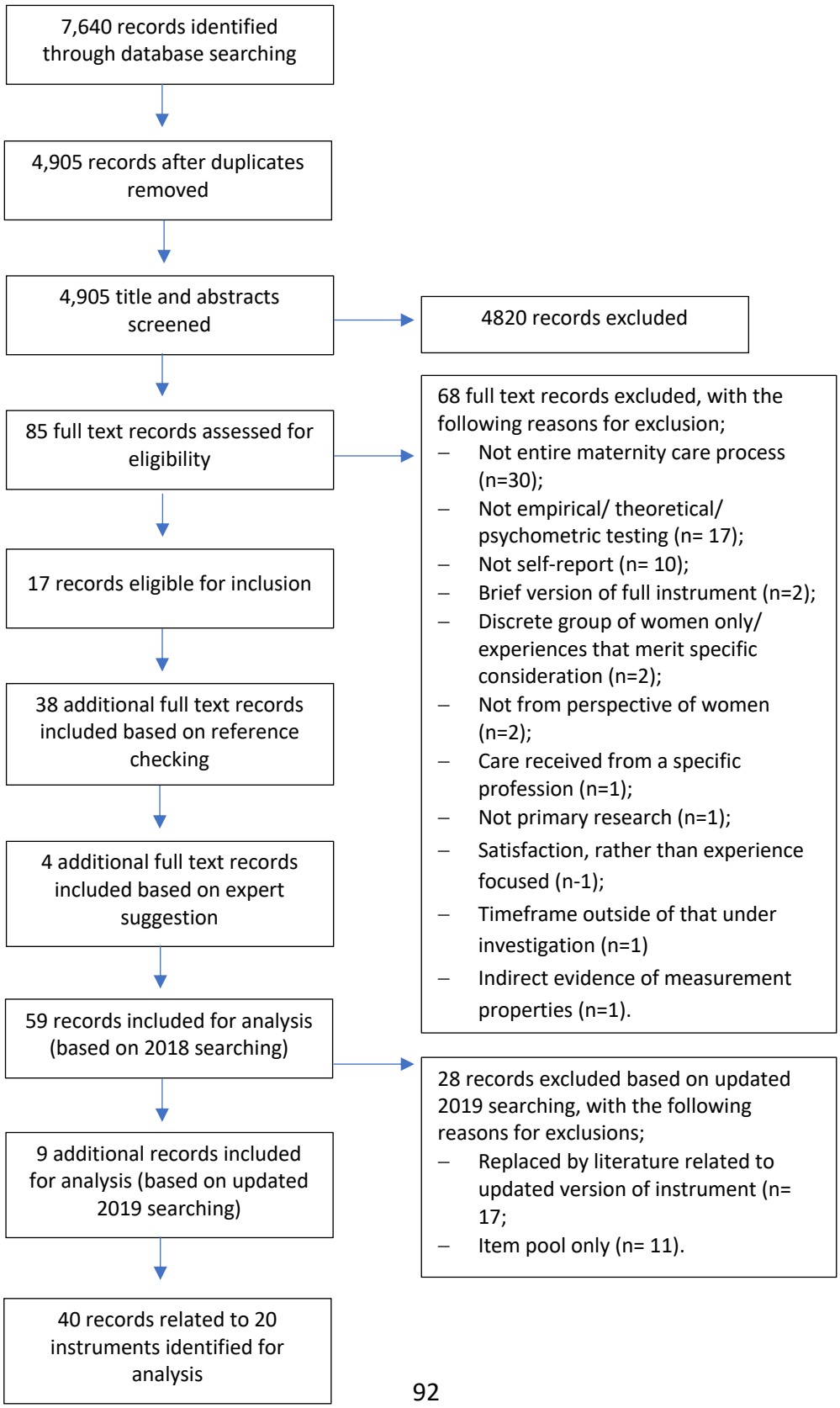

Table 5.1. Characteristics of included instruments (all characteristics refer to the most recent version/ publication date);

No.	*Instrument/ abbreviation*	*No. of associated papers included in review*	*Year of publication*	*Country*	*Timing of administration*	*Response rate*	*Item pool available/ retrieved?*
1	The National Federation of Women's Institutes & NCT	1[29]	2017	England and Wales	Up to 30 months postpartum	Not clearly reported	No
2	Care Quality Commission Maternity Survey	1[30]	2019	England	Not yet reported	Not yet reported	Yes
3	Scottish Maternity Survey	3[31-33]	2018	Scotland	2- 7 months postpartum	40%	Yes
4	Women's views of their Maternity Experience Project	1[34]	2016	Australia	3 -12 months postpartum	10%	Yes
5	Listening to Mothers California	3[35-37] (1 x paper also included in instrument 6 therefore only counted once in number of included papers)	2018	USA	6-11 months postpartum	54%	Yes
6	Japanese Listening to Mothers II	4[37-40] (1 x paper also included in instrument 5 therefore only counted once in number of included papers)	2011	Japan	N/A*	N/A*	Yes

7	Guest & Stamp	3[41-43] (2 x papers also included in instrument 13 therefore only counted once in number of included papers)	2009	Australia	6- 8 weeks postpartum	63%	No
8	ReproQuestionnaire	3[44-46]	2016	Netherlands	6- 8 weeks postpartum (wave 1), not clear (wave 2)	32% (wave 1), 29% (wave 2)	No
9	Scottish Births Survey	2[47,48]	2002	Scotland	10 days postpartum	69%	Yes
10	Having a Baby in Queensland	3[49-51]	2014	Australia	3- 4 months postpartum	30.3%	Yes
11	Pregnancy and maternity care patients' experiences questionnaire	1[52]	2015	Norway	17 weeks postpartum	56.6%	Yes
12	Kolling survey	2[53,54]	2017	Australia	3-4 months postpartum	46%	Yes
13	Survey of Recent Mothers	2[42,43] (2 x papers also included in instrument 7 therefore only counted once in number of included papers)	2002	Australia	5-6 months postpartum	67%	Yes
14	Victorian Healthy Mothers, Healthy Families	3[55-57]	2015	Australia	6-8 months postpartum	52%	Yes

15	Consumer Quality Index	1[58]	2009	Netherlands	Up to 4 weeks postpartum	51%	No
16	'You and your Baby' National Perinatal Epidemiology Unit	2[59,60]	2019	England	3-6 months postpartum	28% (Phase 1) 32% (Phase 2)	Yes
17	Birth NI	2[61,62]	2016	Northern Ireland	3 months postpartum	45.4%	No
18	Lewis	1[63]	2016	Australia	2 weeks postpartum	54%	No
19	Maternity Consumer Survey	2[64,65]	2015	New Zealand	Up to 13 months postpartum	29.4%	Yes
20	Maternity Care Survey	3[66-68]	2018	Australia	3 months postpartum	Not clearly reported	Yes

* this paper focuses only on the development of the survey instrument, rather than the implementation of a pilot/ full survey.

COSMIN state clearly that although instruments that have been modified should be evaluated as a new instrument, it is advised that previously conducted development and content validity studies could be relevant for the rating (excluding comprehensiveness)[23]. Many of the instruments included had generated multiple versions as they were adapted over time and in this case, we analysed the most recent version of the survey in the analysis with older, or original, development and content validity studies included where appropriate (excluding comprehensiveness).

Where the origin of a survey instrument was unclear, the previous literature was sourced. For example, it was apparent from the literature that the genesis of several instruments used within the United Kingdom (produced by the National Perinatal Epidemiology Unit (NPEU), Care Quality Commission (CQC), Scottish Government and Queens University) are intertwined therefore previous literature has been sourced to clarify the process. The genesis of these instruments has been illustrated in Figure 5.2.

Despite figure 5.2 highlighting the genesis of the NPEU survey instruments up to 2014, it was evident that the newest version of the NPEU survey instrument underwent a major redevelopment process in 2019 and therefore only the newest studies were included in the rating of this instrument. Similarly, the CQC 2019 instrument stated clearly that although 2019 was largely comparable to the 2018 instrument, the 2019 instrument had undergone a "significant redevelopment" and therefore only new studies related to this instrument were considered as part of the developmental and content validity rating of the 2019 instrument.

Conversely, it is stated that the 2018 Scottish instrument has been "largely based" on the 2015 and 2013 iterations of that survey. The 2013 survey was then in turn based on the 2013 CQC maternity survey. The 2013 CQC maternity survey and its iterations in 2010 and 2007 are based on the 2006 NPEU survey. Following the 2006 NPEU survey, a development study was undertaken to inform the 2007 CQC survey specifically, therefore the 2007 development study was included as evidence of development and concept elicitation in the Scottish survey. This process was also applied to the Northern Ireland survey with the NPEU 2006 study evaluated as evidence of development and concept elicitation. Similarly, the Listening to Mothers California survey 2018 is noted as being based partly on previous iterations of national Listening to Mothers surveys, in addition to updated studies conducted to inform the use of the survey in California specifically. Therefore studies that related to the original 2002 version of the Listening to Mothers instrument have been included as evidence of development and concept elicitation in the Listening to Mothers California survey.

5.6.3 Evaluation of methodological quality, and quality of results

Data related to the methodological quality, and quality of results, were largely not reported in the retrieved literature.

1. *Evaluation of the methodological quality of each study on measurement properties;*

Table 5.2 highlights the high volume of unreported data related to the quality of studies on measurement properties. Given the impact of content validity of the remaining measurement properties, COSMIN recommends that if there is high-quality evidence that the content validity of an instrument is insufficient then remaining measurement properties need not be evaluated[15]. Although content validity, in line with COSMIN guidance, was only reported in a small number of included studies and therefore the vast majority of included instruments can be rated as having insufficient content validity, we have included the evaluation of any of the reported measurement properties of each instrument to highlight the extent of reporting of all measurement properties across all instruments.

2. *Evaluation of the result of each study on measurement properties against criteria for good measurement properties;*

The results of each individual study on measurement properties of each included instrument were evaluated using an adaptation of the COSMIN recommended criteria for good measurement properties[15]. Based on the retrieved literature, there is no evidence of any more than one published result of a study on any given measurement property, for any of the included instruments. This means that the results on measurement properties against criteria for good measurement properties are, for each study, the same as the summarised results of these measurement properties for that instrument described under 'summarising the evidence'.

3. *Summarising the evidence;*

The results from 1 and 2 above were evaluated for consistency across studies and, based on the minimal amount of data retrieved from the literature, results were found to be consistent and there was no rationale for subgroup analyses to be performed (and insufficient data on which to do so).

Figure 5.2; Genesis of the NPEU & CQC survey instruments[30-32,61,62,69-81] presented in the format; name of instrument/ report; implemented by; area in which it is used (year of survey implementation);

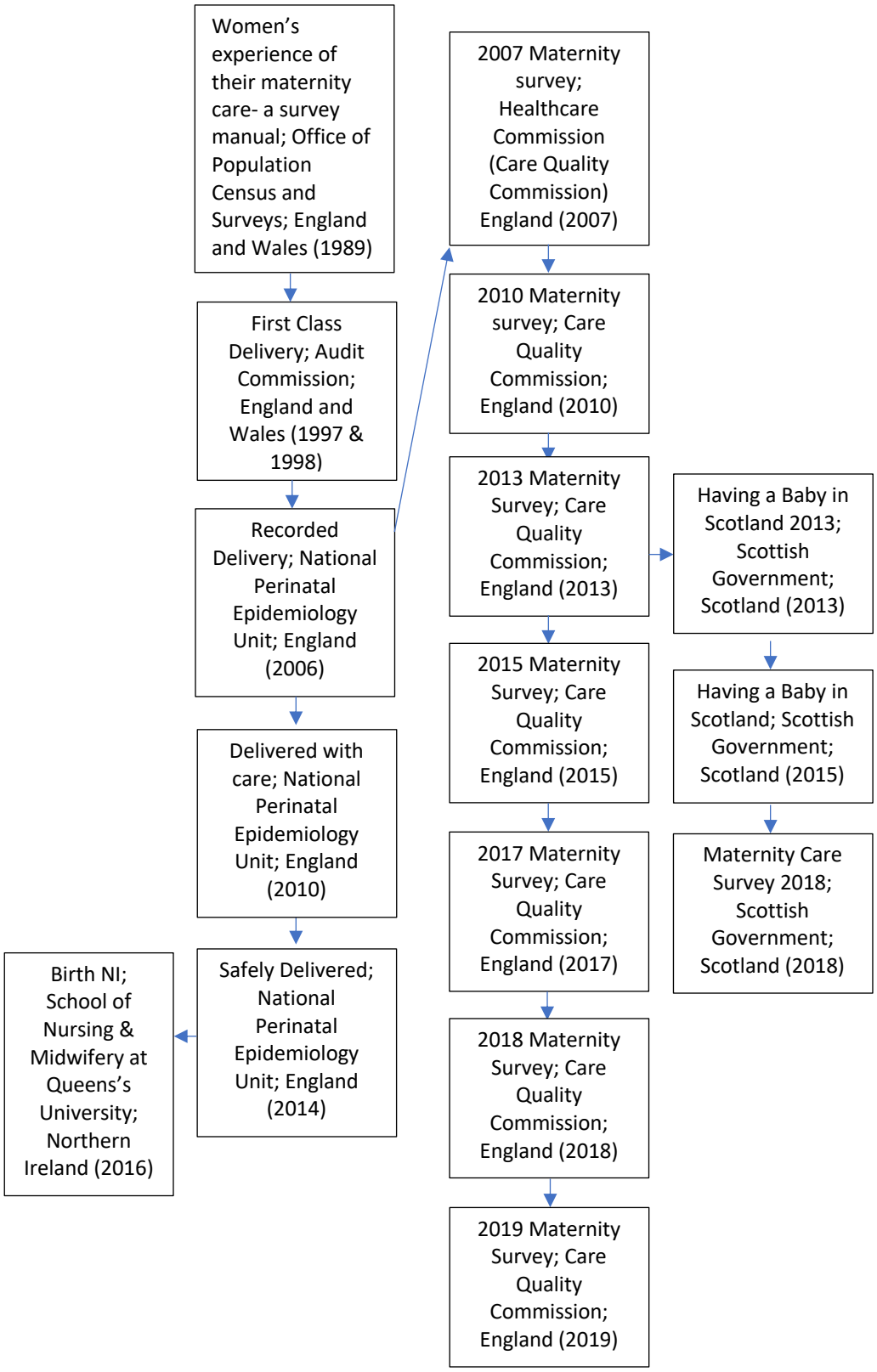

Table 5.2. Quality of the evidence for measurement properties of the survey instrument;

No.	Survey instrument	Content validity				Structural validity	Internal consistency	Reliability	Measurement error	Cross-cultural validity
		Content validity	Relevance	Comprehensiveness	Comprehensibility					
		Overall rating (+/-/±/?)	Overall rating. (+/-/±/?)	Overall rating (+/-/±/?)	Overall rating (+/-/±/?)	Overall rating (+/-/?)	Overall rating (+/-/?)	Overall rating. (+/-/?)	Overall rating (+/-/?)	Overall rating (+/-/?)
1	The National Federation of Women's Institutes & NCT	?	?	?	?					N/A
2[a]	Care Quality Commission Maternity Services Survey	±	±	±	±					N/A
3[a]	Scottish Care Experience Survey Programme-Maternity Care Survey	±	±	±	±					

4[p]	Women's views of their Maternity Experience Project	±	±	±	±	-	+	Information on entire instrument not available	Information on entire instrument not available	N/A
5	Listening to Mothers California	±	±	±	±					?
6	Japanese Listening to Mothers II	±	±	±	±					
7	Guest & Stamp	?	?	?	±					N/A
8[p]	ReproQuestionnaire	?	?	?	?	?	-	Information on entire instrument not available	Information on entire instrument not available	N/A
9[p]	Scottish Births Survey	±	±	±	±					N/A
10	Having a baby in Queensland	±	±	±	±					N/A
11	Pregnancy and maternity care patients' experiences questionnaire	±	±	±		-	+	-		N/A

12	Kolling survey	±	±	±	±					N/A
13	Survey of Recent Mothers	±	±	±	±					N/A
14	Victorian Healthy Mothers, Healthy Families	±	±	±	±					N/A
15	Maternity Consumer Quality Index	?	?	?	?		+			N/A
16[a]	National Perinatal Epidemiology Unit- You and Your Baby	±	±	±	+	-	-			N/A
17[a]	Birth NI	?	?	?	?					
18	Lewis et al	?	?	?	?					N/A
19	Maternity Consumer Survey	±	±	±	±					N/A
20[a]	Maternity Care Survey	±	±	±	±					

[a] = Based on COMSIN guidance included studies have been considered in the analysis as development studies, rather than validity studies, as they had been identified by their developers.

The *overall* evaluation of the content validity of each instrument is presented in table 5.2 with the ratings referring to the relevance, comprehensiveness, comprehensibility, and overall content validity as sufficient (+), insufficient (-), inconsistent (±) or indeterminate (?) in line with COSMIN guidance[24]. It must be noted that although COSMIN state that an overall score of indeterminate (?) is not possible as the reviewer's rating is always available, the decision was taken to include the rating of indeterminate (?) in our overall evaluations based on the extent of lack of information on many developmental and content validity studies being available, and as such it was impossible to make a definitive judgment on these studies as being sufficient (+), insufficient (-) based on little to no information.

The adequacy of results of studies on measurement properties of each included instrument based on a comparison of summarised results with the COSMIN recommended criteria for good measurement properties[15,26,27] are also presented in table 5.2. The adequacy of the results of each study has been rated as sufficient (+), intermediate (?) or insufficient (-). Blank= 'not reported'. Overall, it was found that published evidence of the methodological and psychometric quality of studies on measurement properties, of self-report survey instruments to evaluate women's experiences of their maternity care is lacking. This lack of reporting has led to the majority of instruments receiving an 'indeterminate' or 'inconsistent' rating for content validity and the majority of the remaining measurement properties receiving no rating at all. Of those studies that did report the results of measurement properties, only three have received a sufficient rating in line with COSMIN guidance.

5.7 Discussion

To our knowledge, this is the first systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care. Twenty self-report survey instruments measuring women's experiences of their maternity care were identified. Based on COSMIN guidance[15] the development process and measurement properties of each included instrument have been evaluated.

Data related to the development process and measurement properties of the majority of the 20 instruments is lacking. This has led to low scores across all aspects of the Risk of Bias Checklist and against the criteria for good measurement properties for the majority of instruments, as evident in table 5.2.

An argument could be made that a methodologically sound development process and evaluation of measurement properties may have taken place but has not been reported for

many of the included instruments. This is not withstanding the critical contributions the findings from such instruments has made to the organisation and delivery of maternity care in the contexts in which they are used. This may be inferred, for example, from the overall evaluation of the content validity of each instrument. The majority of the instruments did not report the completion of content validity studies in line with COSMIN guidance, and those that did scored poorly. However, when reviewer ratings were included in the overall evaluation of the content validity of each instrument, the summarised results were higher than those based on published evidence alone. This may suggest, based on the content of the item pool, that had a more complete approach to reporting been adopted, a higher rating of content validity would have been allocated.

Similarly, many of the included instruments were allocated an 'inadequate' rating for their concept elicitation studies based on the score for coding of data retrieved during the concept elicitation process. Based on COSMIN guidelines, if no mention of how the coding of this data was completed, it is assumed that no coding took place and as such an 'inadequate' rating is given. Although studies may have used coding for this data, it is not reported clearly that this was the case. Furthermore, literature that did report on aspects of the development process and measurement properties of an instrument often referred to aspects of their processes in a way that did not align with the guidelines strict criteria, thus leading to low scores. For example, only three instruments[41-43,52] reported content validity studies in line with COSMIN requirements.

5.7.1 Recommendations for practice;

When adhering to COSMIN guidelines, reviewers are advised to make recommendations on included instruments[15]. Given the volume of unreported data and consequently the lower methodological and psychometric quality of included instruments, we recommend more complete reporting of the development processes and measurement properties of instrument's that evaluate women's experiences of their maternity care.

The purpose of this systematic review was to (a) inform the development of the Irish National Maternity Experience Survey and (b) inform future research on the use, adaptation, and development of new self-report survey instruments that measure women's experiences of their maternity care. Although various aspects of instruments used internationally to evaluate women's experiences of their maternity care will inform the development process of the NMES, no existing instrument in its entirety is applicable to the Irish context. This is primarily because of the complex, differing nature of the maternity services currently

provided to women in the Republic of Ireland. This highlights the need to incorporate the interests of Irish key stakeholders to ensure that the items included within the NMES are specific to the maternity care services provided within the Republic of Ireland.

Transparent reporting of each stage of the development processes will be employed with a view to providing a foundation for future research on the use, adaptation, and development of similar instruments.

5.7.2 Research limitation

By adhering to COSMIN's guidance it is possible that included instruments have been critiqued harshly, particularly in relation to issues related to content validity studies and concept elicitation areas in which most of the retrieved literature were focused. Reduced scores because of unreported or unclear information, combined with guidance that 'lowest score counts' as the overall score, led to much of what was reported being scored as either 'doubtful' or 'inadequate'. This is coupled with COSMIN guidance on what should be considered a development study or a validity study leading to many cognitive interviews and pilot studies being critiqued as developmental, rather than validity studies, as they had been identified by their developers[30-34,38,39,46,48,59,61,62,66,68].

5.8 Conclusion

This review identified 20 self-report survey instruments measuring women's experiences of their maternity care. Evidence of the measurement properties of these instruments is largely unreported. This could potentially impact the credibility of the findings of these instruments. Future development processes of survey instruments evaluating women's experiences of their maternity care, including the National Maternity Experience Survey that is being developed for use within Ireland specifically, should be conducted, and reported fully using robust methods that serve as the basis of future research on the use, adaptation, and development of similar instruments.

5.9 Declarations

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5.9.2 Author agreement

- I can confirm that the article being submitted is the original work of the authors submitting;
- I can confirm that this article has not received prior publication and is not under consideration for publication elsewhere;
- I can confirm that all authors have seen and approved the manuscript being submitted;
- I can confirm that the authors abide by the copyright terms and conditions of Elsevier and the Australian College of Midwives.

5.9.3 Authors contributions

I, Claire Beecher as guarantor of the review, confirm that all authors (CB, RG, LO'D, ER, MW, MB & DD) meet the criteria for authorship, have approved the final article and that all those entitled to authorship are listed as authors.

5.9.4 Conflict of interest

I confirm that there are no potential conflicts of interest arising from the authors (CB, RG, LO'D, ER, MW, MB & DD) of this manuscript.

5.9.5 Sources of support for research- funding

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5.9.6 Ethical statement

Not required.

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5.10 Summary of key points

Chapter 5 presents the review and critical appraisal of self-report survey instruments measuring women's experiences of their maternity care. The review had two purposes; 1; inform the development of the NMES and 2; inform future research on the use, adaptation, and development of new self-report survey instruments that measure women's experiences of their maternity care.

The review was conducted using data arising from comprehensive searches of several citation databases, via reference checking and by expert suggestion. Following stepped screening by two reviewers (CB & DD), 40 papers related to 20 instruments were included.

The conduct and design of the review were informed by the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) guidance for completing systematic reviews of patient-reported outcome measures.

The evaluation of the methodological quality of each study on measurement properties was guided by the COSMIN Risk of Bias Checklist, adapted to suit this review. The results of each study on measurement properties of each included instrument were evaluated using an adaptation of the COSMIN recommended criteria for good measurement properties. The arising results were evaluated for consistency across studies and, based on the minimal amount of data retrieved from the literature, results were found to be consistent, and there was no rationale for subgroup analyses to be performed.

In addition to evaluation of the methodological and psychometric quality of included studies, the final item pools of the included survey instruments were documented at the data extraction stage to aid later stages of the project (as presented in chapter 6). The number of items included within each instrument varied widely from 17 to 211 with instruments comprised of items measuring various dimensions of the construct grouped within, or associated with, temporal headings.

In addition to the methods and results reported in paper 4, information related to the operational and feasibility aspects of survey implementation was extracted from the literature related to each survey instrument in line with a request from HIQA. The operational and feasibility aspects of survey implementation were not included in the publication of the systematic review as it was not directly relevant to the development or psychometric properties of included survey instruments. The information retrieved was

given to HIQA prior to their undertaking of phone interviews with lead agencies responsible for developing and distributing national/ large scale maternity surveys. The phone interviews served to fill in any gaps in the operational and feasibility aspects of the survey instruments that had not been identified as part of the review. Data were extracted in relation to operational processes/ feasibility aspects included such as; data protection issues, legislative requirements, distribution methodology, Response medium/ overall response rate/ breakdown of response rate by medium, timing of administration, budget, resources required to manage survey, ease of administration and scoring and survey outputs and method of publishing.

Evidence of the processes of development and evaluation of measurement properties of included instruments was found to be largely unreported, which led to low scores across all aspects of the Risk of Bias Checklist and against the criteria for good measurement properties for the majority of instruments. This finding influenced the decision for publication of paper 5 (Chapter 6) to highlight and transparently report all further processes employed in the development of items for inclusion in the NMES.

Chapter 6: Development of a survey instrument to evaluate women's experiences of their maternity care.

6.1 Introduction

This chapter presents paper 5. Paper 5 describes an adapted two-phase exploratory sequential mixed methods design used to identify and prioritise items for inclusion in the NMES. Phase one focuses on the identification of possible items for inclusion and development of an exhaustive item pool through a systematic review (presented in Chapter 5), focus groups and one to one interviews, and a gap analysis. Phase two focused on the prioritisation of the items for inclusion in the final item bank through a Delphi study and consensus review.

6.2 Paper 5

Development of a survey instrument to evaluate women's experiences of their maternity care

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Submitted to Women and Birth

6.3 Abstract

Background The process of developing a survey instrument to evaluate women's experiences of their maternity care is complex given that maternity care encapsulates various contexts, services, professions and professionals across the antenatal, intranatal and postnatal periods.

Aim To identify and prioritise items for inclusion in the National Maternity Experience Survey, a survey instrument to evaluate women's experiences of their maternity care in the Republic of Ireland.

Methods This study used an adapted two-phase exploratory sequential mixed methods design. Phase one identified items for possible inclusion and developed an exhaustive item pool through a systematic review, focus groups and one to one interviews, and a gap analysis. Phase two prioritised the items for inclusion in the final item bank through a Delphi study and consensus review.

Findings Following iterative consultation with key stakeholder groups, a bank of 95 items have been prioritised and grouped within eight distinct care sections; care during your pregnancy, care during your labour and birth, care in hospital after the birth of your baby, specialised care for your baby, feeding your baby, care at home after the birth of your baby, overall care and you and your household.

Conclusion Robust and rigorous methods have been used to develop a bank of 95 suitable items for inclusion in the National Maternity Experience Survey.

Keywords Midwifery; maternity care; Surveys and Questionnaires; experiences of care; consensus.

6.4 Introduction

The measurement of healthcare, from the perspective of service users, provides a direct link to actions that improve the quality of care that is provided[1]. Given that measurement is crucial to improving the quality of healthcare[2], it is unsurprising that the volume of instruments measuring various aspects of healthcare internationally has increased dramatically in recent decades[3]. In maternity care specifically, there has been a surge in the development and use of instruments that seek to evaluate women's experiences of their maternity care with a view to improving the quality of care provided.

A rise in the development of survey instruments to evaluate women's experiences of their maternity care may be attributable to the complex nature of maternity care and the challenges that this introduces. Maternity care services vary widely internationally and often encapsulate various contexts, services, professions and professionals across numerous time points with instruments developed to evaluate various aspects of these services[4,5]. The increase may also be due to the corresponding decline in the use of survey instruments evaluating satisfaction with care. Although experience surveys originate from satisfaction surveys, there are marked differences in their underlying approaches[6]. The measurement of the experiences of care focuses on what did or did not happen, while the measurement of patient satisfaction focuses on subjective interpretations of the care received. This subjectivity means that data arising from the use of satisfaction surveys are of limited use for quality improvement because although dissatisfaction may identify a need for improvement, it does not usually provide information on where, or how, improvement could be addressed[6].

If findings from survey instruments evaluating women's experiences of their maternity care are to inform both clinical practice and service development, they must be valid (accurately representative of the experiences of care provided) and reliable (provide consistent, predictable measurement)[7,8]. Although large scale instruments are used internationally to evaluate the quality of maternity care provided to various populations and inform quality improvement, such as in the UK for example, there is no evidence that the inferences made from these measures are valid[4]. To ensure the validity and reliability of a survey instrument, a structured development process and robust psychometric testing are needed[3].

This study aimed to develop a survey instrument to evaluate women's experiences of their maternity care in the Republic of Ireland. The survey instrument has been developed in line

with a policy imperative set out in the Irish National Maternity Strategy[9] and the survey will be implemented nationally within the Republic of Ireland as the National Maternity Experience Survey (NMES) by the National Care Experience Programme (NCEP). The NCEP is a partnership between the health service regulator (Health Information and Quality Authority (HIQA)), the national healthcare provider (Health Service Executive (HSE)) and the national policy maker (Department of Health) launched in Ireland in 2019 to measure service users' experiences of health and social care services with the aim to use this information to improve the quality and safety of these services. Given that both robust measurement, and a feedback mechanism to clinicians, are fundamental in improving the quality of healthcare provided[2], this partnership ensures that all data collected is fed back to those providing the maternity services being evaluated.

Based on the uniqueness of the maternity system implemented within the Republic of Ireland, existing survey instruments were limited for our purposes and development of a bespoke, context specific instrument for use within Ireland was judged necessary.

6.5 Methods

A structured approach to the development of the survey instrument was adopted following extensive consideration of the complexity of the concept of women's experiences of their maternity care[10-12] and the various aspects that this entails. For the purpose of this survey, the timeframe of maternity care was defined by the NCEP and research team (CB and DD) as a woman's first antenatal appointment with a healthcare provider through to the care provided up to three months postpartum. The survey is being developed for use by women approximately 3- 4 months postpartum.

In line with the National Inpatient Experience Survey[13], a decision was made a priori by the NCEP and research team that the NMES would be a self-report instrument that relies predominantly on closed items with a minimal number of open text boxes. This format ensures that the data collected will be structured consistently and allow for the comparison of large volumes of data. However, it also imposes the limitation that feedback is only provided on aspects of care that are specifically asked about[6]. This limitation means that the inclusion of appropriate content is vital and, as it has been identified that often the priorities of clinicians may differ from service users in what items they see as important[14], the inclusion of a wide range of stakeholder groups, including service users in the development process is

necessary to ensure that the resulting survey instrument includes aspects that are deemed necessary by all groups[6].

We used an adapted two-phase exploratory sequential mixed methods design for the development of a bank of items for inclusion within the NMES[15]. Phase one identified items for possible inclusion and developed an exhaustive item pool through a systematic review, focus groups and one to one interviews, and a gap analysis. Phase two prioritised the items for inclusion in the final item bank through a Delphi study and consensus review. Following the development process reported here, a psychometric evaluation of the final item bank is required to optimise the final survey instrument and to ensure accuracy and credibility of arising results.

6.5.1 Phase 1: Identification of possible items for inclusion and development of an exhaustive item pool

Items for possible inclusion in the NMES were identified through a systematic review, subsequent focus groups and one to one interviews with key stakeholder groups. While a traditional two-phase exploratory sequential mixed methods design[15] consists ordinarily of a qualitative method that informs a quantitative method, this study also incorporated a preceding systematic review.

The purpose of the systematic review was to identify self-report survey instruments used internationally to measure women's experiences of their maternity care, evaluate the methodological and psychometric quality of each included instrument and to categorise all items identified. Comprehensive searches of online citation databases were completed, inclusion and exclusion criteria were applied and, a stepped approach was employed to facilitate the evaluation of the methodological and psychometric quality of included instruments. The methods and in depth results of these evaluations are reported elsewhere in detail (*accepted for publication*).

6.5.1.1 Focus groups and one to one interviews

The objective of the focus groups and one to one interviews was to elicit opinions from key stakeholder groups on the aspects of care that they consider being of most importance for inclusion within the survey instrument and the identification of any further potential items of importance to the stakeholder groups not identified in the systematic review. The structure of the survey instrument was also included for discussion.

6.5.1.1.1 Ethical approval

Ethical approval for all relevant aspects of the development process was received from the National University of Ireland, Galway (NUI Galway) Research Ethics Committee. All approval letters from the NUI Galway Research Ethics Committee are included in appendices 7, 8, 9 and 10.

6.5.1.1.2 Recruitment

Participants were sampled purposively from the following stakeholder groups- women as service users of the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, general practitioners, policymakers, and funders. Participants were recruited nationally by the NCEP team with assistance from the research team. Members of maternity stakeholder organisations nominated by the NCEP were invited to participate and additionally, primary contacts within maternity care representative groups (Association for Improvements in Maternity Services in Ireland (AIMSI) and Cuidiú) kindly disseminated an invitation to participate to their members. Recruitment material is presented in appendix 11. Efforts were made to recruit service users and their representatives from a diverse range of socio-demographic groups including, for example Pavee Point Traveller and Roma Centres. A full breakdown of all participants is included in appendix 12.

Each invitation to participate was accompanied by a detailed Participant Information Leaflet describing the aim of the study, what taking part involved, the voluntary nature of the study and participants' right to withdraw at any time. The Participant Information Leaflet also included details of focus groups that were planned to take place at three geographically distinct locations within the Republic of Ireland. Participants who wished to take part but could not attend an interview at the designated time were afforded the opportunity to complete a one to one phone interview at a time convenient to them. The Participant information Leaflets are presented in appendices 13 and 14.

To be eligible for inclusion in the interviews, women as service users must have been either a current service user of the Irish maternity services or have been a user of the Irish maternity services within the previous 12 months. All remaining stakeholder groups must have been, at the time, involved in the provision of maternity care to women in Ireland or involved in funding and/or policy decisions on the provision of maternity care to women in Ireland. Women who had experienced an adverse neonatal or maternal outcome were afforded the

opportunity of a one-to-one interview rather than a focus group interview. As funding did not permit the recruitment of translational services, participants who did not have a competent level of fluency in English were excluded.

Before the interviews, all participants who agreed to participate were sent an outline of interview schedule questions and a consent form. The consent form was then signed by each participant and a researcher before the commencement of the interview. The consent form is presented in appendix 15.

6.5.1.1.3 Analysis

Each of the interviews (n= 19) lasted approximately 45mins to one hour and were guided by the interview schedule included in appendix 16. Each interview was conducted by experienced members of the NCEP and/ or research teams. Each person conducting the interviews was provided with a protocol for interviewees experiencing emotional disruption, for use in the unlikely event that this did occur. The protocol, as it was presented in the application for ethical approval, is included in appendix 17. All focus group interviews (n=8) were audio-recorded and transcribed for analysis. Transcription was completed by an outside experienced research transcriptionist. The statement of confidentiality signed by the transcriptionist is included in appendix 18. Transcripts were anonymised and checked with reference to the audio recordings for accuracy. The one to one phone interviews were not recorded, but instead, detailed notes were taken throughout each of the interviews for inclusion in the analysis. All data was coded independently by CB and confirmed by MD.

A hybrid approach to the analysis of the data was adopted with initial inductive analysis and subsequent deductive approach. All eight transcriptions of the focus group interviews and notes taken during the 11 one-to-one phone interviews were imported to NVivo 12 qualitative data analysis computer software (QSR International Pty Ltd, Melbourne, Vic., Australia), and data were labelled verbatim and sorted according to emerging themes in line with the six phases of Braun and Clarke's (inductive) recursive thematic analysis approach[16]. The six phases of Braun and Clarke's approach are gaining familiarity with the data by reading, re-reading and note-taking, the generation of initial codes, collating the initial codes into potential themes, reviewing and refining themes, defining and further refinement of themes and lastly, the final analysis and write up of the report[16]. As inductive analysis advanced, it became apparent that themes emerging broadly aligned with the eight domains of the World Health Organization (WHO) Responsiveness concept[1,17] and consequently

analysis of the data was guided by a (deductive) framework approach[18]. The concept of responsiveness focuses on both the way and the environment in which individuals are treated during health system interactions, and the concept itself was introduced by the WHO as an approach to address the quality of health systems in a way that is comparable internationally[1,19]. The eight domains of the WHO concept are; autonomy, choice, communication, confidentiality, dignity, basic amenities, prompt attention and social considerations[1].

6.5.1.2 Development of an exhaustive item pool

Following the focus groups and one-to-one interviews, a Gap Analysis was completed by mapping the suite of international items (identified in the systematic review) against the themes identified in the focus groups and one-to-one interviews and against Irish policy documents i.e., (i) National Maternity Strategy (Creating a Better Future Together) (ii) HIQA National Standards for Safer Better Maternity Services and (iii) the background document supporting the development of National Standards for Safer Better Maternity Services. The purpose of the gap analysis was to identify items used internationally that were relevant for use within the Irish setting and to identify areas that were not captured either at all or adequately, therefore, highlighting areas for which items should be considered for development. Further information on the completion of the gap analysis is presented in appendix 19.

An exhaustive item pool for inclusion in the prioritisation phase was then developed by combining data identified through the systematic review, focus groups and one-to-one interviews and gap analysis into domains, e.g. choice and continuity of care, communication. The NCEP team then reviewed these domains. Following a review of feedback from the NCEP team, edits were made, and the set of domains for inclusion within the survey instrument finalised within the sections they were expected to be included in, in the survey instrument, e.g. antenatal care, postnatal care. Each domain was then populated with relevant items from the international suite of items identified from the systematic review, in addition to newly developed items. In line with guidance, a large item pool was initially developed and then refined by the research team based on a priori criteria[20]. Criteria for the elimination of items included duplicate items, undesirable similarity to other items, lack of clarity and questionable relevance to the maternity care provided within the Republic of Ireland.

6.5.2 Phase 2: Prioritisation of items for inclusion in the final item bank

Prioritisation of items for inclusion in the final item bank was divided into two stages; (1) items were prioritised for inclusion through a two-round Delphi study, and (2) final consensus on the item bank was achieved through additional iterative reviews.

6.5.2.1 Prioritisation of items for inclusion in the final item bank

A two-round Delphi study was conducted online through Crowdsignal (https://crowdsignal.com) with participants from key stakeholder groups to prioritise the large item pool that had been developed based on the findings of all earlier stages of the project. Examples of rating options in Crowdsignal are included in appendix 20.

Respondents were asked to identify if they felt each item should be included on a 5- point Likert scale, i.e., Definitely yes, Probably yes, Maybe yes/ Maybe no, Probably no, Definitely no. Participants in the second round were also given the opportunity to feedback any comments they may have had on the items that had been included, or not included, in that round.

Following the first round of the Delphi study, the resulting item pool was reviewed by the NCEP team to ensure the aspects of care included would be amenable to care improvement actions, and edits were made to the item pool as necessary.

6.5.2.1.1 Recruitment

Participants were sampled purposively from the following key stakeholder groups; women as service users of the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, neonatal nurses, anaesthesiologists, general practitioners, policymakers, and funders. Participants were considered eligible for inclusion based on the same criteria for recruitment of the focus groups and one to one interviews.

Representatives of key stakeholder groups were invited to participate in both rounds of the Delphi study using several methods. Members of maternity stakeholder organisations nominated by the NCEP, and participants that had previously taken part in the focus groups and one to one interviews, and had consented to further contact related to this project, were emailed an invitation to participate. Primary contacts within maternity care representative groups (AIMSI, Le Leche League of Ireland, Cuidiú, the National Women's Council) were also contacted and asked to assist with nationwide dissemination of an invitation email via their

group email lists and online discussion platforms. Additionally, participants were asked to promote participation in the Delphi study to additional potential participants who might be willing and appropriate for inclusion. Recruitment material is presented in appendices 21 and 22.

Each invitation email contained a detailed Participant Information Leaflet that included information on the aim of the study, what taking part in the Delphi study involved, the voluntary nature of the study and participant's right to withdraw at any time. The Participant Information Leaflet is presented in appendix 23. The invitation email also included an electronic link to the online Delphi study registration and consent page. Explicit consent was obtained for the Delphi study by participants clicking an 'I agree' button to four consenting statements at the end of the registration process. If the participant did not agree to all statements, they were excluded from continuing. An image of the four consenting questions on the consent page is presented in appendix 24.

6.5.2.1.2 Analysis

In round one of the Delphi study, ratings from all stakeholder groups were combined. Items rated by 95% or more of all respondents as 'definitely yes' or 'probably yes' were eligible for inclusion in the second round. In round two, ratings from all stakeholder groups were combined. Items rated 85% of all respondents as 'definitely yes' or 'probably yes' for it to be eligible for inclusion in the additional rounds of feedback. Cut-points were chosen based on iterative discussions with the NCEP team on what might be reasonable, relevant and applicable to include in the final instrument. The open text responses received within round two of the Delphi were collated, and items were reviewed and edited as necessary.

6.5.2.2 Consensus review

Following the second round of the Delphi study, all items that had been rated as necessary for inclusion were reviewed by six organisations/ experts based on their knowledge of either survey development or maternity care in Ireland. The purpose of this review was to assess the draft survey instrument for length, ambiguity, areas not included and any aspect of the construct that may have been missed.

6.5.2.2.1 Recruitment

The NCEP and research teams contacted each of the following organisations and experts directly and requested involvement in the additional rounds of feedback of the item bank resulting from the Delphi study;

1. National Maternity Experience Survey Programme Board;
2. Health Information and Quality Authority (HIQA);
3. Department of Health, Ireland;
4. Picker Institute Europe;
5. Survey methodologist (Professor Laura O'Dwyer (Professor, Department of Measurement, Evaluation, Statistics & Assessment, Boston College, Massachusetts, USA);
6. National Adult Literacy Agency (NALA), Ireland.

6.6 Results

An overview of the survey development process and a summary of results has been provided in figure 6.1. An overview of the stakeholder groups/ participants included at each stage of the development process has been provided in table 6.1.

Table 6.1. Overview of stakeholder groups/ participants included within each stage of the development process

Stage of development	*Stakeholder group/ participants*
Focus groups and one to one interviews	82 participants; – 22 service users – 20 midwives – 6 public health nurses – 5 obstetricians – 3 anaesthesiologist – 5 general practitioners – 3 policymakers – 18 participants classified as 'other' e.g. allied health professionals

Delphi round 1	22 participants; – 9 service users – 2 midwives – 2 public health nurses – 2 obstetricians – 2 anaesthesiologists – 2 neonatal nurses – 1 general practitioner – 1 funder – 1 policymaker
Delphi round 2	127 participants; – 31 service users – 38 midwives – 4 public health nurses – 8 obstetricians – 1 anaesthesiologist – 2 neonatal nurses – 3 neonatologists – 2 general practitioners – 8 policymakers – 30 participants classified as 'other' e.g. allied health professionals and healthcare researchers
Consensus review	6 experts/ organisations; – NMES Programme Board – HIQA – Department of Health, Ireland – Picker Institute Europe – Survey methodologist (Professor Laura O'Dwyer (Professor, Department of Measurement, Evaluation, Statistics & Assessment, Boston College, Massachusetts, USA)) – National Adult Literacy Agency (NALA), Ireland.

6.6.1. Phase 1: Identification of possible items for inclusion and development of an exhaustive item pool

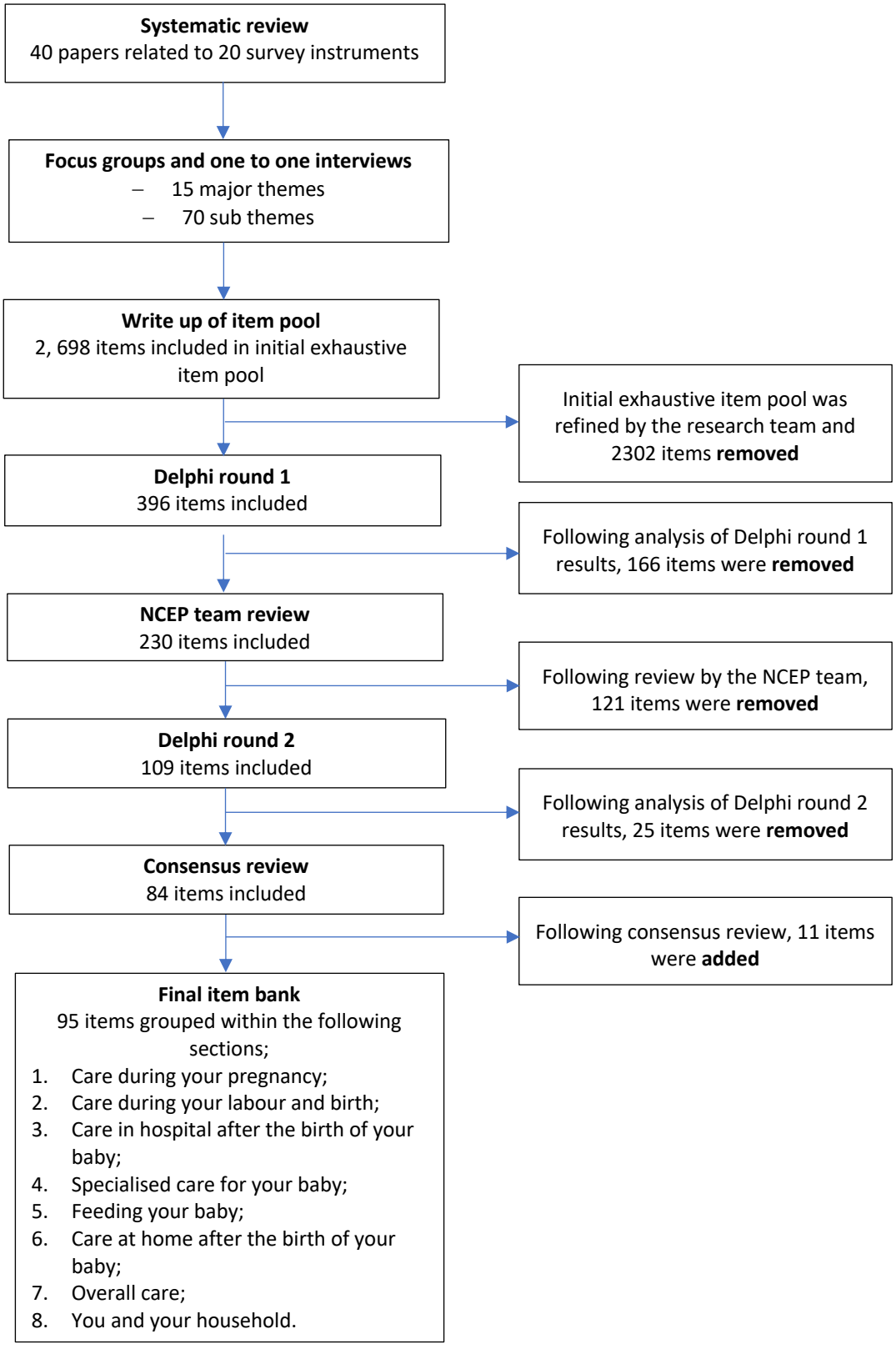
A systematic review of self- report survey instruments used internationally to evaluate women's experiences of their maternity care included 40 papers related to 20 survey instruments. Findings indicate that evidence of the methodological and psychometric quality of the included instruments is largely unreported. All items that were included within each available survey instrument were categorised. For any studies that had not made the full survey instrument available to the public, the author or owner of the instrument was contacted, and a copy requested. In some cases, no replies have been received to date. The methods and in depth results of these evaluations are reported elsewhere in detail (*accepted for publication*).

Analysis was completed on data arising from eight in-depth focus groups and 11 one-to-one interviews which included 82 participants in total with representation from each of the key stakeholder groups, i.e. women as service users of the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, general practitioners, policymakers, and funders (see table 6.1 for further information).

6.6.1.1 Focus groups and one to one interviews

The analysis initially identified 29 major themes and 68 sub-themes representing the aspects considered of most importance by stakeholders for inclusion in the survey instrument being developed. These were further refined resulting in 15 major themes and 70 sub-themes. Most of the categories mapped closely with items identified in the systematic review. Several of the themes that emerged from the analysis are easily identifiable as being specific to one section e.g., antenatal care, postnatal care; however, the majority of themes were suitable for inclusion across multiple sections of the survey instrument. The codebook in appendix 25 highlights the thematic areas for inclusion and the frequency with which codes appear for each.

Figure 6.1. Overview of the survey development process and summary of results;



6.6.1.1.1 WHO responsiveness concept

Table 6.2 presents a subsection of the overall categories, namely the eight major themes that aligned with the WHO responsiveness concept domains. Each of the eight categories is accompanied by illustrative participant quotes from the interviews (quotes are not exhaustive) and reference to the associated sub-themes. The use of the domains of the WHO responsiveness concept in the development of items for inclusion in a survey instrument that evaluates women's experiences of their maternity care had been identified previously in the systematic review. The development of the ReproQ survey instrument in the Netherlands followed the responsiveness concept closely[5,21]. In line with the use of the responsiveness model in the development of the ReproQ survey instrument, for the purpose of analysis, the domain of Choice was also grouped with aspects of care that related to Continuity of care[5,21].

6.6.1.1.2 Additional major themes

In addition to the WHO responsiveness concept related themes presented in table 6.2, seven additional major themes emerged from the data. The seven additional themes were; antenatal specific, labour and birth specific, postnatal specific, woman-centred care, infant feeding, mental health and National Maternity Experience Survey organisation and demographics for inclusion. Table 6.3 presents these seven themes, associated sub themes and (non-exhaustive) illustrative participant quotes from the interviews.

A high number of references were made to antenatal specific aspects of care and participants felt strongly that items related to antenatal care specifically should feature heavily given the impact this has on the care continuum. Under the antenatal specific theme, topics addressed were; antenatal appointments (antenatal clinic, community, volume and timing of antenatal appointments), antenatal education and scans. Similarly, labour and birth specific aspects of care featured throughout the interviews with discussions focusing on women's opportunity to perform skin to skin following birth, access to and the availability of pain relief and comfort measures, processes around the induction of labour, the opportunity to have a home birth, empowerment of women during caesarean section and caesarean section options that were available, e.g. gentle caesarean, and the presence of caregivers during labour and birth specifically.

Additionally, a significant number of recommendations were made for the inclusion of items related specifically to women's postnatal care. A high volume of participants suggested that

items be included related to the availability of postnatal care in the community. Suggestions focused on the availability of and women's experience of use of care provided by a wide range of caregivers (e.g., general practitioners, public health nurses, community midwives). A moderate number of participants also suggested that items related to the availability, and women's experience of use, of a postnatal debriefing service should be included within the survey instrument. Discussions on postnatal care also focused specifically on the care of the baby following birth, for example, aspects of care related to the admission of a baby to a Neonatal Intensive Care Unit (NICU).

Infant feeding featured heavily throughout the interviews. A significant number of recommendations were made to include items related to breastfeeding. In particular, women's experiences of the support they received with breastfeeding and the continuity of advice received. In comparison to breastfeeding, formula feeding was recommended for inclusion a minimal number of times; however, it was suggested that women be asked how well supported they were in their choice of method of infant feeding (both breast and formula).

Discussions related to the importance of including items related to mental health were prominent throughout the interviews with discussions focusing on the importance of asking women if they were asked at each stage about their mental health and if, where necessary, appropriate care plans were made. The theme of woman-centred care includes focuses on the inclusion of items related to individualised care, the cultural and religious needs of women and aspects that focus on women with varying levels of risk and the personalised care that was received based on that level of risk.

The final theme- National Maternity Experience Survey organisation and demographics for inclusion- focused on topics that were specific to the survey organisation including the structure and administration of the survey instrument and demographics items of importance for inclusion, e.g., age, ethnicity and disability status.

6.6.1.1.3 Structure of the survey instrument

Participants agreed that the eight sections identified in the systematic review as the most common for structuring the survey instrument were comprehensive and appropriate for structuring the instrument. As such, these eight sections formed the basic structure of the item pool being developed;

1. You and your baby
2. Care while you were pregnant (antenatal care)
3. Your labour and the birth of your baby
4. Care in hospital after the birth (postnatal care)
5. Feeding your baby
6. Care at home after the birth
7. Overall experience
8. You and your household

6.6.1.2 Development of an exhaustive item pool

A gap analysis was completed to identify gaps between the international items (identified in the systematic review), Ireland's maternity care service, HIQA regulatory standards and the findings from the eight focus groups and eleven one to one interviews with key stakeholder groups. Most gaps identified were deemed to be 'partial' meaning that there are identifiable items used internationally related to these areas, however some needed modification to align with maternity care organisation in the Republic of Ireland specifically.

An exhaustive item pool was developed based on the aspects of care identified through the systematic review, focus groups and one to one interviews and gap analysis. Items were populated within the eight sections that had been confirmed by participants in the focus group and one-to-one interviews. The initial item pool contained 2,698 items and was refined by the research team based on a priori criteria. An item pool comprising 396 items was finalised for use within round one of the Delphi study.

6.6.2 Phase 2: Prioritisation of items for inclusion in the final item bank

6.6.2.1 Prioritisation of items for inclusion in the final item bank

Twenty-two participants representative of key stakeholder groups completed the Delphi round one. A further 127 participants completed the Delphi round two (see table 6.1 for further information).

Table 6.2. Thematic categories aligned with WHO responsiveness domains and illustrative extracts;

Major themes	*Sub themes*	*Illustrative participant quotes*
Autonomy	– Informed consent and informed refusal – Involvement in informed decision making	Focus group 6; *"I mean at the end of the day it's the patient's choice, it's the woman's choice. And informed consent and informed refusal have to be recognised in the Irish maternity system. And they're not currently. And I think if we had that where risks are explained, alternatives are explained, benefits are explained. So that the women herself makes an informed choice about what happens. And that has to be available; women have to be able to give that sort of feedback in a survey like this. To be able to say, it didn't feel like my opinion was valued. It didn't feel like something was explained to me properly, why something needs to be done. The benefits the risks of it. And I think if informed decision making was priority, I think a lot of people wouldn't have that traumatic experience"*
Basic amenities	– Environment – Food provision – Hand hygiene – Interaction with ancillary staff – Parking and transport – Resources – Staffing levels	Focus group 2; *"The toilet facilities, the quality of the toilet facilities, you've got a vulnerable woman, bleeding, whatever you know and it's like well there's one toilet to share with 10, you know you're sitting outside waiting, going come on or even in the antenatal period, the antenatal ward, they're leaking clear liquor, they could have different, and they're still standing outside a toilet because*

		there's only, you know facilities for whatever amount of women. So again it's the environment, it's all that aspect, did it meet your perceived perception"
Choice and continuity	– Choice of model of care – Involvement in research studies – Continuity of care – Access – Access to personal files and records – Accessing maternity services for the first time – Contacting services – Equality of care options – Referral to services – Timely access	Focus group 4; *"I think probably going along in that line it's very important to know that I suppose where care is very inequitable, access to choice is very inequitable around the country in certain hospitals we are lucky we have a domino but it's still related to a postcode. Homebirths, you know we've early transfer home, like with the new strategies supportive care and midwifery led care, be it antenatal or within hospital or outside. I think access in your choice, were you able to choose the type of care you wished to choose"* Focus group 3; *"The point I was making was access to choice. Did they have options available to them; were they actually given information about choices that were available? You know did the GP just say, right so here you go, here's the form, take it to the hospital. Or did they actually have access to information about what services are available to them. Was there any kind of personalised assessment as to whether they would need to take a particular care pathway? Because the reality is in Ireland, most women end up in consultant led clinics and that's it. And they think that maybe a private clinic is better than public, so"*

		Focus group 6; *"Just the continuity of care, it's really important because say for us in XXX, you've had midwives looking after you. Now it wouldn't always be the same midwife. But when you come to the clinic you come today and you see the consultant you come tomorrow and you'll see an SHO, another day you'll see a reg. Another day you'll see a midwife. Then you've the changeover of the docs like very, twice a year like. So you see somebody else, you know you could see five or six people. And you're coming just for you know, to the antenatal clinic. So I suppose a question around you know maybe were you happy with the continuity of care"*
Communication	– Communication between various services; – Information sources – Opportunity to discuss sensitive topics with caregivers – Staff interaction with each other – Staff introduction – Voicing concerns and raising queries – Confidence and trust in caregivers – Confidence in caregivers – Trusting relationship – Information provision – Consistency in information – Delivery of information	Focus group 2; *"I think communication, provision of information, not just because they ask for it but that it's there and good quality information"* Focus group 4; *"We also need to look at where, a bit like what you were saying, it's like where are they getting the information from and how they are getting it. Booklets and leaflets are a thing of the past, most young expectant mothers are online looking for that information and we have to make it easy not trawling through as you had to do loads of different sites that you know may give some good advice but you know it's not reliable. So where and how they are getting that information"*

	– Provision of information – Explanations of the possible development of risk factors and the impact on care option decisions – Understanding information	
Confidentiality	– Confidentiality of medical records – Privacy	Focus group 2; *"Things like curtains actually in the postnatal wards, you do into them and you can't see a lady at all because all the curtains are pulled. So whether something around privacy and dignity"*
Dignity	– Treated with kindness – Treated with respect	Focus group 4; *"I know but if you look at the questions at the moment in the survey we would need to ask the vast majority of those - did you have trust, did you receive all the information? Did you have trust in care, were you treated with dignity and respect? There's all those kinds of general questions..."*
Prompt attention	– Emergency situations – Waiting times	Focus group 2; *"Then there's the whole labour ward experience really, if it is in the hospital, did she have a midwife with her all the time. And again, its communication within it and again kindness and courtesy and especially with an emergency, if an emergency happens. How she felt during that, you know was she reassured"*

		Focus group 2; *"So there's a lot in that isn't there, so the experience of antenatal clinic alone can be, like the crammed antenatal clinics, standing up, no room to sit, waiting up to 3 or 4 hours and also you're forgotten in the waiting room, that type of experience"*
Social consideration	– Additional sources of support – Involvement of partner – Support from family and partner	Focus group 2; *"what about dads, what about, you know a support person that came in with the woman, you know is it about the impact of care in the household"*

Table 6.3.Seven additional thematic categories and illustrative extracts;

Major themes	*Sub themes*	*Illustrative participant quotes*
Antenatal specific	– Antenatal appointments – Antenatal clinic – Community – Volume and timing of antenatal appointments – Antenatal education – Scans	Focus group 2; *"Maybe around consistency, around antenatal education and its similar to the point on, I suppose consistency of information being provided but also do they actually have access to antenatal education"* Phone interview 2; *"In terms of antenatal care, women should be surveyed as to whether they received the time and attention they required, as opposed to feeling rushed along in a factory production line. Was the woman's psychological state assessed? If she had specific fears e.g. with regards to delivery, did she feel she could confide in and gain some reassurance from healthcare staff?"*
Infant feeding	– Asking about method of feeding – Breastfeeding – Formula feeding – Staff knowledge on feeding – Supported in their decision	Focus group 2; *"Were you aware there's a lactation consultant, were you told they could come visit you, you know there's a breast-feeding class on the ward sometimes, did you know about that. Did you get consistent information, you know were you given any volunteer phone numbers, people to call"*

		Focus group 3; *"Yea and everything around you know, breastfeeding support, bottle feeding support. Because you know, my sister bottle fed and I breastfed and she had a different experience in that she felt shamed because she didn't breastfeed. I felt isolated because I did breastfeed. So you know, like there's a lot around even just feeding your baby"*
Labour and birth specific	– Caesarean section – Home birth – Induction – Pain relief – Presence of caregivers (during labour and birth) – Skin to skin	Focus group 6; *"But I think if people are informed on every single step of the journey. Then you know, it makes it easier to I suppose, with the experience, the experience is made easier. If we feel that we've been part of the decision making process. And the birth plans, nobody is against a birth plan in this day and age. It's kind of what's expected if somebody rocks up with their birth plan. If you don't rock up with a birth plan, it's like where's the birth plan. But it doesn't always mean that you can go with the birth plan. Because things change. But as long as you have, you know you have your birth plan, you have your midwife or your obstetrician. And you're on the same page. And that you're being fed the information that you know, I know you wanted this. But this is what has happened now and we're going to have to change that. As long as, so it's about the, for me personally it's about communication, dignity and respect. And being treated, you know being part of, feel that you're on the same page. That's I think and*

		everything else then comes with that. Because if you feel you've been informed all the way along. Then you know when something happens to deviate then you're fine with that. Because you have a relationship with your care provider" Focus group 7; *"So there's the question of what, so what way were your options presented to you, in terms of comfort measures in labour. And then what options were actually available in the unit you attended. And then what options would you have liked to have had that maybe weren't there"*
Mental health		Focus group 1; *"With mental health, that is a huge, mental health, we have seen it I imagine in 3 years, 1 in 3 of our Ladies coming through are recognised as, I could say sufferers even because they are suffering under an anxiety issue or depression or both and possibly of that 50% taking medication at time of admission……And that's a big issue in the strategy, a huge focus in the strategy as you know. How should we capture this with the instrument, what's the thoughts, what should we be doing in the instrument to try and get to that"*

		Focus group 4; *"Especially I think we should be discussing mental health which there's huge issues around mental health, we don't ask those questions. There's such a huge push now in the strategy that each maternity hospital is going to have a mental health midwives, nurse whichever"* Focus group 5; *"Did they get asked antenatally in their booking visit, they should have been, if they positively, if they said they had issues, were those followed up, I'd like to know how timely their appointments were. Because often women get given appointments for after their due date, which is ridiculous. You know and also the difference between people who have perhaps had severe issues when they were already under the treatment of a psychiatrist or a psychotherapist or psychologist, those people do tend to maintain mental health treatment. But people for whom it appears in pregnancy for the first time, they're the people that fall through and then of course we know that the people who have it antenatally, antenatal anxiety and depression are more likely to have postnatal anxiety"*
National Maternity Experience Survey organisation and	– Administration and layout of survey – Bereavement – Open text options – Overarching areas for inclusion	Focus group 1; *"I'd like to know how we're going to capture feedback from the whole of I suppose the socioeconomic grouping. Recently the south, south west had their study produced with regards to women's expectations of the*

demographics	– Termination of pregnancy – Timing of survey implementation – Future suggestions for maternity services – Fertility – Preconception – Demographics – Age – Amenities available – Disability – Ethnicity – Family dynamics – Language barriers – Previous pregnancies – Public, private, semi- private etc – Socioeconomic status	*maternity service within the group and the feedback came from the professional women and it came from the more mature age group, women from their 30s to 40s. So how do we capture women's experiences that are maybe of, maybe lower socioeconomic grouping and a younger cohort of women…And non-English speaking"* Focus group 4; *"I think a pregnancy is a pregnancy. It's your care for the pregnancy. It's a maternity experience. That to me would be your maternity, it's your pregnancy and whether the decision is will it be for women who miscarried, who are having TOP's, having whatever. That's beyond us but your maternity experience is one, as someone who gave birth recently"* Focus group 7; *"I think you'd certainly need free text in it. We don't just want it as tick boxes"* Focus group 3; *"I think the other part of it, just to relate it to loss. I think is also, the timing of which this gets rolled out. Obviously termination of pregnancy services maybe be implemented at that point. Well are highly likely to be implemented by the time that this is rolled out…So are they being captured*

		within that as well…. They probably should be…. Like they'll be part of the maternity experience really" Focus group 5; *"So that I think you know at least 3 months kind of would be. A If that's your window, if you're asking us 6 weeks or 3 months then I'd want to vote for 3 months but if it can be longer than that. A Longer, I think so. Q1 The window is open. A Yeah. A 6 months then"* Focus group 2; *"I suppose the purpose of the survey, there should be a question possibly about whether the pregnancy was planned or not, about how much information they had before they got pregnant, about you know preconception"* Focus group 7; *"Yea so demographics, you do, like I mean you need age, you need ethnic background. You need socioeconomic information"*
Postnatal specific	– Availability of postnatal care in the community – Debriefing – Discharge education – Discharge from hospital	Focus group 4; *"I think post-natal care is essential ….. support for women disappears on discharge essential unless you are part of the domino scheme. I was fortunate to be part of a DOMINO scheme but even after you are*

	– Health of mother postnatally – Postnatal morbity – Relationship between mother and baby – Who to contact postnatally – Access to baby – Care of baby in hospital – Neonatal Intensive Care Unit	*discharged after you know the seven days that's it. And there's very little support for mums after that discharge. So I would say definitely postnatal care"* Focus group 7; *"Can I ask, we've a nice service that our delivery sister asks anyone who had like that hasn't you know an emergency situation or a delivery that didn't go according to plan. She deliberately meets them and debriefs them before they leave the hospital. So I think a question should be, were you debriefed after"* Focus group 2; *"And also I suppose if there was an emergency, if the woman is separated from the baby, did she have access to the baby, was she allowed to stay in the hospital as long as the baby was there, you know was she given adequate areas, support to be with her baby"*
Woman centered care	– Risk – Individualised care – Cultural and religious needs – Maternity care needs	Phone interview 3; *"In the survey, it is important that the experience of all women is captured, referring to both low risk and high risk pregnancies. Women with high risk pregnancies have complex needs requiring additional support and their experiences should be captured also"*

		Phone interview 4; *"Was the woman given a personalised approach to her care?"* Focus group 2; *"Were your cultural needs met exactly, your cultural or religious needs met because those are the things that really get us into a little bit of trouble every so often"*

6.6.2.1.1 Delphi round one

Round one of the Delphi study contained 396 items in total. Of these, 388 items were eligible for rating by participants and an additional eight 'fixed' items were also included. 'Fixed' items such as 'What type of birth did you have?' were presented within the Delphi study but participants were not asked to rate their importance as the inclusion of such items was necessary to structure the survey. Given the volume of items included in the first round of the Delphi study (n=394) and the expected implications that this would have on recruitment rates due to the time commitment required by participants, a small group of participants (n=22) representative of each of the key stakeholder groups was recruited to complete round one. Following analysis of Delphi round one results (95% cut off point), 230 items were eligible for inclusion in round 2 of the Delphi. Of these, 209 were eligible for rating by participants in round two, and 21 items were categorised as 'fixed' items and therefore not eligible for rating. These 230 items were reviewed by the NCEP team to ensure the aspects of care included in the second round would be amenable to care improvement actions, and edits were made to the item pool as necessary. Based on this review, 121 additional items were excluded. The analysis of the Delphi round one results, in addition to the NCEP review therefore reduced the item pool by 72% and resulted in an item pool comprising 109 items in total for inclusion in the Delphi round two. Of these, 101 items were eligible for rating by participants in round two and eight were categorised as 'fixed'. Following refinement of the item pool, participants were recruited widely to complete round two (n=127).

6.6.2.1.2 Delphi round two

Following analysis of the data arising from the rating of items by participants in Delphi round two (85% cut off point), in addition to collation and editing of the open text responses received from participants, the item pool comprised 84 items.[12]

6.6.2.2 Consensus review

An iterative qualitative process with six organisations/ experts resulted in the introduction of 11 additional items, increasing the item pool by 13%. The final item bank comprised of 95 items, identified and prioritised through a rigorous multi-phase process, was transferred to the NCEP team ahead of the pilot of the National Maternity Experience Survey. The bank of 95 items are included in appendix 26.

6.7 Discussion

The use of survey instruments to evaluate health care from the perspective of service users is essential for the generation of data for healthcare providers, policymakers, funders and users of health services on the quality of care provided[6]. Robust, structured methods have been used to inform the development of a bank of items for inclusion in the self- report survey instrument to evaluate women's experiences of the maternity care in Ireland specifically, namely the National Maternity Experience Survey. The development of the survey, and its impending nationwide implementation by the NCEP, meet a policy requirement in Ireland, in line with the Irish National Maternity Strategy[9].

Phase one of the two-phase exploratory sequential mixed methods design that was adopted entailed a systematic review followed by focus groups and one-to-one interviews with key stakeholders that highlighted the vast amount of aspects of care considered to be of most important for inclusion within the survey instrument. Fifteen major themes encompassing 70 sub-themes were identified through a hybrid approach to analysis. These themes and the results of both the systematic review and a gap analysis formed the basis of an initial, exhaustive, item pool comprising 2,698 individual items. This volume of items highlights the complexity of maternity care and is a reflection of the various professionals, contexts, services and time points that it comprises. The initial item pool was refined by the research team extensively based on a priori criteria resulting in 396 items for inclusion in phase two of the study (two-round Delphi study and consensus review), the purpose of which was a further refinement of the item pool in line with key stakeholder priorities.

Based on the results of phase one of the study, round one of the Delphi study contained 396 items. Due to the burden of time completion of a Delphi round comprising this volume of items would impose on participants, a small group of participant's representative of the key stakeholder groups were recruited to complete round one. Following analysis of the round one prioritisation of results (95% cut off point), in addition to a review by the NCEP team, the item pool was reduced by 27%. Participants for round two of the Delphi were recruited widely, and analysis of the results of this round (85% cut off point) resulted in a further reduction in the volume of the item pool with 84 items considered of most importance to stakeholders. Further highlighting the complex nature of the development process of a survey instrument to evaluate women's experiences of their care, multiple consensus reviews resulted in an increase of the volume of the item pool resulting from the Delphi study by 11%. The final bank of items comprised 95 items organised within eight sections spanning

from the first antenatal appointment attended by women through to the care received up to three months postpartum.

6.7.1 Future use

Survey instruments evaluating experiences of healthcare from the perspective of service users, when designed and administered appropriately, provide robust measures of quality[22]. This paper reports the development of a methodologically sound bank of items for use within the Republic of Ireland specifically, namely the National Maternity Experience Survey. Following the selection of the final set of items for inclusion within the survey, a validity study and assessment of the relevant measurement properties of such instruments[23] should be completed to optimise the length of the final survey instrument and to ensure accuracy and credibility of arising results.

The decision to develop a bank of items for use in the Republic of Ireland specifically was based on the hypothesis that the context of the Irish maternity services is not comparable with the maternity services of other countries for which survey instruments are available. Although no existing instrument in its entirety would be applicable to the Irish context, various aspects of such instruments informed the Irish instrument. For example, items were extracted from the instruments included in the systematic review for possible inclusion in the initial item bank, pending confirmation of the need to include those items based on the focus group and one to one interviews and the gap analysis. Similarly, although this item bank has been developed for use within the Republic of Ireland specifically and therefore it would not be directly transferable for use within an alternative context in its entirety, various aspects of the item bank may be considered for use within an alternative context, provided adequate consideration is given to the relevance of each item.

6.7.2 Limitations

Participants in the focus group and one to one interviews, Delphi study and consensus review phases who did not have a competent level of fluency in English were excluded from participation. This decision was taken as funding did not permit the recruitment of a translational service, and therefore, all participants must have had the ability to communicate and express themselves using English and understand all written and oral communication, which were in English only. The exclusion of participants that were not fluent in English excluded the opportunity to gain a valuable insight into aspects of care that are important to key stakeholders, for example, women who are cared for in a country that

may be unfamiliar to them and have care provided by staff that may not speak the same language as them.

6.8 Conclusion

Through the use of an adapted two-phase exploratory sequential mixed methods design, a bank of 95 items has been identified for use in the National Maternity Experience Survey. The design of this study has built on what is implemented currently internationally and incorporated the interests of Irish key stakeholders to ensure that the item bank is specific to the maternity care services provided within the Republic of Ireland. This bank of items will now be used as the basis of the National Maternity Experience Survey in Ireland and the final items chosen, at the discretion of the NCEP, should be psychometrically tested to ensure credibility of results before the national implementation of the survey instrument within the Republic of Ireland.

6.9 Declarations

6.9.1 Acknowledgements

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6.9.2 Author agreement

- I can confirm that the article being submitted is the original work of the authors submitting;
- I can confirm that this article has not received prior publication and is not under consideration for publication elsewhere;
- I can confirm that all authors have seen and approved the manuscript being submitted;

- I can confirm that the authors abide by the copyright terms and conditions of Elsevier and the Australian College of Midwives.

6.9.3 Authors contributions

I, Claire Beecher as guarantor of the review, confirm that all authors (CB, LD, CF, RG, LO'D, ER, MW, MD & DD) meet the criteria for authorship, have approved the final article and that all those entitled to authorship are listed as authors.

6.9.4 Conflict of interest

I confirm that there are no potential conflicts of interest arising from the authors (CB, LD, CF, RG, LO'D, ER, MW, MD & DD) of this manuscript.

6.9.5 Sources of support for research- funding

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6.9.6 Ethical statement

Ethical approval to complete the focus groups and one to one interviews was granted by the Research Ethics Committee of the National University of Ireland, Galway. Approval date: 02 August 2018. Approval number: 18-June-01.

Ethical approval to complete the Delphi study and consensus reviews was granted by the Research Ethics Committee of the National University of Ireland, Galway. Approval date: 17 December 2018. Approval number: 18-Dec-01.

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6.10 Summary of key points

Paper 5 presented an adapted two-phase exploratory sequential mixed method design to identify and prioritise items for inclusion in the NMES. Phase one identified items for possible inclusion and developed an exhaustive item pool through a systematic review (as reported in Paper 4), focus groups and one to one interviews, and a gap analysis. Phase two prioritised the items for inclusion in the final item bank through a Delphi study and consensus review. Ethical approval for all relevant aspects of the development process was received from the National University of Ireland, Galway Research Ethics Committee.

A hybrid approach was adopted to the analysis of data arising from eight in-depth focus groups and 11 one to one interviews which included 82 participants in total with representation from each of the key stakeholder groups, i.e. women as service users of the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, General Practitioners, policymakers, and funders. The analysis resulted in 15 major and 70 sub-themes. Eight of the major themes aligned with the WHO responsiveness concept domains.

A gap analysis mapping the suite of international items (identified in the systematic review) against the themes identified in the focus groups and one-to-one interviews and against Irish policy documents. Subsequently, an exhaustive item pool for inclusion in the prioritisation phase was developed by combining data identified through the systematic review, focus groups and one-to-one interviews and gap analysis. In addition to the information presented in paper 5, at the time of the write up of the initial item pool, the format of the survey instrument was also determined, i.e. identification of the number of scale points to be used as response options, use of filter and fixed items, development of descriptions of maternity care terminology that some service users may not be familiar with.

Twenty-two participants representative of key stakeholder groups completed the Delphi round one, and a further 127 participants completed the Delphi round two. Round one of the Delphi study contained 396 items in total. A 95% cut off point resulted in an item pool comprising 109 items in total for use in round two. Following analysis of the data arising from the rating of items by participants in Delphi round two (cut off point 85%), in addition to collation and editing of the open text responses received from participants, the item pool comprised 84 items. Following the Delphi study, an iterative qualitative process with six organisations/ experts resulted in an item pool comprising 95 items. The items were grouped

within eight sections; care during your pregnancy, care during your labour and birth, care in hospital after the birth of your baby, specialised care for your baby, feeding your baby, care at home after the birth of your baby, overall care and you and your household. This bank of items was then used as the basis of the NMES and the final items chosen at the discretion of the NCEP.

Chapter 7: Discussion

This chapter presents an outline of the thesis, the key findings from each of the five included papers and a discussion of the findings in the context of existing literature. To conclude, the strengths and limitations of the work presented in this thesis are identified, and the implications for practice and further research are presented.

7.1 Outline of thesis

This thesis outlines the work undertaken to develop a bank of items for inclusion in a survey instrument to evaluate women's experiences of their maternity care in the Republic of Ireland. It comprises five papers, four of which are published in peer-reviewed journals, and one has been submitted to a peer-reviewed journal. The first paper was developed in light of challenges that were faced when developing the concept of 'women's experiences of their maternity care'. The paper provided an overview of methodological approaches to concept development (Chapter 2). The methodologies described in that paper informed the development of the concept of 'women's experiences of the maternity care' using the principle-based concept analysis method by Penrod and Hupcey (2005) (Chapter 3). The third paper presents a protocol for a systematic review of self-report survey instruments to measure women's experiences of their maternity care (Chapter 4). Paper three informed a systematic review of the methodological and psychometric quality of self-report survey instruments used internationally to measure women's experiences of maternity care (Paper 4, Chapter 5). Finally, paper five (Chapter 6) describes all additional work undertaken in the development of the item bank, namely, focus group and one to one interviews with key stakeholders, a gap analysis, development of initial item pool, a two-round Delphi study and a consensus review.

7.2 Key findings

7.2.1 Concept development in Nursing and Midwifery: An overview of methodological approaches

Paper one presents a discussion paper that provides an overview of the methodological considerations of the seminal concept development strategies and methods within nursing and midwifery (Penrod and Hupcey, 2005, Norris, 1982, Walker and Avant, 2018, Rodgers and Knafl, 2000). The purpose of this paper was to provide guidance to nurse and midwife

researchers in their choice of concept development methodology. In addition to providing this guidance, the paper highlights that there has been relatively little evolvement of the most commonly used methods of concept development in the nursing and midwifery domain since their inception. Based on this finding, it was concluded that there is a need for a review and possible advancement of these methods to facilitate compatibility with the current concepts within this domain.

7.2.2 Women's experiences of their maternity care: A principle-based concept analysis

The principle-based concept analysis method by Penrod and Hupcey (2005) was used in paper two to conduct an in-depth analysis of the concept of 'women's experiences of their maternity care'. The key finding was that despite the utility of the concept in the literature being high, and the recognition of the importance of women's experiences of their maternity care, the concept itself is philosophically immature. This immaturity can be attributed to the lack of a universally accepted definition of the concept. A theoretical definition of the concept[3] has been developed based on this analysis and, it now serves as a foundation for future research, in particular in the development of a definitive agreed definition of the concept.

7.2.3 Measuring women's experiences of maternity care: protocol for a systematic review of self-report survey instruments

Paper three identified a priori methods for completing a systematic review of self-report survey instruments used internationally to measure women's experiences of their maternity care.

7.2.4 Measuring women's experiences of maternity care: a systematic review of self-report survey instruments

Forty papers related to 20 self-report survey instruments measuring women's experiences of their maternity care were identified in paper four. Following COSMIN guidance (Prinsen et al., 2018), the methodological and psychometric quality of each included instrument were

[3] "Women's experiences of their maternity care' is a complex concept referring to women's interpretation of their care encounters within the maternity services. It is subjective in nature and evolves throughout the course of pregnancy, childbirth and the postpartum period. It is dependent upon a woman's individual needs and expectations, shaped by their personal circumstances and influenced by how their care is organised and delivered".

evaluated. Findings indicate that evidence of the methodological and psychometric quality of many of the included instruments is poorly reported. The apparent lack of reporting led to low scores across all aspects of the COSMIN Risk of Bias Checklist and against the COSMIN recommended criteria for good measurement properties for the majority of instruments. These low scores, although possibly attributable to harsh critique stemming from adherence to COSMIN's strict guidelines, could potentially impact the credibility of the findings of these instruments. The transparent reporting of the robust methods used to develop survey instruments evaluating women's experiences of their maternity care is essential for the foundation of future research on the use, adaptation, and development of similar instruments.

7.2.5 Development of a survey instrument to evaluate women's experiences of their maternity care

Paper five presents an overview of the use of an adapted two-phase exploratory sequential mixed methods design to develop a bank of 95 items for use in a survey instrument to evaluate women's experiences of their maternity care in the Republic of Ireland. Phase one consisted of the systematic review presented in paper four, in addition to focus group and one to one interviews with 82 participants from key stakeholder groups. Following this, a gap analysis was completed. Fifteen major themes encompassing seventy sub-themes were identified through a hybrid approach to the analysis of data arising from the focus groups and one to one interviews. The themes identified in the interviews, in addition to the results of the systematic review and the gap analysis, directly informed the development of an item pool of 396 items for inclusion in Phase two. Phase two entailed a two-round Delphi study and consensus review. Following rating of the 396 items included in round one of the Delphi study by key stakeholder groups and a review by the NCEP team, the item pool was reduced to 109 items for inclusion in round two. Analysis of the data arising from round two of the Delphi study resulted in 84 items going forward for consensus review. Following the consensus review, the final item bank comprised 95 items organised within the following eight sections; Care during your pregnancy; Care during your labour and birth; Care in hospital after the birth of your baby; Specialised care for your baby; Feeding your baby; Care at home after the birth of your baby; Overall care and You and your household. This item bank was transferred to the National Care Experience Programme (NCEP) team for use as the basis of the Irish National Maternity Experience Survey (NMES).

7.3 Discussion

Conceptual clarity is critical in the development of instruments that evaluate experiences of care with a view to improving healthcare quality, as it contributes to the understanding of how healthcare quality is experienced (Holt, 2018). It is widely accepted that maternity care quality is multifaceted (Raven et al, 2012). The contribution of women, as maternity care service users, towards the understanding and contextualisation of maternity care quality is crucial, as apparent from the development process of an evidence-based framework that describes a system for high quality maternal and new born care (Renfrew et al, 2014). The views and experiences of women formed the foundation of the development process of this framework that identifies five interlinked components of quality maternity care; effective practices, the organisation of care, the philosophy and values of the care providers, and the characteristics of care providers.

Despite this growing body of work that aims to contextualise and understand maternity care quality and how it is experienced, and the role that women's experiences are having in its development, the concept of 'women's experiences of their maternity care' remains undefined. Although it is clear that much work has been completed towards a definition of *patient* experiences in general (Wolf et al., 2014) the variances in the spectrum of care provided between general and maternity care mean that ultimately the outcomes of development work towards the definition of either concept are not transferable. Therefore, the development of a theoretical definition of the concept, following the guidance of the principle-based concept analysis method by Penrod and Hupcey (2005), provides a vital foundation on which future work on the advancement of the concept can be based (Paper 2).

Prior work that is comparable to the analysis of 'women's experiences with their maternity care' is the evolutionary concept analysis of 'women's experiences of labour and birth' (Larkin et al., 2009). The focus of this work differs though as Larkin et al. (2009) highlight that the concept was analysed as a multidimensional whole that encompassed both experiences of the care received during labour and birth and women's experience of birth itself. There were evident similarities with the findings of both analyses, however, most notably with the analysis of 'women's experiences of labour and birth' identifying the interchangeable use of experience with satisfaction. This supports the findings of the analysis of 'women's experiences of their maternity care' which found that, under the logical principle, the

boundaries between experiences and satisfaction appear blurred, despite the recognition that there are significant differences in the underlying approaches to the evaluation of each.

The contrast between the underlying approaches of evaluating experiences of, and satisfaction with, care informed one of the exclusion criteria of the systematic review (Paper 3 and 4) where literature that focused on instruments that measure women's level of satisfaction with their care were excluded. Additionally, a significant effort focused on ensuring that each of the items included within the final item bank for use in the NMES, excluding the demographics section, are evaluating women's experience of, and not their satisfaction with, their maternity care.

The theoretical and methodological limitations of using satisfaction to evaluate quality care have been reiterated by Beattie et al. (2015) who excluded all studies that focused on the measurement of satisfaction with care when undertaking a systematic review of instruments to measure patient experiences of healthcare quality in hospitals. Beattie et al. (2015), who relied on an earlier version of COSMIN guidance (Mokkink et al., 2010) for the evaluation of included instruments than that used in this study, acknowledged that in comparison to similar reviews that had taken place within the decade previous, sufficient psychometric information related to the included instruments had been reported, therefore enabling critique. This acknowledgement by Beattie et al. (2015) highlights that, encouragingly, the reporting of such properties within healthcare is improving over time.

This improvement, however, is not reflected in the findings of paper 4 and although it was possible for Beattie et al. (2015) to critique each instrument, it was conceded that some missing data might have led to lower scores for quality being given. These low scores are comparable with the findings in Paper 4, with the majority of instruments included receiving low scores across all aspects of the Risk of Bias Checklist and against the criteria for good measurement properties, as evaluated in line with COSMIN guidance (Prinsen et al., 2018). These low scores may be attributable to inadequate reporting of all developmental processes and psychometric testing of the included instruments. They may also be attributed to being harshly critiqued by adhering to COSMIN's strict guidance, for example, in relation to the application of the 'lowest score counts' scoring method. This observation of the scoring method echoes that of Beattie et al., who identified a possibility that the 'lowest score counts' method led to unfair scoring of instruments included in that review. In addition to the COSMIN checklist, Beattie et al. used an earlier version of the Quality Criteria for

Measurement Properties (Terwee et al., 2007). These criteria were also used in the evaluation of another review completed by (Nilvér et al., 2017). Although the systematic review presented in Paper 4 is the first, to my knowledge, of self-report survey instruments used to measure women's experiences of their maternity care, Nilvér et al. (2017) completed a comparable systematic review to identify and analyse instruments measuring women's childbirth experiences.

The purpose of Nilvér et al. (2017) review was not to focus on the quality of the studies included, rather to identify the psychometric properties of included instruments and apply the Quality Criteria to support researchers in the use and adaptation of instruments. As the focus was not upon the quality of included instruments, three instruments were excluded from the Nilvér et al. (2017) review based on them not reporting psychometric properties. This is in contrast to the review presented in Paper 4, that included all instruments and related material that was identified, with each instrument rated based on the information provided, however minimal. Furthermore, as the focus of the review by Nilvér et al. (2017) was on instruments that measure childbirth experiences specifically and in doing so the authors chose, in line with the analysis of the concept by Larkin et al. (2009), to use a broad definition and include instruments that measure the care received during labour and birth in addition to women's experience of birth itself. Therefore, the focus of a large proportion of the resulting instruments is not congruent with women's experiences of the care they received, with, for example, 36% of included instruments focusing on satisfaction with care/ birth/ childbirth. In contrast to the results presented in Paper 4, Nilvér et al. (2017) identified all 36 included instruments as having a positive rating of content validity. However, many of the instruments were judged to need further testing of their psychometric properties prior to use. The purpose of the review was to support researchers in the use and adaptation of instruments, and as many of the included instruments lacked complete testing, Nilvér et al. (2017) recommend that rather than the development of new instruments, researchers should focus on the adaptation and use of existing instruments. Similarly, the systematic review presented in Paper 4 was completed to serve as a guide for choosing the most appropriate existing instruments to use or adapt. However, the review was also completed to inform the development of new instruments, where it is necessary.

Given the growing focus on minimising research waste and based on recommendations including those from Nilvér et al. (2017), new research, such as the development of new instruments, should not be undertaken if there is existing evidence that adequately

addresses the need (Chalmers and Glasziou, 2009). The decision to develop a new instrument for use in Ireland is based on the hypothesis that the context of the Irish maternity services is not comparable with the maternity services of any existing survey instrument. It could be argued that, as per the Japanese adaptation of the American Listening to Mothers instrument (Kishi et al., 2011), it would have been possible to culturally adapt an existing instrument for use in Ireland. However, as identified in Paper 2 under the linguistic analysis of the concept of 'experiences of care', culture contributes significantly to the complexity of this concept and how it is interpreted. The extensive adaptation of an existing instrument that would have been needed, therefore, would most likely have met or exceeded the resources used to develop the new instrument, as apparent from the translation and cultural adaptation undertaken by Kishi et al. (2011).

It is evident, however, that there are commonalities amongst childbearing women internationally on what matters most to them in the design and provision of maternity care (Downe et al., 2018). In a review of what matters to women during childbirth, Downe et al. (2018) identify that women want a positive experience that either meets or exceeds their existing personal and socio-cultural beliefs and expectations. Given the commonalities amongst childbearing women, it was decided that although no existing instrument in its entirety would be applicable to the Irish context, various aspects would be adapted from existing instruments. For example, items were extracted from the instruments included in the systematic review for possible inclusion in the initial item bank, pending confirmation of the need to include those items based on the focus group and one to one interviews and the gap analysis (Paper 5). Of the item pools to which we had access, five instruments originated from Europe (Survey Coordination Centre, 2019, Scottish Care Experience Survey Programme, 2018, Sjetne et al., 2015, Redshaw et al., 2019, Hundley et al., 2002), seven from Australia and New Zealand (Clark et al., 2016, Prosser et al., 2013, Todd et al., 2016, Yelland et al., 2012, Buchanan and Magill, 2015, Bureau of Health Information, 2018, Brown et al., 2002), one from America (Sakala et al., 2018) and one, based on the Listening to Mothers in America survey, from Japan (Kishi et al., 2011).

While analysing the data arising from the one to one and focus group interviews, we found that emerging themes aligned broadly with the eight domains of the World Health Organization (WHO) responsiveness model (Valentine et al., 2003), namely autonomy, choice, communication, confidentiality, dignity, basic amenities, prompt attention and social considerations. As identified in Paper 5, the development of the ReproQ survey instrument

(Scheerhagen et al., 2015) closely followed this model and, given the link between these eight domains and basic human rights in healthcare (Valentine et al., 2003), it is unsurprising that these domains are common themes within the majority of the instruments identified in the systematic review. As a result, based on the findings of the focus group and one to one interviews and the gap analysis, many of the aspects for inclusion in the Irish instrument aligned to some degree with various aspects that were included in the international instruments for which we had retrieved the item pool.

Consent was sought from the owner or developer of each instrument for preliminary permission to use, or adapt, items that they had developed with the NCEP taking responsibility for retrieving formal permission to use the final bank of items included in the survey instrument. Although ultimately, the majority of the items included in the NMES instrument were adapted from international instruments, no one instrument contributed extensively. Furthermore, the decision was taken a priori that, in line with the National Inpatient Experience Survey (National Care Experience Programme, 2020), the NMES would be a self-report instrument that relies predominantly on closed items with a minimal number of open text boxes. The formatting of the items within the NMES, for example, the Likert scale response options, were adapted from existing instruments.

The systematic review identified that the methodological and psychometric quality for many of the included instruments is lacking. This led to low scores across all aspects of the COSMIN Risk of Bias Checklist and against the COSMIN recommended criteria for good measurement properties for the majority of instruments. As scoring is dependent on the availability of information and the quality of reporting, Terwee et al. (2007) highlight the need for high quality of reporting to enhance quality ratings. In fulfilment of this need, and to facilitate the ease of use or adaptation of the bank of items developed for inclusion in the NMES, paper five was reported in line with the COSMIN Risk of Bias checklist sections 'general requirements and concept elicitation' (Terwee et al., 2018). To enhance the transparency of reporting further, paper five identified the need for psychometric testing prior to the implementation of the NMES, highlighting that the development process of the survey instrument is incomplete up to the point of the reporting of paper five. Additionally, the content of the 95 items that make up the final item bank has also been reported clearly as supplementary material in paper five.

7.3.1 Strengths and weaknesses

The work presented in this thesis has several strengths and limitations. A key strength of the work presented is the sequential nature of the work carried out. Each piece of work that was conducted influenced directly, and was necessary, for completion of the next piece of work to ensure the robust development of the bank of items. Furthermore, large, multi-stakeholder inclusion in the development of the bank of items has led to included items being relevant to the interests of all key stakeholders; women as service users of the Irish maternity services, midwives, public health nurses, obstetricians, neonatologists, anaesthesiologists, general practitioners, policymakers, and funders. A further strength of this work is the co-development of the bank of items with policymakers. This collaboration ensured that reviews took place as work progressed to ensure that included items would be amenable to quality improvement actions to be taken at policy level in response to results arising from such items. This ensured that no item, bar demographics, was included that could not contribute directly to the improvement of quality of care provided to women in the Republic of Ireland.

This thesis also has several limitations. One of the main limitations of the work is the exclusion of participants in the focus group and one to one interviews, Delphi study and consensus review who did not have a competent level of fluency in English. This decision was taken as funding did not permit the recruitment of a translational service, and therefore, all participants must have had the ability to communicate and express themselves using English words and understand all written and oral communication. The exclusion of participants that were not fluent in English excluded the opportunity to gain a valuable insight into aspects of care that are important to key stakeholders, for example, women who are cared for in a country that may be unfamiliar to them and have care provided by staff that may not speak the same language as them. A further possible limitation is the use of the COSMIN guidance to evaluate the methodological and psychometric quality of included instruments in the systematic review (Paper 4). Guidance for completing the systematic review was taken from COSMIN based on the identification of this being the most relevant framework available for use following consultation with COSMIN authors. The guidance by COSMIN (Prinsen et al., 2018) was developed for systematic reviews of patient-reported outcome measures (PROMs) and, given the differences between PROMs and survey instruments that evaluate experiences of care, the guidance provided was adapted to suit the review. By adhering to the guidance provided by COSMIN, albeit adapted, it is possible that included instruments

were critiqued harshly, particularly in relation to the areas of content validity studies and concept elicitation in which most of the retrieved literature was focused. This may be attributable to the COSMIN framework not being entirely applicable to the survey instrument's being evaluated.

7.3.2 Implications for practice and policy

The work presented in this thesis has direct implications for practice and policy given that the bank of 95 items developed formed the basis of the NMES that has now been implemented nationally in the Republic of Ireland. The results arising from this survey will be used to inform quality improvement actions in relation to the care provided to women within the Irish maternity services.

7.3.3 Implications for research

Based on the work completed, it is evident that there are opportunities for future research to be completed to build upon the work presented in this thesis;

1. It is evident from the literature included in paper 1 (Chapter 2) that since the inception of the seminal methods of concept development, there has been relatively little evolvement of these methods. This highlights an opportunity to review and advance the existing methods of concept development. The advancement of these existing methods would provide guidance for the robust development of concepts, a vital component in advancing the knowledge base of nursing and midwifery theory and practice;
2. Paper 2 (Chapter 3) culminates in a theoretical definition of the concept of 'women's experiences of their maternity care'. This theoretical definition serves as a foundation for future research on the advancement of the concept, and in particular the development of a universally accepted definition of the concept. The development of a universally accepted definition of the concept would serve as a means to further differentiate it from related concepts, such as 'women's satisfaction with their maternity care', facilitating the effective utility of the concept;
3. The systematic review (Chapter 5) was completed in line with the COSMIN guideline for systematic reviews of PROMs. Given that there are distinct differences between PROMs and survey instruments that measure experiences of care, there is an evident gap in the literature for the development of a framework for use in systematic reviews of instruments that measure all aspects of experiences of healthcare given the growing focus on this area of research. The development of a framework specifically for this use

would minimise the need for researchers to adapt frameworks such as those provided by COSMIN which would in turn minimise the possibility of harsh critiquing of included instruments, as identified in Chapter 5;

4. The bank of 95 items developed has been transferred to the NMES. The results arising from the implementation of the NMES will influence the direction of limited resources within the Irish maternity services. The items for use in the final survey instrument, as chosen by the NCEP, therefore require psychometric testing to optimise the length of the survey instrument and to ensure the credibility of these results. There is possible opportunity for further research to complete this work via pilot testing of the final instrument, in addition to the pilot testing of the 95 items included in the final bank, as a stand-alone survey instrument. Pilot testing would involve online distribution of the survey instrument to women as service users of the Irish maternity services and assessment of the psychometric properties, such as those identified by COSMIN in Chapter 5, of arising results. The outcomes of these assessments would allow for necessary changes to be made to the items included within the survey instrument, optimising the credibility of results.

7.4 Conclusion

Five papers have been presented in this thesis that report transparently the body of work completed to develop a bank of items for use as the basis of the Irish NMES, a survey instrument that has been implemented nationally to evaluate women's experiences of their maternity care. The results arising from the survey instrument will inform quality improvement actions directly within the Irish maternity services. The policy impact of the development of the bank of items, in addition to the implementation of the survey nationally, is clear given that it satisfies a policy imperative set out in the Irish National Maternity Strategy (Department of Health, 2016).

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Appendices

Appendix 1

Paper 2: List of 87 included literature items.

Appendices

Authors	Year	Title	Journal
Abuya, T.; Warren, C. E.; Miller, N.; Njuki, R.; Ndwiga, C.; Maranga, A.; Mbehero, F.; Njeru, A.; Bellows, B.	2015	Exploring the prevalence of disrespect and abuse during childbirth in Kenya	PLoS One
Simic, P.; Benett, I. J.; Garrod, D.	1995	Women's experience of maternity care in an inner city: a team-based qualitative study	Midwives
Anwar, Shahnaz; Jan, Rafat; Qureshi, Rahat Najam; Rattani, Salma	2014	Perinatal women's perceptions about midwifery led model of care in secondary care hospitals in Karachi, Pakistan	Midwifery
Attanasio, Laura; Kozhimannil, Katy B.	2015	Patient-reported Communication Quality and Perceived Discrimination in Maternity Care	Medical Care
Amroussia, Nada; Hernandez, Alison; Vives-Cases, Carmen; Goicolea, Isabel	2017	"Is the doctor God to punish me?!" An intersectional examination of disrespectful and abusive care during childbirth against single mothers in Tunisia	Reproductiv e Health
Bäckström, Caroline A.; Mårtensson, Lena B.; Golsäter, Marie H.; Thorstensson, Stina A	2016	"It's like a puzzle": Pregnant women's perceptions of professional support in midwifery care	Women & Birth
Baker, S. R.; Choi, P. Y. L.; Henshaw, C. A.; Tree, J.	2005	I felt as though I'd been in jail': women's experiences of maternity care during labour, delivery and the immediate postpartum	Feminism & Psychology
Baldo, M. H.; Al-Mazrou, Y. Y.; Aziz, K. M. S.; Farag, M. K.; Al-Shehri, S. N.	1995	Coverage and quality of natal and postnatal care: Women's perceptions, Saudi Arabia	Journal of Tropical Pediatrics
Beake, Sarah; Acosta, Luisa; Cooke, Pauline; McCourt, Christine	2013	Caseload midwifery in a multi-ethnic community: The women's experiences	Midwifery
Bhattacharyya, Sanghita; Issac, Anns; Rajbangshi, Preety; Srivastava, Aradhana; Avan, Bilal I.	2015	"Neither we are satisfied nor they"-users and provider's perspective: a qualitative study of maternity care in secondary level public health facilities, Uttar Pradesh, India	BMC Health Serv Res
Blackwell, D. A.	2002	Prenatal care services in the public and private arena	Journal of the American

			Academy of Nurse Practitioners
Bondas, T.	2002	Finnish women's experiences of antenatal care	Midwifery
Brown, S.; Lumley, J.	1998	Changing childbirth: lessons from an Australian survey of 1336 women	British Journal of Obstetrics & Gynaecology
Brown, Stephanie Janne; Weetra, Donna; Glover, Karen; Buckskin, Mary; Ah Kit, Jackie; Leane, Cathy; Mitchell, Amanda; Stuart-Butler, Deanna; Turner, May; Gartland, Deirdre; Yelland, Jane	2015	Improving Aboriginal Women's Experiences of Antenatal Care: Findings from the Aboriginal Families Study in South Australia	Birth: Issues in Perinatal Care
Butler, Michelle M.; Sheehy, Lucille; Kington, Mary; Walsh, Maura C.; Brosnan, Mary C.; Murphy, Martina; Naughton, Corina; Drennan, Jonathan; Barry, Theresa	2015	Evaluating midwife-led antenatal care: Choice, experience, effectiveness, and preparation for pregnancy	Midwifery
Carolan, M.; Cassar, L.	2010	Antenatal care perceptions of pregnant African women attending maternity services in Melbourne, Australia	Midwifery
Tiedje, L. B.; Price, E.; You, M.	2008	Childbirth is changing: what now?	MCN: The American Journal of Maternal Child Nursing
Murray, D.; Ryan, F.; Keane, E	2000	Who's holding the baby?--women's experience of their postnatal care	Irish Medical Journal
Cross-Sudworth, Fiona; Williams, Amanda; Herron-Marx, Sandy	2011	Maternity services in multi-cultural Britain: Using Q methodology to explore the views of first- and second-generation women of Pakistani origin	Midwifery
da Silva Albuquerque Melo, Danúzia; de Oliveira e. Silva, Jovânia Marques; Santos, Amuzza Aylla; de Lima Sanches, Maria Elisângela Torres; Ramos Cavalcante, Kariane	2016	WOMAN'S PERCEPTION ON CHILDBIRTH CARE	Journal of Nursing UFPE

Omena; de Santana Jacintho, Kamilla			
De Marco, M.; Thorburn, S.; Zhao, W.	2008	Perceived discrimination during prenatal care, labor, and delivery: an examination of data from the Oregon Pregnancy Risk Assessment Monitoring System, 1998-1999, 2000, and 2001	American Journal of Public Health
Dhar, R. S.; Nagpal, J.; Bhargava, V.; Sachdeva, A.; Bhartia, A.	2010	Quality of care, maternal attitude and common physician practices across the socio-economic spectrum: a community survey	Archives of Gynecology and Obstetrics
Etowa, Josephine B.	2012	Black Women's Perceptions of Supportive Care During Childbirth	International Journal of Childbirth Education
Farquhar, M.; Camilleri-Ferrante, C.; Todd, C.	2000	Continuity of care in maternity services: women's views of one team midwifery scheme	Midwifery
Fawole, A. O.; Okunlola, M. A.; Adekunle, A. O.; Fawole, Adeniran O.; Okunlola, Michael A.; Adekunle, Adeyemi O	2008	Clients' perceptions of the quality of antenatal care	Journal of the National Medical Association
Fenwick, J.; Butt, J.; Dhaliwal, S.; Hauck, Y.; Schmied, V.	2010	Western Australian women's perceptions of the style and quality of midwifery postnatal care in hospital and at home	Women & Birth
Fitzgerald, Elizabeth Moran; Cronin, Sherill Nones; Boccella, Sarah Hess	2016	Anguish, yearning, and identity: Toward a better understanding of the pregnant Hispanic woman's prenatal care experience	Journal of Transcultural Nursing
Forssén, A. S.	2012	Lifelong significance of disempowering experiences in prenatal and maternity care: interviews with elderly Swedish women	Qualitative Health Research
Fraser, D. M	1999	Women's perceptions of midwifery care: a longitudinal	Birth: Issues in Perinatal Care

		study to shape curriculum development	
Fuentes-Afflick, Elena; Odouli, Roxana; Escobar, Gabriel J.; Stewart, Anita L.; Hessol, Nancy A.	2014	Maternal Acculturation and the Prenatal Care Experience	Journal of Women's Health
Gheibizadeh, Mahin; Abedi, Heidar Ali; Mohammadi, Easa; Abedi, Parvin	2016	Iranian women and care providers' perceptions of equitable prenatal care	Nurs Ethics
Halldorsdottir, S.; Karlsdottir, S. I.	1996	Empowerment or discouragement: women's experience of caring and uncaring encounters during childbirth	Health Care for Women International
Harriott, E. M.; Williams, T. V.; Peterson, M. R.	2005	Childbearing in U.S. military hospitals: dimensions of care affecting women's perceptions of quality and satisfaction	Birth: Issues in Perinatal Care
Hatamleh, Reem; Shaban, Insaf Ali; Homer, Caroline	2013	Evaluating the Experience of Jordanian Women With Maternity Care Services	Health Care for Women International
Heberlein, Emily C.; Picklesimer, Amy H.; Billings, Deborah L.; Covington-Kolb, Sarah; Farber, Naomi; Frongillo, Edward A	2016	Qualitative Comparison of Women's Perspectives on the Functions and Benefits of Group and Individual Prenatal Care	Journal of Midwifery & Women's Health
Henderson, Jane; Gao, Haiyan; Redshaw, Maggie	2013	Experiencing maternity care: the care received and perceptions of women from different ethnic groups	BMC Pregnancy & Childbirth
Henderson, Jane; Redshaw, Maggie	2017	Change over time in women's views and experiences of maternity care in England, 1995-2014: A comparison using survey data	Midwifery
Hennegan, Julie; Redshaw, Maggie; Kruske, Sue	2015	Another country, another language and a new baby: A quantitative study of the postnatal experiences of migrant women in Australia	Women & Birth
Hildingsson, I. M.; Sandin-Bojo, A. K.	2011	What is could indeed be better'--Swedish women's perceptions of early postnatal care	Midwifery
Hildingsson, I.; Thomas, J. E	2007	Women's perspectives on maternity services in Sweden:	Journal of Midwifery &

		processes, problems, and solutions	Women's Health
Homer, C. S. E.; Davis, G. K.; Brodie, P. M.	2000	What do women feel about community-based antenatal care?	Australian & New Zealand Journal of Public Health
Homer, C. S. E.; Davis, G. K.; Cooke, M.; Barclay, L. M.	2002	Women's experiences of continuity of midwifery care in a randomised controlled trial in Australia	Midwifery
Ith, Ponndara; Dawson, Angela; Homer, Caroline S. E.	2013	Women's perspective of maternity care in Cambodia	Women & Birth
Jahlan, Ibtesam; Plummer, Virginia; McIntyre, Meredith	2016	WHAT WOMEN HAVE TO SAY ABOUT GIVING BIRTH IN SAUDI ARABIA	Middle East Journal of Nursing
Jenkins, Mary G.; Ford, Jane B.; Morris, Jonathan M.; Roberts, Christine L.	2014	Women's expectations and experiences of maternity care in NSW -- What women highlight as most important	Women & Birth
Jomeen, Julie; Redshaw, Maggie	2013	Ethnic minority women's experience of maternity services in England	Ethnicity & Health
Kambala, Christabel; Lohmann, Julia; Mazalale, Jacob; Brenner, Stephan; De Allegri, Manuela; Muula, Adamson S.; Sarker, Malabika	2015	How do Malawian women rate the quality of maternal and newborn care? Experiences and perceptions of women in the central and southern regions	BMC Pregnancy & Childbirth
Kennedy, Holly Powell; Farrell, Trisha; Paden, Regina; Hill, Shannon; Jolivet, Rima; Willetts, Jacqueline; Rising, Sharon Schindler	2009	"I wasn't alone"-A study of group prenatal care in the military	Journal of Midwifery & Women's Health
Kumbani, L. C.; Chirwa, E.; Malata, A.; Odland, J. O.; Bjune, G	2012	Do Malawian women critically assess the quality of care? A qualitative study on women's perceptions of perinatal care at a district hospital in Malawi	Reproductive Health
Kuo, Su-Chen; Wu, Cheng Jing; Mu, Pei-Fan	2010	Taiwanese women's experiences of hospital midwifery care: a phenomenological study	Midwifery
Ladfors, L.; Eriksson, M.; Mattsson, L. Å; Kylebäck, K.; Magnusson, L.; Milsom, I.	2001	A population based study of Swedish women's opinions about antenatal, delivery and postpartum care	Acta Obstetricia et Gynecologic

			a Scandinavica
Lee, Tsorng-Yeh; Landy, Christine Kurtz; Wahoush, Olive; Khanlou, Nazilla; Liu, Yin-Chun; Li, Chia-Chi	2014	A descriptive phenomenology study of newcomers' experience of maternity care services: Chinese women's perspectives	BMC Health Serv Res
Lewis, Lucy; Hauck, Yvonne L.; Ronchi, Fiona; Crichton, Caroline; Waller, Liana	2016	Gaining insight into how women conceptualize satisfaction: Western Australian women's perception of their maternity care experiences	BMC Pregnancy & Childbirth
Macfarlane, A. J.; Rocca-Ihenacho, L.; Turner, L. R.; Roth, C.	2014	Survey of women's experiences of care in a new freestanding midwifery unit in an inner city area of London, England. 1: Methods and women's overall ratings of care	Midwifery
Macfarlane, Alison J.; Rocca-Ihenacho, Lucia; Turner, Lyle R.	2014	Survey of women's experiences of care in a new freestanding midwifery unit in an inner city area of London, England: 2. Specific aspects of care	Midwifery
Macfarlane, Alison J.; Rocca-Ihenacho, Lucia; Turner, Lyle R.; Roth, Carolyn	2014	Survey of women's experiences of care in a new freestanding midwifery unit in an inner city area of London, England – 1: Methods and women's overall ratings of care	Midwifery
MacKeith, N.; Chinganya, O. J.; Ahmed, Y.; Murray, S. F.	2003	Zambian women's experiences of urban maternity care: results from a community survey in Lusaka	African Journal of Reproductiv e Health
Maia Brasil, E. G.; Oliveira Queiroz, M. V.; Carvalho Fernandes, A. F.; da Costa, R. F.; Xavier, E. O.	2013	Perception of women on the care in the childbirth: Contributions to nursing	Acta Scientiarum - Health Sciences
Mathole, T.; Lindmark, G.; Majoko, F.; Ahlberg, B. M.	2004	A qualitative study of women's perspectives of antenatal care in a rural area of Zimbabwe	Midwifery
Mazul, M. C.; Salm Ward, T. C.; Ngui, E. M	2017	Anatomy of Good Prenatal Care: Perspectives of Low Income African-American Women on	Journal of Racial & Ethnic

		Barriers and Facilitators to Prenatal Care	Health Disparities
McAree, T.; McCourt, C.; Beake, S.	2010	Perceptions of group practice midwifery from women living in an ethnically diverse setting	Evidence Based Midwifery
McKinnon, L. C.; Prosser, S. J.; Miller, Y. D.	2014	What women want: qualitative analysis of consumer evaluations of maternity care in Queensland, Australia	BMC Pregnancy & Childbirth
Messent, P.	2002	Professional issues. Evaluating women's experiences for a MSLC...Maternity Services Liaison Committee	British Journal of Midwifery
Miller, Yvette D.; Dane, Aimée C.; Thompson, Rachel	2014	A call for better care: the impact of postnatal contact services on women's parenting confidence and experiences of postpartum care in Queensland, Australia	BMC Health Serv Res
Mohale, H.; Sweet, L.; Graham, K.	2016	Maternity health care: The experiences of Sub-Saharan African women in Sub-Saharan Africa and Australia	Women & Birth
Murphy, Annette; Wells, John; Chesser-Smyth, Patricia; Sheahan, Linda; Foley, Michelle	2014	An Exploratory Survey of Low-Risk Pregnant Women's Perceptions of Antenatal Care and Services in Southern Ireland	International Journal of Childbirth
Novick, Gina; Sadler, Lois S.; Kennedy, Holly Powell; Cohen, Sally S.; Groce, Nora E.; Knafl, Kathleen A.	2011	Women's Experience of Group Prenatal Care	Qualitative Health Research
Proctor, S.	1998	What determines quality in maternity care? Comparing the perceptions of childbearing women and midwives	Birth: Issues in Perinatal Care
Raine, R.; Cartwright, M.; Richens, Y.; Mahamed, Z.; Smith, D.	2010	A qualitative study of women's experiences of communication in antenatal care: identifying areas for action	Maternal & Child Health Journal 2010
Redshaw, Maggie; Hennegan, Julie; Miller, Yvette	2014	Young women's recent experience of labour and birth care in Queensland	Midwifery

Redshaw, Maggie; Miller, Yvette D.; Hennegan, Julie	2014	Young Women's Experiences as Consumers of Maternity Care in Queensland	Birth: Issues in Perinatal Care
Rice, P.	1999	What women say about their childbirth experiences: the case of Hmong women in Australia	Journal of Reproductive & Infant Psychology
Rice, P. L.; Naksook, C	1998	The experience of pregnancy, labour and birth of Thai women in Australia	Midwifery
Risisky, D.; Asghar, S. M.; Chaffee, M.; DeGennaro, N.	2013	Women's Perceptions Using the CenteringPregnancy Model of Group Prenatal Care	Journal of Perinatal Education
Rosen, Heather E.; Lynam, Pamela F.; Carr, Catherine; Reis, Veronica; Ricca, Jim; Bazant, Eva S.; Bartlett, Linda A.	2015	Direct observation of respectful maternity care in five countries: a cross-sectional study of health facilities in East and Southern Africa	BMC Pregnancy & Childbirth
Sapountzi-Krepia, Despina; Tsaloglidou, Areti; Psychogiou, Maria; Lazaridou, Christina; Vehvilainen Julkunen, Katri	2011	Mothers' experiences of pregnancy, labour and childbirth: A qualitative study in Northern Greece	International Journal of Nursing Practice
Shabila, N. P.; Ahmed, H. M.; Yasin, M. Y.	2014	Women's views and experiences of antenatal care in Iraq: A Q methodology study	BMC Pregnancy and Childbirth
Shabila, N. P.; Ahmed, H. M.; Yasin, M. Y.	2015	Assessment of women's perspectives and experiences of childbirth and postnatal care using Q-methodology	Eastern Mediterranean Health Journal
Shafiei, Touran; Small, Rhonda; McLachlan, Helen	2012	Women's views and experiences of maternity care: A study of immigrant Afghan women in Melbourne, Australia	Midwifery
Chalmers, B., Dzakpasu, S., Heaman, M. & Kaczorowski, J.	2008	The Canadian Maternity Experiences Survey: An Overview of Findings	Perinatology
Stamp, G. E.; Crowther, C. A.	1994	Women's views of their postnatal care by midwives at an Adelaide women's hospital	Midwifery

Sword, Wendy; Heaman, Maureen I.; Brooks, Sandy; Tough, Suzanne; Janssen, Patricia A.; Young, David; Kingston, Dawn; Helewa, Michael E.; Akhtar-Danesh, Noori; Hutton, Eileen	2012	Women's and care providers' perspectives of quality prenatal care: a qualitative descriptive study	BMC Pregnancy & Childbirth
Tobin, Carolyn; Murphy-Lawless, Jo; Tatano Beck, Cheryl	2014	Childbirth in exile: Asylum seeking women's experience of childbirth in Ireland	Midwifery
Todd, Angela L.; Ampt, Amanda J.; Roberts, Christine L.	2017	Very Good' Ratings in a Survey of Maternity Care: Kindness and Understanding Matter to Australian Women	Birth: Issues in Perinatal Care
Tsianakas, V.; Liamputtong, P	2002	What women from an Islamic background in Australia say about care in pregnancy and prenatal testing	Midwifery
Wheatley, R. R.; Kelley, M. A.; Peacock, N.; Delgado, J.	2008	Women's narratives on quality in prenatal care: a multicultural perspective	Qualitative Health Research
Wiegers, T. A.	2009	The quality of maternity care services as experienced by women in the Netherlands	BMC Pregnancy & Childbirth
Wilton, T.; Kaufmann, T.	2001	Lesbian mothers' experiences of maternity care in the UK	Midwifery

Appendix 2

Paper 3: PRISMA- P checklist.

PRISMA-P 2015 Checklist

This checklist has been adapted for use with systematic review protocol submissions to BioMed Central journals from Table 3 in Moher D et al: Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews* 2015 **4**:1

An Editorial from the Editors-in-Chief of *Systematic Reviews* details why this checklist was adapted - Moher D, Stewart L & Shekelle P: Implementing PRISMA-P: recommendations for prospective authors. *Systematic Reviews* 2016 **5**:15

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
ADMINISTRATIVE INFORMATION					
Title					
Identification	1a	Identify the report as a protocol of a systematic review	■	☐	2-3
Update	1b	If the protocol is for an update of a previous systematic review, identify as such	☐	■	N/A
Registration	2	If registered, provide the name of the registry (e.g., PROSPERO) and registration number in the Abstract	■	☐	52
Authors					
Contact	3a	Provide name, institutional affiliation, and e-mail address of all protocol authors; provide physical mailing address of corresponding author	■	☐	5-28
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review	■	☐	313-315
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments	☐	■	N/A
Support					
Sources	5a	Indicate sources of financial or other support for the review	■	☐	308-311
Sponsor	5b	Provide name for the review funder and/or sponsor	■	☐	308-309

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Role of sponsor/funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol	■	☐	308-311
INTRODUCTION					
Rationale	6	Describe the rationale for the review in the context of what is already known	■	☐	77-85
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)	■	☐	86-92
METHODS					
Eligibility criteria	8	Specify the study characteristics (e.g., PICO, study design, setting, time frame) and report characteristics (e.g., years considered, language, publication status) to be used as criteria for eligibility for the review	■	☐	101-103; 149-177
Information sources	9	Describe all intended information sources (e.g., electronic databases, contact with study authors, trial registers, or other grey literature sources) with planned dates of coverage	■	☐	99-138
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated	■	☐	107
STUDY RECORDS					
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review	■	☐	140-143
Selection process	11b	State the process that will be used for selecting studies (e.g., two independent reviewers) through each phase of the review (i.e., screening, eligibility, and inclusion in meta-analysis)	■	☐	140-148
Data collection process	11c	Describe planned method of extracting data from reports (e.g., piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators	■	☐	178-193
Data items	12	List and define all variables for which data will be sought (e.g., PICO items, funding sources), any pre-planned data assumptions and simplifications	■	☐	86-92
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale	■	☐	86-92

Section/topic	#	Checklist item	Information reported		Line number(s)
			Yes	No	
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis	■	☐	203-215
DATA					
Synthesis	15a	Describe criteria under which study data will be quantitatively synthesized	■	☐	225-229
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data, and methods of combining data from studies, including any planned exploration of consistency (e.g., I^2, Kendall's tau)	■	☐	225-229
	15c	Describe any proposed additional analyses (e.g., sensitivity or subgroup analyses, meta-regression)	■	☐	261-270
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned	■	☐	228-229; 261-270
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (e.g., publication bias across studies, selective reporting within studies)	☐	■	N/A
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (e.g., GRADE)	☐	■	N/A

Appendix 3

Paper 4: Data screening form.

1. Does the publication describe the theoretical or empirical development, or tests the psychometrics, of self- report instruments that measure women's experiences of their maternity care?

   Yes ⟶ go to question 2 No ⟶ reject Maybe

2. Does the publication focus on self- report instruments that measure women's experiences of their maternity care from the perspective of women, rather than staff, families or others?

   Yes ⟶ go to question 3 No ⟶ reject Maybe

3. Is the publication reported/ available in English?

   Yes ⟶ go to question 4 No ⟶ reject Maybe

4. Is the publication primary research?

   Yes ⟶ go to question 5 No ⟶ reject Maybe

5. Does the publication focus on women's perceptions or views on their maternity care?

   Yes ⟶ go to question 6 No ⟶ reject Maybe

6. Does the publication focus on the measurement of women's experiences of their entire maternity care process, rather than one temporal aspect of care specifically, e.g. antenatal care?

   Yes ⟶ go to question 7 No ⟶ reject Maybe

7. Does the publication focus on the measurement of experiences of maternity care as received by women in general, rather than a focus on participants by specific demographics e.g. teenage pregnancy?

   Yes ⟶ go to question 8 No ⟶ reject Maybe

8. Is the publication a case report, series, systematic reviews or meta- analysis?

   Yes ⟶ reject No ⟶ go to question 9 Maybe

9. Does the publication focus on indirect evidence of measurement properties of an instrument; for example, if an instrument is being used within a randomised controlled trial or alternative study?

   Yes ⟶ reject No ⟶ go to question 10 Maybe

10. Does the publication focus on instruments that measure women's level of satisfaction with their care, rather than their actual experience of that care?

    Yes ⟶ reject No ⟶ go to question 11 Maybe

11. Does the publication focus on care received from a specific profession, e.g. midwives?

Yes → reject No → go to question 12 Maybe

12. Is the focus of the publication a brief version of a full instrument that has been reported elsewhere;

Yes → reject No → go to question 13 Maybe

13. Does the publication focus on childbirth experiences that merit specific consideration, for example stillbirths?

Yes → reject No → **retain** Maybe

Appendix 4

Paper 4: Modified COSMIN Risk of Bias checklist.

Concept elicitation (relevance and comprehensiveness)		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
6	Was an appropriate qualitative data collection method used to identify relevant items for a new instrument?	Widely recognized or well justified qualitative method used, suitable for the construct and study population	Assumable that the qualitative method was appropriate and suitable for the construct and study population, but not clearly described	Only quantitative (survey) method(s) used or doubtful whether the method was suitable for the construct and study population	Method used not appropriate or not suitable for the construct or study population	
7	Were skilled group moderators/interviewers used?	Skilled group moderators/ interviewers used	Group moderators /interviewers had limited experience or were trained specifically for the study	Not clear if group moderators /interviewers were trained or group moderators /interviewers not trained and no experience		Not applicable
8	Were the group meetings or interviews based on an appropriate topic or interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable

9	Were the group meetings or interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings of interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews	No recording and no notes	Not applicable
10	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	
11	Was at least part of the data coded independently?	At least 50% of the data was coded by at least two researchers independently	11-49% of the data was coded by at least two researchers independently	Doubtful if two researchers were involved in the coding or only 1-10% of the data was coded by at least two researchers independently	Only one researcher was involved in coding or no coding	Not applicable
12	Was data collection continued until saturation was reached?	Evidence provided that saturation was reached	Assumable that saturation was reached	Doubtful whether saturation was reached	Evidence suggests that saturation was not reached	Not applicable
13	For quantitative studies (surveys): was the sample size appropriate?	≥100	50-99	30-49	<30	Not applicable

1b. Cognitive interview study or other pilot test					
	very good	**adequate**	**doubtful**	**inadequate**	**NA**
14 Was a cognitive interview study or other pilot test conducted?	YES			**NO (SKIP items 15-35)**	
General design requirements					
15 Was the cognitive interview study or other pilot test performed in a sample representing the target population?	Study performed in a sample representing the target population	Assumable that the study was performed in a sample representing the target population, but not clearly described	Doubtful whether the study was performed in a sample representing the target population	Study not performed in a sample representing the target population	
Comprehensibility					
16 Were patients asked about the comprehensibility of the instrument?	YES		NO (SKIP items 17-25)	Not clear **(SKIP items 17-25)**	
17 Were all items tested in their final form?	All items were tested in their final form	Assumable that all items were tested in their final form, but not clearly described	Not clear if all items were tested in their final form	Items were not tested in their final form or items were not re-tested after substantial adjustments	

18	Was an appropriate qualitative method used to assess the <u>comprehensibility</u> of the instrument instructions, items, response options, and recall period?	Widely recognized or well justified qualitative method used	Assumable that the method was appropriate but not clearly described	Only quantitative (survey) method(s) used or doubtful whether the method was appropriate or not clear if patients were asked about the comprehensibility of the items, response options or recall period or patients not asked about the comprehensibility of the instrument instructions or the recall period	Method used not appropriate or patients not asked about the comprehensibility of the items or the response options	
19	Was each item tested in an appropriate number of patients? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
20	Were skilled interviewers used?	Skilled group moderators/ interviewers used	Group moderators /interviewers had limited experience or were trained specifically for the study	Not clear if group moderators /interviewers were trained or group moderators /interviewers not trained and no experience		Not applicable

21	Were the interviews based on an appropriate interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable
22	Were the interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings or interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews	No recording and no notes	Not applicable
23	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	
24	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis		

25	Were problems regarding the comprehensibility of the instrument instructions, items, response options, and recall period appropriately addressed by adapting the instrument?	No problems found or problems appropriately addressed and instrument was adapted and re-tested if necessary	Assumable that there were no problems or that problems were appropriately addressed, but not clearly described	Not clear if there were problems or doubtful if problems were appropriately addressed	Problems not appropriately addressed or instrument was adapted but items were not re-tested after substantial adjustments.	Not applicable

Comprehensiveness		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
26	Were patients asked about the comprehensiveness of the instrument?	YES		NO or not clear **(SKIP items 27-35)**		
27	Was the final set of items tested?	The final set of items was tested	Assumable that the final set of items was tested, but not clearly described	Not clear if the final set of items was tested or not the final set of items was tested or the set of items was not re-tested after items were removed or added		
28	Was an appropriate method used for assessing the comprehensiveness of the instrument?	Widely recognized or well justified method used	Assumable that the method was appropriate but not clearly described or only quantitative (survey) method(s) used	Doubtful whether the method was appropriate or method used not appropriate		

29	Was each item tested in an appropriate number of patients? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
30	Were skilled interviewers used?	Skilled interviewers used	Interviewers had limited experience or were trained specifically for the study	Not clear if interviewers were trained or interviewers not trained and no experience		Not applicable
31	Were the interviews based on an appropriate interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable
32	Were the interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings or interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews or no recording and no notes		Not applicable

33	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate or approach not appropriate		
34	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis		
35	Were problems regarding the comprehensiveness of the instrument appropriately addressed by adapting the instrument?	No problems found or problems appropriately addressed and instrument was adapted and re-tested if necessary	Assumable that there were no problems or that problems were appropriately addressed, but not clearly described	Not clear if there were problems or doubtful if problems were appropriately addressed or instrument was adapted but items were not re-tested after substantial adjustments	Problems not appropriately addressed	Not applicable

Box 2. Content validity

2a. Asking patients about relevance

Design requirements		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
1	Was an appropriate method used to ask patients whether each item is relevant for their experience with the condition?	Widely recognized or well justified method used	Only quantitative (survey) method(s) used or assumable that the method was appropriate but not clearly described	Not clear if patients were asked whether each item is relevant or doubtful whether the method was appropriate	Method used not appropriate or patients not asked about the relevance of all items	
2	Was each item tested in an appropriate number of patients? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
3	Were skilled group moderators/interviewers used?	Skilled group moderators/ interviewers used	Group moderators /interviewers had limited experience or were trained specifically for the study	Not clear if group moderators /interviewers were trained or group moderators /interviewers not trained and no experience		Not applicable
4	Were the group meetings or interviews based on an appropriate topic or interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable

5	Were the group meetings or interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings or interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews	No recording and no notes	Not applicable
Analyses						
6	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	
7	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis		

2b Asking patients about comprehensiveness						
Design requirements		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
8	Was an appropriate method used for assessing the comprehensiveness of the instrument?	Widely recognized or well justified method used	Only quantitative (survey) method(s) used or assumable that the method was appropriate but not clearly described	Doubtful whether the method was appropriate	Method used not appropriate	
9	Was each item tested in an appropriate number of patients? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
10	Were skilled group moderators/interviewers used?	Skilled group moderators/ interviewers used	Group moderators /interviewers had limited experience or were trained specifically for the study	Not clear if group moderators /interviewers were trained or group moderators /interviewers not trained and no experience		Not applicable
11	Were the group meetings or interviews based on an appropriate topic or interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable

12	Were the group meetings or interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings or interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews	No recording and no notes	Not applicable
Analyses						
13	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	
14	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis		

2c Asking patients about comprehensibility						
Design requirements		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
15	Was an appropriate qualitative method used for assessing the comprehensibility of the instrument instructions, items, response options, and recall period?	Widely recognized or well justified qualitative method used	Assumable that the method was appropriate but not clearly described	Only quantitative (survey) method(s) used or doubtful whether the method was appropriate or not clear if patients were asked about the comprehensibility of the items, response options or recall period or patients not asked about the comprehensibility of the instrument instructions	Method used not appropriate or patients not asked about the comprehensibility of the items, response options, or recall period	
16	Was each item tested in an appropriate number of patients? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
17	Were skilled group moderators/interviewers used?	Skilled group moderators/ interviewers used	Group moderators /interviewers had limited experience or were trained specifically for the study	Not clear if group moderators /interviewers were trained or group moderators /interviewers not trained and no experience		

18	Were the group meetings or interviews based on an appropriate topic or interview guide?	Appropriate topic or interview guide	Assumable that the topic or interview guide was appropriate, but not clearly described	Not clear if a topic guide was used or doubtful if topic or interview guide was appropriate or no guide		Not applicable
19	Were the group meetings or interviews recorded and transcribed verbatim?	All group meetings or interviews were recorded and transcribed verbatim	Assumable that all group meetings or interviews were recorded and transcribed verbatim, but not clearly described	Not clear if all group meetings or interviews were recorded and transcribed verbatim or recordings not transcribed verbatim or only notes were made during the group meetings/ interviews	No recording and no notes	Not applicable
Analyses						
20	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	
21	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis		

2d. Asking professionals about relevance						
Design requirements		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
22	Was an appropriate method used to ask professionals whether each item is relevant for the construct of interest?	Widely recognized or well justified method used	Only quantitative (survey) method(s) used or assumable that the method was appropriate but not clearly described	Not clear if professionals were asked whether each item is relevant or doubtful whether the method was appropriate	Method used not appropriate or professionals not asked about the relevance of all items	
23	Were professionals from all relevant disciplines included?	Professionals from all required disciplines were included	Assumable that professionals from all required disciplines were included, but not clearly described	Doubtful whether professionals from all required disciplines were included or relevant professionals were not included		
24	Was each item tested in an appropriate number of professionals? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
Analyses						

25	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate
26	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis	

2e. Asking professionals about comprehensiveness						
Design requirement		**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
27	Was an appropriate method used for assessing the comprehensiveness of the instrument?	Widely recognized or well justified method used	Only quantitative (survey) method(s) used or assumable that the method was appropriate but not clearly described	Doubtful whether the method was appropriate	Method used not appropriate	
28	Were professionals from all relevant disciplines included?	Professionals from all required disciplines were included	Assumable that professionals from all required disciplines were included, but not clearly described	Doubtful whether professionals from all required disciplines were included or relevant professionals were not included		
29	Was each item tested in an appropriate number of professionals? For qualitative studies For quantitative (survey) studies	 ≥7 ≥50	 4-6 ≥30	 <4 or not clear <30 or not clear		
Analyses						
30	Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	

31	Were at least two researchers involved in the analysis?	At least two researchers involved in the analysis	Assumable that at least two researchers were involved in the analysis, but not clearly described	Not clear if two researchers were included in the analysis or only one researcher involved in the analysis

Box 3. Structural validity

Does the scale consist of effect indicators, i.e. is it based on a reflective model? yes / no [1]

Does the study concern unidimensionality or structural validity? [2] unidimensionality / structural validity

Statistical methods	**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
1 For CTT: Was exploratory or confirmatory factor analysis performed?	Confirmatory factor analysis performed	Exploratory factor analysis performed		No exploratory or confirmatory factor analysis performed	Not applicable
2 For IRT/Rasch: does the chosen model fit to the research question?	Chosen model fits well to the research question	Assumable that the chosen model fits well to the research question	Doubtful if the chosen model fits well to the research question	Chosen model does not fit to the research question	Not applicable
3 Was the sample size included in the analysis adequate?	FA: 7 times the number of items and ≥100	FA: at least 5 times the number of items and ≥100; OR at least 6 times number of items but <100	FA: 5 times the number of items but <100	FA: < 5 times the number of items	
	Rasch/1PL models: ≥ 200 subjects	Rasch/1PL models: 100-199 subjects	Rasch/1PL models: 50-99 subjects	Rasch/1PL models: < 50 subjects	
	2PL parametric IRT models OR Mokken scale analysis: ≥ 1000 subjects	2PL parametric IRT models OR Mokken scale analysis: 500-999 subjects	2PL parametric IRT models OR Mokken scale analysis: 250-499 subjects	2PL parametric IRT models OR Mokken scale analysis: < 250 subjects	

Other						
4 Were there any other important flaws in the design or statistical methods of the study?	No other important methodological flaws		Other minor methodological flaws (e.g. rotation method not described)	Other important methodological flaws (e.g. inappropriate rotation method)		

[1] If the scale is not based on a reflective model, unidimensionality or structural validity is not relevant. In this case, the study can be ignored.
[2] In a systematic review, it is helpful to make a distinction between studies where factor analysis is performed on each (sub)scale separately to evaluate whether the (sub)scales are unidimensional (unidimensionality studies) and studies where factor analysis is performed on all items of an instrument to evaluate the (expected) number of subscales in the instrument and the clustering of items within subscales (structural validity studies).

Box 4. Internal consistency

Does the scale consist of effect indicators, i.e. is it based on a reflective model? yes / no [1]

Design requirements	**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
1 Was an internal consistency statistic calculated for each unidimensional scale or subscale separately?	Internal consistency statistic calculated for each unidimensional scale or subscale		Unclear whether scale or sub scale is unidimensional	Internal consistency statistic NOT calculated for each unidimensional scale or sub scale	
Statistical methods					
2 For continuous scores: Was Cronbach's alpha or omega calculated?	Cronbach's alpha, or Omega calculated		Only item-total correlations calculated	No Cronbach's alpha and no item-total correlations calculated	Not applicable
3 For dichotomous scores: Was Cronbach's alpha or KR-20 calculated?	Cronbach's alpha or KR-20 calculated		Only item-total correlations calculated	No Cronbach's alpha or KR-20 and no item-total correlations calculated	Not applicable
4 For IRT-based scores: Was standard error of the theta (SE (θ)) or reliability coefficient of estimated latent trait value (index of (subject or item) separation) calculated?	SE(θ) or reliability coefficient calculated			SE(θ) or reliability coefficient NOT calculated	Not applicable
Other					
5 Were there any other important flaws in the design or statistical methods of the study?	No other important methodological flaws		Other minor methodological flaws	Other important methodological flaws	

[1] If the scale is not based on a reflective model, internal consistency is not relevant. In this case, the study can be ignored.

Box 5. Cross-cultural validity\Measurement invariance						
Design requirements	**very good**	**adequate**	**doubtful**	**inadequate**	**NA**	**NA****
1 Were the samples similar for relevant characteristics except for the group variable?	Evidence provided that samples were similar for relevant characteristics except group variable	Stated (but no evidence provided) that samples were similar for relevant characteristics except group variable	Unclear whether samples were similar for relevant characteristics except group variable	Samples were NOT similar for relevant characteristics except group variable		
Statistical methods						
2 Was an appropriate approach used to analyse the data?	A widely recognized or well justified approach was used	Assumable that the approach was appropriate, but not clearly described	Not clear what approach was used or doubtful whether the approach was appropriate	Approach not appropriate	Not applicable	
3 Was the sample size included in the analysis adequate?	Regression analyses or IRT/Rasch based analyses: 200 subjects per group MGCFA*: 7 times the number of items and ≥100	150 subjects per group 5 times the number of items and ≥100; OR 5-7 times the number of items but <100	100 subjects per group 5 times the number of items but <100	< 100 subjects per group <5 times the number of items		
Other						

4	Were there any other important flaws in the design or statistical methods of the study?	No other important methodological flaws		Other minor methodological flaws	Other important methodological flaws

**MGCFA: multi-group confirmatory factor analyses*
***NA refers to 'Not Applicable' as per description in methods section of manuscript*

Box 6. Reliability					
Design requirements	**very good**	**adequate**	**doubtful**	**inadequate**	**NA**
1 Were patients stable in the interim period on the construct to be measured?	Evidence provided that patients were stable	Assumable that patients were stable	Unclear if patients were stable	Patients were NOT stable	
2 Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval was appropriate or time interval was not stated	Time interval NOT appropriate	
3 Were the test conditions similar for the measurements? e.g. type of administration, environment, instructions	Test conditions were similar (evidence provided)	Assumable that test conditions were similar	Unclear if test conditions were similar	Test conditions were NOT similar	
Statistical methods					
4 For continuous scores: Was an intraclass correlation coefficient (ICC) calculated?	ICC calculated and model or formula of the ICC is described	ICC calculated but model or formula of the ICC not described or not optimal. Pearson or Spearman correlation coefficient calculated with evidence provided that no systematic change has occurred	Pearson or Spearman correlation coefficient calculated WITHOUT evidence provided that no systematic change has occurred or WITH evidence that systematic change has occurred	No ICC or Pearson or Spearman correlations calculated	Not applicable
5 For dichotomous/nominal/ordinal scores: Was kappa calculated?	Kappa calculated			No kappa calculated	Not applicable
6 For ordinal scores: Was a weighted kappa calculated?	Weighted Kappa calculated		Unweighted Kappa calculated or not described		Not applicable

7	For ordinal scores: Was the weighting scheme described? e.g. linear, quadratic	Weighting scheme described	Weighting scheme NOT described	Not applicable
Other				
8	Were there any other important flaws in the design or statistical methods of the study?	No other important methodological flaws	Other minor methodological flaws	Other important methodological flaws

Box 7. Measurement error					
Design requirements	**very good**	**adequate**	**doubtful**	**Inadequate**	**NA**
1 Were patients stable in the interim period on the construct to be measured?	Patients were stable (evidence provided)	Assumable that patients were stable	Unclear if patients were stable	Patients were NOT stable	
2 Was the time interval appropriate?	Time interval appropriate		Doubtful whether time interval was appropriate or time interval was not stated	Time interval NOT appropriate	
3 Were the test conditions similar for the measurements? (e.g. type of administration, environment, instructions)	Test conditions were similar (evidence provided)	Assumable that test conditions were similar	Unclear if test conditions were similar	Test conditions were NOT similar	
Statistical methods					
4 For continuous scores: Was the Standard Error of Measurement (SEM), Smallest Detectable Change (SDC) or Limits of Agreement (LoA) calculated?	SEM, SDC, or LoA calculated	Possible to calculate LoA from the data presented		SEM calculated based on Cronbach's alpha, or on SD from another population	Not applicable
5 For dichotomous/nominal/ordinal scores: Was the percentage (positive and negative) agreement calculated?	% positive and negative agreement calculated	% agreement calculated		% agreement not calculated	Not applicable
Other					
6 Were there any other important flaws in the design or statistical methods of the study?	No other important methodological flaws		Other minor methodological flaws	Other important methodological flaws	

Appendix 5

Paper 4: Modified COSMIN recommended criteria for good measurement properties.

Measurement property	Rating	Criteria
Structural validity	+	**Classical Test Theory (CTT)** Confirmatory factor analysis: Comparative Fit Index or Tucker Lewis Index or comparable measure > 0.95 OR Root Mean Square Error of Approximation < 0.06 OR Standardised Root Mean Residuals < 0.08 **Item Response Theory (IRT)/Rasch** No violation of unidimensionality: Comparative Fit Index or Tucker Lewis Index or comparable measure > 0.95 OR Root Mean Square Error of Approximation < 0.06 OR Standardised Root Mean Residuals < 0.08 *AND* no violation of local independence: residual correlations among the items after controlling for the dominant factor < 0.20 OR Q3's < 0.37 *AND* no violation of monotonicity: adequate looking graphs OR item scalability > 0.30 *AND* adequate model fit: IRT: $\chi 2 > 0.001$ Rasch: infit and outfit mean squares ≥ 0.5 and ≤ 1.5 OR Z-standardized values > −2 and < 2
	?	**CTT**: not all information for '+' reported **IRT/Rasch**: model fit not reported
	-	Criteria for '+' not met
Internal consistency	+	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) ≥ 0.70 for each unidimensional scale or subscale
	?	Criteria for "At least low evidence for sufficient structural validity" not met
	-	At least low evidence for sufficient structural validity AND Cronbach's alpha(s) < 0.70 for each unidimensional scale or subscale
Reliability	+	Interclass Correlation Coefficient (ICC) or weighted Kappa ≥ 0.70
	?	ICC or weighted Kappa not reported
	-	ICC or weighted Kappa < 0.70
Measurement error	+	Smallest Detectable Change (SDC) or Limits of Agreement (LoA) < Minimal Important Change (MIC)
	?	MIC not defined
	-	SDC or LoA > MIC
Cross-cultural validity\measurement invariance	+	No important differences found between group factors (e.g. age, language) in multiple group factor analysis OR no important differential item functioning (DIF) for group factors (McFadden's R < 0.02)
	?	No multiple group factor analysis OR DIF analysis performed
	-	Important differences between group factors OR DIF was found
	NA	Not applicable

Appendix 6

Paper 4: List of the final item pools of the included survey instruments.

Instrument/ organisation/ author title	Region/ Country implemented
Care Quality Commission	UK
New Zealand Maternity Services Satisfaction Survey	New Zealand
Scottish Maternity Care Survey	Scotland
New South Wales- Maternity Care Patient Survey	NSW, Australia
Listening to Mothers	California, USA
Clark	Australia
Having a Baby in Queensland	Queensland, Australia
Kuopio Instrument for Mothers	Greece
Pregnancy- and maternity-care patients' experiences questionnaire	Norway
Victorian Health Mothers, Healthy Families survey	Victoria, Australia
Maternity Care in New South Wales	NSW, Australia
National Perinatal Epidimiology Unit	UK

Appendix 7

Paper 5: Ethical approval letter from NUI Galway Research Ethics Committee to hold focus groups and one to one interviews

.

OÉ Gaillimh
NUI Galway

Leas-Uachtarán um Thaighde
Vice President for Research

02 August 2018

Ref: **18-Jun-01**

Claire Beecher
School of Nursing & Midwifery
NUI Galway

Dear Claire,

Re: 'The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland'

I write to you regarding the above proposal which was submitted for ethical review. Having reviewed your response to my letter of provisional approval, I am pleased to inform you that your proposal has been granted **APPROVAL**.

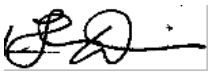
All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 19 July 2019.

When the decision was taken I was chairing the meeting and the following members were also present:

Dr Maura Dowling	Dr Cormac Forkan	Dr Martina Kelly
Ms Marcella Kelly	Mr Patrick Towers	Dr Stacey Scriver

See annual and final statement of compliance forms below. Section 7 of the REC's Standard Operating Procedures gives further details, and also outlines other instances where you are required to report to the REC.

Yours sincerely



Kevin Davison

Chair, Research Ethics Committee

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Appendix 8

Paper 5: Ethical approval amendment letter from NUI Galway Research Ethics Committee to hold focus groups and one to one interviews at an additional site.

OÉ Gaillimh
NUI Galway

Leas-Uachtarán um Thaighde
Vice President for Research

02 August 2018

Ref: 18-Jun-01; Amend 1808

Claire Beecher
School of Nursing & Midwifery
NUI Galway

Dear Claire,

Re: 'The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland'

I write to you regarding amendment to above proposal. I am pleased to inform you that your amendment, namely

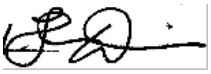
- collecting data from stakeholders in an additional location (Cork)

has been APPROVED**.**

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 01 August 2019.

See annual and final statement of compliance forms below. Section 7 of the REC's Standard Operating Procedures gives further details, and also outlines other instances where you are required to report to the REC.

Yours sincerely



Kevin Davison

Chair, Research Ethics Committee

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Appendix 9

Paper 5: Ethical approval letter from NUI Galway Research Ethics Committee to conduct Delphi study and consensus reviews.

OÉ Gaillimh
NUI Galway

Leas-Uachtarán um Thaighde
Vice President for Research

02 January 2019

Ref: 18-Dec-01

Claire Beecher
School of Nursing and Midwifery
NUI Galway

Dear Claire,

Re: 'The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.'

I write to you regarding the above proposal which was submitted for ethical review. I am pleased to inform you that your proposal has been granted **APPROVAL.**

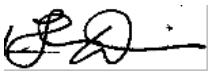
All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 02 January 2020.

When the decision was taken I was chairing the meeting and the following members were also present:

Dr Linda Biesty	Dr Brian Hallahan	Dr Victoria Hogan
Dr Martina Kelly	Dr Veronica McCauley	Dr Stacey Scriver
Mr Patrick Towers		

See annual and final statement of compliance forms below. Section 7 of the REC's Standard Operating Procedures gives further details, and also outlines other instances where you are required to report to the REC.

Yours sincerely



Kevin Davison

Chair, Research Ethics Committee

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Appendix 10

Paper 5: Ethical approval amendment letter from NUI Galway Research Ethics Committee use snowball sampling as an additional method of recruitment for the Delphi study and consensus reviews.

OÉ Gaillimh
NUI Galway

Leas-Uachtarán um Thaighde
Vice President for Research

10 April 2019

Ref: 18-Dec-01; Amend 1903

Claire Beecher

School of Nursing and Midwifery

NUI Galway

Dear Claire,

Re: The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland'

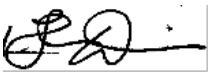
I write to you regarding your proposed amendment to above project. Having considered your changes, which are outlined below, I am pleased to inform you that the amendment has been APPROVED**:**

- The inclusion of snowball sampling as a recruitment method for each of the three phases remaining in the project (Delphi study and review by experts, cognitive interviews and pilot of the survey instrument).

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 9 April 2020.

See annual and final statement of compliance forms below. Section 7 of the REC's Standard Operating Procedures gives further details, and also outlines other instances where you are required to report to the REC.

Yours sincerely



Kevin Davison

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Appendix 11

Paper 5: Recruitment material for the focus groups and one to one interviews.

NUI Galway
OÉ Gaillimh

Dear XXXX

The National Patient Experience (NPE) Survey Programme is a partnership between the Health Information and Quality Authority (HIQA), the Health Service Executive (HSE) and the Department of Health. The partnership has developed and managed the implementation of the largest national healthcare survey capturing the experience of people that use public acute care in Ireland. The partnership is now extending to capture the experience of women in Irelands maternity care.

The NPE Survey Programme is working with the National University of Ireland, Galway to develop a survey instrument to capture the experience of women in Ireland's maternity sector. Given your extensive experience of maternity care in Ireland, we would like to invite you to attend a Focus Group to inform the development of same.

As part of the development of the survey, several focus group interviews will take place with key stakeholder groups. These stakeholder groups include women as service users of the Irish maternity services, midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders. The purpose of the focus groups is to gain an insight into what outcomes each of these groups considers of most importance for inclusion in the final survey instrument. Each stakeholder group has been chosen based on their key role in the use and provision of the Irish maternity services. We are contacting you to invite you to participate in a focus group interview on this topic.

A copy of the Participant Information Sheet for this study is attached. This Participant Information Sheet explains in detail the aim and purpose of the study, what participating in this study would involve for you, the voluntary nature of the study and your right to withdraw at any time. **If you are available and interested in participating, we would appreciate it if you could contact Trudi Mason on 01-814-7650 or tmason@hiqa.ie**.

The focus group interview that you are invited to participate in is scheduled to take place in the HIQA offices at George's Court, George's Lane, Smithfield, Dublin 7 on Wednesday, November 7th at 10:30am.

Please could you confirm or decline participation in this focus group **by 5pm on Friday October 19th.**

We're committed to excellence in healthcare

Health Information and Quality Authority
Health Service Executive
An Roinn Sláinte
DEPARTMENT OF HEALTH

This study has received approval from the National University of Ireland, Galway Research Ethics Committee.

The principal researcher developing the maternity survey is Claire Beecher who is a registered midwife currently undertaking a PhD in the National University of Ireland, Galway funded by the HSE Programme for Health Service Improvement. Claire is being supervised by Professor Declan Devane of the National University of Ireland, Galway and co-supervised by Professor Richard Greene of Cork University Maternity Hospital.

Please do not hesitate to contact me if you require any further information on this study.

Kindest Regards,

M. Rachel Flynn

Director of Health Information and Standards

Health Information and Quality Authority

Cc: Claire Beecher, Midwife and PhD Fellow, NUI Galway

Prof. Declan Devane, Professor of Midwifery, NUI Galway

Appendix 12

Paper 5: Full breakdown of all focus group and one to one interview participants.

- 5 x General Practitioner;
- 6 x public health nurses;
- 1 x pave point representative;
- 3 x anaesthetist;
- 14 x midwife;
- 2 x Feileacain representative;
- 3 x HIQA senior staff;
- 1 x NPEC staff member;
- 3 x AIMS Ireland representative;
- 1 x Le Leche League representative;
- 1 x statistician;
- 5 x obstetrician;
- 1 x hospital manager;
- 4 x director of Midwifery;
- 4 x Cuidiu representative;
- 8 x service user;
- 1 x Maternity Service Policy Unit staff member;
- 1 x patient liaison manager;
- 3 x Department of Health staff member;
- 1 x maternity hospital quality manager;
- 1 x National women's council representative;
- 2 x lactation consultant;
- 2 x Assistant Director of Midwifery;
- 1 x state claims agency staff member;
- 1 x Nursing and Midwifery Board of Ireland staff member;
- 1 x Sage Advocacy representative;
- 1 x Cairde representative;
- 1 staff member Office of the Ombudsman;
- 2 x maternity quality and safety department staff member;
- 1 x physiotherapist;
- 1 x Department of Children and youth affairs representative.

Appendix 13

Paper 5: Focus groups and one to one interviews Participant Information Sheet for participants from women representative groups nationwide.

Study information for women representative groups nationwide for upcoming

Focus Group Interviews

You are invited to take part in a research study;

You are invited to take part in a focus group interview as part of a research study. Before you decide if you would like to take part, it is important to understand why this research is being done and what it would involve for you. This Participant Information Sheet will explain the aim and purpose of the research, what taking part will involve, the voluntary nature of the study and the right to withdraw at any time. Please take the time to read this information carefully and feel free to contact the National Patient Experience Survey (NPES)/ research team if you have any questions. Contact details are included towards the end of this Participant Information Sheet.

Title of study;

The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.

Aim and purpose of this research;

The overall aim of this research study is to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. The survey instrument will be used nationally as the maternity version of the National Patient Experience Survey (NPES). The NPES is a collaboration between the Health Information and Quality Authority (HIQA), Health Service Executive (HSE) and the Department of Health launched in 2017 to measure patients' experiences annually across the public acute healthcare services. This research is important as the purpose of implementing this survey instrument is to identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high quality care.

The focus group interviews that you are being asked to participate in will inform the development of this instrument as we are looking to recruit women, as service users of the Irish maternity services, who are willing to discuss the aspects of care that they consider to be of most importance for inclusion within this survey instrument. We will also be asking other key stakeholder groups to participate such as midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders.

How do I know if I am eligible?

You are eligible to take part in this focus group interview if you are over 18 years of age and are currently receiving care within the Irish maternity services, or if you are over 18 years of age and

have received care within the Irish maternity services over the past 12 months. Due to the unavailability of translational services, you must also have a competent level of fluency in English to take part in the study.

What does taking part involve?

Participation will involve taking part in *one* focus group interview with up to 6 other participants from key stakeholder groups such as other service users of the Irish maternity services, midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders. A focus group interview is a group discussion that focuses on a particular topic. In this case, the topic of discussion will be the aspects of care that are considered by women to be of most importance for inclusion within the survey instrument being developed. The discussion will be facilitated by a researcher and by one- two members of the NPES team and will last approximately one hour. The interview will be audio reordered and then analysed at a later date. This study does not involve any access to medical records. If you wish to participate in the research study by taking part in a one to one interview with a researcher, rather than a focus group interview, please contact the NPES/research team to confirm. Contact details are included towards the end of this Participant Information Sheet.

Where and when will the focus group interview take place?

The focus group interview that you are invited to participate in is scheduled to take place in the HIQA offices at George's Court, George's Lane, Smithfield, Dublin 7 on the XXXX at XXXXX.

Are there any benefits or risks to me taking part?

Your participation will benefit you and other stakeholders as the views and opinions that you provide within the focus group interview will be used to inform the development of a survey instrument that will be used to identify areas for improvement within maternity care in Ireland and facilitate the provision of safe, effective, high quality care. No physical risks are associated with participating in this study. There is always a chance that talking about certain topics may upset you. If this occurs, you will be asked if you would like to take a break and have the audio recording paused. The NPES/ research team will respect the decision of all participants to walk away from the focus group interviews at any time.

Voluntary participation

Participation is entirely voluntary, and you have the right to withdraw from the study at any time. If you decide not to participate in this study, or if you withdraw, there will be no negative consequences, and you will not be expected to give any reason for your decision. If you decide not to participate, or to withdraw from the study, your care will not be affected in any way. If you do decide to withdraw from the study at any time, I would ask that you send an email declaring withdrawal to the NPES/research team. Contact details are included towards the end of this Participant Information Sheet.

Confidentiality

Your identity will remain confidential. All data will be coded, meaning that your name will not be published, and it will not be disclosed to anyone outside the focus group. Audio data from the focus

group interviews will be transcribed by an outside experienced research transcription service. The function of a transcription service is to write out everything that has been audio recorded within the interview. The transcriber for this study will have signed a confidentiality and non- disclosure agreement document for the study and they will only receive audio recording with non-identifying details. All data retrieved from the focus group interview will be securely stored in the National University of Ireland, Galway under the stewardship of the research team and destroyed after a period of 5 years as in accordance with the National University of Ireland, Galway Data Retention Policy.

If any participant should disclose information during the research study regarding unacceptable work practices or issues of risk, the researcher is obliged to report this information to the appropriate management/ authority. In such cases, confidentiality may be broken.

What will happen to the findings of this study?

As stated previously, the findings of the focus group interviews inform the development of a survey instrument that will evaluate women's experiences of their maternity care in Ireland. Prior to completion of the survey development, the findings of the focus group interviews may also be submitted to peer reviewed research journals for publication.

Compensation

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Funding

This study has been funded through the Programme for Health Service Improvement, as part of the Health Service Executive.

Travel costs

If you are travelling from outside Dublin to the focus group interview, your travel costs will be reimbursed by HIQA, based on Public Sector Policy allowances.

Has this study received ethical approval?

Yes, this study has received approval from the following research ethics committee;

National University of Ireland, Galway Research Ethics Committee
Research Office
Room 212
Research and Innovation Centre
NUI Galway
Tel: 353 91 495312

Is there someone available to answer any questions that I may have about taking part?

Yes. You can get more information about the study, your participation in the study and your rights by contacting the NPES/research team. Contact details are as follows;

National Patient Experience Survey team, Health Information and Quality Authority

Claire Beecher, Midwife and PhD Fellow, NUI Galway

Prof. Declan Devane, Professor of Midwifery, NUI Galway

If you would like to take part in this focus group please contact *Freephone number-1800 314 093* **or email** info@patientexperience.ie **to discuss your participation in the focus group interview and ask any questions you may have. To ensure that you have had sufficient time to consider your involvement in this study, recruitment will cease 48 hours prior to the scheduled date of the focus group interview. Please be aware that if there is an over demand for participants in these focus group interviews, a random sample of women wishing to participate will be selected.**

Thank you for taking the time to read the information within this participant information sheet. We hope you will consider taking part.

Appendix 14

Paper 5: Focus groups and one to one interviews Participant Information Sheet for participants from all other stakeholder groups.

Study information for HIQA maternity standards advisory group for upcoming

Focus Group Interviews

You are invited to take part in a research study;

You are invited to take part in a focus group interview as part of a research study. Before you decide if you would like to take part, it is important to understand why this research is being done and what it would involve for you. This Participant Information Sheet will explain the aim and purpose of the research, what taking part will involve, the voluntary nature of the study and the right to withdraw at any time. Please take the time to read this information carefully and feel free to contact the National Patient Experience Survey (NPES)/ research team if you have any questions. Contact details are included towards the end of this Participant Information Sheet.

Title of study;

The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.

Aim and purpose of this research;

The overall aim of this research study is to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. The survey instrument will be used nationally as the maternity version of the National Patient Experience Survey (NPES). The NPES is a collaboration between the Health Information and Quality Authority (HIQA), Health Service Executive (HSE) and the Department of Health launched in 2017 to measure patients' experiences annually across the public acute healthcare services. This research is important as the purpose of implementing this survey instrument is to identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high quality care.

The focus group interviews that you are being asked to participate in will inform the development of this instrument as we are looking to recruit women, as service users of the Irish maternity services, who are willing to discuss the aspects of care that they consider to be of most importance for inclusion within this survey instrument. We will also be asking other key stakeholder groups to participate such as midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders.

How do I know if I am eligible?

You are eligible to take part in this focus group interview if you are over 18 years of age and are a member of the HIQA maternity standards advisory group representing one of the following

stakeholder groups; service user of the Irish maternity services, midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders. Due to the unavailability of translational services, you must also have a competent level of fluency in English to take part in the study.

What does taking part involve?

Participation will involve taking part in *one* focus group interview with up to 6 other participants from key stakeholder groups such as service users of the Irish maternity services, midwives, obstetricians, neonatologists, General Practitioners, policy makers and funders. A focus group interview is a group discussion that focuses on a particular topic. In this case, the topic of discussion will be the aspects of care that are considered by women to be of most importance for inclusion within the survey instrument being developed. The discussion will be facilitated by a researcher and by one-two members of the NPES team and will last approximately one hour. The interview will be audio reordered and then analysed at a later date. This study does not involve any access to medical records. If you wish to participate in the research study by taking part in a one to one interview with a researcher, rather than a focus group interview, please contact the NPES/research team to confirm. Contact details are included towards the end of this Participant Information Sheet.

Where and when will the focus group interview take place?

The focus group interview that you are invited to participate in is scheduled to take place in the HIQA offices at George's Court, George's Lane, Smithfield, Dublin 7 on the XXXX at XXXXX.

Are there any benefits or risks to me taking part?

Your participation will benefit you and other stakeholders as the views and opinions that you provide within the focus group interview will be used to inform the development of a survey instrument that will be used to identify areas for improvement within maternity care in Ireland and facilitate the provision of safe, effective, high quality care. No physical risks are associated with participating in this study. There is always a chance that talking about certain topics may upset you. If this occurs, you will be asked if you would like to take a break and have the audio recording paused. The NPES/research team will respect the decision of all participants to walk away from the focus group interviews at any time.

Voluntary participation

Participation is entirely voluntary, and you have the right to withdraw from the study at any time. If you decide not to participate in this study, or if you withdraw, there will be no negative consequences, and you will not be expected to give any reason for your decision. If you are a service user of the Irish maternity services and decide not to participate, or to withdraw from the study, your care will not be affected in any way. If you do decide to withdraw from the study at any time, I would ask that you send an email declaring withdrawal to the NPES/research team. Contact details are included towards the end of this Participant Information Sheet.

Confidentiality

Your identity will remain confidential. All data will be coded, meaning that your name will not be published, and it will not be disclosed to anyone outside the focus group. Audio data from the focus group interviews will be transcribed by an outside experienced research transcription service. The function of a transcription service is to write out everything that has been audio recorded within the interview. The transcriber for this study will have signed a confidentiality and non- disclosure agreement document for the study and they will only receive audio recording with non-identifying details. All data retrieved from the focus group interview will be securely stored in the National University of Ireland, Galway under the stewardship of the research team and destroyed after a period of 5 years as in accordance with the National University of Ireland, Galway Data Retention Policy.

If any participant should disclose information during the research study regarding unacceptable work practices or issues of risk, the researcher is obliged to report this information to the appropriate management/ authority. In such cases, confidentiality may be broken.

What will happen to the findings of this study?

As stated previously, the findings of the focus group interviews inform the development of a survey instrument that will evaluate women's experiences of their maternity care in Ireland. Prior to completion of the survey development, the findings of the focus group interviews may also be submitted to peer reviewed research journals for publication.

Compensation

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Funding

This study has been funded through the Programme for Health Service Improvement, as part of the Health Service Executive.

Travel costs

If you are a member of the HIQA maternity standards advisory group representing one of the following stakeholder groups; midwives, obstetricians, neonatologists, General Practitioners, policy makers or funders, and travelling from outside Dublin for the focus group interview, you are eligible to claim reimbursement for your travel costs from your host institution. If you are a member of the HIQA maternity standards advisory group representing service users of the Irish maternity services and travelling from outside Dublin, you will be reimbursed by HIQA for your travel costs, based on Public Sector Policy allowances.

Has this study received ethical approval?

Yes, this study has received approval from the following research ethics committee;

National University of Ireland, Galway Research Ethics Committee
Research Office
Room 212

Research and Innovation Centre
NUI Galway
Tel: 353 91 495312

Is there someone available to answer any questions that I may have about taking part?

Yes. You can get more information about the study, your participation in the study and your rights by contacting the NPES/research team. Contact details are as follows;

National Patient Experience Survey team

Health Information and Quality Authority

Claire Beecher, Midwife and PhD Fellow, NUI Galway

Prof. Declan Devane, Professor of Midwifery, NUI Galway

If you would like to take part in this focus group please contact *Freephone number-1800 314 093* **or email** info@patientexperience.ie **to discuss your participation in the focus group interview and ask any questions you may have. To ensure that you have had sufficient time to consider your involvement in this study, recruitment will cease 48 hours prior to the scheduled date of the focus group interview. Please be aware that if there is an over demand for participants in these focus group interviews, a random sample of women wishing to participate will be selected.**

Thank you for taking the time to read the information within this participant information sheet. We hope you will consider taking part.

Appendix 15

Paper 5: Consent form for participants in the focus groups and one to one interviews.

Participant Consent form (non- medical research)

Title of study;

The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.

Participant Identification Number: _____ (to be completed by researcher)

Declaration of the participant- please tick (√) the relevant box	YES	NO
I have read the participant information sheet for this focus group interview and I understand the contents.		
I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.		
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason and without any negative consequences.		
I agree to the focus group interview being recorded.		
I agree that the audiotape and transcript of the focus group interview will be securely stored in the National University of Ireland, Galway, for a period of 5 years after the completion of this study.		
I consent to taking part in the study through the completion of a focus group interview as a woman who is/ has been a service user of the Irish maternity services within the last 12 months and is over 18 years of age.		
I consent to taking part in the study through the completion of a focus group interview as a midwife/obstetrician/ neonatologist/ general practitioner/ funder/ policy maker involved in the provision of maternity care to women in Ireland.		

Participant;
Participant name; _____
Participant signature; _____
Date; _____

Researcher / person taking consent;
Name of person taking consent; _____
Signature of person taking consent; _____
Date; _____

Appendix 16

Paper 5: Interview schedule for the focus groups and one to one interviews.

Introduction;

- Thank participants for their time.
- (Establish rapport) My name is XXX and I am XXXXX. The purpose of these focus group interviews is to inform the development of a survey instrument, to be used nationally, to evaluate women's experiences of their maternity care in Ireland. The purpose of implementing this instrument is to identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high quality care.
- I would like to ask you some questions about what you would consider to be the most important aspects of care for inclusion in this questionnaire.
- A number of focus group interviews are being held with various stakeholder groups relevant to this project. The information you give will help identify the common things these different groups (women, midwives, obstetricians, neonatologists, GP's, funders, policy makers etc) involved in maternity care regard as important in the evaluation of women's experiences of their maternity care in Ireland.
- (Time line) The interview should take about 60 minutes.
- Reassure participants re confidentiality of data and advise that they have the right to withdraw participation at any time.
- Ensure consent form for each participant is signed.

Transition;

- Let me begin by asking what aspects of care would you rate as being most important for inclusion in a survey instrument such as that being developed?
- Follow this up with why do you think these aspects of care are so important to include? (If not already explained by participant).
- How would the aspects of care you are suggesting positively or negatively influence a women's experience of care?

- According to a recent review of the literature, the most common aspects of care that are included in surveys such as the one being developed include (moderator to choose from the following);
    - You and your baby
    - Care while you were pregnant (antenatal care)
    - Your labour and the birth of your baby
    - Care in hospital after the birth (postnatal care)
    - Feeding your baby
    - Care at home after the birth
    - Overall experience
    - You and your household

  Would you agree or disagree that these are the most important aspects of care to be included in such a survey?
- Is there anything else, aside from the aspects of care discussed here, that you would like to see being asked in the survey instrument?

Close:

- Would you like to make any other comments?
- Thank you again for taking the time to attend these interviews and for your expertise.
- As you heard in the presentation earlier, following these focus group interviews a gap analysis will be completed to map the suite of international questions (identified in the systematic review) against Ireland's maternity structure, HIQA regulatory standards and the findings from these focus group interviews. The purpose of the gap analysis is to identify areas that are not captured within the international suite of questions. A question pool will then be written up from which questions will be selected for inclusion in the cognitive interviews and pilot survey. The pilot of the survey instrument is expected to be completed in November 2019. All publications and reports related to the development of the survey instrument, including the results of these focus group interviews, will be available as they are completed on the National Maternity Experience Survey website. Thank you all for your time.

Appendix 17

Paper 5: Protocol for interviewees experiencing emotional disruption.

From my clinical experience as a midwife I have dealt with many women, and their partners, who have been experiencing emotional disruption. As such, I am confident that if any participant were to experience emotional disruption during the focus group interviews, I would recognise both visual and verbal cues of same. In the event of a participant experiencing emotional disruption, the following procedural protocol will be enacted;

1. I will ask the participant if they would like to take a break and the audio recorder paused.
2. If the participant continues to be upset, they will be attended to immediately. They will be asked if they would like to end their participation in the focus group interview.
3. If the participant decides that they are able to continue, the focus group/ interview will be resumed.
4. If the participant decides to end their participation;
    - In the case of a focus group interview, they will be escorted to a private area by the second researcher in the room. The participant will be asked if they would like to talk about how they are feeling, or if they would prefer someone to be called to come and spend time with them (partner, neighbour, friend).
    - In the case of a one to one interview, the audio recording will be stopped, and the will be asked if they would like to talk about how they are feeling, or if they would prefer someone to be called to come and spend time with them (partner, neighbour, friend).
5. If the participant wishes to talk, they will be listened to attentively and provided with neutral, confirming statements that validate their emotions/ experiences. If the participant does not wish to talk, their choice will be respected.
6. Before leaving, it will be ascertained if the participant would think it acceptable that they are called by the principal applicant later in the day, or the following day, to ensure that they are feeling better.
7. Before leaving, any participant that experienced emotional disruption will be given contact details for local and national help groups such as voluntary service providers, community workers and public health representatives, amongst others. The help group information provided will be appropriate to the nature, and cause, of the emotional disruption that is experienced.

Appendix 18

Paper 5: Statement of confidentiality signed by transcriptionist.

National Patient Experience Survey

NUI Galway
OÉ Gaillimh

Statement of confidentiality for transcriptionist

Title of study;

The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.

Statement of Confidentiality;

1. As the transcriptionist to be employed in the above-named study, I, Rosaleen Rogers, Managing Director, Audiotrans Ltd. agree to maintain full confidentiality of all research data received in relation to this study;
2. I will hold in strictest confidence the identity of any individual that may be revealed during the transcription of the focus group interviews or in any associated documents;
3. I will not make copies of any audio-recordings or other research data, unless specifically requested to do so by the principal researcher;
4. I will not provide the research data to any third parties without the principal researcher's consent;
5. I will store all study-related data in a safe, secure location as long as they are in my possession;
6. Following completion of transcription all data provided or created for purposes of this study, including any back-up records, will be returned to the research team or permanently deleted.

Name; Rosaleen Rogers _____ Date: 15/10/18

Appendix 19

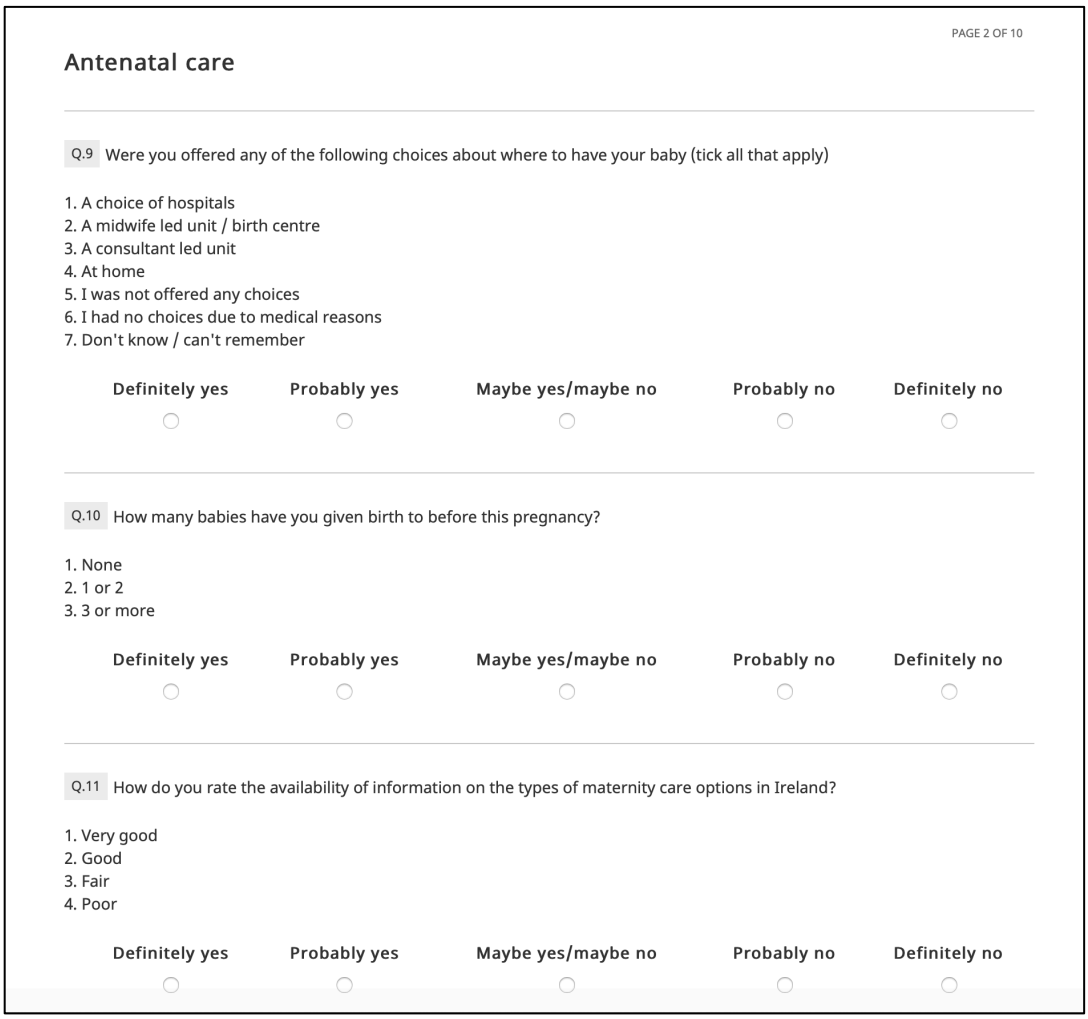
Paper 5: Further information on the completion of the gap analysis.

Using a tabular format created specifically for the gap analysis, the gap analysis was completed using the following steps;

1. Identification of all aspects of care that must be included within the Irish survey as per the following three documents and the focus group and one to one interview codebook;
   - HIQA National Standards for Safer Better Maternity Services;
   - HIQA 'Background document to support the development of National Standards for Safer Better Maternity Services';
   - National Maternity Strategy (Creating a Better Future Together).
2. Identification of items currently being utilised internationally;
3. Gap identification & description;
   - Comparison of data collated through step one and two to highlight where gaps exist;
   - Each standard within the 'HIQA National Standards for Safer Better Maternity Services' was mapped against both the thematic areas within the focus group and one to one interview codebook and relevant items sourced from the international suite of items;
   - Themes have been identified related to each aspect of the 'National Maternity Strategy (Creating a Better Future Together)' and HIQA 'Background document to support the development of National Standards for Safer Better Maternity Services' documents. These themes have then been mapped against both the thematic areas within the focus group and one to one interview codebook and relevant items sourced from the international suite of items.
4. Recommendations made on actions to be taken/ areas that must be included in the survey to bridge the evident gaps.

Appendix 20

Paper 5: Delphi study- examples of rating options in Crowdsignal.



PAGE 2 OF 10

Antenatal care

Q.9 Were you offered any of the following choices about where to have your baby (tick all that apply)

1. A choice of hospitals
2. A midwife led unit / birth centre
3. A consultant led unit
4. At home
5. I was not offered any choices
6. I had no choices due to medical reasons
7. Don't know / can't remember

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Q.10 How many babies have you given birth to before this pregnancy?

1. None
2. 1 or 2
3. 3 or more

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Q.11 How do you rate the availability of information on the types of maternity care options in Ireland?

1. Very good
2. Good
3. Fair
4. Poor

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Labour and birth

What type of birth did you have?

This is a fixed question and therefore does not require your rating

(If you had twins or more than two babies this time, please fill in this question about the baby who was born first)

1. A vaginal birth (no forceps or ventouse suction cup)
2. An assisted vaginal birth (e.g. with forceps or ventouse suction cup)
3. A planned caesarean birth
4. An emergency caesarean birth

Did you have a labour?

This is a fixed question and therefore does not require your rating

1. Yes
2. No

Q.35 If you had written a birth plan or things that were important to you for your labour and birth of your baby, were your wishes respected?

1. Yes, completely
2. Yes, to some extent
3. No
4. Not applicable to my situation
5. Don't know / can't remember

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Postnatal care

Q.52 Where did you spend most of the postnatal period while in hospital?

1. Single-bed room in maternity ward
2. Multiple-bed room in maternity ward
3. Don't know / can't remember
4. I did not spend time in hospital

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Q.53 During your stay in hospital after the birth of your baby, did the health care providers caring for you introduce themselves?

1. Yes, all of my healthcare providers introduced themselves
2. Some of my healthcare providers introduced themselves
3. Very few or none of my healthcare providers introduced themselves
4. Don't know / can't remember

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Q.54 After your baby was born, did you have the opportunity to ask questions about your labour and the birth?

1. Yes, always
2. Yes, sometimes
3. No
4. I did not have any questions
5. Don't know / can't remember

Definitely yes	Probably yes	Maybe yes/maybe no	Probably no	Definitely no
○	○	○	○	○

Appendix 21

Paper 5: Recruitment material for the Delphi study round 1.

Dear Sir/Madam,

You are invited to take part in a two-round Delphi study to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. The survey instrument will be used nationally, as Ireland's **National Maternity Survey.**

You have been selected as one of 28 representative maternity service stakeholders to participate in Round 1 of the Delphi Study. We would be very grateful if you would consider giving your time and input to responding, in order to help identify the most important questions to be included in the National Maternity Survey.

We have selected stakeholders from each maternity service stakeholder group: these groups include women as service users of Irish maternity services, midwives, public health nurses, obstetricians, anaesthesiologists, neonatologists, General Practitioners, policy makers and funders.

Round 1 may take approximately 60-70 minutes of your time to complete. We know this is valuable time but it is vital that the National Maternity Survey has the right balance of questions so that the results can drive improvements in our maternity services.

We would really appreciate your input and time, however, if you do not have sufficient time to respond, I would be grateful if you would advise same by return e-mail, in order that we may request another representative stakeholder to respond in your place.

The first round is now open and will remain so until **Friday week**, **31st May 2019.**

Please see the **attached Participant Information Leaflet** for more information and please **click here to access the survey.**

Please feel free to contact us if you have any questions or are having problems completing this Delphi study. Contact details are included below.

We would be very grateful for your participation in the development of the National Maternity Survey.

Best wishes

Rachel Flynn

Director, National Care Experience Programme

National Care Experience Programme team
E-mail: info@patientexperience.ie
Freephone number-1800 314 093

Dr. Linda Drummond, Project Lead, National Care, Experience Programme, Health Information and Quality Authority: 021 2409618; ldrummond@hiqa.ie

Claire Beecher, Midwife and PhD Fellow, NUI Galway

Prof. Declan Devane, Professor of Midwifery, NUI Galway

Appendix 22

Paper 5: Recruitment material for the Delphi study round 2.

Dear Sir/Madam

You are invited to take part in a Delphi study to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. The survey instrument will be used nationally, as Ireland's **National Maternity Experience Survey.**
We are looking to recruit women as service users of Irish maternity services, midwives, public health nurses, obstetricians, anaesthesiologists, neonatologists, General Practitioners, policy makers and funders who are willing to rate the importance of questions for inclusion within this survey instrument.

This study may take approximately 20-30 (TBC) minutes of your time to complete. We know this is valuable time but it is vital that the National Maternity Experience Survey has the right balance of questions so that the results can drive improvements in our maternity services.

The study is now open and will remain so until **Tuesday 16th July 2019.**
Please see the **attached Participant Information Leaflet** for more information and please **click here to access the Delphi study.**
Please feel free to contact us if you have any questions or are having problems completing this Delphi study. Contact details are included below.
We would be very grateful for your participation in the development of the National Maternity Experience Survey.

Best wishes
Rachel Flynn

Director, National Care Experience Programme

National Care Experience Programme team
E-mail: info@patientexperience.ie
Freephone number-1800 314 093

Dr. Linda Drummond, Project Lead, National Care, Experience Programme, Health Information and Quality Authority: 021 2409618; ldrummond@hiqa.ie

Claire Beecher, Midwife and PhD Fellow, NUI Galway

Prof. Declan Devane, Professor of Midwifery, NUI Galway

Appendix 23

Paper 5: Delphi study Participant Information Sheet for all participants.

National Maternity Experience Survey

NUI Galway OÉ Gaillimh

Delphi Study – Development of the National Maternity Experience Survey

Participant Information Leaflet

You are invited to take part in a Delphi study as part of a research study to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. Before you decide if you would like to take part, it is important to understand why this research is being done and what it would involve for you.

This Participant Information Leaflet explains the aim of the research, what taking part will involve, the voluntary nature of taking part and the right to withdraw at any time. Please take the time to read this information carefully and feel free to contact the National Care Experience Programme (NCEP) / research team if you have any questions. Contact details are included towards the end of this Participant Information Leaflet.

Title of study:

The development and validation of a survey instrument to evaluate women's experiences of their maternity care in Ireland.

Aim of this research;

The overall aim of this research study is to develop a survey instrument to evaluate women's experiences of their maternity care in Ireland. The survey instrument will be used nationally as The National Maternity Experience Survey by the National Care Experience Programme (NCEP).

The NCEP is a partnership between the Health Information and Quality Authority (HIQA), Health Service Executive (HSE) and the Department of Health established in 2019 to develop and implement surveys of Ireland's health and social care services. The aim of the Programme is to encourage people to share their experiences of care and to use this information to improve the quality and safety of these services.

This research is important because the National Maternity Experience Survey will help identify areas for improvement within maternity care in Ireland to facilitate the provision of safe, effective, high quality care.

We are looking to recruit women, as service users of the Irish maternity services, midwives, public health nurses, obstetricians, anaesthesiologists, neonatologists, General Practitioners, policy makers and funders who are willing to identify questions that are of most importance for inclusion within this survey instrument.

How do I know if I am eligible?

You are eligible to take part in this Delphi study if you are over 18 years of age and represent one of the following stakeholder groups; service users of the Irish maternity services during the past 24 months, midwives, public health nurses, obstetricians, anaesthesiologists, neonatologists, General Practitioners, policy makers and funders.

National Maternity Experience Survey

NUI Galway
OÉ Gaillimh

What does taking part involve?

We will provide you with a list of possible questions for inclusion in the survey we are developing and ask you to rate the importance of each question for inclusion on a scale. **The questions have been developed based on a review of questions that are included in similar surveys internationally and focus group interviews with relevant stakeholder groups in Ireland.**

Completing the Delphi study will take approximately 20-30 minutes. This study does not involve any access to health care records.

Where and when will the Delphi study take place?

The Delphi study is taking place online from Friday 5 July 2019 to Tuesday 16 July 2019.

Are there any benefits or risks to me taking part?

Your participation will benefit you and other stakeholders as the views and opinions that you provide through the Delphi study will be used to inform the development of a survey instrument that will be used to identify areas for improvement within maternity care in Ireland and facilitate the provision of safe, effective, high quality care. No physical risks are associated with participating in this study. There is always a chance that reflecting on certain topics may upset you. If this occurs, you may contact a member of the research team. The NCEP/research team will respect the decision of all participants to walk away from the Delphi study at any time.

Voluntary participation

Participation is entirely voluntary, and you have the right to withdraw from the study at any time. If you decide not to participate in this study, or if you withdraw, there will be no negative consequences, and you will not be expected to give any reason for your decision. We do hope that you will consider completing all questions within the Delphi study but if you do decide to exit the study early, all questions that you had completed up to that point will be submitted as complete. If you are a service user of the Irish maternity services and decide not to participate, or to withdraw from the study, your care will not be affected in any way. If you do decide to withdraw from the study at any time, I would ask that you send an email declaring withdrawal to the NCEP/research team. Contact details are included towards the end of this Participant Information Leaflet.

Confidentiality

Your identity will remain confidential. All data will be coded, meaning that your name will not be published, and it will not be disclosed. All data retrieved from the Delphi study will be securely stored in the National University of Ireland, Galway under the stewardship of the research team and destroyed after a period of 5 years as in accordance with the National University of Ireland, Galway Data Retention Policy.

National Maternity Experience Survey

NUI Galway
OÉ Gaillimh

If any participant should disclose information during the research study regarding unacceptable work practices or issues of risk, the researcher is obliged to report this information to the appropriate management/ authority. In such cases, confidentiality may be broken.

What will happen to the findings of this study?

As stated previously, the findings of the Delphi study inform the development of a survey instrument that will evaluate women's experiences of their maternity care in Ireland. Prior to completion of the survey development, the findings of the Delphi study may also be submitted to peer reviewed research journals for publication.

Compensation

This study is covered by standard institutional indemnity insurance. Nothing in this document restricts or curtails your rights.

Funding

This development of this survey instrument has been supported by the Programme for Health Service Improvement, as part of the Health Service Executive.

Has this study received ethical approval?

Yes, this study has received approval from the following research ethics committee;

National University of Ireland, Galway Research Ethics Committee
Research Office
Room 212
Research and Innovation Centre
NUI Galway
Tel: 353 91 495312

Is there someone available to answer any questions that I may have about taking part?

Yes. You can get more information about the study, your participation in the study and your rights by contacting the NCEP/research team. Contact details are as follows;

National Care Experience Programme
E-mail: info@patientexperience.ie
Freephone number-1800 314 093
Dr. Linda Drummond, Project Lead, National Care Experience Programme: 021 2409618;
ldrummond@higa.ie

Claire Beecher, Midwife and PhD Fellow, NUI Galway
Prof. Declan Devane, Professor of Midwifery, NUI Galway

Thank you for taking the time to read the information within this Participant Information Leaflet. We hope you will consider taking part.

Appendix 24

Paper 5: Delphi study consent page- four consenting questions.

Q.5 Please confirm that you understand the information provided and what taking part in the study will involve. *

- ○ Yes, I understand what taking part will involve

Q.6 Please confirm that you understand that taking part is voluntary and that you are free to withdraw from the study at any time without giving reason; *

- ○ Yes, I understand that participation is voluntary

Q.7 Please confirm that you understand that the data that you provide will be securely stored at the National University of Ireland Galway for 5 years following the completion of the project and understand that members of the study team will have access to this data. *

- ○ Yes, I understand that the data I provide will be securely stored for 5 years following the completion of the project

Q.8 If you are happy to take part in this study, please tick "I agree" and then "continue" to be taken to first page of the Delphi study. *

- ○ I agree

Continue

PAGE 1 OF 10

Appendix 25

Paper 5: Focus groups and one to one interviews codebook.

Codebook colour indicators (name column): Red= major theme;

Blue= sub theme;

Black= minor theme.

Name	Description	Files	References
Antenatal specific	Items for inclusion related to antenatal care specifically	0	0
Antenatal appointments	Discussion focused on specific aspects of appointments antenatally	0	0
Antenatal clinic	Discussion focused upon the antenatal clinic specifically (waiting times, adequate time with staff)	3	6
Community	Aspects for inclusion in relation to community care specifically antenatally (e.g. community midwives, GP)	6	13
Volume and timing of antenatal appointments	Adequacy of number and timing of antenatal appointments	4	5
Antenatal education	Antenatal classes and the provision of education in general antenatally (access to antenatal classes, timing of same, content and uptake)	10	21
Scans	Discussion focused on scans and the inclusion of items re same (timing, equality, rationale for fewer/ additional scans)	6	12
Autonomy	As per WHO responsiveness model	0	0
Informed consent informed refusal	Women's experiences of giving informed consent/ informed refusal	5	7
Involvement in informed decision making	Women's involvement in decisions about their own care having being provided with adequate information.	9	16
Basic amenities	As per WHO responsiveness model	0	0
Environment	Women's experiences of the medicalised environment	3	6
Food provision	Adequacy of the food provided within maternity units and the timing of same	3	6
Hand hygiene	Adequacy of staff hand hygiene	1	1
Interaction with ancillary staff	Women's interpretation of their interaction with ancillary staff	2	2
Parking and transport	Adequacy of parking or transport availability for women accessing maternity services	3	4
Resources	Women's interpretation of resources (physical space, shower facilities etc) within the maternity	8	22

Name	Description	Files	References
	services and equality of same across units		
Staffing levels	Women's interpretation of staffing levels within the maternity services	4	5
Choice and continuity	Choice as per WHO responsiveness model. Choice and continuity have been grouped as a major heading in line with the development of the ReproQ survey instrument	0	0
Involvement in research studies	Opportunity to participate in research studies during their care	1	1
Access	Focus upon women's choice in accessing various aspects of care	0	0
Access to personal records & files	Women's access to their health care records	2	3
Accessing maternity services for the first time	Women's awareness of how to access maternity services (barriers and enablers to access)	5	11
Contacting services	Knowledge, and availability, of a point of contact within maternity services (for scheduling appointments or placing complaints)	2	4
Equality of care options	Focus upon the various models of care that are available nationwide, however not available to each woman. Considerable focus on rural Vs urban.	8	26
Referral to services	Referral to the appropriate services (includes wanting or needing referral)	9	18
Timely access	Timeliness of access to care (e.g. referral to particular clinics)	4	4
Choice of model of care	Extent of choice of model of care Awareness of and access to pathways of care	12	43
Continuity of care	Items for inclusion related to continuity of care/ caregiver and the implications of same (e.g. the impact that a lack of continuity of care has on the opportunity for a woman to build a trusting relationship with her caregiver)	7	17
Birth preference (plan)	Support for the use of and outcome of birth preferences (plans)	6	10
Communication	As per WHO responsiveness model	0	0
Communication between various services	Effectiveness/ efficiency of information exchange between the various care providers along the care continuum	5	5
Information provision within maternity services	Extent to which women are provided with relevant information to meet their needs	0	0
Consistency in information	Consistency in information provided both within and across disciples/ professions (e.g. midwives, obstetricians, GP's)	6	9

Name	Description	Files	References
Delivery of information	The tone used to deliver information, use of plain English	4	10
Explanations on the possible development of risk factors and the impact on care option decisions	Women's experiences of explanations regarding the possible development/ development of risk factors and the potential impact on care option decisions	4	5
Provision of information	Adequacy of information provided to women throughout all encounters within the maternity services	8	17
Understanding information	Understanding of information provided	5	9
Information sources	Where do women source their information on maternity care from? How do they access this? E.g. Online, leaflets, word of mouth	7	17
Opportunity to discuss sensitive topics with caregivers	Opportunity to raise a sensitive topic with care givers (e.g. domestic violence)	2	3
Staff interaction with each other	Perception of how well staff interacted with each other	2	3
Staff introduction	Did staff introduce themselves to women?	1	2
Voicing concerns and raising queries	Concerns and queries were listened to by caregivers	3	6
Confidence and trust in caregivers	Women's confidence and trust in the staff that cared for them.	0	0
Confidence in caregivers	Confidence in caregivers to provide safe care	4	8
Trusting relationship	Trust in caregivers (and opportunity to build trust)	4	6
Confidentiality	As per WHO responsiveness model	0	0
Confidentiality of medical records	Respect for confidentiality of women's medical records and data protection	1	1
Privacy	Respect for women's privacy	2	3
Dignity	As per WHO responsiveness model	0	0
Treated with kindness	Treated with kindness by caregivers	1	2
Treated with respect	Treated with respect by staff members	6	13
Woman centered care	Provision of care based on each individual woman and her specific needs	0	0
Risk	Items related to the high/ low risk pregnancies	4	4
Individualised care	Extent to which care was provided in line with the woman who received it- i.e. individualised	4	6

Name	Description	Files	References
Cultural & religious needs	Cultural or religious needs met	2	2
Maternity care needs	Extent to which women felt their needs (e.g. support, appointments etc.) were met	1	2
Infant feeding	Items for inclusion related to infant feeding specifically	0	0
Asking about method of feeding	How women were asked/approached about their choice/ method of feeding	1	2
Breastfeeding	Discussion related specifically to breastfeeding (support offered for same, continuity of advice)	13	35
Formula feeding	Discussion related specifically to formula feeding (support offered for same)	3	4
Staff knowledge on feeding	Staff knowledge of feeding options	1	1
Supported in their decision	Perception of support in decision on infant feeding method- whether that be breast or formula	4	10
Labour and birth specific	Items for inclusion related to labour and birth specifically	0	0
Caesarean section	Items for inclusion related to Caesarean section (did women feel empowered, were options discussed with them e.g. gentle caesarean)	2	2
Home birth	Discussion on items for inclusion related to home birth specifically (availability of same, number of caregivers, items related to transfer to hospital having planned a home birth if that occurred)	1	2
Induction	Items for inclusion related to induction of labour (fully informed about what is happening, what are the options and possible consequences)	3	4
Pain relief	Discussion focused on the inclusion of items related to pain relief during labour and birth (e.g. availability of/ access to pain relief and comfort measures)	4	6
Presence of caregivers (labour and birth)	Physical presence of caregivers during labour and birth (were women accompanied by a caregiver throughout their labour and birth?)	2	2
Skin to skin	Skin to skin discussed/ performed?	1	1
Mental health	Discussion on the importance of including items related to women's mental health e.g. were women asked about their mental health, were the appropriate referrals made?	11	20
Postnatal specific	Items for inclusion related to postnatal care specifically	0	0
Availability of postnatal care in the community	The availability of care to women following postnatal discharge (GPs, PHN, community midwives etc)	13	36
Debriefing	Availability and use of a postnatal debrief service (discussing all aspects of care)	9	13

Name	Description	Files	References
Discharge education	Provision of discharge education (postnatally from ward)	4	5
Discharge from hospital	Process of discharge from hospital (postnatally) including timing of discharge	4	5
Health of mother postnatally	Health of the mother postnatally, e.g. availing of 6 week check up	6	11
Postnatal morbidity	Experience of postnatal morbidity (e.g. incontinence) and appropriateness of response	3	4
Relationship between mother and baby	Items related to the growing relationship/ bonding between mother and baby	1	1
Who to contact postnatally	Awareness of who to contact (within maternity services) postnatally	5	8
Access to baby	Women's access to their baby postnatally- for e.g. following a C/S	4	6
Care of baby in hospital	Aspects of care for inclusion related directly to women's experiences of the care their baby received in hospital	1	2
NICU	Discussion related to items for inclusion on the admission of baby's to NICU (e.g. information provision, facilities for women when baby is in NICU)	5	6
Prompt attention	As per WHO responsiveness model	0	0
Emergency situation	Experience of care in an emergency situation?	2	5
Waiting times	Waiting times encountered at any stage of maternity services	3	5
Social consideration	As per WHO responsiveness model	0	0
Additional sources of support	Availability of additional sources of support- e.g. Doula, community groups	4	9
Involvement of partner	Inclusion of partners at each stage of maternity care (and within the survey instrument)	6	13
Support from partner and family	Support/ support system from partner/ family at home	4	5
NMES organisation and demographics	Aspect for inclusion specific to the NPES and aspects of care discussed but decision has been made that not for inclusion within this instrument e.g. bereavement, preconception, future suggestions for maternity services.	0	0
Administration and layout of survey	Aspects for consideration in administering and developing the survey e.g. paper Vs online.	9	30
Bereavement	Inclusion of women who have experienced a bereavement and items re same	6	9
Open text options	Discussion focused upon the inclusion of open text options within the survey (importance of, number of etc)	6	7
Overarching areas for inclusion	Overarching areas that have been mentioned as being important for inclusion e.g. antenatal etc	6	9

Name	Description	Files	References
Termination of pregnancy	Aspects of care/ the care pathway of termination of pregnancy within the survey instrument.	3	3
Timing of survey implementation	Timing of the survey implementation e.g. postnatal only or both antenatally and postnatally plus optimum timing of same	7	12
Future suggestions for mat services	Suggestions focusing on the inclusion of items asking women what they would like from the maternity services in future	2	4
Fertility	Fertility/ fertility journey	2	2
Preconception	Preconception care and women's knowledge at this point	5	9
Demographics	Items for inclusion related to demographics	0	0
Age	Asking women about their age	5	6
Amenities available	Asking women about their accommodation at home- running water etc	2	2
Disability	Asking women if they have any disabilities	1	2
Ethnicity	Asking women about their ethnicity and the impact of same	8	13
Family dynamics	Items for inclusion in demographics section related to family dynamics	1	1
Language barriers	Availability of translator services and/ or education materials (e.g. leaflets) in languages other than English for women who need these	6	9
Previous pregnancies	Asking women about any previous pregnancies they may have had	5	7
Public, private, semi- private etc	Type of care women accessed i.e. public, private, semi- private etc	5	9
Socioeconomic status	Asking women about their socioeconomic status	4	8

Appendix 26

Paper 5: Final bank of items for inclusion in the National Maternity Experience Survey.

- Purple text gives explanations of terminology or instructions for participants;
- Red text is 'routing' items. Based on the participants' answers to these items they will be brought to the next item relevant to them, therefore, bypassing irrelevant items.

Section 1- Care during your pregnancy

No.	Question/ & response option
	The following section asks about your experience of care **during your pregnancy**.
1	Did you give birth to a single baby, twins or more, in your most recent pregnancy? 1. A single baby 2. Twins 3. Triplets, quads or more If you had more than one baby at this time, please complete this survey for the baby who was born **first**.
2	Women can have different types of maternity care. Were you offered any of the following **types** of maternity care? Please tick **all** that apply 1. Consultant-led care (private or semi-private) Semi-private care is only available in Dublin hospitals 2. Consultant-led care (public care) 3. Midwifery-led care with birth in a public hospital 4. Midwifery-led care with birth in a midwifery-led unit - Cavan General and Our Lady of Lourdes Hospital Drogheda only 5. Home birth with hospital-based or self-employed community midwives (SECM) 6. I was not offered any choices 7. I had no choices due to medical reasons 8. Don't know or can't remember
3	How do you rate the availability of information on your choices about **types** of maternity care? 1. Very good 2. Good 3. Fair 4. Poor 5. Don't know or can't remember
4	What **type** of maternity care did you choose? Please tick **one** box only 1. Consultant-led care (private or semi-private) Semi-private only available in Dublin hospitals 2. Consultant- led care (public care) 3. Midwifery-led care with birth in a public hospital 4. Midwifery-led care with birth in a midwifery-led unit – Cavan General and Our Lady of Lourdes Hospital Drogheda only 5. Home birth with hospital-based or self-employed community midwives (SECM)

Thinking about all the care you received **during your pregnancy**, how much information was given to you about each of the following:

		Not enough	The right amount	Too much	I did not want or need this information
5	Physical changes to your body during pregnancy				
6	Mental health changes that may occur				
7	Nutrition and healthy eating during pregnancy				
8	Giving up smoking and other tobacco-related products (e-cigarettes, vaping devices, and so on)				
9	Impact of alcohol and or drug abuse on you and your baby				
10	Pain relief options for labour and birth				
11	Feeding options for your baby				

Thinking about all the care you received **during your pregnancy**, did you feel that …

		Yes, always	Yes, sometimes	No	Don't know or can't remember
12	… you were listened to?				
13	… you were involved in making decisions about your care?				
14	… your decisions were respected?				
15	… your privacy was respected when you were being examined or treated?				
16	… you were treated with respect and dignity?				
17	… you had confidence and trust in the staff treating and caring for you?				
18	… your questions were answered in a way that you could understand?				
19	… the benefits and risks of all tests, procedures and treatments were explained to you in a way you could understand **before** you were asked for your consent?				
20	… you had someone to talk to about worries and fears?				

21	Overall, how would you rate your experience of the care you received during your pregnancy? **Scale of 0 to 10** **Example of lowest and highest score:** **0** = "I had a very poor experience of care during my pregnancy." **10** = "I had a very good experience of care during my pregnancy." Choose a score you feel is fair for your experience.

Section 2- Care during your labour and birth

No.	Question/ & response option
	The following section asks about your experiences of care **around the time of your labour and birth** of your baby. 'Birth' includes babies born vaginally or by caesarean.
22	What type of birth did you have? 1. A vaginal birth (no forceps **or** ventouse suction cup) 2. An assisted vaginal birth (for example, forceps or ventouse suction cup was used) 3. A planned caesarean birth 4. An emergency caesarean birth

Thinking about all the care you received **during your labour and birth**, did you feel that …

		Yes, always	Yes, sometimes	No	Don't know or can't remember
23	… you were listened to?				
24	… you were involved in making decisions about your care?				
25	… your decisions were respected?				
26	… your privacy was respected when you were being examined or treated?				
27	… you were treated with respect and dignity?				
28	… you had confidence and trust in the staff treating and caring for you?				
29	… your questions were answered in a way that you could understand?				
30	… the benefits and risks of all tests, procedures and treatments were explained to you in a way you could understand before you were asked for your consent?				
31	… you had someone to talk to about worries and fears?				

32	Did you feel that you had enough help to enable you to cope with your pain during labour and birth? 1. Yes, definitely 2. Yes, to some extent 3. No – I didn't get enough help 4. I did not need or want any help 5. Not relevant to my situation 6. Don't know or can't remember

33	If you had written a birth plan, a list of birth preferences **or** things that were important to you for your labour and the birth of your baby, were your wishes respected? 1. Yes, definitely 2. Yes, to some extent 3. No - my wishes were not respected 4. No, but this was not possible for medical reasons 5. Not relevant to my situation 6. Don't know or can't remember
34	Did you have the opportunity to hold your baby as soon as you would have liked after birth? 1. Yes 2. No 3. No, but this was not possible for medical reasons 4. Not relevant to my situation 5. Don't know or can't remember
35	Did you have skin-to-skin contact (baby naked on your chest or tummy) with your baby shortly after the birth? 1. Yes 2. No 3. No, but this was not possible for medical reasons 4. I did not want skin-to-skin contact with my baby 5. Don't know or can't remember
36	Overall, how would you rate your experience of the care you received during your labour and birth? **Scale of 0 to 10** **Example of lowest and highest score:** 0 = "I had a very poor experience of care during my labour and birth." 10 = "I had a very good experience of care during my labour and birth." Choose a score you feel is fair for your experience.

Section 3- Care in hospital after the birth of your baby

No.	Question/ & response option
	The following section asks about your experiences of care **in hospital after the birth of your baby**. If you had a home birth and did not go to hospital, please continue to the next section of the questionnaire
37	After your baby was born, did you have the opportunity to ask questions about your labour and the birth (often called a 'debriefing')? 1. Yes, definitely 2. Yes, to some extent 3. No 4. I did not have any questions 5. Don't know or can't remember

Thinking about all the care you received **during your stay in hospital after the birth of your baby**, did you feel that …

		Yes, always	Yes, sometimes	No	Don't know or can't remember
38	… you were listened to?				
39	… you were involved in making decisions about you and your baby's care?				
40	… your decisions were respected?				
41	… your privacy was respected when you were being examined or treated?				
42	… you were treated with respect and dignity?				
43	… you had confidence and trust in the staff treating and caring for you and your baby?				
44	… your questions were answered in a way that you could understand?				
45	… the benefits and risks of all tests, procedures and treatments for you or your baby were explained to you in a way you could understand before you were asked for your consent?				
46	… you had someone to talk to about worries and fears?				

Thinking about all the care you received **before you were discharged from hospital**, how much information was given to you about the following:

		Not enough	The right amount	Too much	I did not want or need this information
47	What to expect with your own physical recovery after the birth				
48	Any changes you might experience to your mental health after having your baby				
49	How to care for your baby				

50	Before you were discharged from hospital, were you told who to contact if you were worried about your health or your baby's health after you left hospital? 1. Yes 2. No 3. Don't know or can't remember
51	Overall, how would you rate your experience of the care you received in hospital after the birth of your baby? **Scale of 0 to 10** **Example of lowest and highest score:** **0** = "I had a very poor experience of care during my stay in hospital after the birth of my baby." **10** = "I had a very good experience of care during my stay in hospital after the birth of my baby." Choose a score you feel is fair for your experience.

Section 4- Specialised care for your baby

No.	Question/ & response option
	After birth, some babies need specialist care – for example, help with breathing – and are admitted to a **neonatal intensive care unit (NICU) or similar unit**. The following section asks about your experiences of care if your baby was admitted to one of these units.
52	Did your baby spend any time being cared for in a neonatal intensive care unit (NICU) or similar unit? 1. Yes 2. No 3. Don't know or can't remember
53	Were you able to stay with your baby as much as you wanted while they were being cared for in the NICU or similar unit? 1. Yes 2. No 3. No, but there was a reason. **Please explain why**
54	While your baby was in the NICU or similar unit, were you involved in making decisions about your baby's care as much as you would have liked? 1. Yes, always 2. Yes, sometimes 3. No 4. I did not want or need to be involved 5. Don't know or can't remember
55	While your baby was in the NICU or similar unit, did you receive enough emotional support from hospital staff? 1. Yes, always 2. Yes, sometimes 3. No 4. I did not want or need any emotional support 5. Don't know or can't remember
56	Overall, how would you rate your experience of the care your baby received in the NICU or similar unit? **Scale of 0 to 10** **Example of lowest and highest score:** **0** = "I had a very poor experience of the care my baby received while in the NICU or similar." **10** = "I had a very good experience of the care my baby received while being cared for in the NICU or similar." Choose a score you feel is fair for your experience.

Section 5- Feeding your baby

No.	Question/ & response option
	The following section asks about your experiences of care in relation to **feeding your baby**
57	In the first few days after the birth, how was your baby fed? Please tick one box only 1. Breast milk (or expressed breast milk) only 2. Both breast and formula (bottle) milk 3. Formula (bottle) milk only 4. Other, **please specify**
58	Did your healthcare providers discuss with you the different options for feeding your baby? Please tick all that apply 1. Yes, during pregnancy 2. Yes, during labour or immediately after birth 3. Yes, after birth while in hospital 4. Yes, after birth while at home 5. No 6. Don't know or can't remember
59	Did you feel that your decisions about how you wanted to feed your baby were respected by your healthcare providers? 1. Yes, always 2. Yes, sometimes 3. No 4. Don't know or can't remember
60	During your stay in hospital after the birth of your baby, did your healthcare providers give you enough support and encouragement with feeding your baby? 1. Yes, definitely 2. Yes, to some extent 3. No 4. Don't know or can't remember
61	When you were at home after the birth of your baby, did your healthcare providers give you enough support and encouragement with feeding your baby? 1. Yes, definitely 2. Yes, to some extent 3. No 4. Don't know or can't remember

Section 6- Care at home after the birth of your baby

No.	Question/ & response option
	The following section asks about your experiences of care when you were **visited at home or seen by a health care provider in the community after the birth of your baby**.
62	When you were at home after the birth of your baby, did you have the details of a healthcare professional so that you could contact them if you needed to? 1. Yes 2. No 3. Don't know or can't remember
63	When you were at home after the birth of your baby, were you able to get help from healthcare providers for you and your baby if you needed it? 1. Yes, always 2. Yes, sometimes 3. No 4. I didn't need help 5. Don't know or can't remember

Thinking about all the care you received **at home after the birth of your baby**, how much information was given to you about the following:

		Not enough	The right amount	Too much	I did not want or need this information
64	Your own physical recovery after the birth				
65	Any changes you might experience to your mental health after having your baby				
66	Contraception				
67	Caring for your baby				
68	Your baby's health				
69	Safe sleeping for your baby				
70	Vaccines for your baby				
71	Local support groups				

Thinking about all the care you received **at home after the birth of your baby**, did you feel…

		Yes, always	Yes, sometimes	No	Don't know or can't remember
72	.. you were listened to?				
73	… you were involved in making decisions about your care?				
74	… your decisions were respected?				
75	… your privacy was respected when you were being examined or treated?				
76	… you were treated with respect and dignity?				
77	.. you had confidence and trust in the staff treating and caring for you?				
78	… your questions were answered in a way that you could understand?				
79	… the benefits and risks of all tests, procedures and treatments were explained to you in a way you could understand before you were asked for your consent?				
80	… you had someone to talk to about worries and fears?				

81	Did your baby receive a 2-week check-up with your General Practitioner (GP)? 1. Yes 2. No, I did not know about the 2-week check 3. I attended another healthcare provider for the 2-week check 4. Not relevant to my situation 5. Don't know or can't remember

Thinking about all the care you received **at the postnatal check-up (around 6 weeks after the birth),** did the GP …

		Yes, definitely	Yes, to some extent	No	I have not had a postnatal check-up	Don't know or can't remember
82	… spend enough time talking to you about your own physical health?					
83	… spend enough time talking to you about your own mental health?					
84	… give enough care and support to you and your baby?					

85	Overall, how would you rate your experience of the care you received at home, or in the community, after the birth of your baby? **Scale of 0 to 10** **Example of lowest and highest score:** 0 = "I had a very poor experience of care while at home, or in the community, after the birth of my baby." 10 = "I had a very good experience of care while at home, or in the community after the birth of my baby." Choose a score you feel is fair for your experience.

Section 7- Overall care

No.	Question/ & response option
	The following section asks about your overall experiences of care from the time your pregnancy was confirmed, through labour and birth, and after your baby was born
86	Thinking about all of the care you received from the time your pregnancy was confirmed, through labour and birth, and after your baby was born, if you had wanted to make a complaint, would you have known how to do it and where to send it? 1. Yes 2. No 3. Not relevant to my situation 4. Don't know or can't remember
87	Overall, how would you rate how involved you were in decisions about your care during from the time your pregnancy was confirmed, through to labour and birth and after your baby was born? **Scale of 0 to 10** **Example of lowest and highest score:** 0 = "I was not at all involved in decisions about my care." 10 = "I was very involved in decisions about my care." Choose a score you feel is fair for your experience.
88	Overall, how would you rate your experience of the care you and your baby received from the time your pregnancy was confirmed, through to labour and birth and after your baby was born? **Scale of 0 to 10** **Example of lowest and highest score:** 0 = "I had a very poor experience of care." 10 = "I had a very good experience of care." Choose a score you feel is fair for your experience.
89	Was there anything particularly good about your maternity care? (open text)
90	Was there anything that could be improved? (open text)
91	Have you any other comments or suggestions? (open text)

Section 8- You and your household

No.	Question/ & response option
	The following questions will help us to describe the women taking part in the survey and to find out whether or not the care offered to women is the same regardless of their background or circumstances.
92	In what year were you born? (open text)
93	How many babies have you given birth to before this pregnancy? 1. None 2. 1 or 2 3. 3 or more
94	What is your ethnic group? **White** 1. Irish 2. Irish Traveller 3. Roma 4. Any other White background **Black or Black Irish** 5. African 6. Any other Black background **Asian or Asian Irish** 7. Chinese 8. Indian/ Pakistani/ Bangladeshi 9. Any other Asian background **Other, including mixed group/ background** 10. Arabic 11. Mixed, **please specify** Other, **please write your ethic group here:**
95	Do you have any of the following? Please tick all that apply 1. Blindness or a serious vision impairment 2. Deafness or a serious hearing impairment 3. A condition that substantially limits one or more basic physical activities 4. An intellectual disability 5. Difficulty in learning, remembering or concentrating 6. Mental health, psychological or emotional condition 7. Difficulty in dressing, bathing or getting around inside the home 8. Difficulty in going outside home alone 9. Difficulty in working or attending school/college 10. Difficulty in taking part in other activities 11. Other disability, including chronic illness