DEVELOPMENT OF A MINIMUM DATA SET FOR POSTNATAL DISCHARGE SUMMARY

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Master of Science in Health Informatics

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Declaration

I declare that the work described in this dissertation is, where otherwise stated, entirely my own work, and has not been submitted as an exercise for a degree at this or any other university.

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DEDICATION

This work is dedicated to

Thressiamma Pious

My Mother

"All my love to her, for finding me the light,

Whenever it was far away"

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Abstract

Discharge summaries are one of the major modes of communication between secondary/tertiary care and primary care. The *"National Standard for Patient Discharge Summary Information*" developed by HIQA is specific to general discharge summaries. This addresses the quality of contents in a general discharge summary; however, a gap in the standard requirement for discharge summaries for specialties like maternity care is evident.

This research developed a "minimum data set" for postnatal discharge summaries with a view to improve their quality content. A lack of previous studies on the content of maternity discharge summaries and the information requirements of the major stakeholders of maternity care prompted this study to explore the information requirements of Public Health Nurses, General Practitioners, Consultant Obstetricians and Midwives.

A mixed methodology with sequential explanatory design is used for the purpose of this study. A minimum data set development process is used to harmonise the data sets in the newly developed discharge summary. An analysis of the discharge summaries collected from 15 maternity hospitals in Ireland and a review of the literature identified the required data sets for the draft discharge summary. The submissions received from public health nurses, general practitioners, consultant obstetricians, and midwives (total=50) on the draft discharge summary and from the questionnaire led to the development of a minimum data set for postnatal discharge summaries. The data set definitions were identified using national and international data dictionaries. SNOMED-CT is used to achieve a terminology standard.

The analysis of postnatal discharge summaries from different maternity hospitals and its findings identified significant gaps in communicating valuable information using maternity specific data sets. It was recognised that the present maternity specific data sets are inadequate to deliver quality information to the primary care team in the community to offer continuity of care. The information requirement assessment of the stakeholders in maternity care revealed that a wide variation in information

requirement exists among the stakeholders and the role and accountability of the health care professional is directly proportional to the information requirement of that professional. It is also identified that the current "*National Perinatal Reporting System Data Dictionary"* is insufficient in defining the maternity data sets currently in use in Ireland. HIQA (2014) recommended the deployment of SNOMED-CT as a terminology standard in Ireland and therefore each data set in the newly developed postnatal discharge summary is paired with SNOMED-CT in order to identify that this shadows international terminology standards ensuring interoperability.

This study provides a positive contribution towards the development of postnatal discharge summaries in the upcoming Maternity and Neonatal Clinical Management system (MN-CMS) in Ireland and has the potential to be included in the MN-CMS project. The sub-data sets used under "antenatal, delivery, and postnatal clinical information" headings are similar to most of the National Perinatal Mortality and Morbidity Data sets. Once accepted by the MN-CMS, this newly developed discharge summary has the potential to support strategic planning by providing information on maternity health indicators, maternity care outcome measures, national and perinatal mortality and morbidity statistics and national and international data comparisons. As this is the first study of its kind in maternity care, the prospective benefits of this study will be diverse.

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Abbreviations

Abbreviations	
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health And Welfare
BMI	Body Mass Index
BP	Blood Pressure
CCA	Community Care Area
CCTP	Care Transition Programme
CFHN	Community family Health Nurse
CIA	Central Intelligence Agency
ACSQHC	Australian Commission on Safety and Quality in Health Care
AIHW	Australian Institute of Health And Welfare
CO	Consultant Obstetrician
DOB	Date of Birth
DS	Discharge Summary
EDS	Electronic Discharge Summary
epSOS	European Patient Smart Open Services
EU	European Union

FBI	Federal Bureau of Investigation
GBS	Group B Streptococcal infection
GP	General Practitioners
HIPE	Hospital In-Patient Enquiry
HIQA	Health Information and Quality Authority
HIT	Health Information Technology
HSCIC	Health and Social Care Information Centre
HSE	Health Service Executive
ICD	International Classification of Diseases
ICS	Irish Coding standard
ICT	Information and communications technology
ID	Identification
IEEE	Institute of Electrical and Electronics Engineers
IOM	Institute of Medicine
IPIMS	Integrated Patient Information Management System
ISF	Integrated Services Framework
ITK	Interoperability tool kit
LIS	Laboratory Information System
LSCS	Lower Segment Caesarean Section
MDS	Minimum Data Set

MIM	Maternity Information Matrix
MMR	Mumps, Measles, Rubella vaccine
MN-CMS	Maternity and Neonatal Clinical Management System
NBS	New Born Screening
NEHTA	National E-Health Transition Authority
NHS	National Health Services
NICE	National Institute for Health Care and Excellence
NPEC	National Perinatal Epidemiology Centre
NPRS	National Perinatal Reporting System
NPSA	National Patient Safety Agency
NSA	National Security Agency
PAS	Patient Administrative System
PHN	Public Health Nurse
QPSD	Quality & Patient Safety Directorate
RCOPI	Royal College of Physicians of Ireland
SNOMED – CT	Systematized Nomenclature of Medicine--Clinical Terms
SVD	Spontaneous Vaginal Delivery
TPR	Temperature, Pulse, Respiration
UK	United Kingdom of Great Britain
UKCC	United Kingdom Central Council for Nursing and Midwifery

USA	United States of America

Glossary of Terms

Table 1 Glossary of Terms

Terms	***Description***
Antenatal care	Antenatal care is the care given by the healthcare professionals during pregnancy (NICE, 2013)
Anti –D	Injection of Anti-D immunoglobulin to prevent sensitization to Rhesus positive blood (NICE, 2013)
Apgar Score	The score is based on the five characteristics of heart rate, respiratory condition, muscle tone, reflexes and colour. The maximum or best score being 10 (NPRS, 2014).
Birth order	Order of birth in multiple birth episodes (NPRS, 2014).
BMI	A standard for recording obesity statistics derived from maternal weight and height (MIM, 2014)
Clinical Terminology	This concerns the meaning, expression and use of concepts in statements in the medical records or other clinical information systems (MIM, 2014)
Confidentiality	Confidentiality refers to a duty that a person owes to safe guard information that has been entrusted to him or her by another (Craig et al, 2007).
Data	Data is raw unorganised facts that need to be processed or organised. Data can be numbers, symbols, words, images and

	graphics that have to be organised or analysed (AIHW, 2007)
Data Dictionary	"Centralised repository of information about data such as meaning, relationships to other data, origin, usage, and format" (Parente, 2009).
Data standard	Data standard describes the agreed meaning of the term and acceptable representation of data for use within a defined context (MacArthur C, 2002)
Denominator	Denominator is target group and includes all the service users (Cresswall, 2007).
Discharge summary	Discharge summary "information required in a generic clinical discharge summary produced at the time of discharge from a secondary care or tertiary care" (HIQA, 2013).
Electronic Heath Record	A longitudinal electronic record of patient health information across multiple care setting. Contains multiple EMR and EPRs which is shared and interoperable across setting (HIQA, 2013)
Encrypting	Encrypting means that the health information cannot be read or understood by the person except by those who can decrypt with a key (Fernández-Alemán, 2013).
Episiotomy	An episiotomy is the surgical procedure that enlarges the opening of the vagina through the cutting of the perineum, the skin and the muscles between the vulva and the anus (Stedenfeldt, 2012).

Gestation	Gestation is measured from the first day of the last normal menstrual period. Gestational age is expressed in completed days or completed weeks. Where the date of last normal menstrual period is not available, gestational age should be based on the best clinical estimate (NPRS, 2014)
Head circumference	Head circumference of the baby at birth in centimetres, to the nearest one decimal point. WA: The measurement the nearest centimetre with the tape just above the eyebrows anteriorly and at the maximum point of the occiput posteriorly (MIM, 2014).
Healthcare professional	A registered medical practitioner, or nurse, or allied health professional professionals.
HIQA	HIQA are an independent authority established by the government and responsible for driving quality, safety and accountability in health and social services in Ireland. They develop and publish standards, monitor compliance with standards, carry out health technology assessments, publish health and social care service delivery performance statistics and carry out investigations (HIQA, 2013)
ICD	ICD is clinical coding for epidemiology reporting, health management purposes and clinical use in acute and primary care settings (WHO, 2014).
Interoperability	Interoperability The Institute of Electrical and Electronics Engineers (IEEE 1990) defines interoperability as ability of two or more systems or components to exchange information and to use the information that has been exchanged.

Maternal Serology	If the result reported in this field affects the management of the pregnancy, report the associated condition in medical conditions or pregnancy complications (MIM, 2014).
Maternity care	Maternity care refers to the care given to the mum and the baby throughout pregnancy, birth and up to six weeks after the birth (NICE, 2014)
Midwifery Led Care	The philosophy behind midwife-led continuity models is normality, continuity of care and being cared for by a known, trusted midwife during labour (Begley, 2011).
Minimum data set	Minimum data set (MDS) is “the name given to a selective core of data standard identified by user and stakeholders as minimum for collection for specific purpose” (AIHW, 2007- A guide to data development p-13)
Mixed Method	Mixed Method: an enquiry that combines or associates with qualitative and quantitative forms. Quantitative research: formal, objective, systematic process in which numerical data are used to establish the relation ship between variables and statistical method to test the strength and significance of relationship (Burns & Grove, 2005)
Mode of birth	The method of complete expulsion/extraction from its mother of a product of conception in a birth event (MIM, 2014). Method of delivery for this birth (NPRS, 2014).
Model Of Care	Plan of mother in choosing a maternity care provider MIM, 2014).
Numerator	Numerator is the service user included in the selected stakeholders group Cresswell, 2007).

Parity	The total number of previous pregnancies experienced by the woman that have resulted in a live birth or a stillbirth (NPRS, 2014).
Positivism	Positivism refers to the positive knowledge based on the natural phenomena and their properties and relations as verified by the empirical sciences (Creswell, 2014).
Postnatal care	Postnatal care is the basic care a woman and her baby should receive appropriate to their needs, during the 6 weeks after the birth, based upon the best evidence available (NICE, 2014).
Pragmatism	Pragmatism is a research approach arises out of action, situation, and consequences. Instead of focusing on one particular methodology, researcher emphasis the research problem and use all methods available to understand the problem (Cresswell, 2014).
Presentation at birth	The presenting part of the foetus at birth (MIM, 2014)
Privacy	Privacy is defined as "the right of the individuals to keep information about themselves from being disclosed to others; the claim of individuals to be let alone, surveillance or interference from other individuals, organisations or the government" (Health Information Technology dictionary 1999:Rognehaugh).
Rubella	Immunity to Rubella: An affirmative answer should be recorded only where there is documented evidence of a rubella antibody test (NPRS, 2014).
Security	Security is defined as the extent to which personal information can be stored and transmitted, in such a manner, that access to the

	information is limited to authorised parties (Brands, 2003).
SNOMED-CT	SNOMED-CT-comprehensive clinical terminology that provides clinical content and expressively for clinical documentation and reporting. It can be used to code, retrieve, and analyse, clinical data International Health Terminology Standards Development Organisation, 2013).
Terminologies	Are structured lists of terms that are used to capture clinical information at the point of care (AIHW, 2007).
Type of birth	Identifies event as live birth or stillbirth (NPRS, 2014).

CHAPTER 1 INTRODUCTION

> *"Soon after 11 September 2001, a Director of the United States Counter Intelligence Agency was interviewed on television. He was asked, 'with all of the money that is spent by the USA government on intelligence, why was it that no one was aware that a terrorist attack was imminent?' The answer was that the Central Intelligence Agency (CIA), the Federal Bureau of Investigation (FBI), and the National Security Agency (NSA) managed their data independently of each other. Without sharing of data, it was impossible to identify and prevent problems across the organizations. Besides the motivation or incentive to share data and technology to ensure software interoperability, data standards are needed in order to share data from different sources" (Seiner 2001, p3).*

1.1 Introduction

Maternity care system in general, in Ireland is a model of shared care/integrated care system. Integration involves "connecting health care systems (acute, community and primary) with other service systems" (Quality & Patient Safety Directorate (QPSD, 2014), whereby the multi-disciplinary professionals in the health sector work together for a common goal, sharing resources through coordinated care delivery. The inability to share the information between maternity care to primary care, leads to unnecessary delays in mother and baby receiving appropriate care in the community. The information should follow the patient along the entire care pathway. Institute of Medicine (IOM, 1999) estimates that out of 44,000 – 98,000 deaths each year from medical errors, 80% of errors caused by miscommunication. A safe integrated health care system depends on its communication-networking system. The inability to share the information across healthcare systems interrupts continuity of care and leads to unnecessary duplication of services (HIQA, 2013[1]). A Discharge Summary is one of the core means of communication between hospitals and primary care. The information should follow the patient along the entire care pathway. To address the communication issue in integrated care delivery, HIQA (2013[1]) developed *"National standard for Patient Discharge summary information"* outlining the content requirement of a general discharge summary. These generic data sets are unfortunately not sufficient enough to meet the information needs of clinical specialties such as maternity care. Focusing on this standard, this study is going to investigate the quality content requirement of a postnatal discharge summary to produce a Minimum Data Set for Postnatal Discharge Summaries. This chapter provides a brief outline of background, significance, and motivation of conducting this study. The research questions, aims, and objectives are listed separately. Steps in conducting this study and an overview of the dissertation are described. This chapter is summarized at the end with conclusion.

Development of Minimum Data Set is a confusing terminology used in literature. It is constantly misinterpreted as *minimum information requirement* in literature (McCormick et al, 2005; Leong & White, 2010; Ahmadi et al 2015). "Development of minimum data set" is the process of collecting core information and developing it into data standards (AIHW, 2007). Data set development is the significant component of minimum data set development. Data sets should be based on single set of agreed definitions. National Data Dictionaries are main sources for the data definitions. Therefore, the process of minimum data set development should follow appropriate methodology. There is limited literature explaining the minimum data set development process. Therefore, this study used international guidelines for developing data standards and is explained in chapter 3.

1.2 Background and Significance of the Study

Concerns about the quality of discharge summaries in all disciplines of health care are not new. A 1975 study (Tulloch, et al) on discharge summaries in English hospitals identified the need for improvements in both timeliness and content. There is limited literature relating to the content of high quality discharge summaries. The national standard for discharge summary in Ireland, developed by HIQA (2013[1]), recommends that the discharge summary should include demographic details, diagnosis, examinations, test results, medications, and follow up information. This is consistent with general hospital discharge summary. Maternity services are unique and the contents of its discharge summary are different. Jenkinson *et al* (2014) examined the different maternity discharge process and practices in Queensland, Australia and concluded that the discharge summaries should be consistent, comprehensive, and specific to maternity services. However, no studies evaluated the quality of content of maternity discharge summaries. This study seeks to contribute to this gap by developing a high quality discharge summary for postnatal discharges.

In other countries like United Kingdom, mother and baby are visited by a community midwife for at least the first 7-10 days postpartum as part of routine midwifery care (United Kingdom Central Council for Nursing (UKCC) 1993, Wray & Bick 2012), usually from same midwifery team the mother attended antenatally. In Ireland, the care of the mother and baby is handed over to the Public Health Nurses (PHN) for the postnatal period. These professionals have had no role in antenatal or intranatal care of the mother. Therefore, they have no direct access to maternity care records antenatally or postnatally. This highlights the need for additional information requirement for community professionals in Ireland compared to other countries.

Shared care models in maternity care system in Ireland play a major role in reducing unnecessary hospital stays. Statistics shows that, average length of stay in hospital following the birth of a baby was 6 hours to 2 days following spontaneous delivery in 78% of singleton births (National Perinatal Reporting System (NPRS, 2014). This is partly because the effective maternity care services are interdependent on primary care, specialist service, and the range of early year services provided in the community setting *(Commissioning Maternity Services, NHS, 2012). Horizon-2020* (2013) advocates the need for increasing the use of information technology in healthcare to enhance the communication and sharing of information. Data standards are the stepping-stone for an interoperable information System. Using standardized clinical language in a discharge summary will contribute to interoperability. To address these issues of sharing data and data standards, this study is going to develop a minimum data set for the postnatal discharge summaries. This study will contribute by developing guidelines for discharge summary by identifying the necessary postnatal discharge summary related National data standards available in Ireland and will make recommendations for those data sets not available in Data Dictionaries in Ireland.

*"The information needs of community-based health care providers involved in postnatal care are an under-investigated area. Our review of academic literature did not identify any studies that have examined the information needs of GPs and CFHNs or their views on current discharge communication practices"(*Jenkinson et al 2014, p-20). The first study of its kind, this study is going to contribute by assessing the information requirement of PHNs, GPs, Obstetricians, and Midwives in a discharge communication.

1.3 Motivation

The researcher is a Clinical Midwife Manager in a maternity hospital in Dublin, which is one of the largest maternity hospitals in Europe. Routinely, an encrypted discharge summary is emailed to the Primary care team, as a part of the postnatal discharge process. However, frequent phone calls from the primary care team members to the postnatal ward requesting further information on antenatal, intranatal, or postnatal events stresses that the current discharge summary is lacking enough information to provide continuity of care in the community. This showed a gap in the information flow from hospital to the primary care team. Verbal information obtained from other maternity hospitals in Dublin revealed similar problems, which highlighted the importance of a standardized discharge summary across the maternity hospitals.

To provide further information to the primary care team upon request, the Clinical Midwife Manager has to retrieve the paper based patient record from the medical record section. This is a time consuming process. Also, currently this hospital uses four different clinical and administrative information systems –Laboratory Information System (LIS), Patient Administrative System (PAS), Integrated Patient Information Management System (IPIMS), and K2 Medical system. From the consequences of lack of interoperability between these systems, each health care professional has four different security passwords in order to use these systems. These scenarios highlight the importance of interoperable Electronic Heath Record for better communication and continuity of care. This study is going to contribute by developing minimum data set using data standards, which is the first step in e-health strategy.

1.4 Research Question

1. What type of information does each of the maternity care settings in Ireland hand over to the community health Care professionals in their postnatal discharge summary?
2. Does the draft discharge summary address the information requirement of the General practitioners and Public Health nurses in the primary care team?
3. Are all the clinical terminologies used in the postnatal discharge summaries included in Data dictionaries in Ireland? If not, what additional data sets need to be included in Data dictionaries related to postnatal discharge summary?
4. How health care professionals feel about having a standard discharge summary across Ireland?
5. Does all the data sets used in the postnatal discharge summary are in existence in Systematised Nomenclature of Medicine-Clinical Terms (SNOMED – CT)?

1.5 Research Aims

The aims of this research are,

- To analyse and evaluate the data sets from current postnatal discharge summaries in use in Maternity Hospitals in Ireland.
- To develop a minimum data set for postnatal discharge summaries in order to facilitate sharing of relevant information from Maternity Hospitals to Community care professionals.

- To examine the information requirement of the major stakeholders of maternity care in a postnatal discharge summary in Ireland.

1.6 Research Objectives

Objectives of this research are,

1. To find the frequently used information content in postnatal discharge summaries in Ireland and to identify the content and format difference in postnatal discharge summaries in different maternity hospitals in Ireland.
2. To identify the existing data sets available in Ireland for postnatal discharge summary.
3. To identify the postnatal discharge summary related maternity data sets available in data dictionaries in Ireland in order to report the data sets not available in data dictionaries.
4. To identify whether the new discharge summary data sets are in agreement with SNOMED clinical terminologies.

1.7 Outline of Research

This research study will include the following steps:

- Identification of information gap in the literature and need for development of minimum data set for postnatal discharge summaries.
- Perform a quantitative examination on the de-identified discharge summaries collected from all the maternity hospitals in Ireland.
- Identify the data sets in existence from the above analysis.
- Identify the minimum content requirement in a postnatal discharge summary from literature review.
- Develop a draft discharge summary for postnatal discharge summaries.
- Develop a questionnaire to get consultation feed back from the participants.
- Validate the questionnaire tool by undertaking *Informal test* and *Pilot study.*
- Refine the draft discharge summary and questionnaire after pilot study.

- Develop a semi-structured questionnaire to obtain stakeholders view on standardized maternity discharge summary.
- Obtain expert opinion and feedback from major stakeholders in maternity care.
- Assess the information requirement of the major stakeholders in maternity care
- Perform necessary qualitative and quantitative analysis on the feedback.
- Develop a minimum data set for postnatal discharge summary.
- Identify the clinical terminologies not present in the data dictionary in Ireland.
- Locate the clinical terminologies in the new discharge summary in SNOMED-CT.

1.8 Outline of Dissertation

Table 2 Outline of dissertation

Chapters	**Contents**
Glossary	Explanation of terms used
List of Abbreviations	List of Abbreviations
Chapter 1 Introduction	Background and significance of the study Motivation Research question Research aims and objectives Outline of research and dissertation
Chapter 2 Literature Review	Postnatal discharge summary and minimum data set – definitions Maternity care in Ireland & Difference between a generic discharge summary and maternity discharge summary

	Complexity of maternity health record and issues for discharge summary & Contents of Discharge summary Discharge summary guidelines in Ireland Legal requirements for Data management in Ireland Implications of discharge summary & Challenges of discharge summaries European & International initiatives in discharge summary Electronic Discharge summary (EDS) Health Information Technology (HIT) & Interoperability Minimum data set (MDS) Privacy, Confidentiality and Security SNOMED-CT
Chapter 3 Methodology	Research Approach Research Designs - justification and chellenges Research Methodology - phase 1, phase2, phase3 & phase 4 Minimum Data Set Development Process - rationale and steps in minimum data se development Sampling - recruitment method, inclusion & exclusion criteria and sample size Data Collection Methods - collecting discharge summary, tool development, questionnaire and pilot study

	Data analysis Ethical consideration
Chapter 4A Result (1) Collation of discharge summaries from 15 maternity hospitals in Ireland	Type of participant maternity hospital Type of discharge summary Format & frequently used information Contents of discharge summary
Chapter 4B Result (2) Survey findings	Development Of Minimum Data Set Information requirement of GPs, PHNs, Midwives, Consultant Obstetricians about mother & baby in a postnatal discharge summary Questionnaire
Chapter 5A Discussion (1) on discharge summaries from 15 maternity hospitals in Ireland	Discharge summary Contents of Discharge summary Maternity data set Future work

Chapter 5B Discussion (2) Stakeholders view	Minimum data set for postnatal discharge summaries Information requirement of GPs, PHNs, Consultant Obstetrician and Midwives about mother in a postnatal discharge summary Questionnaire
Chapter 5C Discussion (3) Context and Implications	Data Dictionary and SNOMED – CT Achievement of aims and objectives Recommendations Study Implication and Limitations Future works and Reflection
Chapter 6 Summary and Conclusion	Summary and Conclusion

1.9 Summary

Inability to provide enough information in a maternity discharge summary jeopardizes the continuity of care for mother and baby. Although the national standard for discharge summaries may appear to resolve the problem, it does not meet the informational requirement for a clinical specialty such as maternity care. Therefore, developing a minimum data set for a discharge summary is going to meet the information requirements of the major stakeholders in maternity care in Ireland. Chapter 1 described the background, research question, motivation, aims & objectives, and outline of the research study. Next chapter will review relevant literature related to this research.

Chapter 2 Literature Review

2.1 Introduction

The transition from “maternity care to child and family health care services” is acknowledged by national and international guidelines and strategies. The postnatal period marks the establishment of a new level of family life for women, their partners, and the beginning of the lifelong health record for newborn babies. NICE (2014) guidelines recommend that there is an expectation that postnatal health services will be delivered with the full participation of the women acknowledging the role of the primary care team in clinical care, informational and education support of the family. To compare the Irish model of postnatal care, consisting of routine home visits with a PHN using non standardised postnatal discharge summaries with the UK model of postnatal midwifery care, consisting of routine home visits for 7- 10 days using hand held maternity records raises a real concern. This highlights the need for high quality postnatal discharge summaries in order to bridge the information gap.

In this chapter, an in depth literature review is discussed. The literature search covers from the period from 1999 to 2015. A study from 1975 is also included which demonstrates the depth of the problem. The studies from such a long time period has been included to demonstrate the progression in information requirement in this area over the past two decades. Quantitative, qualitative and mixed method studies are used in this literature review. The search was extended to include all types of studies, as the topic of development of **minimum data** set for **postnatal discharge** summaries does not lend itself to many results. The core sections of this literature review are

1.Discharge Summary

2.Minimum Data Set

The following key areas were examined.

Discharge Summary

- Postnatal discharge summary & minimum data set development – definitions
- Maternity care in Ireland
- Complexity of maternity health record and issues for discharge summary
- Contents of discharge summary
- Discharge summary guidelines in Ireland
- Implications of discharge summary
- Challenges of discharge summary
- Discharge summaries across Europe
- Electronic discharge summary
- Health information technology, interoperability, discharge summary and minimum data set

Minimum Data Set

- Definition and meaning
- Principles of minimum data set development
- Benefits of minimum data set
- Procss of developing minimum data set
- Legal requirements in Ireland for data management
- Privacy and confidentiality
- SNOMED – CT

2.2 Postnatal Discharge Summary and Minimum Data Set: Definitions

*A **Discharge summary** is a "collection of information about events during care by a provider or organisations. Its purpose is to provide/share both clinical and administrative information about the patient's hospital stay such that the health care provider in the community can maintain continuity of care"* (Interim Australian Standard–Implementation of HL7 Version 2.4 Part 6:Referrals, Discharge and health record messaging 2007, p. 43).

HIQA (National standard for discharge summaries 2013[1], p.9) defines a ***discharge summary***, *as "information required in a generic clinical discharge summary produced at the time of discharge from a secondary care or tertiary care"*.

Maternity care refers to the care given to the mum and the baby throughout pregnancy, birth and up to six weeks after the birth (NICE, 2014). ***Postnatal care*** is the basic care; a woman and her baby should receive appropriate to their needs, during the 6 weeks after the birth, based upon the best evidence available (NICE, 2014).

Postnatal discharge summaries communicate information necessary for continuing patient care of the mother and baby after delivery.

A data set "is a set of data that is collected for a specific purpose". ***Minimum data set* (MDS)** is "the name given to a selective core of *data standard* identified by user and stakeholders as minimum for collection for specific purpose" (AIHW, 2007- A guide to data development p-13). MDS will not preclude the collection of additional data to meet individual agency or local need. ***Data standard*** describes the agreed meaning of the term and acceptable representation of data for use within a defined context (MacArthur, 2002).

2.3 Maternity Care in Ireland

The Model of maternity care in Ireland is constructed on the National Maternity and Infant care scheme, dating back to 1953, whereby the mother and the baby receive care during antenatal and postnatal period. It is delivered in the form of eight assessments with a General Practitioner, mostly through a model of shared care with hospital maternity units. Following birth, the care is handed over to the community. PHN and General practitioners (GP) are the key health care personnel in the community to continue care and management following discharge (Begley, 2011). PHN will visit the mother and baby at home and will provide advice, information, and guidance in relation to the care of mother and baby (Glavin & Leahy-Warren, 2013). They also carry out assessments and follow the developmental progress of the baby. It is essential that complete, relevant, reliable, and valid information about mother and baby should be sent to the primary care health professional in a timely manner. This will allow the primary care team to provide care following discharge.

2.4 Difference between a Generic Discharge Summary and Maternity Discharge Summary

HIQA (2013[1]) defines discharge summaries, as “information required in a generic clinical discharge summary produced at the time of discharge from a secondary care or tertiary care”. The contents of this standard are related to demographic details, primary health care professional’s details, admission discharge details, clinical narrative, medications, and follow-ups. In maternity services, the discharge summaries provide information about antenatal, labour and postnatal events (Wray & Bick, 2012) The maternity care starts with preconception care and ends 6 weeks after birth (NICE, 2014). A discharge summary should be a conceptual form of this period in order to provide continuous care and support by the primary care team. Sandall et al (2013) stresses that there is a need for greater continuity of care in the community for mothers and babies, and the roles of the GP and the PHN need to be supported in order to maximize the provision of quality services. Therefore, an accurate documentation of antenatal care, intranatal incidents, and immediate postnatal events in a summary should be handed over to the primary care team. Compared to a general hospital discharge summary, a maternity care summary is the combined report of multiple clinic visits and inpatient visits.

Having a baby is the single largest reason for admission to the hospital in a maternity care setting. The experience families have during pregnancy, and postnatally often colour their long-term health and wellbeing and their use of health services (NHS, 2012). Maternity services are unique: it cannot be demand managed and activity cannot be controlled through referrals.

The fundamental biological and social characteristics of mothers and babies are different to that of patients admitted to a general hospital. As per, the 2012 Irish Perinatal Statistics report (2013), the average mothers postnatal length of stay was from 6 hours to 2 days or less following spontaneous delivery in 78% of singleton births. The complexity of the information increases when the dynamic labour and delivery (of baby) process completes. This demands the inclusion of extensive information about the biophysical outcomes of birth. Information such as birth weight, length, head circumferences etc. are important biophysical measurements. Also discharge summaries should ensure that information can be shared effectively and efficiently to protect the privacy and confidentiality of the mother and the baby. A maternity discharge summary comprises discharge summaries of two individuals.

I. Discharge summary of Mother
II. Discharge summary of Baby

Even though there are two parts, they are interlinked. Discharge summaries share some common information about both mum and baby. For example, the GP should be aware of the mother’s antenatal, intranatal and postnatal events in order to carry out a two weeks infant check. The baby discharge sheet also includes information on type of delivery and gestation. Mothers discharge sheet includes information on postnatal checks and referrals for other supports.

2.5 Complexity of Maternity Health Record and Issues for Discharge Summary

The complexity of a maternity health record is that the mother registers to the hospital at booking visit with one maternity record and one unique hospital number and discharges from the hospital with two health care records - one for mother and one for baby, with two different hospital identification numbers. Then the question arises, what is the ideal time to produce the second record (baby record). No standards exist across maternity hospitals in Ireland in this regard. Therefore, different hospitals use different guidelines in producing and exercising the infant charts (HSE, 2013). Some maternity hospitals create an infant chart only if the baby is admitted to the neonatal unit. Another area of concern is linking the two health care records. Both records should identify each other in order to identify the mother and her baby.

2.6 Contents of Discharge Summary

The discharge summaries are vehicles used to carry the information on the details of patient's hospital stay to the primary care team. The Joint commission, USA (2009) has established standards for the following components of the discharge summary **-** reason for hospitalisation, significant findings, procedures and treatment provided, patient discharge condition, patient and family instruction (as appropriate) and attending physician's signature. In Australia, the National E-Health Transition Authority's (NEHTA) Discharge summary (2010, version 2.1) has the same components except that NEHTA's discharge summary requires information to be provided in broad categories of events with additional reports and documents to be included in the summary. Studies show that, there are various viewpoints on what is considered most important in a discharge summary. Studies in late 1990s (Crosswhite et al, 1997; Archbold et al 1998; Carey & Hall, 1999) agree that admission discharge details, initial diagnosis, information given to the patient, medication, investigation and follow up, are the **most important information** in a discharge summary. But Solomon (1995) *et al* and Adam (1996) et al choose diagnosis, drugs at discharge, investigations and follow up care as the most important information in a discharge summary. However, Kripalini *et al* (2007) and O'Leary (2006) argue that **highly ranked items** in terms of importance in a discharge summary are,

- Primary and secondary diagnosis
- Pertinent medical history and physical findings
- Dates of hospitalization, treatment provided & brief hospital course
- Result of procedures and abnormal laboratory test results
- Recommendations by any subspecialty consultant
- Information given to the patient and the family
- The patient's condition and functional status at discharge
- Reconciled discharge medication regime with reasons for any changes and indications for newly prescribed medications.
- Details of follow up and specific follow up needs, including appointments or procedures to be scheduled and tests pending at discharge

This is consistent with the HIQA (2013[1]) National standard for discharge summary information. A number of studies looked into how to improve the quality of discharge summaries. A survey on hospital and community care physicians by Walraven and Rokesh (1999) to identify the core essentials of high quality discharge summary, showed that high quality discharge summaries were short, contained appropriate information and were delivered quickly.

The literature on the topic of content of maternity discharge summary is very scant. The published pioneer study on content of postnatal discharge summary was conducted in Australia by Jenkinson et al (2014). This review on "Maternity Services and Discharge Process: A Review of Practices in Queensland", concluded that commonly incorporated information in a mother's discharge summary included personal identification details, biophysical information and feeding information. Details on the content of discharge summary details of this study are given below in table 3.

Table 3 Contents of postnatal discharge summary

Item	Information	Universally included	Frequently included	Rarely included
Mother	Personal Information	Name Hospital Number Contact information		Cultural Background Interpreter service Destination upon discharge
	Biophysical Information	Induction/Augmentation of Labour Type of Birth Pain relief Estimated Blood Loss Perineal Trauma	Blood Group Administration of Anti – D Latest Hb	
	Psychosocial Information		Edinburgh Postnatal Depression Scale	Alternative temporary contacts available Domestic violence External family & other support Substance Abuse Other stress factors
	Other Information			Support services used in hospital Serology status BMI GTT requirement

				Post discharge health care Written information given
Baby	Personal Information	Hospital Number Sex Date and time of Birth		Name Cultural Background
	Biophysical Information	Birth Weight Length Head circumference Apgar `score	Outcome of routine Screening tests Date of routine newborn screening	Information relevant for sick baby Physical examination Sensitive information about perinatal death

(*Adapted from Jenken B.,Young K & Kruske S.Maternity services and discharge process:A review of practice in Queensland. Women and Birth 27,114 – 120*).

Combinations of qualitative and quantitative studies are explored to identify the content specification for both general and maternity discharge summaries. Most of the studies looked into the problems of discharges summaries. Studies looking into the content and recommendations for further improvements are very scarce in literature. The scarcity in maternity discharge summary may be due to,

- American countries have long hospital inpatient stay for mother and baby and follow up services are arranged by the hospitals.
- Other European countries have Midwifery Led Models of maternity care ensuring good postnatal care support by the community midwifery team
- The Hand held midwifery patient records gives full access to the mothers records at point of care

2.7 Discharge Summary Guidelines in Ireland

The Health Information and Quality Authority (HIQA) is the independent Authority established to drive continuous improvement in Ireland’s health and personal care services. Under Section (8)(1)(k) of the Health Act 2007, the authority has the responsibility for setting standards or all aspect of health Information and monitoring compliance with those standards. The main discharge summary standard in Ireland is,

- *HIQA (2013[1]) National Standard for Patient Discharge Summary Information.*

The other national guidelines to help developing discharge summary standard includes,

- *HIQA (2013[3]) National Standard Demographic Data set and Guidance for Use in Health and Social Care Settings in Ireland Version 1.0*
- *HIQA (2013[2]) Guiding Principles for National Health and Social Care Data Collection*
- *HIQA (2012) What You Should Know About Data Quality-A guide for health and social care staff*
- *HIQA (2014) Recommendations regarding the adoption of SNOMED Clinical terminology for Ireland*

“Delivering eHealth Ireland – Office of the chief Information officer”, published three new documents (after this study has been finished) throws light on the need for standard requirement electronic patient record and integrating different organisational records at National Level. These documents includes,

1. HSE Design Authority (2015[1]) – ISF Program ICT Asset base Work stream 2.4-Standards Catalogue.
2. HSE Design Authority (2015[2])– ISF Program ICT Asset base Work stream 2.4-Asset Classification Model.

3. HSE Design Authority (2015[3]) – ISF Program ICT Asset base Work stream 2.2- Application & Technological “T Be” Logical Architecture

2.8 Legal Requirements for Data Management in Ireland

HIQA (2013[3]) recommends that each organisation should ensure that standardised procedures for data collection are in place. Each professional has the legal, ethical and professional obligation to ensure data quality. The legislative acts pertaining to this are listed in table 4.

Table 4 Legal requirements for Data management in Ireland

No	Legislative Acts
1	Data Protection Act 1988, Data Protection Acts Amendments (2003) and subsequent regulations
2	Data Protection (Access Modification) (Health) Regulation 1989
3	Freedom Of Information Act 1997 and 2003 and subsequent regulations
4	Health (Provision of Information) Act, 1997
5	Health Act 2007
6	Health Information Bill 2014

European Statistics Code of Practice (2011) is relevant to all collections and reporting of National statistical data to the Department of Health for submission to Eurostat.

2.9 Implications of Discharge Summary

Discharge summaries are multipurpose documents and serve to provide summary data, which clinical coders rely upon in the data process of clinical classification (Craig, et al 2007). They are vital documents for medical legal cases, financial and administrative functions and they have long been the mainstay in the communication process between hospitals and the primary care team.

A discharge summary provides a full picture of patient's inpatient stay, including patient details, admission and discharge details, medication details and treatment plan. Despite the role in providing continuity of care, discharge summaries have great role in epidemiological tracking, service planning and research. High quality discharge summaries promote patient safety by communicating relevant, accurate and correct information and avoiding medication related inaccuracies. It ensures consistency in treatment provided in hospital and community (Yemm et al, 2014).

2.10 Challenges of Discharge Summaries

Poor communication between hospitals and the community has been recognized in the literature for many years (Tulloch et al, 1975) and continues to be a problem all over the world (Van Walraven & Rokosh, 1999; Kripalani et al, 2007). Discharge summaries are a fundamental communication tool that warrants safe and on-going management of patients conditions. A number of studies looked into how to improve the quality of discharge summaries.

A literature review by the Australian Commission On Safety And Quality In Health Care (2010) on electronic discharge summaries identified key problems of discharge summaries were delay in communication, omission of important information and inclusion of inaccurate information. These concerns are well documented in literature. In a study of communication and information transfer between hospital base and primary care physicians, Kripalini *et al* (2007) identified that the availability of a discharge summary at the first visit after discharge to the GP was low (12 – 20%). They also identified important information missed in discharge summaries, which is included in the table 5 below.

Table 5 Missed information in discharge summary

Type of information missing	Missing the information (%)
Diagnostic test results	63%
Treatment or hospital course	7- 22%
Discharge medication	2 - 40%
Test result pending at discharge	65%
Patient family counselling	90-92%
Follow up plans	2-43%

Adapted from *Kripalani et al (2007) 'Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care', JAMA, vol. 8, p. 836.*

Low quality discharge summaries can be a principal reason for poor communication and cause negative consequences for patients. According to Forster et al (2008), the leading causes of preventable or ameliorable adverse events are due to the poor communication between hospitals and the primary care team.

McMillan et al (2006) reviewed 100 discharge summaries and identified 222 medication errors. Out of 222 medication errors 13% were potentially harmful and could have caused readmission. Another evaluation study done on 622 discharge summaries in (Perren, et al 2008) revealed that drug omissions affected 40% of patients, 32% which were considered to be potentially harmful. Out of all the drugs included in the discharge summaries, 17% of medications given were to be unjustified and of these unjustified medications, 165 medications were considered to be potentially harmful (Mcmillan et al, 2006). Between 30 and 70% of patients have an error or an unintentional change to their medication when they are discharged from one health care facility to another (NICE, 2008).

Discharge summaries should reach the GP before the patient visits for the follow up visit with GP. Greater risk of readmission due to inadequate monitoring and wrong decision-making is also documented when the GPs treated the patients before the discharge summary reaches them. (Walraven et al, (2002). Other problems associated with uncoordinated, and incomplete discharge summaries are (Russell et al, 2013),

- Increased mortality (O'Brien, 2006).
- Increased morbidity (Wong et al, 2008; Scott, 2010).
- Increased adverse events such as falls, infection, & medication problems (Bywood, et al, 2011).
- Delays in treatment or medication supply issues (Mcdonald, 2007; Elliot, et al 2012).
- Additional primary health care or emergency department visits (Mcdonald, 2007; Wong 2008).
- Additional or Duplicate tests (Wong, 2008; Gobel, *et al* 2012).
- Preventable readmission to hospitals (AIHW, 2012; Rothwell, 2011).
- Additional Costs –No studies looked into the additional cost due to poor clinical hand over. But the direct hospital costs of adverse events were estimated in the quantity of Australian Health Care Study as $900 million per year. (Rigby, et al 2002, Richardson & McKie, 2007).
- Emotional and physical suffering - A few studies looked into the family experiences of poor discharge handover between primary and secondary care. But no studies quantified the pain and suffering. (Wong, et al 2008, Bywood, *et. al* 2011).

- Dissatisfaction of patients – 18 % of the respondents felt that time had been wasted because their care was poorly organized after discharge (Schoen, et al 2008, Wong et al, 2008).

This literature review shows that no standardised definition for discharge summary quality is available and no guidelines available to measure the quality of discharge summaries produced. Therefore, different studies adopted diverse methods to evaluate discharge summaries. Also, a suboptimal information transfer system is currently in use to transfer accurate, reliable, valid, timely, legible, and complete patient discharge information data.

The lack of uniformity in discharge summary may be due to the fact that each doctor completes the discharge summary differently. In an attempt to endorse solutions for the identified problems, some studies recommended that discharge summary must contain minimum data set (Stainkey et al, 2010). Too often the research suggests that summaries contain insufficient and unnecessary information and fail to reach the primary care team in time for the follow up visit (Louden, 2009). The reason is that every physician does a discharge summary differently. It is concluded that the problems of discharge summaries are related to unavailability of the discharge summary at right time, incomplete and inaccurate information in the discharge summary, compiling discharge summary by inexperienced authors, and lack of timeliness and quality.

2.11 European & International Initiatives in Discharge Summary:

There are a number of clinical handover programmes to enhance hand over or to reduce readmissions that are implemented internationally and across Europe. In UK, the Royal College of Physicians initiated a project to improve the transfer of medication information and developed standardised data set for discharge summary with templates, a patient fact sheet and an organisational system to support safe transfer of information. The key information are generated by Royal College of

Physicians, and Royal Pharmaceutical Society NHS 2012 (Russell et al 2013) issues further updates.

In Scotland, the Scottish Safety Program is working with GP Surgeries to identify the key risk areas on patient journey across health care organisations. This program mainly addressed medicinal reconciliation and discharge communication between primary care and hospital outpatients. It ensures that discharge summaries are entered into the practice workflow on day of receipt and medicines reconciliation occurs with in 2 working days. It also ensured that changes to the medications are discussed with patient and their relatives (Health Improvement Scotland - Safety improvement in primary care final report -2011).

In United States, A number of projects carried out to improve the transition care of patient from secondary to primary care after the report of Institute of Management (IOM, 1999). None of the programmes had handover at transfer of care as between care settings as a programme theme. One example is the Care Transition Program in which patients with complex care needs are supported by a transition coach. In Colorado, this program reduced 30-day hospital readmission by 30% and reduced cost by nearly 20% (Coleman et al, 2007). Another initiative was launched in 2011 called Community based Care Transition Programme (CCTP) to improve transitions from inpatient hospital to other care settings to reduce readmissions (Logue). The annual report in 2013 shows significant reduction in readmission, the generalizability of this report is questionable as it is too early to evaluate as the programme run for 5 years (CCTP 2014).

In Australia, the ACSQHC (Australian Commission on Safety and Quality in Health Care, 2009) developed standards to ensure timely, relevant and structured clinical handover. The Standard No. Six 6 developed by the National Safety and Quality Health Service focuses on clinical standard. The ACSQHC developed a number of resources including OSSIE guide to clinical handover (ACSQHC 2010), Electronic resource portal for Clinical handover and Electronic Discharge summary system Self-evaluation tool kit.

Australian Common Wealth Government and States/Territory Government initiatives aimed to improve the communication between primary and secondary/tertiary care. The New South Wales Clinical Handover Programme achieved best practice in hospital to GP clinical handover by building a patient centred shared care culture. This programme engaged patients and cares in the clinical handover process to standardise the two-way exchange of clinical information between primary and secondary care (Russell, 2013).

In Europe, the “HANDOVER” project was initiated by the European Union in 2008 to optimise the continuum of clinical care between primary care and hospital to reduce unnecessary treatment, medical errors and avoidable harm. The objectives of this programme were to identify the best practices, create standardised approaches to hand over and to measure the cost effectiveness (Philibert & Barrack, 2012). It concluded that each European country has its own distinct health care delivery system to improve the quality and safety of handover practice between primary and secondary care. It also found that it lacks patient centeredness and empowerment.

An exploratory analysis of hospital discharge summaries across Europe, done by Glonti et al (2013) concludes that there are no standardised discharge summaries or guidelines present in European Union (EU). Some countries have proposed methods to standardise national discharge summaries (Poland and Lithuania) either through minimum data set requirement (Spain & Scotland), standard electronic discharge summaries (Denmark), standard structures and content headings (England), or standards issued by hospital accreditation bodies (France & Finland) (Glonti et al, 2013). They identified that, there is wide variation in quality especially, contents of discharge summary across and within EU countries. Lack of disease classification such as International Classification of Diseases (ICD – 10), incomplete information on medication and lab results, and inadequate details of treating clinicians are identified as key problems of discharge summaries across countries which are important factors for continuity of care.

The author asserts that the European hospital discharge summary engenders insufficient support for follow up care when a patient returns to their home country (Glonti et al, 2013). The discharge summary guidance available in seven EU Member States was compared in this study, and there was agreement on a core set of categories that should be included, but when comparing actual discharge summary templates from 15 countries, wide variations existed in the categories of information included and the grouping of data sets are not well represented to provide continuity of care. These findings were also reflected in a systematic review of the contents of discharge summaries, which resulted in the suggested minimal data requirement for a harmonised discharge summary across Europe (Glonti Et Al, 2013)

The '*European Observatory on Health System and Policies*' supports and promotes the "evidence based health policy making in Europe". The policy summary (No. 14) on "Cross–border health care in Europe"(Footman, et al 2014) states that discharges from hospital and follow up care have been found to be the weakest points of cross border care. The European Patient Smart Open Services (epSOS)" developed patient summary for cross border use in European Country.

The ***Guideline On Minimum/Non-Exhaustive Patient Summary Data Set For Electronic Exchange In Accordance With Cross-Border Directive 2011/24/EU (eHealth network adopted in 2013)*** summarised the data sets required in a discharge summary in order to improve the cross border care for emergency and unplanned events. It provides the health care professional with a data set of essential and comprehensible information at the point of care. While abroad if a person requires medical care the epSOS patient summary can be used. It's a clinical document with medical and legal value to assure continuity of care in unexpected or emergency situations. The physician can request it after patient authorization. The content of epSOS patient summary consist of Basic Mandatory section and Extended optional sections as stated below in the table 6

Table 6 epSOS Minimum data set for patient discharge summary

No.	Basic mandatory information	Extended optional section*
1.	Header information to identify the patient, date and document creator, signature	Insurance information, contact information
2	Allergies and medical alert	Vaccines
3	Active problems	Resolved problems
4	Recent surgical procedures	Surgical procedures not older than 6 months
5	List of current medicines	Treatment recommendation
6	Medical device and implants	Social history – smoking, alcohol.
7	Allergies and medical alert	Pregnancy /Date of expected delivery
8		Physical findings…. Vital signs
9		Diagnostic tests

*Extended sections can be omitted if it is not relevant.

The ***Trillium project*** by the European Union aims to deliver a transatlantic exchange of patient summaries. The ***Blue Button + initiative*** started in 2010 with US Department of Veterans Affairs allowing patients to download their medical records in standard format. Estelrich *et al* (2014) compared the European patient summary and continuity care documents (U.S) and concluded that even though the same base standards are used, structural and terminology differences challenge the exchange of information among systems. They also suggest that strategies need to be developed that allows sharing of interoperability assets that are quality assured, combined and elaborated.

2.12 Electronic Discharge Summary

Traditionally the discharge summaries are created either handwritten or dictated. Over time, in an attempt to improve the discharge summaries, structured formats were introduced. Further endeavour to improve the quality of discharge summary, computer generated summaries have been developed. Recent advances in Health Information Technology (HIT) enabled the integration of administrative and clinical hospital information systems, to provide patient data for Electronic Discharge Summary (EDS).

The EDS were ideal in respect of comprehensiveness, clarity, timeliness, and quality information on continuity of care (Reinke et al, 2014). A greater improvement in timeliness is reported with the majority of them completed on the day or day before discharge. Other benefit of the EDS is the ability to edit and capture information from multiple providers through out the course of hospitalization (Reinke, 2014). However, Callen et al (2010) who conducted an evaluation of documentation in electronic discharge summary concluded that it is debatable whether the electronic summaries are higher quality than the handwritten discharge summary. Conversely, he suggests that the free text area for summary of patient progress was more likely to be omitted in handwritten discharge summaries resulting in incomplete information.

2.13 Health Information Technology & Interoperability

The role of Health Information Technology in improving quality, safety, and efficiency of health care is well documented (Shekelle, 2005, Walker, 2005). The advanced use of HIT makes the uniform availability of comparable and combatable data across the healthcare organisation by capturing and re-using the data collected at the point of care. Postnatal discharge summaries in maternity settings are the concise report of the antenatal, intranatal and postnatal events. The information should be made available across the organisations to provide continuity of care for the mother and baby. Therefore, the technology that generates and transfers maternity discharge summaries should be interoperable and should maintain the privacy and security of the information it transmits.

Transforming Maternity care – 2020 (Angood, 2010) recommends the development and use of Health Information Technology to improve the maternity care services across the U.S.A valid suggestion includes increasing the **interoperability** across all the settings of maternity care by creating a core set of standardised data elements for maternity care records. The Institute of Electrical and Electronics Engineers (IEEE, 2012) defines interoperability as ability of two or more systems or components to exchange information and to use the information that has been exchanged. The main goal of interoperability is to exchange information between systems.

This involves common understanding of the information being exchanged. The outcome of this common understanding leads to standardisation of information, in other words also called data standards. The Electronic Health Record (EHR) interoperability addresses the standardization in four layers: - content, structure, technological and organisational (Tolk et al, 2009). The content level addresses the coding and uses nationally and internationally accepted clinical terminologies. Therefore, discharge summary should use data standards in order to follow the content interoperability standards. According to Kalra (2006), state of art clinical terminology standards is not available as preservation of clinical terminology across heterogeneous systems is extremely difficult. SNOMED – CT is an example for clinical terminology standard.

The U.K, introduced an interoperability tool kit (ITK) to support interoperability. ITK is a set of common specifications, frameworks and implementation guide to support interoperability across health and social organisations (HSCIC 2012). The ITK benefited by reducing the cost on expenditure on local system integration by standardizing the technology and interoperability standards.

Antilope is a European initiative for interoperability by defining eHealth standards and specification and by certifying eHealth solutions and services in Europe (HSE Design Authority 2015[1]).

2.14 Minimum Data Set

A data set “is a set of data that is collected for a specific purpose and minimum data set (MDS) is the core data identified as the minimum required for that purpose” (AIHW 2007,HIQA 2013[1]). Data standards describe the agreed meaning and acceptable representation of data for use within a defined context. The benefit of the agreed data standard is that it will enable data from different sources, organisations or systems to be exchanged and compared in a meaningful way. It also helps to improve the quality by minimizing the effects of human factors through reducing and simplifying the steps in the reporting process as well as providing strong prompts to users to include certain type of information.

Health care standards aim to improve the quality of patient care, improve safety, and reduce adverse events and errors (HIQA, 2012) The National E- Health Transition Authority (2006) recommends using standardised clinical language to improve the communication between the health sectors. Strong advocacy to develop minimum data sets for collection and dissemination of information are observed in literature (Chea, et al 2005;Pagliary et al, 2004). Also, distinguishable research supports is identified to use discharge summary templates for the completion of electronic discharge summaries to promote the standardisation and consistency.

Standardisation will improve the user acceptance by saving time and increasing the quality of discharge summary. Quin *et al* (2009) conducted an evaluation on the accessibility of standardised clinical hand over tools at four Victorian health care services. The participants in this project considered that the clinical handover template containing the minimum data set was a useful foundation, which could be customised for individual organisations.

Where as in Scotland, the Scottish Immediate Discharge document corroborates that the deficit in content, structure and production of the discharge summary can be addressed by the minimum data set (Scottish Intercollegiate Guideline Network, 2008). The data set for the immediate discharge summary permits the production of a single discharge document for the maximum number of patients and serves as the template for the discharge summaries. Discharge summaries have an important role in bridging the communication gap between primary care and secondary or tertiary care. The importance of the minimum data set is that it will be the basis for system specification with a view to electronic data transfer. A minimum data set should be evidence based and should include all those items seen as essential.

2.15 Benefits of the Minimum Data Sets for Discharge Summary

The concept of minimum data sets garnered significant attention from health care professionals over the last few years due to the advancement in HIT and clinical terminologies (Bean, 2005; Butler 2006,Paleses *et al*, 2013). Compared to narrative discharge summaries, the use of minimum data sets is ideal for its completeness, readability, conciseness and ease of locating key information. This structured format for discharge summaries can be easily produced by computer systems. Studies shows that GP's prefer a structured discharge document rather than one with a narrative format (Kripalini et al2007). The Australian National Maternity Data development project (AIHW, 2014) identified the need for a nationally agreed, consistent, and standardised minimum data set that could provide an evidence-based platform upon which a national benchmarking programme for maternity services could be built. For ease of description, the benefits are listed under subheadings.

2.15.1 Benefits for People

A standardised minimum data set will increase efficiency and safety, as there will be clear understanding of what each data elements mean. It also improves the accuracy in the recording and interpretation of the data allowing for safe communication. It will remove the repetitions and will reduce the administrative cost and time waste thus increasing the clinical utilisation of time and money (Rahaman 2014). Using the same demographic and clinical data sets across the organisation prevents the recitation of personal and general health related information by the patient and health care profession. It will provide an accurate analysis of demands and health need of the mother and baby.

2.15.2 Benefit for the Primary Care Team

Obtaining a high quality discharge summary by using minimum data set can provide safe and better continuity of care. It will save cost and time by preventing duplication of testing/prescribing and reducing identification errors (HIQA 2013[1]). Minimum data set will act as a base platform for information system and will allow information flow between different systems faster, therefore reducing administrative tasks (Ahmadi 2015).

2.15.3 Benefits for the Hospitals

The main benefit of the minimum data set is that it will improve the communication flow to the community thus improving the accountability. Transferring complete and accurate information improves the critical clinical decision and will decrease the hospital readmission (Butler 2006).

2.15.4 Other Benefits

Minimum Data sets guarantee the consistency and comparability of content and definition of the data. A minimum data set with internationally agreed clinical terminologies helps consistent retrieval of clinical information and is beneficial for a wide variety of purposes such as decision support, audit, epidemiology, research, service management, billing and policy making (Sermeus, 2005). Moreover, using the minimum data set will help to have comparable data available at local, national, and international level (Saliba, 2012). Another important use is in conducting comparative research on patient care, interventions, outcome, and referral services.

2.16 Principles of Minimum Data Set Development

According to Australian Institute of Heath and Welfare (AIHW 2007), the principles of data set developments and national data standards are;

- ***Creating data standards are part of data set development***

Data standards increase the quality, consistency and comparability of data. Therefore, development of data standards should follow the operational procedures.

- ***National and international standards should be used wherever available and applicable***

Data sets should be based on a single set of *agreed definitions* and standards to ensure a higher degree of consistency and reducing data development time and cost.

- ***Data sets should serve the purpose and objectives of data collection***

The purpose of the data collection should be clearly defined before developing standards to help to deliver more efficient and effective services. Once the purposes of the data sets are defined, the collecting data set should meet the objectives to help to reduce the cost of developing, collecting, validating, and reporting the data.

- ***Create once, use often***

The important principle of data development is that the collected primary data set should support secondary use of information such as reporting, policy & governance development, research and statistical/computing purposes.

- ***Acknowledge the limitations of data***

Some data that is suitable for some purposes may have limited use for other purposes. For example, reason for admission will be very suitable for general hospitals but may not be adequate for maternity settings.

- ***Data development is system independent***

The data sets should be well defined and standardised and data development should not be limited by the potentials of any particular system.

- ***Data development should be in compliance with privacy and security policies and should also be in compliance with the relevant legislation and standards.***
- **The responsible person must be aware of and adhere to the appropriate national, international, general and health specific legislation.**
- ***Data development should minimise the collectors burden.***

- ***Data development should reflect practice.***

The data should be relevant and meaningful. Data development must take into account the business needs, feasibility of data collection, scientific evidence and guidelines of the subject.

2.17 Process of Developing a Minimum Data Set

Minimum data sets are developed by many organisations to generate reliable and accurate information. The introduction of the Electronic Health Records demanded the need for capturing high quality data. In relation to the “create once, use often” objective of Information management, development of data sets and standards necessitated to follow nationally agreed guidelines and methodology to obtain high quality data (Svensson–Ranello et al 2011). Scant studies looked into developing a methodology for developing minimum data sets. A literature scan done by the researcher on the different approaches used by other researchers produced the following methodologies.

- Using hired consultants (Bean, 2005)
- Formation of experts or representatives (Ireland et al, 2001)
- Stake holder committee (Evans et al, 2010)
- Stake holder Interview (Evans et al, 2010)
- Distribution survey (Mistry et al, 2010)
- Delphi Technique (Bagley et al, 2010)
- Systematic literature Reviews, charts review and review of existing clinical Information system (Ireland et al, 2001)
- Clinical data collection tool (Chan et al, 2010)
-

Svensson–Ranello *et al* (2011) developed a framework and standardised methodology for developing a minimum data set and concluded that a multimodal method utilizing the patient record, a review of the literature and expert opinion is an ideal solution for minimum data set development. Australia, developed a framework for Specialist

Minimum data set for specific cancers in Clinical Cancer registration (Commonwealth of Australia, 2008).

International guidelines recommend that developers should use data dictionary definitions approved by the National Health Information Standards. The purpose of a data dictionary is to standardise the definitions for data items and to ensure consistency in collection of data. In UK, the NHS Data Model and Dictionary maintained by Health and social care `information Centre is the reference source for the data definitions. Australia's "National Health Data dictionary" is another example of a national data dictionary. The Data dictionaries in **Ireland** are,

- Hospital In-Patient Enquiry (HIPE) Data Dictionary (HIPE, 2015)
- Irish Coding standard (ICS - 2015) Version 7.0, 8th Edition ICD- 10-AM/ACHI/ACS (ICS, 2015)
- National Perinatal Reporting System Data Dictionary (NPRS, 2015)

HIPE is the health information system designed to collect demographic, clinical, and administrative information on discharges and deaths from acute hospitals nationally. HIPE uses coding classification.

> *"ICD – 10 AM (Australian Modification) is used in conjunction with the Australian classification of Health Interventions (ACHI), and Australian Coding Standards (ACS) to reflect an accurate health episode of care"(ICS, 2015; HIPE, 2015).*

The literature review on process for development of minimum data set shows further studies required developing a state of the art methodology. The current best available guide for minimum data set development is the publication by the Australian Institute of Health and welfare on "A guide to Data Development" (AIHW 2007).

2.18 Privacy, Confidentiality and Security

Privacy is defined as “the right of the individuals to keep information about themselves from being disclosed to others; the claim of individuals to be let alone, surveillance or interference from other individuals, organisations or the government” (Rognehaugh, 1999).

Confidentiality refers to a duty that a person owes to safe guard information that has been entrusted to him or her by another (Craig, et al 2007). In health care, the providers have legal and ethical responsibilities in maintaining confidentiality.

Security is defined as the extent to which personal information can be stored and transmitted, in such a manner, that access to the information is limited to authorized parties (Brander, 2003). It is the procedures and the systems used to restrict the access and maintain the integrity of information.

Any document containing clinical data pertaining to a patient should maintain privacy and confidentiality. When it takes measures to sustain privacy and confidentiality it conserves security. The security and privacy are related but the two concepts are different. But security safeguards are necessary to achieve privacy. Concerns about the privacy and confidentiality of electronic and paper format Discharge summaries are prevalent in Literature (Craig et al 2007). Uncontrolled secondary use of health information is one of the biggest threats for the privacy in health care records. However, Brander (2003) reports that the threats to privacy in e-health system are, insiders who cause accidental disclosure, insiders who abuse their record access privileges, insiders who knowingly access information for spite and profit and vengeful employees.

The discharge summary whether it is in handwritten or in electronic form, should keep the privacy, confidentiality and security principles. Paper format discharge summaries are kept in secure places to prevent access by unauthorized persons. Sending discharge summaries to primary care team is in the form of fax or post should ensure privacy and confidentiality. Electronic discharge summary applications should provide a stakeholder with only the data needed in right time in secure manner. When the discharge summary is shared among health care providers, it should use Public key infrastructure using encrypting and strong authentication. Discharge summaries contain sensitive information about mother and baby. The security mechanism should deal with identification, authentication, authorization, access control, audit trial, accountability, encryption, digital signature, protection of remote access, and integrity of data.

Encrypting means that the health information cannot be read or understood by the person except by those who can decrypt with a key (Fernández-Alemán, 2013). Audit Trial is appraising the records against who accessed the information, what changes were made and when. Digital signatures ensure accountability. In Ireland, recent updates from “Delivering eHealth Ireland”, HSE Design Authority (2015 May) published “Standards Catalogue” to articulate the technical, data exchange and security standards and to provide a clear guide which outlines the most suitable standards for the present and near future.

2.19 SNOMED-CT

SNOMED CT is a “comprehensive clinical terminology that provides clinical content and expressively for clinical documentation and reporting. It can be used to code, retrieve, and analyse, clinical data” (International Health Terminology Standards Development Organisation, 2013).

SNOMED CT is currently used in more than fifty countries around the world. Currently in Ireland, healthcare associated data are fragmented and is located in unconnected silos by using different coding system. SNOMED CT is the most comprehensive clinical terminology currently available to improve the quality of clinical data in a patients record. The ability for cross mapping by linking with other terminology system makes the SNOMED system complimentary than other systems. Cross mapping with ICD-10 code helps to support epidemiological, statistical, and administrative reporting needs of the International Health Terminology standards. SNOMED CT will reduce the number of multiple requests for the same information, by facilitating meaningful sharing of information between health care providers. The benefits of using SNOMED clinical terminologies for developing contents of postnatal discharge summary will facilitate the exchange of high quality, consistent and meaningful information between health care practitioners. The other benefits are,

- Encoded clinical information in patient discharge summary enables computers to support subsequent pregnancies with clinical decision support by providing relevant information at the point of care.
- Searching and retrieval of clinical information from a reliably coded clinical data. It also helps the searcher to identify the missing data easily.
- The SNOMED clinical terminologies in a postnatal discharge summary will help the searcher to identify the mothers and babies eligible for certain screening programs such as Cervical Screening Program and patients at high risk of developing a disease. E.g. Mothers with Gestational Diabetes are high risk for developing diabetes in later life and requires close monitoring.
- Potential reduction of adverse reactions to the treatments and drugs due to better quality data and reporting.
- Completeness of the clinical data
- Key up-to-date data for each patient
- Enables sharing of data between the organisations
- Tracking patient progress using integrated tools
- Point of care support
- Medical Research
- Elimination of repeated data entry
- Cost effective and sharing of information
- Secondary use of the data such as quality improvement, service planning, research, and epidemiology are supported.

2.20 Summary

Maternity care involves the care of pregnant women through the transition into motherhood. Postnatal discharge summaries ease this transition by bridging the communication gap between secondary/tertiary healthcare facility and primary care team in the community. Although HIQA (2013[1]) developed *'National Standard for Discharge summary Information'*, unfortunately, these data sets are not sufficient enough to meet the informational requirement of the primary care team in specialties like Maternity care. Studies from 1975 till date show a literature gap in the quality content of discharge summaries in general and specialities of health care. National and International initiatives are reported to standardise discharge summaries leading to more exploration towards privacy, confidentiality security and interoperability of information exchange. However, scant attention was given to maternity care settings. Developing a minimum data set for postnatal discharge summary will bridge this information gap and utilizing the HIT will increase the accuracy, relevance and timeliness of reaching discharge summaries to the relevant health professionals. Next chapter (Chapter 3) will outline the research methodology in two separate sections. Section -1 will explain the methodology for developing a draft discharge summary in different phases and section 2 will explain the methodology for developing the minimum data set.

Chapter 3. Research Design & Methodology

Key Information

3.1 Introduction

3.2 Research approach is Pragmatism

3.3 Research design is mixed Method approach with Sequential Explanatory Research Design

3.4 Methodology section 1 consists of 4 phases

3.5 Methodology section 2 describes steps in Minimum Data set development process

3.6 Sampling method is Purposeful Stratified sampling with 4-stratum and sample size of 50

3.7 Data collection method primarily through questionnaire

3.8 Data analysis through descriptive statistics

3.9 Ethical Considerations

3.10 Summary

3.1 Introduction

HIQA(2013[1]) defines discharge summaries as "information required in a generic clinical discharge summary, produced at the time of discharge from a secondary care or tertiary care" (HIQA,*National standard for discharge summaries* 2013[1], p.9). A reliable maternity service depends on the accuracy and relevancy of information it produces and disseminated in right time across the multidisciplinary healthcare team with in hospital and community. The *National Standard for Discharge summary Information* (HIQA 2013[1]) aims to be a generic data set .The content of discharge summary in a clinical specialty will be different from a general discharge summary. Therefore, each specialty requires a discharge summary that has been individualised. Using data standards to develop a discharge summary guarantees that it can be shared across the multidisciplinary teams and health care organisations. However, to date, there is limited research looking into developing a discharge data standard for the maternity care setting. Moreover, there is a scarcity of policies and guidelines on a Minimum Data Set Development Process for clinical specialties. Any methodologies chosen to develop a minimum data set should follow a National or International Standard by using internationally accepted clinical terminologies. HIQA (2013^2) Guideline on "*Guidance on developing key performance indicators and minimum data Set to Monitor Healthcare Quality*" and HIQA (2013^1) "*National Standard Demographic Data Set And Guidance For Use In Health And Social Care Settings In Ireland*" are two contributive guidelines to develop data standards in Ireland. This research study will contribute by developing minimum data set for a postnatal discharge summary for mother and baby using data standards to assure interoperability.

This chapter discusses the research methodology and other key elements - research approach, research design, methodology, sampling, data collection, analysis and ethical consideration. A short literature review is included to justify the reason for choosing a pragmatic approach for this study. *(A mixed Method approach with Sequential Explanatory Research Design* is selected after thorough literature review. It includes both quantitative and qualitative methods). A detail of research design, its justification and expected challenges are described in section 3.3, to 3.3.3. In *Phase 1*, de-identified discharge summaries were collected from all maternity hospitals in Ireland. A *Quantitative analysis* is carried out to identify the contents of discharge summary and to recognize the existing data sets in use.

The result of this analysis leads to *Phase 2* of the study – development of a draft discharge summary (Appendix 2). ***Minimum Data Set Development Process*** is used to develop a draft minimum data set using national and international guidelines and recommendations. The minimum data set development process is described in section 3.5. In *Phase 3*, the draft discharge summary is circulated among the experts and major stakeholders in maternity care settings to obtain expert opinion and agreement on the content of the draft discharge summary. A qualitative analysis is carried out to reach consensus on the content of the discharge summary. In Phase 4, a semi-structured questionnaire will be used to collect information on the use of standard data set in discharge summaries across maternity hospitals.

A short literature review on sampling and data collection pertaining to this particular study is included in section 3.6 and 3.7. The expertise of consultant obstetricians ranging from Professors, Directors of maternity hospitals to lecturers in Obstetrics in Dublin also will be used for the collection of data for this study. Data Analysis and Ethical Consideration is shown under headings 3.8 and 3.9 at the end of this chapter.

3.2 Research Approach

The Researchers mainly utilizes three different approaches

- ***Positivism*** refers to the positive knowledge based on the natural phenomena and their properties and relations as verified by the empirical sciences (Creswell, 2013).
- ***Interpretivism*** is “associated with the philosophical position of idealism, and is used to group together diverse approaches, including social constructionism, phenomenology; approaches that reject the objectivist view that meaning resides within the world independently of consciousness”(Collins, 2010, p-38)
- ***Pragmatism*** is a research approach arising out of action, situation, and consequences. Instead of focusing on one particular methodology, researcher emphasis the research problem and use all methods available to understand the problem (Cresswell, 2013). Pragmatism believes that knowledge can be attained from different sources and theories. In this approach, the researcher chooses the methods, technique, and procedures of research that best meet its needs and purposes (Trochim, 2009). Pragmatists researchers look to the *why* and *how* to the research and will not see the world in an absolute unity. Thus, the researcher uses both quantitative and qualitative data to provide the understanding of a research problem.

After considering the different approaches discussed in section 3.2, this study will choose the pragmatic approach, in which a mixed methodology will be used to meet the objectives of this study. The health care context of this study and the need for multiple forms of health related knowledge including health informatics knowledge and critical constructionist knowledge indicates the suitability of this approach.

3.3 Research Designs

A research design is a "set of advance decisions that make up the master plan specifying the methods and procedures for collecting and analyzing the needed information"(Densecobe 2010). The three major research designs are

- ***Quantitative research:*** formal, objective, systematic process in which numerical data are used to establish the relationship between variables and statistical method to test the strength and significance of relationship (Burns & Grove 2005).
- ***Qualitative research:*** explores and understands the meaning of how an individual or a group ascribe to a problem in the form of opinion, reason or motivation.
- ***Mixed Method***: an enquiry that combines or associates with qualitative and quantitative forms. It utilises the philosophical assumptions of pragmatism and mixes the approaches of quantitative method and qualitative method. As it uses both approaches, the overall strength of the study will be greater than either qualitative or quantitative design (Creswell & Plano-Clark 2007).

Many terminologies such as integrating, synthesis, multi-method, mixed methodology, etc. are used to describe this methodology in the literature but recent researches use the term Mixed Method (Bryman, 2006). The first comprehensive review of the mixed methods was published in 2003 (Teddlie & (Tashakkori 2003). Researchers have been using different strategies to integrate quantitative and qualitative research. ***Sequential exploratory design*** uses qualitative analysis first followed by quantitative analysis. In ***Sequential Explanatory design*** the quantitative analysis is the first phase followed by the collection and analysis qualitative data. ***Concurrent triangulation*** uses the both method concurrently. This study is going to use the sequential explanatory design and details will be explained below.

3.3.1 The Sequential Explanatory Design

The Sequential Explanatory design is a popular strategy for mixed method. It is characterized by the collection and analysis of quantitative data in first phase of research followed by the collection and analysis of qualitative data in a second phase that builds on the result of the initial quantitative results. Figure 1 explains the sequential explanatory design.

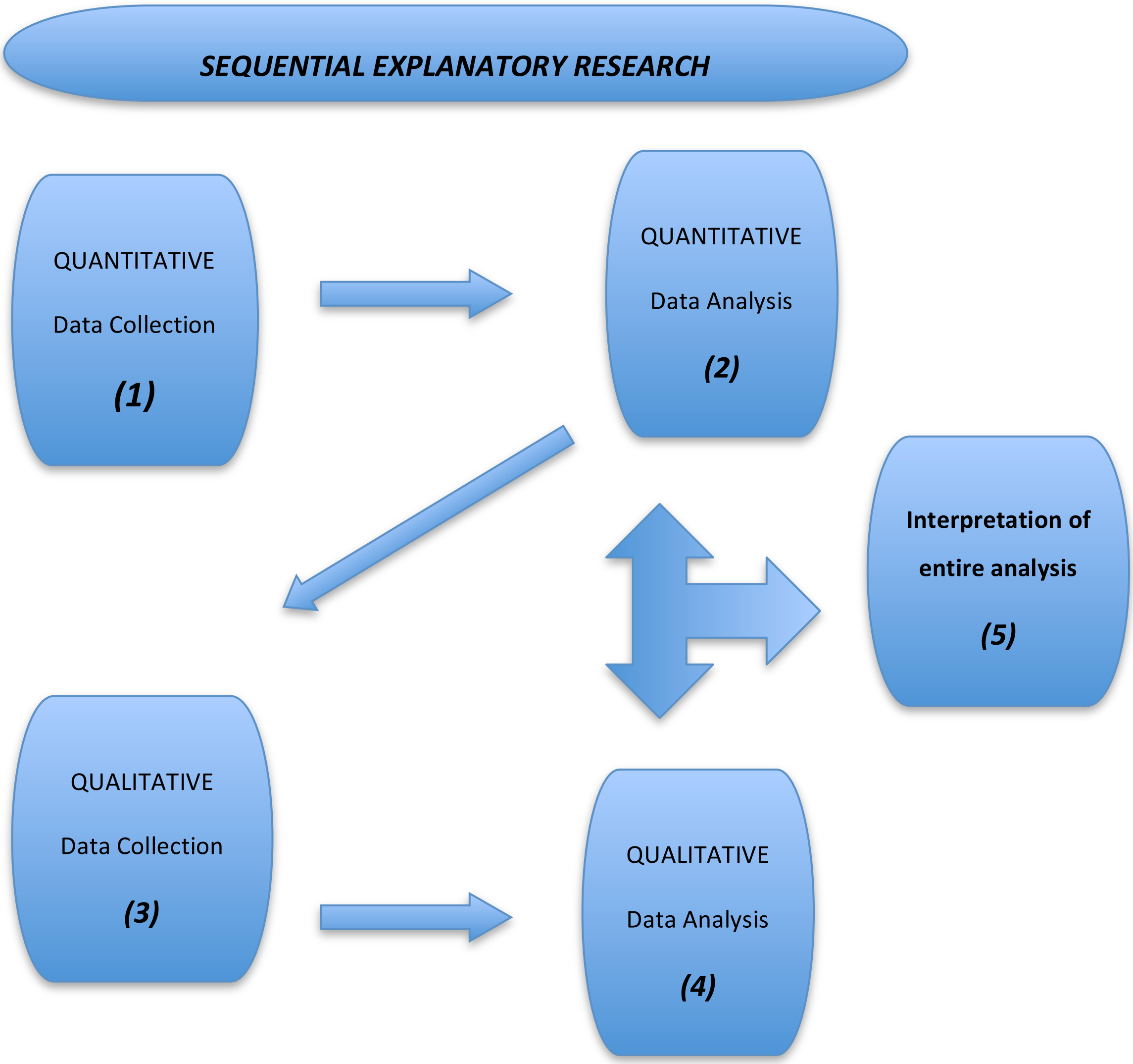

Figure 1 Sequential explanatory research

3.3.2 Justification

The design selected must be appropriate to the study purpose and should have minimum threat to validity and reliability (Burn & Grove 2005). Neither quantitative nor qualitative research designs alone would be sufficient enough to address the aims and objectives of this study. After thorough Literature review (section 3.3 & 3.3.1) on different types of research designs and understanding of the research problem, a mixed method with sequential explanatory design is identified as the most appropriate approach to answer the research question.

The main components of this study are

- A quantitative assessment of the content of de- identified discharge summaries collected from fifteen maternity hospitals in Ireland. The data analysis will provide the existing data sets used in postnatal discharge summaries in Ireland, which will be used to produce a draft for a minimum data set discharge summary. This initial quantitative method is followed by the next steps,
- A qualitative assessment of the expert opinions on the draft discharge summary collected from the major stakeholders in maternity care. This will also help to meet the information requirement of the major stakeholders in maternity care setting. The final discharge summary is developed afterwards.
- A descriptive field study, mixing qualitative, quantitative and a Minimum Data Set Development Process Methodology. A questionnaire with open ended and closed ended questions will be collected from the major stakeholders. This analysis will increase the validity and reliability of the qualitative study in this research. Quantitative analysis will be done on the closed ended questions in the questionnaire. Minimum Data set Development Process Methodology is used in various stages of this study and will be described in *Methodology section 3.4.1*

3.3.3 Challenges of Study Design

Mixed Method approach is more time consuming as it requires extensive data collection for both quantitative and qualitative method. Another challenge is that the work context of the major stakeholders of this study are in different settings of health care (Hospital and community). The mixed method requires more sample size as it combines both designs.

3.4 Ethical Consideration

The Ethical approval of this study was authorized by the Research Ethics Committee of the School of Computer Science and Statistics (SCSS) of Trinity College Dublin (Appendix 3) and National Maternity Hospital, Dublin (Appendix 4). The researcher ensured full compliance with principles of autonomy, beneficence, and maleficence, Justice and Data Protection Act- 2003 (Ireland). Anonymised draft discarge summary and questionnaire (Appendix 7) were collected from the participants to ensure beneficence and maleficence. All participation was voluntary and the participants selected were 18 years or older and was competent to provide informed consent. Informed written consent (Appendix 5) was obtained from all the participants after giving participation information Leaflet to comply with principles of autonomy (Appendix 6). Participants were informed that they could withdraw from the study at any time.

3.5 Research Methodology

The research methodology involves the description of sampling, data collection method, analysis, and interpretation that researchers propose for their studies (Creswell, 2013). This study intends to develop a minimum data set for postnatal discharge summaries. The research will be mainly grounded on one of the major Dublin teaching maternity hospital.

3.5.1 Phase 1

In this phase, discharge summaries are collected from all the maternity hospitals in Ireland. All the maternity hospitals are contacted through the Director of Midwifery from the base maternity hospital as per the hospital protocol. E- mails are sent to Director of Midwifery and Postnatal Clinical Midwifery Manager Grade 3 to obtain the de-identified postnatal discharge summary. Quantitative analysis on the content of the postnatal discharge summary helped to identify the existing data sets for the next part and to explore explicit elements and attributes required in the minimum data set development process. Some steps of *Minimum Data set Development Process* will be carried out during this phase as outlined in 3.5.

3.5.2 Phase 2

A draft minimum data set for postnatal discharge summary is developed,

- After analysing discharge summaries collected from different maternity hospitals in Ireland
- After conducting a literature review (outlined in Chapter 2) on standards for maternity care minimum data set in Ireland and other countries
- After consultation with experts in maternity care settings
- After analyzing *National Standard For Discharge Summary Information (*HIQA 2013[1]) and
- After examining related data dictionary along with SNOMED-CT.

3.5.3 Phase 3

The draft discharge summary and a questionnaire are posted/e-mailed to the major stakeholders of the maternity care system to obtain consultation feedback using a Questionnaire method. HIQA (2014[1]) “Guidelines for Stakeholders Engagement in Health Technology Assessment In Ireland” is referred and principles and key steps in stakeholder engagement are followed to choose the major stakeholders in Maternity care. A combined ***Top- Down*** *and* ***Bottom-Up approach*** is adapted in selecting the stakeholders (HIQA 2014[1)]. A *Bottom-Up* approach encompasses consultation with health professional, those who are directly involved in collecting and recording data and understands the context and feasibility of the data. A *Top-Down approach* comprises consulting professionals involved in planning service requirements, staff allocation, recruitments, and policymaking. The major stakeholders are selected from primary, secondary, and tertiary care setting including Consultant Obstetricians, Midwives, Public Health Nurses, and General Practitioners. Information requirement of these stakeholders are assessed through the feedback received on the draft discharge summary. Also, qualitative and quantitative analysis of the consultation feedback provides the data set required for the next stage. Some steps of *Minimum Data set Development Process* are also carried out during this phase as outlined in Section 3.5.

3.5.4 Phase 4

The analysed questionnaire with appropriate inclusions/exclusions will be utilized for the new minimum data set for postnatal discharge summary. Harmonisation of the data set is done using Minimum data set Development process to finalise the minimum data set for the postnatal discharge summary.

3.6 Minimum Data Set Development Process

3.6.1 Methodology

Development of the Minimum Data set (MDS) is a methodological process, which includes modeling data needs and clarifying the relationships between data (AIHW, 2007). Key data concepts in postnatal discharge summaries are identified and data elements are used to standardize the discharge summary. Standardisation ensures consistent collection and use of the data set. However, limited studies have been reported the state of art for Minimum Data Set Development Process. To suit the aims and objectives of this study, a methodology will be developed by examining national and international guidelines /standards on Data Development, different minimum data sets developed by a number of accredited agencies both within and outside Ireland and National data Dictionaries. The following National and international standards were reviewed.

Analyzing the Data dictionaries specific to Health care –

- Hospital In-Patient Enquiry (HIPE) Data Dictionary 2015
- Irish Coding standard (ICS - 2015) Version 7.0, 8th Edition ICD- 10-AM/ACHI/ACS
- National Perinatal Reporting System Data Dictionary (2015)

Analyzing National Guidelines specific to data development

- HIQA (2013[3]) Guiding Principles for National Health and Social care Data Collection
- HIQA (2013[2]) Guidance on Developing Key Performance Indicators and minimum data set to Monitor Health Quality
- HIQA (2014[2]) Recommendations regarding the adoption of SNOMED Clinical Terminology for Ireland

Analyzing International Guidelines and Reports

- Australian Institute of Health and welfare (2007) A Guide to data Development. Report No 94.
- Commonwealth of Australia (2008) A Frame work for Specialist MDS Development for specific cancers in Clinical Cancer Registration, Technical Monograph (1).
- Health and social Care Information Centre, United Kingdom (HSCIC,2014): Maternity Service Data set V1.5 Standard Specification.

3.6.2 Rationale for Choosing Minimum Data Set Development Process

Literature review shows that the commonly used methods for Minimum Data Set Development Process are –

- Using hired consultants (Bean, 2005)
- Formation of Experts or representatives (Ireland et al, 2001)

- Stakeholder committee (Evans et al, 2010)
- Stakeholder Interview (Evans et al, 2010)
- Distribution survey (Mistry et al, 2010)
- Delphi Technique (Bagley et al, 2010)
- Systematic literature Reviews (Ireland et al, 2001)

Most of these methods are about obtaining a common agreement among the experts. The problems associated with the above methods are that these methods lack the core component of “clinical data analysis”. Therefore, this study used a top – down & *bottom- up multimodal approach* in which data items are identified from literature, discharge summaries collected from different maternity hospitals in Ireland and consultation feedback from stakeholders. This approach helps to utilize the study result at managerial level for staff allocation, resource need assessment and policy making. Linking the MDS content with standard vocabularies such as SNOMED – CT will help to integrate MDS interoperable with other health information infrastructure.

“Development of Minimum Data Set” is a confusing terminology used in literature. It is constantly misinterpreted as the “minimum information requirement”. “Development of minimum data set” is the process of collecting core information and developing it into data standards. Data development is the significant component of minimum data set development. Data sets should be based on single set of agreed definitions. National Data Dictionaries are main sources for the data definitions. Therefore, the process of minimum data set development should follow appropriate methodology. There is limited research explaining the minimum data set development process. Therefore, this study mostly relies on international guidelines for developing data standard.

The review of Discharge summary process is the core component, as this will provide insights into many implicit representations of clinical constructs that may not exist in the literature review. The literature review will help to obtain evidence based clinical terminologies.

3.6.3 Steps in Minimum Data Set Development Process

The different steps used in the development of minimum data set are described below.

Step 1: Business Context and Information Need Identification

The different steps in this section include problem statement, target identification, service environment identification and specifying expected outcome.

Step 1.a: Problem Statement

The problem statement of this study is described in Chapter 1, section 1:2.

Step1.b: Identify the Target Population

The target populations benefiting from postnatal discharge summary will be identified. HIQA (2013[2]) recommends that while defining a *target population*, denominator and numerator of the population should be clearly defined. The **Denominator** is target group and includes all the service users and the **Numerator** is the service user included in the selected stakeholders group.

In this study the ***Denominator*** is all the service users including all the health care professionals working in all maternity care services, Midwives specialists, Advanced Nurse Practitioners Independent and Community Midwives, Doulas, Consultant Obstetricians and all the Health care professionals in primary care. As this study is specific to the development of a minimum data set for postnatal discharge summaries, only those professionals currently practicing in this area will be included as the Numerator. The ***Numerator*** in this study is,

- Consultant obstetricians
- Midwives
- Public Health Nurse and
- General Practitioners.

Step1.c: Identify the Service Environment

The service environment for this research study falls under two broad areas of health care services in Ireland namely, maternity Hospitals and primary care. Maternity care delivery is through Obstetricians, Midwives, PHNs and GPs.

Step1.d: Expected Outcome

The expected outcome of this MDS development is to develop data standard for postnatal discharge summaries using nationally and internationally acceptable clinical terminologies in order to meet the informational requirement of the stakeholders in maternity care setting.

Step 2: Feasibility Analysis

Feasibility analysis includes the identification of stakeholders and their relevant level of interest, the data needed to support information requirements, analysis of what are currently collected, and if sufficient resources are available to proceed with the data development project.

Step 2.a Identify Stakeholder's Information Requirement

HIQA (2014[1]) "Guidelines for Stakeholders Engagement in Health Technology Assessment In Ireland" is referred to and principles and key steps in stakeholder engagement is followed, to choose the major stake holders in Maternity care. The aim is to identify their information needs and subsequent use of that information (HIQA 2013[2]). This study assessed the information requirement of midwives, consultant obstretions, PHNs and Gps using a survey questionnaire and a draft discharge summary.

Step 2.b: Identify Currently Existing Data Sets

It is important to identify the existing data source and method of data collection. For this study the existing data sets are identified by,

- Analysing discharge summaries from different maternity hospitals in Ireland
- Analysing and synthesizing the literature review. This will help to assess scientific evidence regarding the potential relevance of core data sets.

Step 3: Development of Draft Discharge Summary

This study developed a minimum data set for postnatal discharge summaries. Details of developing discharge summary are described in section 3.4 Phase 2. Analysing the postnatal discharge summary will help to explore explicit elements and attributes in the data sets. Literature review will identify quality content required in a postnatal discharge summary. SNOMED clinical terminology is used to standardize the data set as per recommendations by *e-Health Action Plan 2020 (2012).*

Step 4.Consultation and Collaboration

Consultation with stakeholders are carried out to obtain participant feed back. Adequate time and opportunity was given to the participants to provide written feedback. This study performed a mixed method analysis on the feedback from participants. Details of the consultation process are earlier outlined in *section 3.4 phase 3.*

Step 5.Harmonisation of Data

Once the content data sets are identified and operationally defined, final harmonization was done to avoid terminology discrepancy. Harmonisation of the data facilitates exchange of meaningful information between health care systems (HIQA 2013[2]). To ensure the standardisation, the draft discharge summary data sets are linked with SNOMED – CT clinical terminology and data dictionaries. First preferences was given to the National clinical terminologies and where data standard was not available then, other country's data standards are used. A recommendation is made for the data sets not available in Ireland. Data Standardization was done,

- After analysing the Data dictionaries specific to Health care (described in section 3.5)

- After analysing National Guidelines specific to data development (described in section 3.5) and

- After analysing and synthesising the literature review on discharge summary.

Step 6.Identifying Data for Development

Developing a new data standard is beyond the scope of this study and recommendations will be given for the clinical terminology used in the discharge summary without data standard.

Step 7.Development of Minimum Data Set for Postnatal Discharge Summary

Once the final standardisation is done, the data sets will be written with its representation in standard classification system to finalise the minimum data set for a postnatal discharge summary.

3.7: Sampling

Sampling is the process of selecting units from a population of interest so that studying the sample may fairly generalise the result back to the population from which they are chosen. ***Purposeful sampling*** is a technique involving identifying and selecting individuals that are especially knowledgeable about or experienced with phenomena of interest (Sandelowski, 2014). Bernard (2002) debates that in addition to knowledge and experience, a purposeful sample notes the importance of availability and willingness to participate, and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner. Palinkas *et al (*2013) argues that for developing and implementing evidence based practices and data standards in a nationwide system where the relationship among key stakeholders extends both vertically and horizontally (between organizations nation wide), a mixed method approach with purposeful sampling is the most apropriate sampling method . Even though there are different types of purposeful sampling, ***purposeful stratified sampling*** is used as the most applicable sampling method for this study. Purposeful stratified samples are the samples within samples where each stratum is fairly homogenous (Suri, 2011). The purpose of this sampling is “to capture major variations and common core”(Mertens, 2014). Moreover, purposeful stratified sampling is designed to achieve both quantitative and qualitative data and will increase the credibility of the overall result (Palinkas et al.2013).

The different stratums selected are,

- Consultant Obstetrician
- Midwives
- Public health Nurses
- General Practitioners

3.7.1 Recruitment Method

To reduce research errors, increase the validity and to increase the generalisation of the result, randomisation is used to select representative stratum from highly populated group.

3.7.1.a Inclusion Criteria

- General Practitioners enrolled in the Maternity and Infant Care Scheme only were included.
- Public Health Nurses currently practising postnatal care in the community were included.
- Obstetricians working with Maternity care were included.
- Midwives in the postnatal ward were included.

3.7.1.b Exclusion Criteria

- ➢ General Practitioners not enrolled with the Maternity and Infant Care Scheme were excluded.
- ➢ Public Health Nurses currently not practising postnatal care in the community were excluded.

- Obstetricians not working with Maternity Care or only working with gynaecology were excluded.
- Midwives not working in the postnatal ward were excluded

This study utilised samples from both community and maternity hospital settings. Randomization is carried out to select community care area for PHNs and GPs. Consultant obstetricians and Midwives are selected from the three maternity hospitals in Dublin. A draft discharge summary and a questionnaire is posted/ emailed/ or hand delivered to the participants. A period of two weeks is given prior to collecting replies. Reminder notification was sent to the participants one week after distributing the draft discharge summary and questionnaire.

A total of 15 **consultant Obstetricians** are contacted from the three maternity hospitals and 10 participants returned completed draft discharge summary and questionnaires. The initial plan at the beginning of this study was to select samples through Royal College of Obstetricians & Gynaecologicts. Inadequate response from Royal college of Obstetricians led to contacting the three Dublin Maternity Hospitals. The level of expertise of Consultant obstetrician ranged from Professors, Directors to lectures in Obstetrics. 15 **Midwives** working in the postnatal ward are randomly selected from the base maternity hospital.

The Director of Public Health Nursing in Communty care area nine of the Health Service Executive (HSE) is contacted via telephone by the researcher. 20 **PHNs** working with postnatal services are contacted through the Director of Public Health Nursing.Draft dischrge summary and questionnaire are posted out. A (random Selection) total of 20 rsponses are received.

For recruiting **General Practitioners**, community care area six of the HSE is randomly selected and GPs, who are enrolled in Maternity and Infant care scheme of Ireland in this area, were approached through Emails/Posts.

3.7.2 Sample Size

When determining the sample size for this qualitative study, three factors were considered–the sample size should give enough data saturation of consistent patterns, it should represent the population and it should represent the information requirement data variation in the target population. For Phase 1, all 19 maternity hospitals from Ireland are contacted to send a de-identified copy of discharge summaries. A total of 16 discharge summaries were returned. One discharge summary is excluded, as it was a general hospital discharge summary. For Phase 3, total numbers of 50 samples are selected including 5 General Practitioners, 10 Obstetricians, 15 Midwives, and 20 Public health Nurses.

3.8 Data Collection Methods

A combination of data collection methods were used in this study including the collection of discharge summaries from various maternity hospitals, survey and questionnaire. Data collection was done from 1st March to 30th April 2015.

3.8.1 Development of Data Collection Tools, Purpose and Usage

3.8.1 (a) Collecting Discharge Summary

All the 19 maternity hospitals in Ireland were invited to take part in this study. The Director of Midwifery and Clinical Midwife Manager 3 of these hospitals were contacted by E-Mail to send a de-identified copy of their postnatal discharge summary of mother and baby. These e-mails are sent through the Director of Midwifery from one of the largest teaching maternity Hospitals in Dublin, where the researcher is working.

3.8.1 (b) Tool Development for Consultation Process

The draft discharge summary prepared for this study consists of two separate sections for mother and baby. The ***postnatal maternal discharge summary*** consist of nine subheadings such as *Demographic details, Primary care professionals details,* *Admission and discharge details, Previous Obstetric History, General health history, Antenatal clinical information, Delivery clinical information, Neonatal information and maternal Discharge details.*

Section two of the draft discharge summary consists of ***Baby details*** with two subheadings – *Baby Demographics and Baby clinical*. Consultation process encompasses expert opinion on agreement on the draft discharge summary data items and their opinion on what information needs to be included and excluded from the draft discharge summary. Therefore, this study planned to add three questions to each subheading in the draft discharge summary; such as, agreement of the term, optionality for the agreement and inclusion/exclusion data items. The draft discharge summary used for the consultation process is described in Appendix 7.

3.8.1 (c) Questionnaire

A questionnaire is a research instrument consisting of a list of questions with instructions on how to record answers (European Statistical System, 2006). One of the advantages of using a questionnaire is that it permits uniformity and anonymity (Giesen, 2012). It also permits the respondent to consider the questions carefully and write their expert knowledge and opinion without interference from the researcher resulting in more meaningful data. This study utilised a self-administered questionnaire where the respondent completes the answers and returns it to the researcher. The aim of these questionnaires are,

- To get expert opinion on the content of questionnaire
- To obtain feedback on optionality of data items to be included in the discharge summary
- To gain the opinion of the participant on standardising discharge summaries and using a single discharge summary across the maternity hospitals in Ireland.

Errors due to insufficient information on questionnaires can hardly be compensated for at data collection time. Therefore, this study adopted a systematic questionnaire design and testing procedures to improve data quality and minimize errors recommended by the European Statistical System (2006). The process of questionnaire design consist of the following steps – development of conceptual framework, writing and sequencing the questions, making proper use of visual element, testing and implementation.

This study used ***semi - structured questionnaire*** comprising a mixture of closed ended and open-ended questions to maximize the data quality and to gain insight into participant's views and opinions. A Likert Scale with 5 point response scale is also included in the questionnaire. Once developed, ***Informal testing*** is carried out on the questionnaire by distributing the first draft to the researchers colleagues and acquaintances to get their views and to detect possible mistakes in design wordings. The research guide and maternity experts from the Maternity health care organisation reviewed the questionnaire to determine ease of completion and usability. Also a pilot study (outlined in section 3.8.1.d) was conducted to identify the errors and ambiguity in questionnaire and also to validate the questionnaire.

3.8.1 (d) Pilot Study

A pilot study is an "investigation designed to test the feasibility of methods and procedures for a later use on large scale or to search for possible effects and associations that may be worth following up in a subsequent large study"(Everitt 2006, *Medical Statistics from A – Z,* p. 176). A pilot study provides the researcher with ideas, approaches, and clues that the researcher may not have seen before conducting the pilot study. It is also an opportunity to test the questionnaire tool (Thabane 2010). For this study, ***Informal testing*** (European statistical System 2006) is carried out on the questionnaire by distributing the first draft to the researcher's colleagues and acquaintances to detect the mistakes in design and wordings and to get their views towards the tool. Necessary inclusions and exclusions were brought to the questionnaire afterwards. Piloting on ***Expert Group*** (European Commission grant agreement- European statistical System 2006) was done by distributing the draft discharge summary and the questionnaire to the three experts from a maternity care setting- A staff midwife, a clinical midwife manager in postnatal ward and a senior

Registrar in Obstetrics. After analyzing the responses, the researcher brought the following changes to the draft.

- Several misrepresented clinical terminologies and wordings were changed in “Maternal postnatal discharge summary” section,
- Rearranged the order for the subheading in the draft,
- The subheadings are reiterated in the introduction page of the draft discharge summary to avoid confusion in the lay out,
- The responses in the draft discharge summary changed to “agree/disagree” and
- Typographical errors were corrected.

To avoid misleading in the sample calculations, the results from the pilot study were not used in this main study.

3.9 Data Analysis

Descriptive Analysis was used to analyze the data. Microsoft Excel Spread sheets are used for easy use, aggregation and analysis of data collected from all the discharge summaries collected from different maternity hospital. To analyse the data obtained from draft discharge summary and questionnaire, HIQA (2013[1]) data analysis for developing national standard for discharge summary information was followed. Each submission was read and its comments are recorded into the database. Agreed Mandatory or optional or conditional responses from all participants are entered categorically into the data base. Each category is then examined and statistical analysis is carried out. Data sets with 80 percent or more mandatorally agreed responses are considered as as mandatory data sets in the discharge summary.

3.10 Summary

This chapter described the methodological over view of developing a minimum data set for a postnatal discharge summary. This research utilises a pragmatic paradigm using a mixed method sequential explanatory research design. The rationale for selecting this research design, and the challenges expected are also explained. This research involved four phases (section 3.4) and used quantitative and qualitative mixed research design. To meet the aims and objectives of this study, minimum data set development process is developed using international and national guidelines and reports and is described step by step in section 3.5.

Purposeful stratified sampling is used with 4 different stratums of Consultant Obstetrician, Midwives, PHNs and GPs with total sample size 50. Rationale for choosing the sampling methods are also examined. In Phase 1, the discharge summaries were collected from all the maternity hospitals in Ireland and a survey questionnaire was used to get expert opinion. A semi-structured questionnaire is used for data collection after testing. A pilot study is carried out and necessary inclusions and exclusions were brought. Data analysis was done using descriptive statistics. Finally, ethical considerations were outlined.

Chapter 4A and Chapter 4B describes the findings of this study. Chapter 4A describes the findings of the discharge summaries collected from 15 maternity hospitals in Ireland and Chapter 4B describes the minimum data sets and findings of the data collected from the different participants. It also refers to the SNOMED – CT concepts of each data sets used in the new discharge summary.

Chapter 4A Result 1

Collation of Discharge Summaries from 15 Maternity Hospitals

4A.1 Introduction

Maternity care is a part of a continuum of women's health care through the life span. All childbearing women have access to an evidence based, high quality, and high value maternity care system. An ideal maternity care system hugely depends on its communication system. Discharge summaries are one of the major modes of communication between primary care and secondary/tertiary care. As a part of developing a minimum data set for postnatal discharge summary, this study reviewed discharge summaries from different maternity hospitals in Ireland. This chapter will be discussing the findings of analysis done on discharge summary formats from 15 maternity hospitals in Ireland. Each discharge summary is carefully examined for its content and data is entered into Microsoft Excel for Statistical analysis. Tables, graphs and charts are used to illustrate some of the result. Chapter 4B describes the new minimum data set for postnatal discharge summary, information requirement of stakeholders in a discharge summary and analysis of questionnaire result.

There are 19 public maternity hospitals in the Republic of Ireland, which provides a wide range of services such as public, semiprivate, and private care to pregnant women. Upon request, 16 out of 19 Public Maternity Hospitals forwarded a de-identified copy of their discharge summary for analysis. Out of received 16 numbers, 15 (78.94%) discharge summaries were included for this analysis. Reason for exclusion of one discharge summary from the analysis was as it was a general hospital discharge summary instead of maternity discharge summary.

4A.2 Type of Participant Maternity Hospitals

Out of 19 Maternity Hospitals in Ireland, there are two Midwifery led units, six teaching hospitals and 11 non teaching hospitals. Fifteen Maternity Hospitals forwarded a de-identified copy of their discharge summary for analysis. Out of 15 Hospitals, 2(13%) discharge summary received from Midwifery Led units, 6(40%) from Teaching Hospitals and 7(47%) from Non-Teaching Hospitals. Teaching Hospitals and Midwifery Lead units had excellent representation in this study. Figure 2 shows the type of participant maternity hospitals.

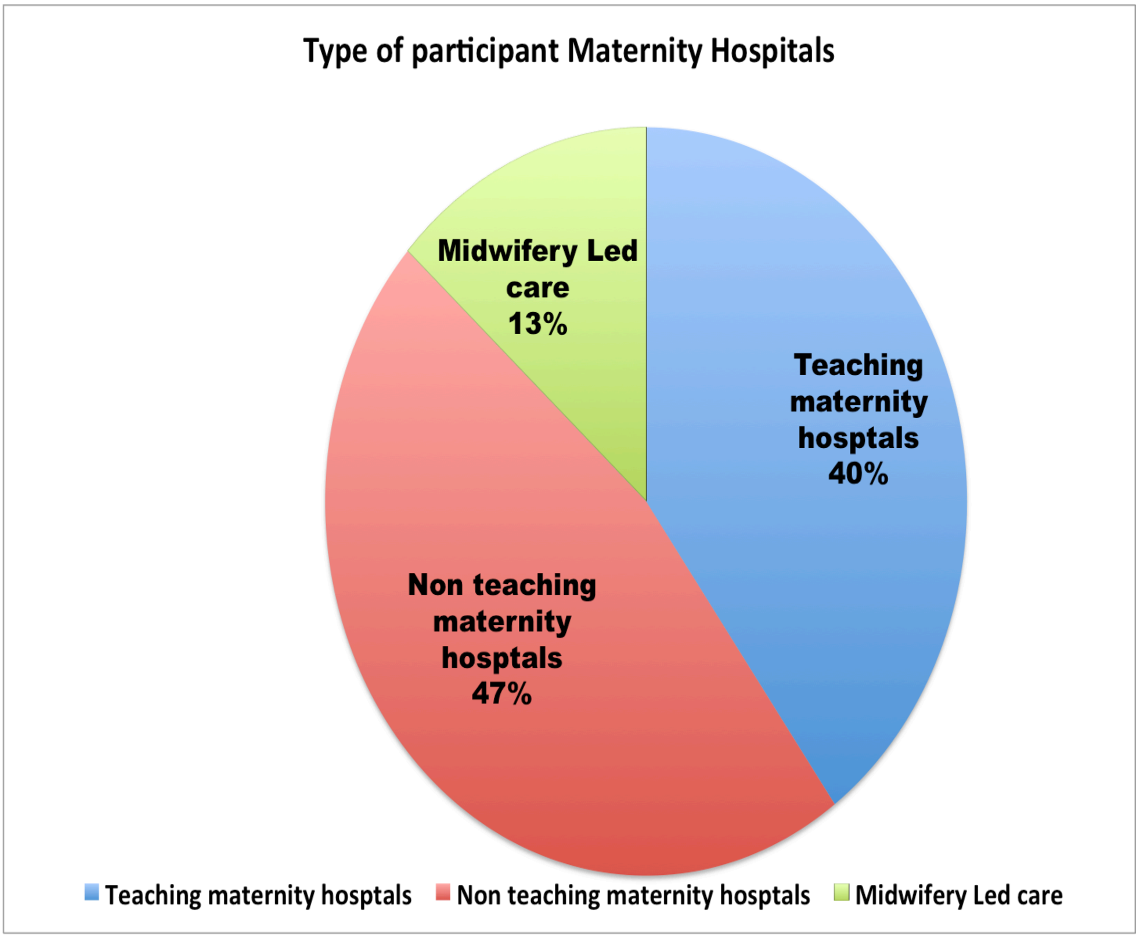

Figure 2 Type of participant maternity hospitals

4A.3 Type of Discharge Summaries

Out of 15 maternity hospitals participated, 9 (60%) hospitals had computerized discharge summaries and 6(40%) had handwritten discharge summaries.

4A.4 Format & Frequently Used Information

Discharge Summaries took a wide variety of forms: some were handwritten (40%), others were electronically generated (60%). Handwritten forms were single page in a triplicate form – (one copy filed in Mothers Health Care Record, second copy goes to the General Practitioner, and third copy goes to Public Health Nurse). These formats contained very minimal information. Some of the electronically generated discharge summaries were too long and contained on an average 5-6 pages. From the collected Discharge summaries, nine different types of formats were identified. Irrespective of the format used, there was marked variation in the content of discharge summaries reviewed. The *most commonly* used information in the format is given below in the table 7.

Table 7 Frequently used information in discharge summary formats

Frequently used information (Mother)	Frequently used information (Baby)
• Demographic details such as Name, Date of Birth, Address, and Hospital Number. • Delivery details including Date and Time of Delivery, Type of Delivery, Perineum and Estimated Blood Loss • Discharge details including date of discharge, name of the discharging person and signature • Other details such as Mother Blood Group, Complications and Postnatal problems.	1. Date &Time of birth 2. Sex 3. Birth Weight 4. Discharge Weight 5. Type of feeding 6. Newborn Blood Spot Screening 7. Gestation

4A.5 Contents of Discharge Summaries

All the received discharge summaries are examined and each data set are classified under eight subheadings described under section 4A.5 and its subheadings.

4A.5.1 Demographics

The discharge summary forms typically included four major demographic details such as name, date of birth, hospital number and address. On the other side, these discharge summaries largely omitted additional information such as age, marital status, religion, nationality, and next of kin information. Contact phone number of the mother was identified in eleven discharge summaries (73.33%). PHNs completely rely on discharge summaries for the contact details of the mother following discharge from the hospital. Table 8 describes the contents of demographic details of mother.

Table 8 Demographic details of mother

No.	Demographics	Present (Total No.)	Percentage (%)	Absent (Total No.)	Percentage (%)
1.	Forename & Surname	15	100	0	0
2.	Address	15	100	0	0
3.	Hospital Number	15	100	0	0
4.	Date of Birth	15	100	0	0
5.	Phone Number	11	73.33	4	26.67
6.	Age	8	53.33	7	46.67
7.	Marital Status	3	20	12	80

8.	Religion	1	6.67	14	93.33
9.	Nationality	1	6.67	14	93.33
10.	Next of Kin Details	1	6.67	14	93.33

4A.5.2 Relevant Previous History

A relevant previous medical or surgical history of mother is important in a discharge summary so that, the Primary Care Team can arrange appropriate postnatal follow up for mother and baby. The reviewed discharge summaries did not consistently incorporated information about medical, surgical, psychological or other relevant history of mother, outside pregnancy (33.33%).

4A.5.3 Discharge Information

The discharge summary forms analysed, extensively included the information about discharging professionals Name and signature (100 %). A standard discharge summary should include information such as date of discharge, time of discharge, discharge method, follow up care etc. Out of the 15 discharge summaries collected, 86.67% included date of discharge while 53.33% included discharge time as well. General Practitioners name and address were identified in 73.33% of the discharge summary formats but PHNs name or address was not found in any of the collected discharge summaries. Only two (13.33%) discharge summaries revealed the HSE Community Care Area (CCA) number. It has been noted that 60% of the discharge summaries did not included the name of a consultant. Discharge information is described in table 9.

Table 9 Discharge Information

No	Discharge Information	Present (Total No)	Percentage (%)	Absent (Total No)	Percentage (%)
1.	Discharging persons Name & Signature	15	100	0	0
2.	Date of Discharge	13	86.67	2	13.33
3.	Destination	11	73.33	4	26.67
4.	Discharge Method	11	73.33	4	26.67
5.	GP Name & Address	11	73.33	4	26.67
6.	Follow up Care	11	73.33	4	26.67
7.	Consultants Name	6	40.00	9	60.00
8.	GP Phone No	6	40.00	9	60.00
9.	Time of Discharge	8	53.33	7	46.67
10.	Community Care Area	2	13.33	13	86.67

4A.5.4 Follow up

Discharge summaries frequently documented advising the woman to see their General Practitioner for follow up. This may be due to the fact that in Ireland, GPs conducts mother's six-week follow up checks as a part of Maternal And Infant Scheme.

4A.5.5 Antenatal Information

Discharge summaries were found to frequently omit important aspect of women's antenatal information. 33.33% of the total discharge summaries avoided, information on antenatal complications, such as Gestational Diabetes Mellitus, Pregnancy induced Hypertension etc. Serology status of the mother was cited only in 40% of the discharge summaries. It is important for the primary care team to know the HIV or Hepatitis status of the mother in order to assure continuity of safe care to the mother and the baby. Antenatal Scan Report was indicated in 20% of the Discharge Summaries.

Most of discharge summaries communicated women's basic information such as parity and blood group (80%). Only 6.67% of the discharge summaries inquired about special needs in relation to physical difficulties and language requirements in relation to interview difficulties, which is crucial information for the primary care team for arranging translation services and extra special assistance to offer help to mothers. History of smoking reported in 26.67% of the discharge summaries. Figure 3 displays the percentage of antenatal information in discharge summaries.

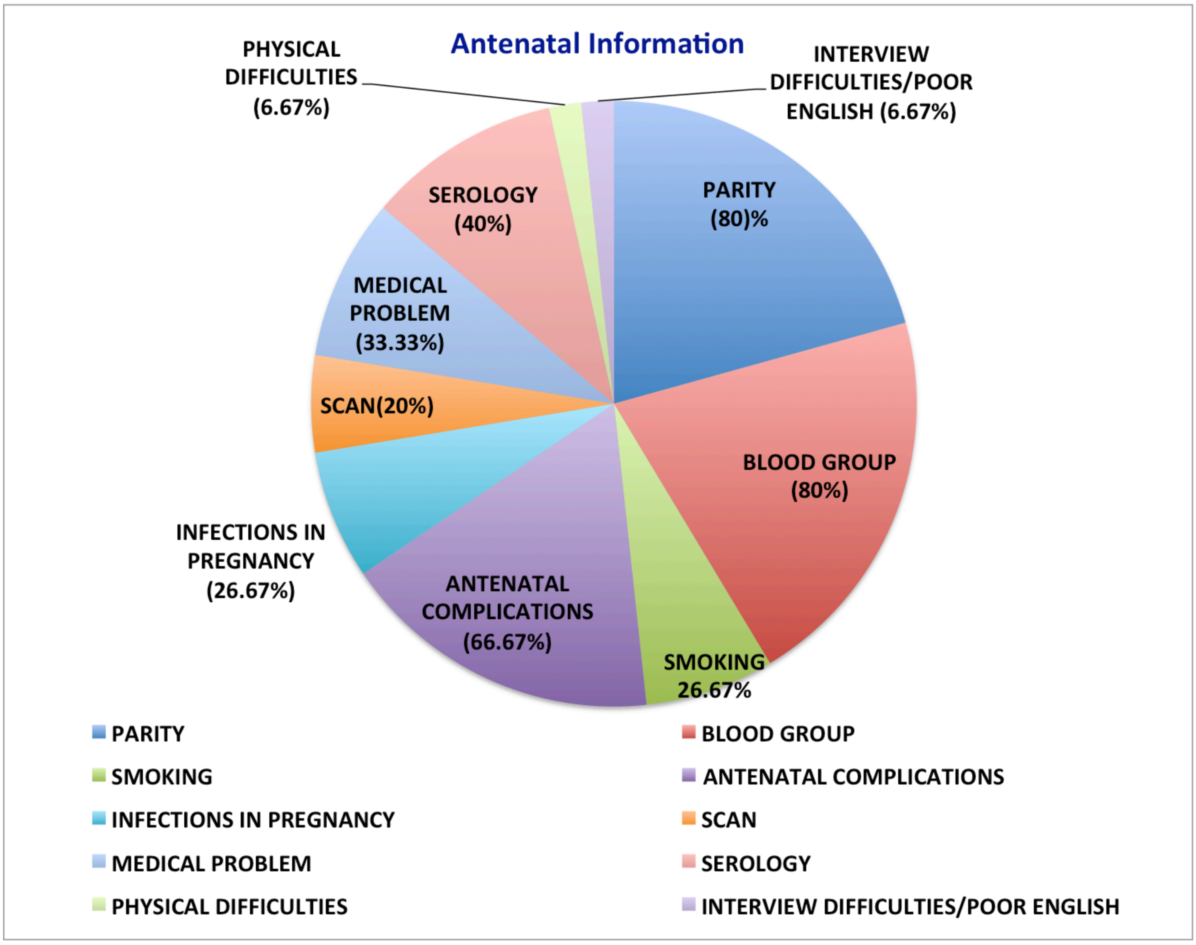

Figure 3 Antenatal clinical information

4A.5.6 Delivery Clinical Details

Intra partum analgesia (60%), blood loss (60%), intra partum problems (73.33%) and status of perineum after delivery (73.33%) were the more frequently included information in the collected discharge summaries. The less frequently incorporated information included onset of labour (40%), placental examination (40 %), and length of first stage, second stage and third stage of labour (20%).

Figure 4 shows that few discharge summaries contained information on oxytocin or other drugs usage (33.33%) in the third stage to control bleeding and to enhance placental separation. Even though 53.33% of the discharge summaries included maternal diseases, only 13.3% stated whether the mother required a High Dependency Unit transfer and reason for admission.

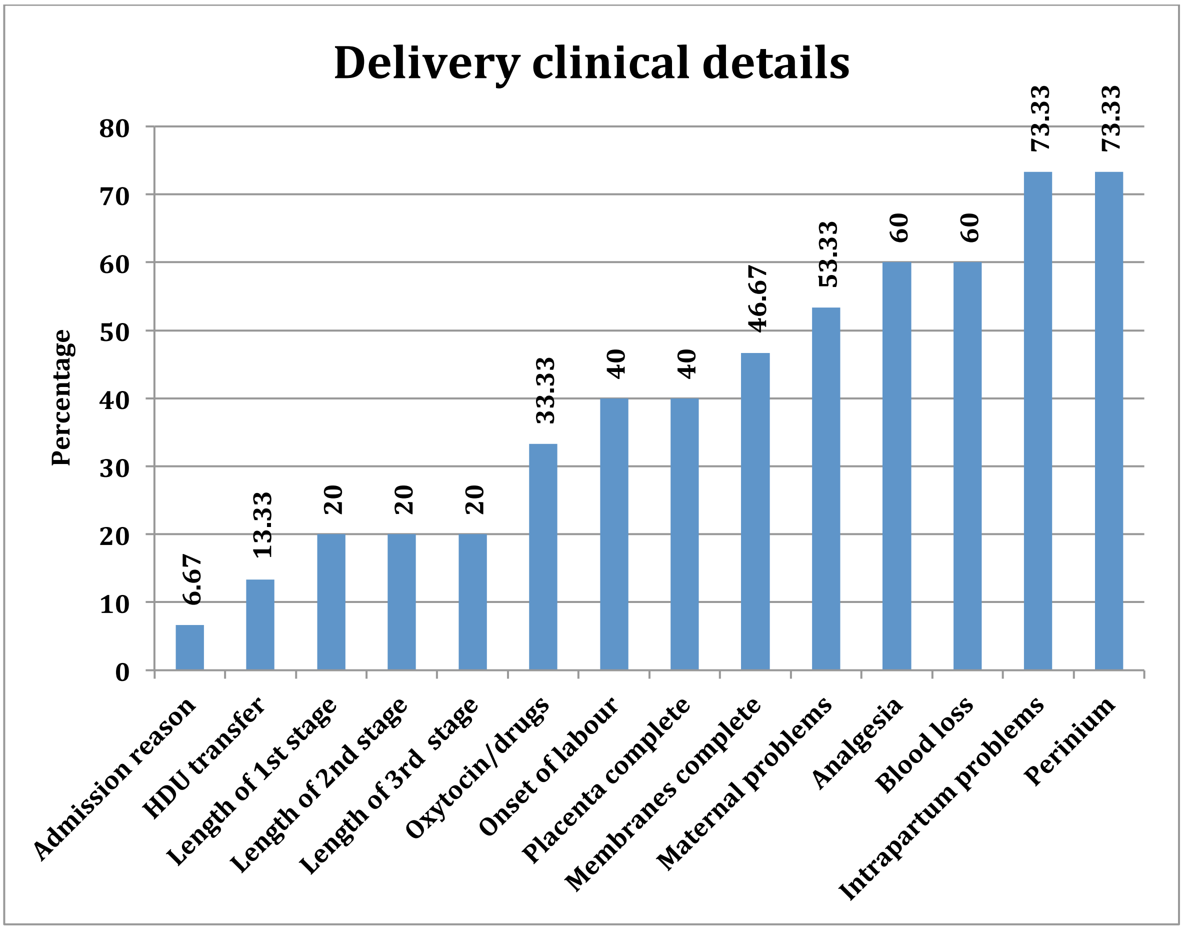

Figure 4 Delivery clinical details

4A.5.7 Postnatal Details

4A.5.7 (a) Rarely Included Postnatal Information

Irish Maternity Early Warning System- IMEWS is a nationally agreed system developed for early detection of life threatening illness in pregnancy and postnatal period. Only 20 % of the discharge summaries mentioned the heart rate and temperature of the mother at the time of discharge and only 46.67% contained blood pressure at the time of discharge, which are crucial parameters in the early detection life threatening illness.

Only 20% of the discharge summaries provided information on blood transfusion, whereas the Post Partum Haemorrhage rate in Ireland has increased from 1.5% to 4.1% in the last ten years, which is a threefold increase (Lutomski 2012). Figure 5 demonstrates that 46.67% of discharge summaries gave indication on abdominal wound status. 13.37% of mother's discharge summary mentioned about type of feeding. Only 26.67% included breast-feeding problems at the time of discharge.

It is also noted that 26.6% gave space for including breast-feeding support notes. RCOPI (2013) 'Clinical Practice Guideline on venous thromboprophylaxis in pregnancy recommends that all women should have a risk assessment for venous thromboembolism at the booking visit, at every episode of hospitalisation and after delivery, yet 13.33% of the discharge summaries only documented information on postnatal use of thrombolytic agents. Postnatal discharge summaries largely omitted information on psychosocial wellbeing of the mother. Psychosocial information was only identified in six hospital discharge summaries.

Group B Streptococcal infection (GBS) is one of the major causes for septicaemia in newborns. One in every 2000 newborn babies born in Ireland is diagnosed with GBS infection and majority of GBS infection is passed from mother to baby at the time of birth (RCOG-2013). Only 13.33% of discharge summaries included mothers GBS carriage status.

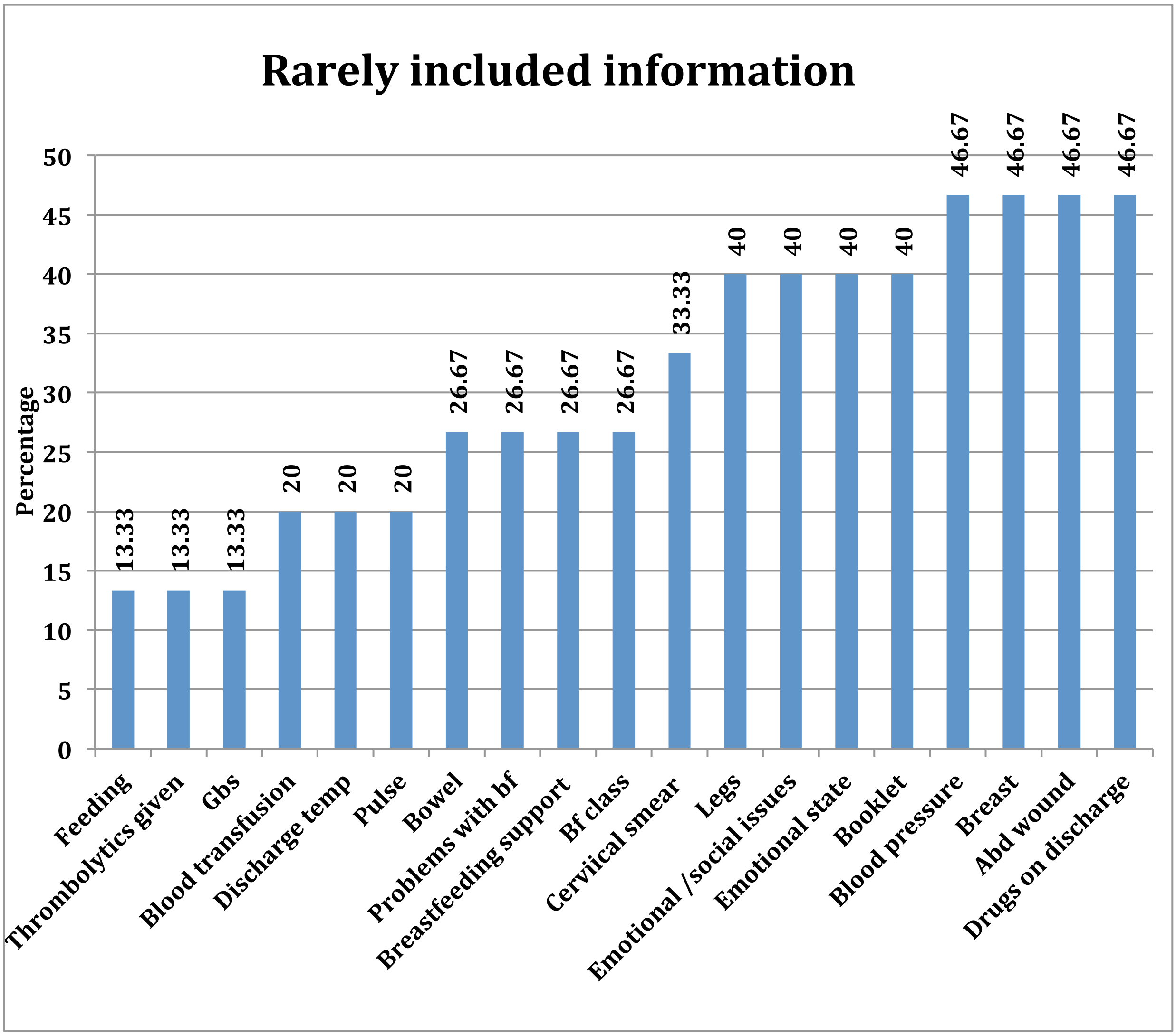

Figure 5 Rarely included postnatal clinical details

4A.5.7 (b) Frequently Included Postnatal Information

Majority of postnatal discharge summaries included information on blood group (100%), perineum (100%) follow up information (93.33%), postnatal problems (93.3 %), agencies involved, Haemoglobin level and additional comments. 93.33% of discharge summaries included information on postnatal problems. There was descriptive space provided in all of the discharge summaries for including additional information. Figure 6 shows that 80% of the discharge summaries included information on investigations carried out. 73.33% of discharge summaries included information on medication at the time of discharge. 80% of the discharge summaries contained information on Anti-D status.

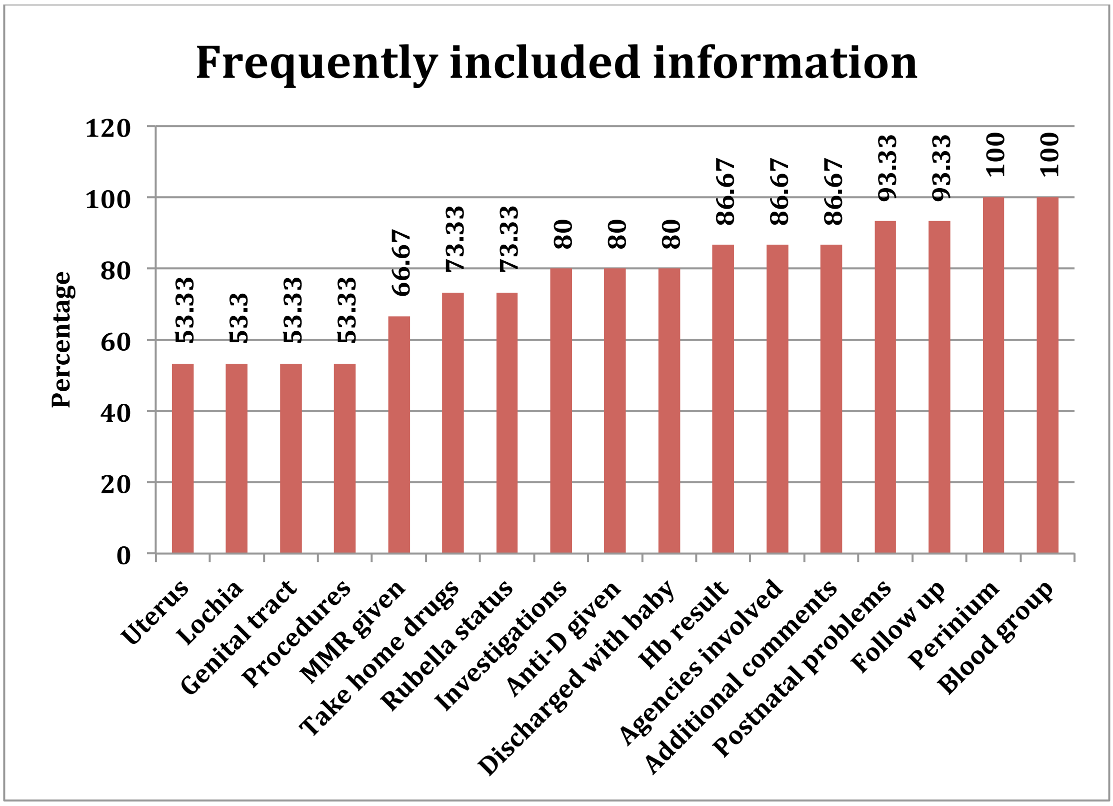

Figure 6 Frequently included postnatal information

4A.5.8 Neonatal information

Neonatal information is a distinct part of postnatal discharge summaries. Discharge summaries were found frequently omitting important aspects of neonatal information. Table 10 indicates that most of the reviewed discharge summaries communicated following basic information about the Neonates – Date of birth, time of birth, birth weight and sex. 93.33% of discharge summaries included the discharge weight, gestation, and new born blood spot screening.

Table 10 Most frequently used neonatal information in a discharge summary

No	***Most frequently included data***	***Percentage***	***Frequently included data***	***Percentage***
1	Date and time of delivery	100.00%	Birth order	86.67%
2	Gender	100.00%	Follow up	86.67%
3	Birth weight	100%	Comments	86.67%
4	Discharge weight	93.33%	Drugs at discharge	73.33%
5	Newborn blood spot screening	93.33%	Apgar	66.67%
6	Gestation	93.33%	Fetal problem in labour	60.00%
7			Feeding	60.00%
8			Jaundice	60.00%
9			Antenatal fetal problem	60.00%

Figure 7 displays the rarely included neonatal information in the analysed discharge summary. Many discharge summaries did not include information related to resuscitation, Jaundice, biophysical measurements, investigations, and hearing test results. Time of first feed was only mentioned in 6.67% of discharge summaries, which is major information for carrying out metabolic screening for babies.

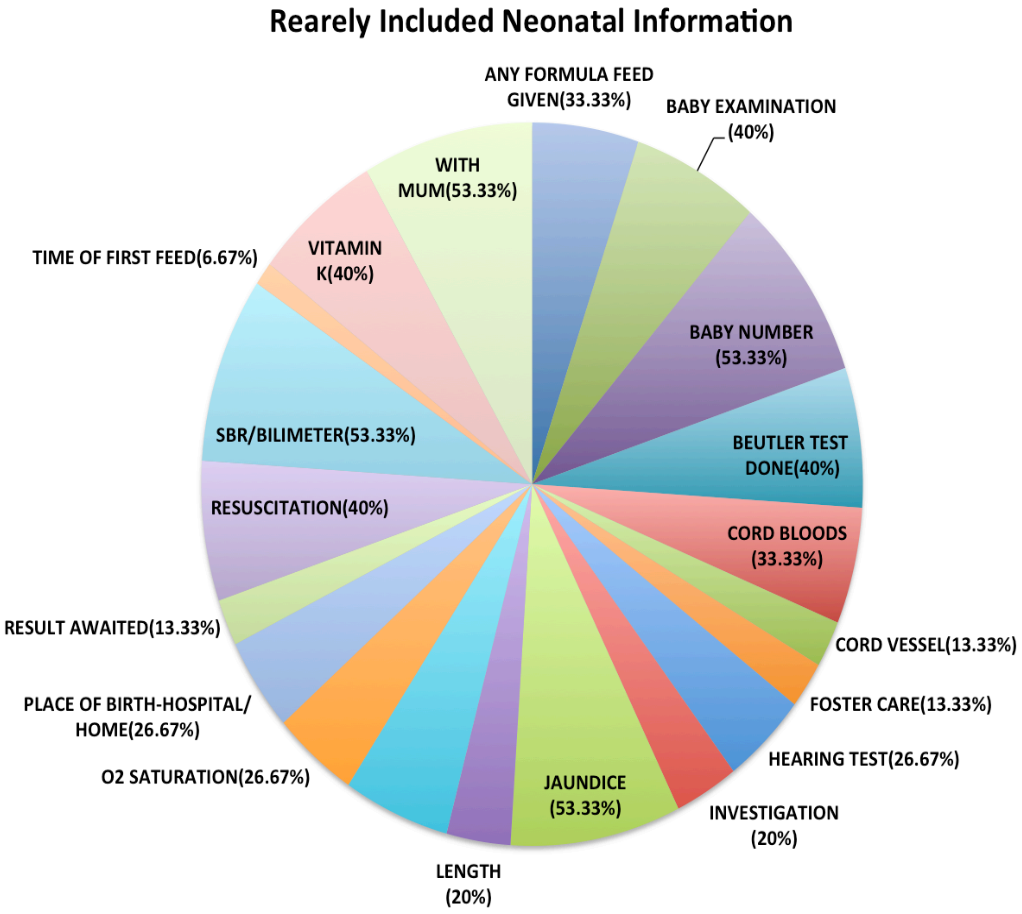

Figure 7 Rarely included neonatal information in a discharge summary

4A.6 Summary

Discharge summaries are source of information for primary care team regarding antenatal, intranatal and postnatal events. The content analysis on 15 discharge summary formats showed that current discharge summaries are not communicating standardised information in Ireland. The available data sets in the current discharge summary format are identified and will be used to develop a minimum data set. Next Chapter 4B illustrates the survey findings on draft discharge summary from different stakeholders. The new postnatal discharge summary includes data definitions, optionality and SNOWMED-CT concept ID. Information requirement of different stakeholders in maternity care for mother and baby is also discussed in Chapter 4B.

4B.Result 2

Survey findings

Key Findings

1.Development Of new Minimum Data Set for postnatal discharge summary with data definitions, optionality, and SNOMED-CT concept ID.

2.Information requirement of GPs, PHNs, Midwives, and Consultant Obstetricians regarding mother in postnatal discharge summary.

3. Information requirement of GPs, PHNs, Midwives, and Consultant Obstetricians about baby in postnatal discharge summary.

4.Questionnaire.

5.Summary.

4B.1 Introduction

Discharge summary is essential and understandable health information that is made available at the point of care to deliver safe continuity of patient care (eHealth Network, *epSOS* 2013). Therefore, the designers of discharge summary have huge responsibility in including adequate information in a discharge summary and also the beneficiaries in delivering safe continuity of care. This chapter discusses the survey findings of the draft minimum data set for postnatal discharge summary and information requirement of different stakeholders in maternity care for mother and baby. A draft discharge summary and a questionnaire are sent to the stakeholders and 50 submissions were received. Statistical analysis is carried out on quantitative data and thematic analysis is carried out on qualitative responses. Participant’s view on having a standardised postnatal discharge summary across Ireland is obtained using a questionnaire. This chapter concludes with a summary.

4B.2 Development of Minimum Data Set

A total of 50 submissions (Midwives = 15, PHNs = 20, GPs = 5, Consultant obstetricians = 10) were received during the consultation process. Each submission is broken down into individual data set and recorded to create a database. The data sets agreed by all the participants are classified into mandatory, optional, and conditional data sets. Additional qualitative comments received are carefully examined and appropriate changes are brought to the final data sets. The *National Standard for Patient Discharge Summary Information* (HIQA 2013[1]), *NPRS data dictionary*, and national and international Data dictionaries are referred to define each data set. ***NPEx SNOMED-CT Browser UK Clinical Edition 2015*** and ***SHRIMP Terminology browser:SNOMED Clinical Terms Australian Extention*** are used to draw SNOMED clinical terminology concept IDs and entities. The postnatal discharge summary is grouped under 10 headings. Each group consists of data set, definition, optionality, and SNOMED-CT Identifier (Concept ID). The newly developed minimum data set for postnatal discharge summary and its details are included in Appendix 2.

4B.3 Information requirements of GPs, PHNs, Midwives, Consultant Obstetricians about Mother in a Postnatal Discharge Summary

4B.3.1 Demographic Details of Mother

This section includes the "identity of the mother" to whom this discharge summary relates to. All the participants agreed to include the name, address, date of birth, health identifier number, and next of kin. However, contact details of 'next of kin' is not incorporated in *National Standard for Patient Discharge Summary Information* (HIQA 2013[1]). PHNs and midwives consider that, information on next of kin is mandatory and should include the name and contact number. For instance, one of the study participants wrote: "*next of kin's phone number is mandatory and should be checked to see if it is correct pre discharge*". Another Public Health Nurse stated*: "destination address is often a problem in the community; going to stay with relatives* *temporarily".* All the participants disagreed to include the data set 'gender' in mother's demographic details.

4B.3.2 Primary Care Healthcare Professional Details

This group comprises the contact details of the primary care professionals to ensure that the discharge summary can be delivered to the correct health care practitioner. Majority of the participants agreed (mandatory) to include the name, address, and phone number of the General Practitioner. It is evident from figure 8 that the responses to include the information about work e-mail address of the primary care professionals in a discharge summary could not reach in an agreement among participants.

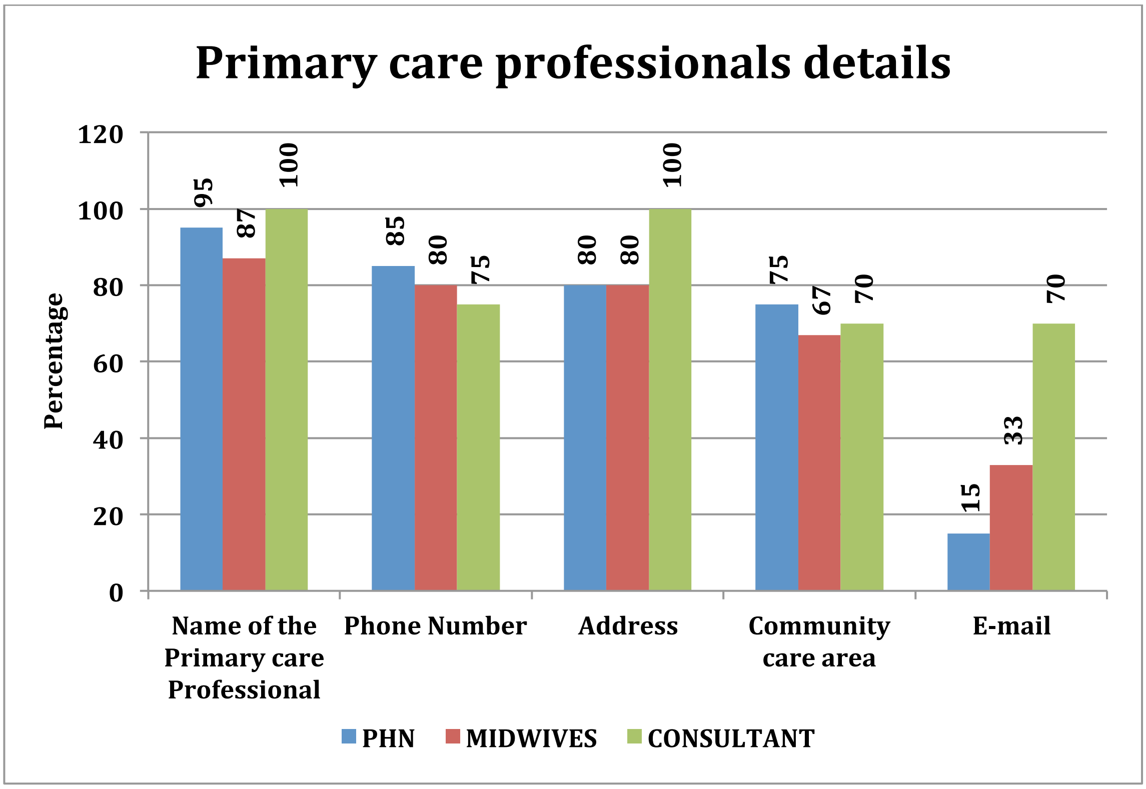

Figure 8 Primary care professional details

4B.3.3 Admission and Discharge Details

More than 80% of participants agreed that date of admission, reason for admission, date of discharge, discharge method, date of death (where applicable) and post-mortem flag (where applicable) should be included in a discharge summary as mandatory information. Although information on 'source referral, discharge method and method of admission' were included in the draft discharge summary in accordance with the HIQA (2013[1]) national guidelines, participants deemed these as optional information.

4B.3.4 Previous Obstetric History

Maternity care discharge information is not only beneficial for postnatal follow up care but also necessary for planning and coordinating future pregnancies. Therefore, Previous obstetric history in a discharge summary assists the primary care professionals to provide pre-pregnancy care and counselling for subsequent pregnancies. Figure 9 shows that more than 80% PHNs and GPs reported to include data sets such as parity, date of birth, weeks of gestation, type of birth, sex of the baby, condition of the baby and complications encountered during antenatal, intranatal and postnatal period in the previous pregnancies in the discharge summary.

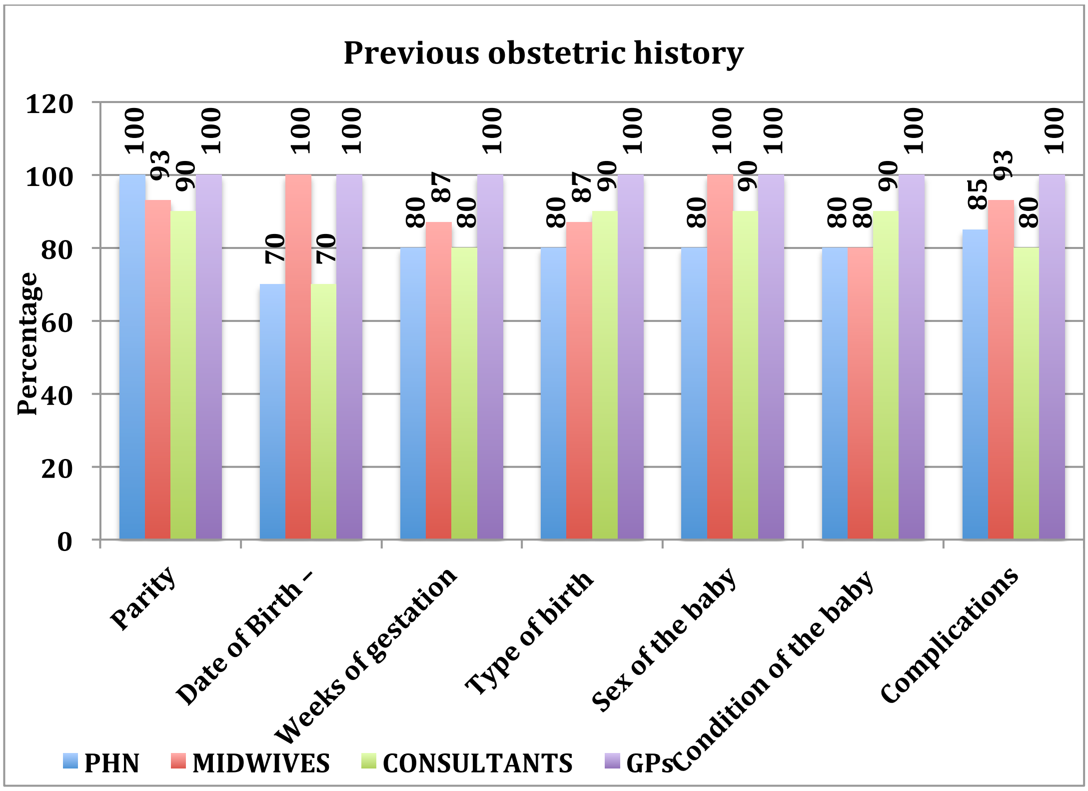

Figure 9 Previous obstetric history

4B.3.5 General Health History

Marked variation noted among participants for the information requirement for the section ‘general history’. In this section, fourteen data sets were included in the draft discharge summary. Out of fourteen, four data sets were approved as mandatory by most of the participants (> or=80 %) from all categories. Also, information on BMI, maternal serology, smoking, and alcohol consumption was reported to include optionally where applicable. It is evident from the figure 10 that primary health care professionals are in favour of including more information on mental health. This may be due to the fact that the symptom of postnatal depression is more evident after discharge from the hospital. Also, mental health status of the mother has prime role in determining how well she will be able to look after her newborn baby. Figure 10 shows the percentage of the participant’s agreement on mandatory data sets for the section ‘general history’. Participants remarked to the question “Additional data sets to be included in this section”. Maternal medical and surgical history was one of the main point. One of the PHN participant mentioned that pre-existing maternal morbidity should be added to this section.

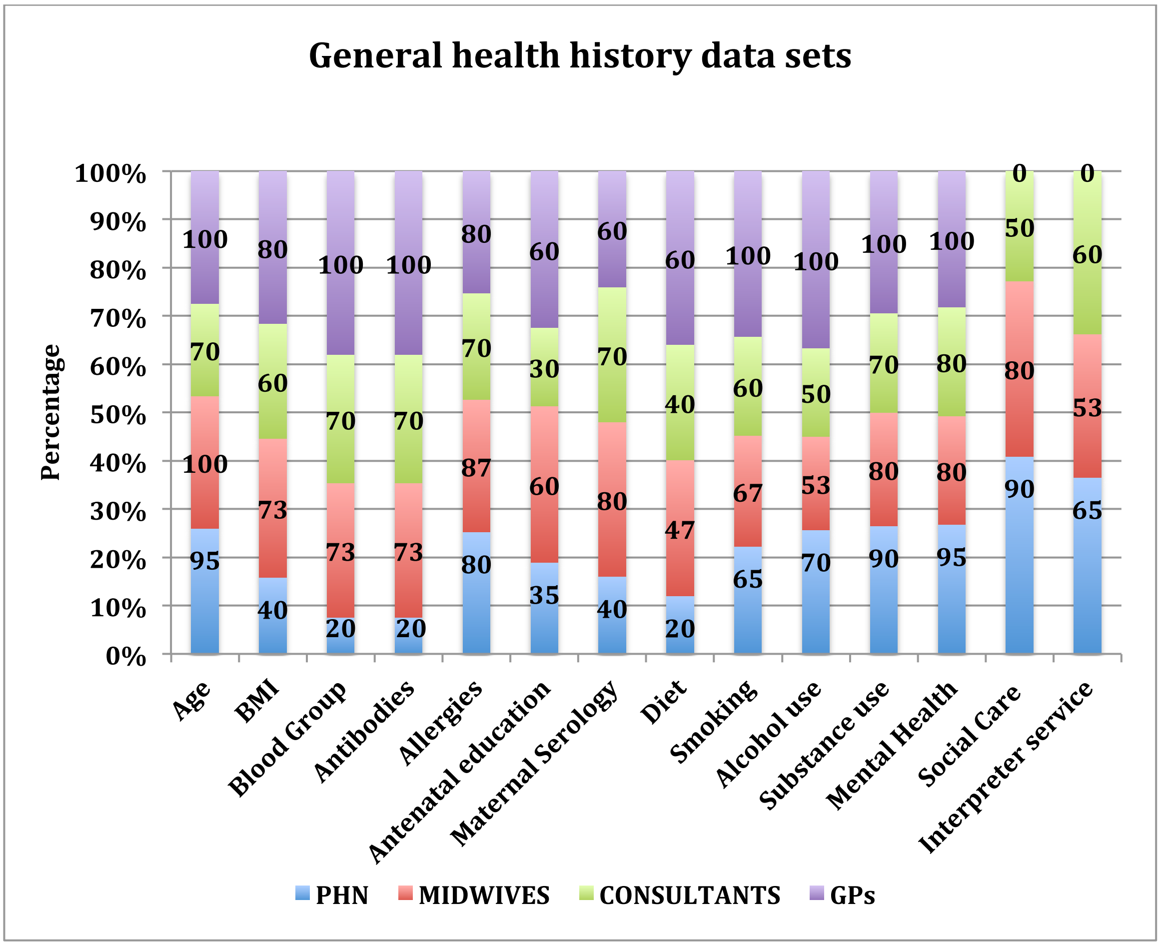

Figure 10 General health history data clinical information

4B.3.6 Antenatal Clinical Information

Pregnancy is a crucial time for mother and her unborn baby. WHO (2014) estimates that maternal antenatal morbidity causes 25% of maternal death worldwide. Therefore, it is important to handover relevant information related to antenatal period. The stakeholders in this study admitted to include data sets such as parity, gestation, antenatal complications, and infections during pregnancy as mandatory information. Table 11 demonstrates that although Consultant obstetricians and GPs were in favour of including EDD and scan report in the discharge summary, PHNs and Midwives did not prefer to add this to the discharge summary. One of the PHN remarked that *"PHNs are not qualified to read scan report"; "Major findings will be described in the discharge summary"; "only include if scan report is abnormal".*

Model of care is another data set created mixture of interpretations. 40%(n=9) of PHNs specified to include this in the DS. Their concern was confusion for the patient and the staff for providing follow-up home visits. Some of the areas of Community care area nine is covered by the Community Midwives Early Transfer Home Programme established by the major maternity hospitals in Dublin: *"Notification early if under the care of the midwife as PHN will not have to visit until day 8.avoid confusing mother with phone call from 2 services".*

Table 11 Antenatal clinical information

No	Antenatal Data set	PHN	Midwives	Consultant Obstetrician	GP
1.	EDD by scan (Estimated Date of Delivery)	55.00% (11)	60.00% (9)	70.00% (7)	100.00% (5)
2	Scan report	20.00% (4)	40.00% (6)	60.00% (6)	100.00% (5)
3	Model of care	40.00% (8)	53.33% (8)	0.00% (0)	80.00% (4)
4	Method of induction	55.00% (11)	53.33% (8)	50.00% (5)	100.00% (5)
5	Parity	85.00%	93.33%	70.00%	100.00%

		(17)	(14)	(7)	(5)
6	**Gestation**	**95.00%** **(19)**	**86.67%**	**80.00%** **(8)**	**100.00%** **(5)**
7	**Infection during pregnancy**	**85.00%** **(17)**	**86.67%** **(13)**	**80.00%** **(8)**	**100.00%** **(5)**
8	**Antenatal Complication**	**80%** **(16)**	**86.67%** **(13)**	**80.00%** **(8)**	**100.00%** **(5)**

4B.3.7 Delivery Clinical Information

The data sets in delivery clinical Information is major source of information in terms of mother and baby's follow up care. These are the stepping-stones data of maternity care. Table 12 indicates that five data set are agreed by the participants as mandatory. They are "type of birth" (PHN=19/20, MW=15/15, CO=9/10, GP=5/5), "perineum" (PHN=19/20, MW=14/15, CO=7/10, GP=5/5), "estimated blood loss" (PHN=20/20, MW=14/15, CO=7/10, GP=5/5), "antibiotics in labour" (PHN=16/20, MW=11/15, CO=7/10, GP=5/5) and "intra partum complication" (PHN=19/20, MW=13/15, CO=7/10, GP=5/5). The other data set such as onset of labour, rupture of membranes, amniotic fluid status and intra partum analgesia are excluded from the final discharge summary as most of the participants disagreed to include it in the DS.

Table 12 Delivery clinical information

No	Delivery Data set	PHN	Midwives	Consultant Obstetrician	GP
1	Onset of labour	65.00% (13)	53.33% (8)	60.00% (6)	40.00% (2)
2	Rupture of membrane	55.00% (11)	46.67% (7)	50.00% (5)	100.00% (5)
3	Amniotic fluid status	85.00% (17)	53.33% (8)	50.00% (5)	40.00% (2)
4	Intrapartum analgesia	15.00% (3)	53.33% (8)	60.00% (6)	40.00% (2)
No	**Delivery Data set**	**PHN**	**Midwives**	**Consultant Obstetrician**	**GP**
5	Antibiotics in labour	80.00% (16)	73.33% (11)	70.00% (7)	100.00% (5)
6	Monitoring in labour	30.00%	46.67%	30.00%	40.00%

		(6)	(7)	(3)	(2)
7	Type of birth	95.00 % (19)	93.33% (15)	90.00% (9)	100.00 % (5)
8	Perineum	95.00 % (19)	93.33% (14)	70.00% (7)	100.00 % (5)
9	Placenta and Membranes	80.00 % (16)	40.00% (6)	40.00% (4)	100.00 % (5)
10	Estimated blood loss	100.00 % (20)	93.33% (14)	70.00% (7)	100.00 % (5)
11	Intrapartum complications	95.00 % (19)	86.67% (13)	70.00% (7)	100.00 % (5)

4B.3.8 Postnatal Clinical Information

Postnatal period is a very special time for mother where she undergoes the transition into motherhood. WHO (2014) specifies that postnatal period is the most critical yet sometimes neglected phase of mother’s life. The health and wellbeing of the mother is directly proportional to the care she can provide to her newborn baby. It is obvious from the figure 11 that the information on perineal status such as first/second/third/fourth degree tear or episiotomy are required to provide appropriate follow up in the postnatal period.

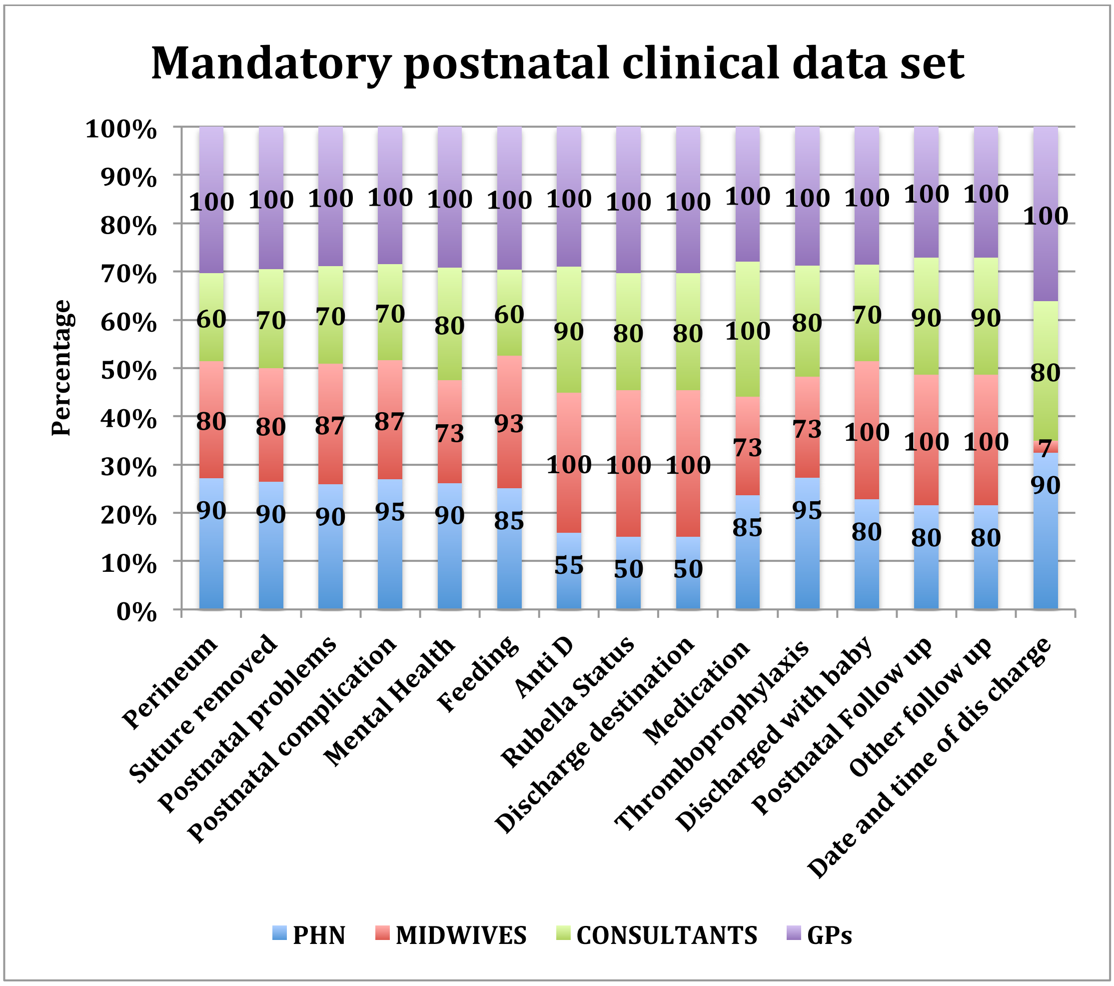

Figure 11 Mandatory postnatal clinical information data set

Although the draft discharge summary included questions on abdominal wound and sutures, the participants only agreed to include whether the abdominal suture requires to be removed postnatally. This may be due to the fact that, most of the obstetricians uses absorbable suture and special instructions on suture type will highlight the need for removal. Mental health, feeding information, rubella and Anti-D, postnatal complications, postnatal problems, follow-up information and discharge date & time are other data sets included in this section.

RCOPI (2013) recommends that every pregnant woman should have a documented risk assessment for venous thromboembolism. The number of the patient requiring postnatal thromboprophylaxis increased dramatically over the last 10 years. Therefore, postnatal thromboprophylaxis is an important data set to be included in discharge summary.

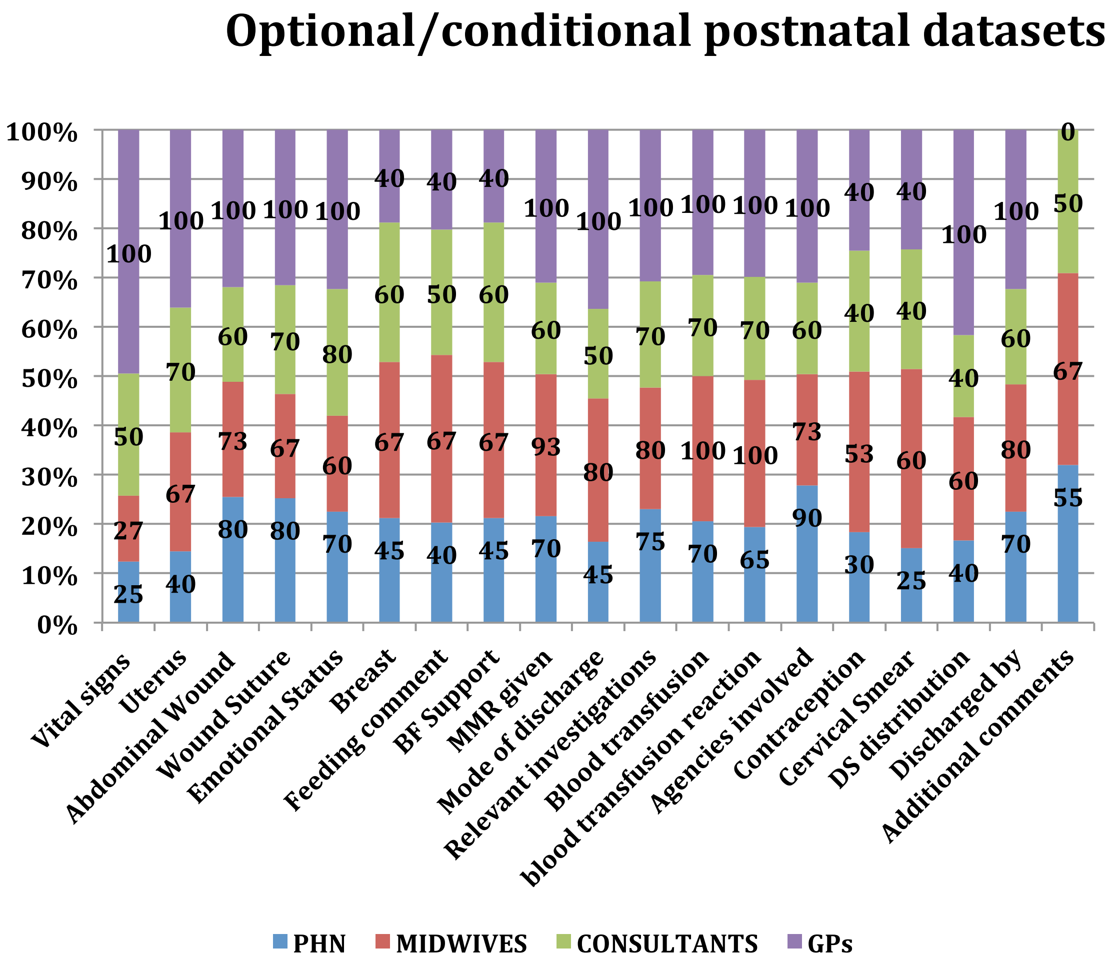

Figure 12 Optional/conditional postnatal clinical information datasets

Figure 12 displays the optional data sets in postnatal discharge summary incorporating uterus, abdominal wound, wound suture, emotional status, condition of breast, lactation support, MMR vaccine, mode of discharge, relevant investigation, blood transfusion, blood transfusion reaction, agencies involved, and details of the person discharging (discharges by). Its also evident that data sets such as vital signs at the time of discharge, feeding comment, contraception, cervical smear test could not reach in agreement by majority of the participants. Therefore these data sets will be excluded from the study.

4B.4 Information Requirement of GPs, PHNs, Midwives, Consultant Obstetricians about Baby in a Postnatal Discharge Summary

Postnatal discharge summary consist of mother and baby's information. Baby details are important information for the primary care team as this is the first set of information facts upon which the rudimentary record of baby built. Also this is the first information record of baby from where their life begins.

4B.4.1 Demographic Details of Baby

All the participants agreed to include the demographic details of baby in the discharge summary including hospital number, name of the baby, date and time of birth, gender, gestation at birth, and date and time of discharge. The name of the baby led to some discussion; however, majority commented that name should be under the mum's surname to avoid confusion for health care professionals on the discharge summary. Most of the participants could not agree on including consultant neonatologist's name and GP details for the baby. It may be due to the fact that GP details are already included in the mother's postnatal discharge summary.

4B.4.2 Baby Clinical Details

Baby clinical details are important information for all maternity related healthcare professionals. Figure 13 indicates the mandatory information needed in a discharge summary. It is apparent that there is not a huge difference in the information requirement among the four groups of participants. Therefore, a postnatal discharge summary must include all the details of baby in the discharge summary.

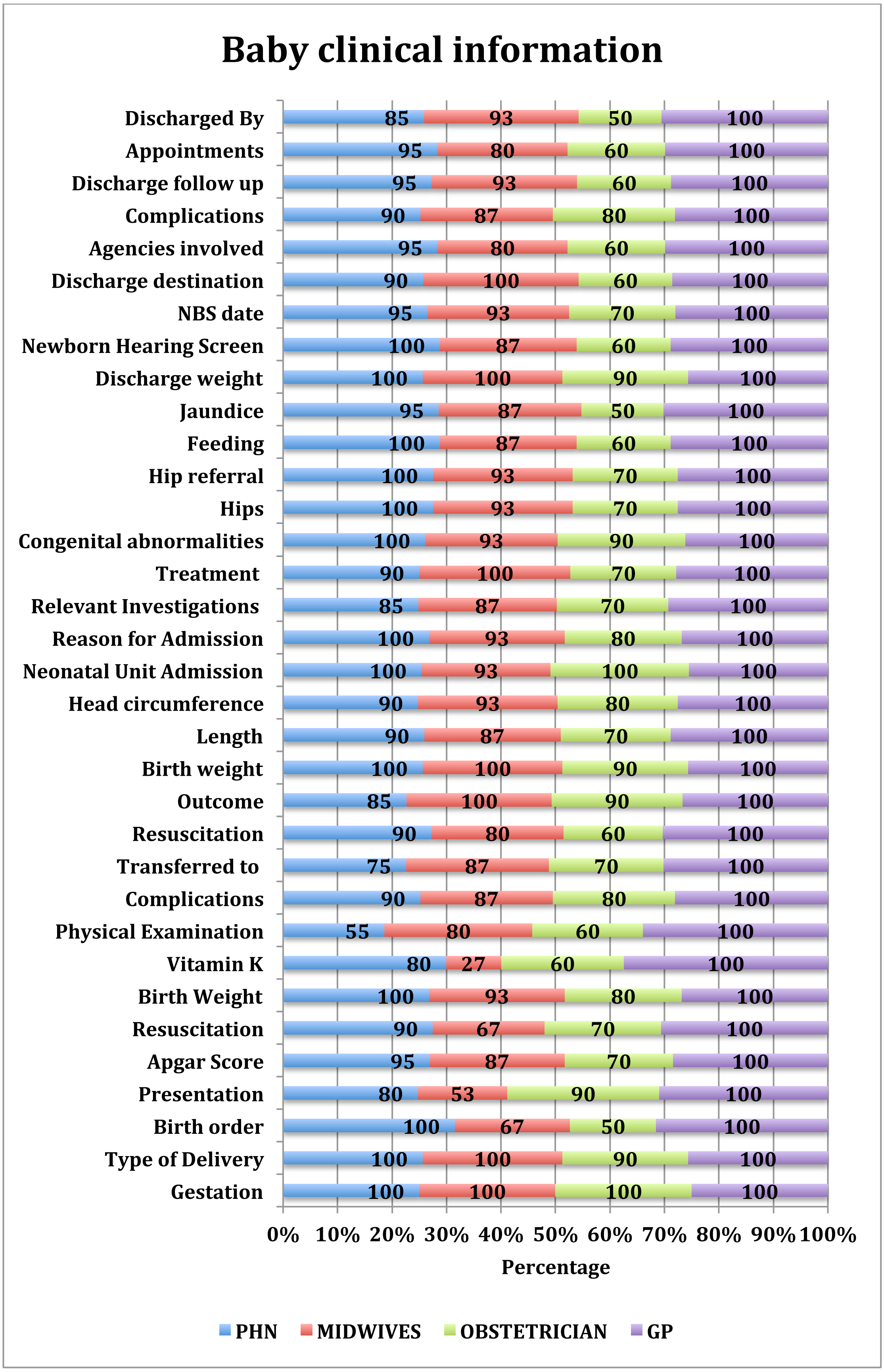

Figure 13 Mandatory data set for baby clinical information

4B.5 Questionnaire

A semi-structured questionnaire with 4 questions was distributed to the participants along with the draft discharge summary.

Q.1 How useful is it to have a standardized data set for postnatal clinical discharge summaries?

This Likert scale question offered the responses as very useful (5), useful (4), neutral (3), slightly useful (2), and not at al useful (1). 41/50 (82%) participants acknowledged that a standardized data set will be extremely useful and 7/50 (14%) respondent commented that it is useful. One participant (2%) answered neutral and another participant (2%) answered as not at all useful. It is concluded that most of the participants are in favour of a standardized discharge summary.

Q.2 What are the benefits/disadvantages of standardized postnatal discharge data set in your professional view?

This question generated many responses. Main themes emerged are as follows. A standardized discharge summary reduces the chances of missing information and provides good continuity of care. It establishes a unique method in providing maximum information. It will be quick and easy for staff to process the information in a standardised discharge summary. A standardised discharge summary provides rapid and easy access to information and improves the quality of care. This standardized discharge summary included all the patient details in an easily accessible and straight-forwarded way. The main theme emerged was that the standardized discharge summary provides uniformity of information in an easily accessible way to facilitate the plan of care. One of the GP responded that the uniqueness of the postnatal discharge summary is that it provides for future referral for mother and baby for subsequent pregnancies. It also provides further continuity of care between primary and secondary care. Another consultant obstetrician commented that a standardized discharge summary delivers consistency in analysis and research. It provides comprehensive data for better decision-making and excludes irrelevant data. PHNs remarked that all the PHNs across the country would get same type of information about mum and baby. A standardized discharge summary certainly will reduce the time used by the primary care professionals in contacting the maternity hospital for further information. It increases the consistency in information transfer and ensures the maternal and child safety. One of the PHN revealed that a standardized discharge summary reduces the issues like missing contact details or vital medical information. Also, it flags certain important issues prior to client contact such as agencies involved and mental health issues. It provides necessary information that it will be easy to identify the changes from norm. Some time mother will be very vague about the follow up details and a standardized discharge summary will definitely provide follow up information.

The disadvantages are that, it takes long time to fill it and adds extra burden to already overloaded paper work job. Too much information in a discharge summary will not serve the purpose. People will skim through the discharge summary and will miss important information.

Q.3 Have all the appropriate grouping of data items been included in this draft discharge summary?

88 % of the participants verbalized that the draft discharge summary contains appropriate grouping of data. One participant noted that the maternal medical and surgical history should be included in the discharge summary. Another participant conceded that maternal morbidity history should be included in general history.

Q.4 How do you feel about having a single discharge summary across the maternity hospital in Ireland?

82% of the respondents acknowledged that it is very useful to have a single discharge summary across the maternity hospitals in Ireland.16% of the respondent mentioned it as useful and 2% of the participants remained neutral.

Q.5 Preference for type discharge summary

Maternity care record is a complex document and it yields enormous amount of data. Discharge summaries are snapshot of this record. The participants were asked to respond what type of postnatal discharge summary they prefer for a standardized discharge summary. Table 13 illustrates that 50% (n=25) of the correspondents preferred a separate but linked discharge summary. 24% (n=12) wished to have separate discharge summary for mother and baby. 12% (6) of participants desired to have combined discharge summary. 12%(6) has “don’t know” response and 2% (1) marked “other”.

Table 13 Participant’s preference for type of discharge summary

No.	Type	PHN	Midwives	Obstetrician	GP	Total
1	Two separate DS for Mother and baby	8	1	0	3	12 (24%)
2	Two separate but linked DS for Mother and baby	10	6	7	2	25 (50%)
3	Combined DS for Mother and baby	1	3	2	0	6 (12%)
4	Don’t Know	0	5	1	0	6 (12%)
5	Other	1	0	0	0	1 (2%)

4B.6 Summary

Development of minimum data set for postnatal discharge summary is a first attempt of this kind in Ireland. Therefore, stakeholders view has prime important in obtaining relevant information. The new discharge summary shows that some of the data sets currently in use in Ireland are not available in SNOWMED – CT and variation exists among data definitions. Lack of maternity data dictionary is a major concern. This study also looked into the information requirement of all the participants and noted that significant variation exists for information need among stakeholders for mothers discharge summary. However, consistency noted among stakeholders for including data sets in baby discharge summary. Questionnaire revealed that 96% (82+14) of the respondent desires to have standardised discharge summary for maternity care and 98% of the respondent wishes to have single discharge summary programme in all maternity hospital across Ireland. A standardised discharge summary has lot of advantages and 50% of the responses showed that two separate but linked discharge summary is more useful. Next chapter is going to discuss the findings of discharge summaries from 15 maternity hospitals in Ireland in light of related published literature and research objectives.

Chapter 5A Discussion on Discharge Summaries from Fifteen Maternity Hospitals in Ireland

Key Findings

Wide variation was noted among the contents of different postnatal discharge summaries from different maternity hospitals in Ireland.

The majority of discharge summaries followed a general hospital discharge summary pattern; where in important maternity related information was missing.

Obtaining a common maternity data set was difficult due to non-uniformity among content of discharge summary formats.

5A.1 Introduction

The Quality of content of discharge summaries is always a concern as reported in literature. Few studies have looked into the contents of general hospital discharge summaries. National and International initiatives such as national standards, minimum data sets, and electronic discharge summaries are reported to improve overall quality of discharge summaries. However, only one published study has examined maternity service and discharge process (Jenkinson et al, 2014). This is the first study of its kind in Ireland, in fact in Europe, which has reviewed the content of a maternity discharge summary. This chapter discusses the findings from analysis of discharge summaries collected from fifteen maternity hospitals in Ireland using published literature.

5A.2 Discharge Summary

Fifteen out of the 19 maternity hospitals in Ireland forwarded a de-identified copy of their postnatal discharge summary. 60% of the discharge summaries were electronically generated and 40% were handwritten. Although 60% of discharge summaries were in electronic form, maternity care facilities most often sourced information for the discharge summaries from a review of women's paper records rather than from the database. This is a time consuming and non-standardized process (Pockligton & Al-Dhahir, 2011). This finding may reflect the lack of resources available for an electronic data base and electronic transfer of discharge summaries.

Significant gaps in communicating useful information by discharge summaries were evident. Most of the discharge summaries communicated the information about the mother's hospital stay rather than maternity related relevant information. The majority of the handwritten discharge summaries followed a pattern of general discharge summaries. Postnatal discharge summaries should be consistent, comprehensive, and specific to maternity services (Jenkinson *et al* 2014). Many of the discharge summaries received failed to include maternity specific data sets, therefore, were inadequate to support continuity of care in the community. The general nature of these discharge summaries shows a tendency to include the physiological aspect of labour and excluded postnatal clinical information and other psychosocial aspects of maternity care.

5A.3 Content of Discharge Summary

Irrespective of the format used, there were marked variations noted in the content of discharge summaries. Wide variation was noted whilst using same data set across the maternity hospital. For example, "type of birth" in one hospital gave the option for "live born/stillborn" while other hospitals used the option "SVD/Instrumental delivery/LSCS". Such inconsistencies will compromise both the communication and continuity of care and emphasizes the need for a nationally agreed predefined data sets and also emphasises the need for a national maternity data dictionary. National Perinatal Reporting System (NPRS, 2014) Data Dictionary, Version 1.0 is the only maternity related data dictionary available in Ireland. This dictionary provides definitions and codes for data collected within NPRS.

Discharge summaries largely omitted personal information such as next of kin's detail. This may be due to the nonexistence of this data set in "National Standard for Discharge information" (HIQA 2013[1]).

Discharge summaries included extensive information on the biophysical outcome of delivery but did not consistently incorporate information about medical, surgical, psychological or other relevant history of the mother outside of pregnancy (only 33.33% included this information). All the discharge summaries included the information about the discharging professionals name and signature. Most of discharge summaries communicated women's basic information such as parity and blood group (80%). Only 6.67% of the discharge summaries inquired about special needs in relation to physical difficulties and language requirements with regard to interview difficulties, which is crucial information for the primary care team for arranging translation services and extra special assistance to offer help to mothers. 60% of the discharge summaries excluded maternal serology. Similar findings were noted in Australia by Jenkinson *et al* (2014) study on "*Maternity Services And Discharge Process: Review Of Practice In Queensland*".

The postnatal discharge summaries largely omitted information on psychosocial wellbeing of the mother. Psychosocial information was only identified in six hospital discharge summaries. NICE guideline (2014^2) reports that between 2006 to 2008 there were 1.27 maternal death per 100,000 in UK due to mental health problems. Even though responses to treatment for mental health problems are generally good, these problems frequently go unrecognized and untreated in pregnancy and the postnatal period. Most discharge summaries did not include support services the mother had availed of antenatally and during her hospital stay. RCOPI (2013) 'Clinical Practice Guideline on venous thromboprophylaxis in pregnancy recommends that all women should have a risk assessment for venous thromboembolism at the booking visit, at every episode of hospitalisation and after delivery. The number of patients requiring postnatal thrombo-prophylaxis has increased dramatically over the past 10 years. This study showed that only 13.33% of the discharge summaries included information on postnatal use of thrombolytic agents.

This study found that the potential of discharge summaries to contribute to a variety of public health approaches was under estimated. Postnatal discharge summaries can provide information for national databases such as NPRS. Only 46.67% of mothers discharge summaries discussed feeding method and breast-feeding problems at the time of discharge. History of smoking is reported only in 26.67% of the discharge summaries.

Neonatal information in the reviewed discharge summaries tends to focus around DOB, time, sex, birth weight, and gestation. Information such as hearing screening results, jaundice, Apgar score, agencies involved, and investigations carried out were rarely included. Although neonatal resuscitation was included in 40% of discharge summaries, there was no space allocated to relay information relevant to the sick babies. Information on birth length and head circumferences was seldom included in the discharge summaries.

Group B Streptococcal infection (GBS) is one of the major causes for septicaemia in newborns. One in every 2000 newborn babies born in Ireland and UK is diagnosed with GBS infection and the majority of GBS infection is passed from mother to baby at the time of birth (RCOG 2013), yet only 13.33% of discharge summaries included the mothers GBS carriage status.

5A.4 Maternity Data Set

This analysis generated enormous maternity specific data sets. To achieve a meaningful use of these data sets, each data set should be defined using nationally acceptable data definition (AIHW 2007). In Ireland, the National Perinatal Epidemiology Centre (NPEC) and the National Perinatal Reporting System (NPRS) are responsible for reporting maternal morbidity and mortality. The NPRS data sets are the only currently available national minimum data sets in Ireland and they are specific to birth notification forms (NPRS 2013). This study found that the currently available national maternity related data sets are insufficient to define the data sets required in a postnatal discharge summary. Therefore, the second part of this study made use of maternity data sets from other countries.

5A.5 Future Work

This study found lack of uniformity in the definitions of data sets used in a postnatal discharge summary. Therefore, further investigations into maternity data sets and development of maternity data dictionaries are recommended. A descriptive space was provided in all of the discharge summaries for including additional information. Any investigation on utilisation of these spaces was beyond the scope of this study, but would be useful for further research.

5A.6 Summary

This chapter discussed the findings of content analysis of discharge summaries collected from various maternity hospitals in Ireland. A lack of uniformity in delivering quality information to the primary care team was observed in this study. It is a major concern as it questions the ability of health professionals in providing continuity of care in the community to mother and baby. A section on related future work is also included in this chapter. The next chapter 5B will be outlining the stakeholders view on minimum data sets for a postnatal discharge summary and their information requirement in maternity care. It will also discuss the need for a standardised maternity discharge summary from the findings of questionnaires filled up by the 50 participants of this study. Recommendations, future work, limitations of the study and reflection are outlined at the end and the chapter finishes with a summary.

Chapter 5B Discussion 2 Stakeholders View

Key Findings

A minimum data set for postnatal discharge summary is developed including data definitions, optionality and SNOMED-CT concept ID.

The information requirements of PHNs were ranked as the highest among 4 groups and this was done on the basis of maximum number of data inclusion and scoring.

Standardised discharge summaries across maternity hospitals in Ireland were preferred by most of the participants.

Two separate but linked discharge summaries for mother and baby is recommended by the stakeholders in view of keeping separate record for future use.

5B.1 Introduction

An important part of Maternity care involves the care of women through their transition into motherhood. It is vital that information should follow the women all the way through her patient journey. Such a flow of information should ensure that relevant, accurate, concise information is communicated across all the health care professionals involved. This chapter discusses the findings of a minimum data set for a postnatal discharge summary, information requirement of major stakeholders of maternity care, and questionnaire. This chapter discusses the findings using published literature. Achievement of objectives, recommendations, study impact, and study limitations are explained. Reflections are included at the end of this chapter.

5B.2 Minimum Data Set for Postnatal Discharge Summaries

This study of development of a minimum data set (MDS) for a postnatal discharge summary is the first study of its kind in Ireland. The academic literature search for the topics MDS and synonyms for postnatal discharge summaries for maternity care did not yield any result. However specialties such as mental health (Burgess 2012) and dental health (Ireland et al 2001) have developed minimum data sets in other countries. As there were no precedents to draw upon for developing a minimum data set for a postnatal discharge summary, this study was carried out within the framework of the *National Standard For Discharge Summary Information* in Ireland AIHW (2007) *Data development process.* Australia was the first country to look into the maternity care discharge process in 2014 (Jenkinson *et al* 2014). This study highlights the need for consensus on information requirement in a postnatal discharge summary and will be a powerful tool to improve the content quality of postnatal discharge summaries. Sketching a draft discharge summary from a review of already existing discharge summaries in Ireland and from maternity data sets from other countries was the appropriate means of accomplishing basic step for the minimum data set development. The methodology of obtaining submissions from four groups of major stake holders of maternity care with a semi-structured questionnaire and using a minimum data set development process to harmonise the data sets were used for this study. This was ideal for gaining feedback on a representative view of maternity care health professionals. Open ended and closed ended questions on the questionnaire in the draft postnatal discharge summary permitted much more in depth exploration into the data sets. If a participant agreed to include a data set in the discharge summary, the questionnaire provided optionality for mandatory, optional, and conditional agreement. On the other hand, “optionality” gives further classification to minimum data sets into basic data sets and extended data sets as described by the *epSOS* minimum data set developed by the European Union for cross border care (eHealth network, 2013).

The list of minimum data sets included two separate sections for mother and baby. The 10 headings included in this postnatal discharge summary includes demographics of mother, primary health care professionals details, admission and discharge details, previous obstetric history, general health history, antenatal clinical information, delivery clinical information, postnatal clinical information, baby demographic details and baby clinical details. The “demographic details” and “primary care professional details”, “admission and discharge details” sub-data sets are drawn from HIQA national

Guideline (2013[1]). However, the stakeholders added further sub-data sets to these headings. Including “next of kin’s details”, especially phone number perhaps indicates that the maternity stakeholders recognised that data subsets from a general discharge summary does not uniquely equate the information requirement in specialties. “Gender” data set is excluded for the “demographic details of mother” as it is solely dealing with women’s health. Although information on ‘source of referral and method of admission’ were included in the draft discharge summary in accordance with the HIQA (2013[1]) national guidelines, participants deemed these as optional information.

Previous obstetric history and general history, antenatal, delivery and postnatal clinical information data subsets are drawn from combining the result of the first part of this study – a review of postnatal discharge summaries from different maternity hospitals in Ireland – and maternity data sets from the UK and Australia. Although these subsets had strong emphasis on the professional measurement of maternity specific items, the stakeholders group brought relevant inclusion/exclusion criteria based on their forward information requirement.

Some of the sub-data sets used in this study concurs with the core set of outcome measures for maternity care developed by Devane *et al* (2007). The literature pertaining to maternity data sets is from literature over the last decade (Steer, 2002; Hawley *et al,* 2014; Ap Dewi, 2011, Knight et al, 2013).

Many inconsistencies on data definitions related to maternity care such as mode of delivery, caesarean section, pre-existing maternal medical conditions (previous history), and complications of pregnancy are reported in the literature (Knight *et al*, 2013; Joseph *et al,* 2009; Lain *et al,* 2008; Lydon-Rochelle *et al,* 2005) and postnatal discharge summary data sets. This is consistent with this present study where, data definitions for type of birth could not find a consensus on meaning through data dictionary definitions. This current study noted that meaning (data definitions) of maternity data sets is an area under-investigated and is an area, which needs to be investigated in depth.

The baby clinical details sub-data sets are very capable of communicating necessary information to the primary care team. The four groups of stakeholders reached in agreement with ease on the subsets of baby clinical information. The data sets produced by review on postnatal discharge summaries (Chapter 4B 3.2) are consistent with the newly developed minimum data set for the postnatal discharge summary.

The sub-data sets used under “antenatal, delivery, and postnatal clinical information” headings are similar to most of the National Perinatal Mortality and Morbidity Data sets. Therefore, the minimum data sets developed for the postnatal discharge summaries has the potential to support strategic planning by providing information on maternity health indicators, maternity care outcome measures, national perinatal mortality and morbidity statistics, national and international data comparisons. Using this format, clinicians could compare their performances against health improvements goals. The need for a common platform of information exchange across maternity care and primary care has become more evident with the development of a minimum data set for a postnatal discharge summary.

5B.3 Information Requirements of GPs, PHNs, Consultant Obstetrician and Midwives about the Mother in a Postnatal Discharge Summary

Discharge summaries have a vital role in the effective delivery of care of mother and baby across the hospital-community continuum. The postnatal hospital stay of a mother has been significantly reduced in the past few years due to the community multidisciplinary support. In light of this move, it is vital to explore the information requirement of major stakeholders of maternity care. No published studies were identified that looked into the information requirement of the primary care team and the hospital maternity care team in relation to postnatal discharge summaries.

This study investigated the information requirements of GPs, PHNs, midwives and consultant obstetricians from a postnatal discharge summary and these information requirements were listed under 10 subheadings. These are, demographics of mother, primary health care professionals details, admission and discharge details, previous obstetric history, general health history, antenatal clinical information, delivery clinical information, postnatal clinical information, baby demographic details and baby clinical details. Results from this study suggest that there were major differences in the information requirement of all four groups in relation to the information in mother's discharge summary. It is also noted that the majority of the participants uniformly accepted the information in the draft baby discharge summary.

According to Rowlands *et al* (2010) the information needs of the health care professionals are determined by their role or functions the care provider needs to perform in relation to the patient. This study ranked the information requirements of PHNs as the highest among 4 groups and this was done on the basis of maximum number of data inclusion and scoring. The PHNs scored to include maximum sub-data sets under the headings of demographic details, primary health care professionals details, admission and discharge details, previous obstetric history, antenatal clinical information, delivery clinical information, and postnatal clinical information. The one data subset that the PHNs didn't support was using the e-mail address of primary care professionals in the discharge summary. The "next of kin" data set evoked a very positive support and comments from PHNs and this may be due to their difficult experience in accessing the patients while on post discharge visits. It was interesting to note that previous obstetric history data sub sets were supported by more than 80% of PHNs as compared to 70% of stakeholders from maternity hospitals.

Public Health Nurses: The PHNs are the first point of contact with the mother and baby and are in the prime position to provide care in the community. In Ireland, PHNs are mandated to visit all new mothers within 48 hours of discharge from the hospital. Given the short stay in the hospital this visit has curative care effect than a preventive effect. Moreover, Ireland has a generalist PHN system, which means that PHNs offer care for all persons within their geographic area. Other countries like Norway, specialist PHNs are responsible for maternity and child care services (Glavin & Leahy – Warren, 2013). These key professionals in the community continue to provide the postnatal plan of care to the mother and child initiated in the maternity hospital. The role and scope of public health nurses has expanded in recent years to include significant number of patients requiring clinical interventions following discharge from hospitals (HSE 2011). Continuing complex care needs in the community requires constant input from maternity hospitals and other multidisciplinary teams. PHNs are the lead clinicians in continuing care needs and health promotion in the community (Hanafin & Cowley, 2005). Therefore, the information requirement of a PHN is much higher than other stakeholders due to the multi faceted roles they are required to play in the community for the care and welfare of mother and baby. It can be undoubtedly inferred that the above literature supports the findings from this study and concludes that the role and accountability of the health care professional is directly proportional to the information requirement of that professional.

In other countries like United Kingdom, the mother and baby in the community are allowed to hold the "Hand Held Maternity Care Record" sometimes up to six weeks, which benefits the primary care team for easy access of information during postnatal visits. PHNs in Ireland are more compromised in this regard as they do not have access to such records in the community and therefore a postnatal discharge summary needs to be more representative of the care given in hospital.

In other countries the mother and baby is being visited by the same team of community midwives after discharge from a maternity hospital to offer the continuity of care. In Ireland the PHNs do not have a role in the antenatal or intranatal care of the mother and this leads to a situation in which these key professionals in the community are deprived of potentially important information from hospital maternity care records. This also highlights the requirement of a more representative postnatal discharge summary.

General Practitioners: GPs followed almost the same trend as with PHNs in information requirement except feeding type and associated problems. However, the number of GP participants in this study (5) makes this result non-generalisable when comparing with the number of PHN participants (20). It is noted that primary health care professionals are in favour of including more information on mental health history of the mother in the discharge summary. This may be due to the fact that the symptoms of postnatal depression mostly appear after discharge from the hospital. The usual primary contact with the GP is at two weeks check up for the baby postnatally as laid down by the Maternal and Infant Care Scheme.

Midwives and Consultant Obstetricians: While comparing the other two stakeholders, midwives and obstetric consultants, midwives included more information in the discharge summary than obstetricians. However, the majority of obstetricians preferred including problems and treatment modalities in the discharge summaries such as antenatal, intranatal and postnatal complications, thromboprophylaxis, abdominal and perineal wound status, and reasons to admit to neonatal unit in comparison with midwives.

5B.4 Questionnaire

In this study, the views of different stakeholders on the usefulness of a standardised discharge summary, its advantages and disadvantages, and preferences for type of discharge summary for mother and baby were explored. All the participants highlighted the need for standardised discharge summaries for maternity care. The stakeholders provided many opinions regarding the advantages/disadvantages of using a standardised discharge summary. Many of the participants thought that the standardized discharge summary might reduce the chances of missing information. Similar conclusions are reported by Kripalini *et al* (2007) and Louden (2009).

A standardised discharge summary provides uniformity of information in an easily accessible manner to provide continuity of care. It also delivers consistency in analysis and research and provides comprehensive data for better decision-making and nationally and internationally comparable data sets for computing. While reflecting on the findings from previous review of literature (Chapter 2), the views of participants were also identified in the literature (Cheah, 2005; Quin et al 2009; Chen 2010;HIQA 2013[1]). The uniqueness of the postnatal discharge summary is that it provides future referral information for mother and baby for subsequent pregnancies. These views are consistent with the literature and gives an insight into the adoption of a standard discharge summary.

The complexity of a maternity health record is that the mother registers to the hospital at booking visit with one maternity record and one unique hospital number, but on discharge from the hospital there will be two health care identification numbers - one for mother and one for baby. Therefore, the participants of this study were asked to give their preference for the type of discharge summary, resulting in mixed responses. Half of the participants believed that two separate but linked discharge summaries would be ideal. A small percentage (24%) preferred a separate discharge summary for mother and for baby. Consensus in relating the health record of the mother and the baby might be a contributing factor for this response.

5B.5 Summary

This chapter discussed the findings of the stakeholders view on the development of a minimum data set for a postnatal discharge summary and their information requirement. It also discussed the stakeholders view on having a standardised discharge summary across the maternity hospitals in Ireland. The newly developed minimum data set for a postnatal discharge summary is included in the Appendix-2. An information requirement of the stakeholders depends on the role and functions; the carer has to perform for their client. The information requirement of the PHNs is much higher than other stakeholders. Next chapter 5 C will describe the context and implications of this research.

Chapter 5C Discussion 3 Context and Implications

Key Findings

The currently available maternity related data dictionaries in Ireland have to be further developed to explain the maternity data sets in use.

The newly developed discharge summary data sets shows that further investigation into the SNOMED-CT is required.

This research has the capacity to contribute to the upcoming MN-CMS national electronic health record for maternity care.

This study recommends the use of standardised discharge summary across maternity hospitals in Ireland.

5 C.1 Introduction

Maternity shared care approach between secondary/tertiary hospital and primary care team is one of the most acceptable model of care for maternity services. Health information technology plays a major role in this continuity care model by enhancing communication. The discharge summary is one of the main modes of communication. In the context of a common platform for communication, using standard data sets not only saves time but also improves the outcome. This chapter discusses the context of this study and its implications. The findings of choosing data definitions for the newly developed discharge summary using data dictionaries and selecting SNOMED clinical terminologies were discussed. Recommendations from this study and how this study achieved its aims and objectives were also described. Suggestions for future work and limitations of the study are also included in this chapter. The reflection on the entire process of this research is explained in section 10 of this chapter.

5 C.2 Context

The research on development of a minimum data set for the postnatal discharge summary explored varied under investigated areas of maternity care in Ireland. This is the first study of its kind selecting major stakeholders of maternity care as study participants in developing the minimum data set for postnatal discharge summaries. Therefore, this research is carried out in the framework of *National standard for discharge summary information* developed by HIQA 2013[1]. This research develops a minimum data set in the context of health informatics leading to the exploration of relevant data dictionaries and SNOMED-CT. To avoid data definition discrepancies, this research explored the data dictionaries available in Ireland and other countries. Being the first study of its kind, the current study harmonized the discharge summary data sets with SNOMED clinical terminologies. This ensures that the newly developed discharge summary is analogous with international maternity discharge summaries.

5 C.3 Data Dictionary

A data dictionary provides a descriptive list of names, definitions, and attributes of data elements to be captured in an information system (AHIW, 2008). A data dictionary promotes data integrity by supporting adoption and use of elements and terminology within health IT systems (Department of Health & Human Resources 2010). One of the research questions of this study is intended to check whether the newly developed discharge summary clinical terminologies were present in the data dictionaries in Ireland. The findings of this research shows that the currently available maternity related data dictionaries in Ireland have to be further developed to explain most of the data sets in the proposed discharge summary. Therefore, this study made use of the available UK and Australian maternity data dictionary definitions to explain the postnatal discharge summary clinical terminologies. Wide variations in definitions are noted in the clinical terminologies of present postnatal discharge summaries from various maternity hospitals. To suggest an example, "type of birth" in one hospital gave the option for "live born/stillborn" while other hospitals used the option "SVD/Instrumental delivery/LSCS". Such inconsistencies will compromise both the communication and continuity of care and emphasises the need for nationally agreed predefined data sets. This highlights the need for a national maternity data dictionary. National Perinatal Reporting System (NPRS-2014) Data Dictionary, Version 1.0 is the only maternity related data dictionary available in Ireland. This dictionary provides definitions and codes for data collected within the NPRS.

5 C.4 SNOMED – CT

This study utilized the already existing data sets from the postnatal discharge summaries from different maternity hospitals. As explained in Chapter 3, section 5.2, step-6, developing “new data sets” was out of the scope of this study. The result shows that some of the data sets are not a part of SNOMED-CT (Appendix 2). HIQA (2014) guideline on *Recommendations Regarding the Adoption Of SNOMED-CT As the Clinical Terminology for Ireland* proposes that adoption of standard terminology system like SNOMED-CT is essential to the implementation of the eHealth strategy including *Electronic Health Records* and *ePrescribing*. It is also essential to the delivery of a health information infrastructure based on the principle “create once use many times”. There is currently no deployment of SNOMED-CT in Ireland. However, this study provided a small glance into the status of SNOMED- CT in a postnatal discharge summary in Ireland. The purpose of this attempt was to assess the current status of terminology use in Ireland. It also proposes the need for further investigation into this area to explore the extent of maternity data sets availability in SNOMED-CT.

5 C.5 Study Implications

This study explores an under investigated area of the postnatal discharge summary and recommended a minimum data set for postnatal discharge summaries. In line with eHealth Strategy of Ireland a Maternity and Neonatal Clinical Management system (MN-CMS) is under development. In Ireland, this is the design and implementation of an electronic health record for all woman and babies in maternity services in Ireland. This study provides a positive contribution towards the development of a postnatal discharge summary in the MN-CMS project. The recommendations for the further development of a data dictionary also contribute to the national ehealth policy. This study highlighted the information requirement of major stakeholders in maternal and infant health. This not only gave the background information for developing a postnatal discharge summary but also opens the gate for further collaboration with the primary care team in developing and implementing curative, preventive, and health promotion initiatives for mother and baby. This research identifies a major gap in the information flow from the secondary/tertiary health care system to the primary care system in relation to maternity care. Furthermore, appreciation received from primary care teams for the initiative of looking into the requirements in a discharge summary from the end point user view shows that this was an area of under exploration.

5 C.6 Recommendations

To ensure the safety and support in the transition from hospital based postnatal care to community-based family and child care of mother and baby, this study proposes the following recommendations.

- To develop a standardised discharge summary template using identified minimum data set for use across maternity services in Ireland to meet the information requirements of the primary care teams to ensure continuity of care.
- To include biophysical outcomes as well as psychosocial needs of a mother in the postnatal discharge summary.
- To link the upcoming MN-CMS (Maternity and Neonatal Clinical Management System) with relevant community databases to minimise human error and maximise efficiency, in producing and disseminating a postnatal discharge summary in a timely and effective manner.
- To use a separate but linked discharge summary for postnatal discharges of mother and baby for more effective use in primary care teams, as they use a separate record for mothers and babies.
- To include extensive information specific to maternity care and to avoid using general discharge summary templates.

- To develop a national data dictionary specific to maternity care to improve data integrity and interoperability.

This study also recommends that further data development related to maternity care in line with SNOMED clinical terminology for better standardisation procedures.

5 C.7 Achievement of Aims and Objectives

The present study on “development of a minimum data set for postnatal discharge summary” achieved the predefined aims and objectives.

5 C.7.1- Aims

The first aim was to analyse and evaluate the data sets from current postnatal discharge summaries in use in maternity hospitals in Ireland and its results are described in chapter 4A.

The second aim was to develop a minimum data set for postnatal discharge summaries in order to facilitate the sharing of relevant information from maternity hospitals to community care professionals. Chapter 4B explains the result of Minimum data set development and is further described in Appendix-2.

The third aim was to examine the information requirement of the major stakeholders of maternity care in a postnatal discharge summary in Ireland. This study identified PHNs, GPs, midwives and consultant obstetricians as major stake holders of the maternity care system in Ireland and their information requirement is explained in Chapter 4B under sections 4B.2 and 4B.3.

5 C.7.2- Objectives

This study accomplished the first objective of finding frequently used information content and format difference in postnatal discharge summaries in different maternity hospitals in Ireland and is described in Chapter 4A.4.

The second objective was the identification of existing data sets available in Ireland. The present study examined the contents of discharge summaries from different maternity hospitals and identified the data sets. For easy navigation, this section is explained under Chapter 4A.5 into subsections from 4A.5.1 to 4A.5.8.

The third objective of identification of the postnatal discharge summary related maternity data sets available in Data Dictionaries in Ireland and is labelled in the “definition” sections in the newly developed minimum data set for the postnatal discharge summary (Appendix-2).

The fourth objective was to identify whether the new discharge summary data sets are in agreement with SNOMED clinical terminologies. The findings are categorised in the “SNOMED-CT” sections in the newly developed minimum data set for postnatal discharge summary (Appendix-2).

5 C.8 Future Work

This study identifies a lack of uniformity in the definitions of data set used in a postnatal discharge summary. Therefore, further exploration into maternity data sets and the development of maternity data dictionaries are recommended. A descriptive space was provided in all of the discharge summaries for including additional information. Any investigation on utilisation of these spaces was beyond the scope of this study, but would be useful for further research.

Irish literature on maternity discharge communication is scant; further study to assess the effectiveness of this minimum data set is needed for better understanding of information requirements of all the stakeholders of the maternity care system.

The current study noted that meaning (data definitions) of maternity data sets is an area under explored and is an area that needs to be investigated in depth.

This study identified scarce guidance nationally and internationally on the development of a minimum data set in line with eHealth strategies. This lack of consensus for developing a minimum data set in the literature proposes an exploration into this area.

This study performed a glance into the status of SNOMED- CT in the context of postnatal discharge summaries. The purpose of this attempt was to pair the current status of maternity related terminologies with SNOMED CT. It also proposes the need for further investigation into this area to explore the extent of maternity data sets availability in SNOMED-CT.

An investigation into the accuracy or completeness of the existing discharge summaries was beyond the scope of this study and will be a useful area for future work.

5 C. 9 Limitations of this Study

As there were no precedents to draw upon for developing minimum data set for a postnatal discharge summary, this study has to rely on the existing data sets and various national and international guidelines and frameworks. Therefore, this study utilised all available data sets in maternal and newborn health in the draft discharge summary, which resulted in a long draft questionnaire. On the other hand, providing a draft discharge summary with less information may have resulted in scarcity of information garnered.

The present study included study samples only from Dublin, and consequently may not be representative of all hospitals and primary care populations within Ireland. However, this study randomised the community care area to choose the primary care team to support the generalisation. The disproportionate sample sizes of the stakeholders also have an impact in the generalisation of the result of this study. Although this study attempted to obtain a representative sample, the noncompliance with returning the questionnaire from some stakeholders minimally affected the over all representation.

5 C.10 Reflection

The researcher, while on the discussion phase of the study, faced overwhelming comments on the feasibility of this study, but a step by step slow but certain exploratory approach helped in fulfilment of this study.

The current system of summarising maternal health information poses inadequacies and is not communicating enough information. In other words, the information requirement of the beneficiaries of a maternal discharge summary is not being reflected in the current discharge summary. Even though the plan was to develop a minimum data set, while initiating the study, the researcher developed an in-depth knowledge into the current state of the available discharge summaries. On further exploration into the topic, subtopics were added into this research. The new knowledge of developing a data set and its background requirement of information opened the door for further exploration in this area.

Even though providing a long discharge summary draft to collect the participant's opinion was daunting, the responses and comments collected reflected the long anticipated need for a change, especially from PHNs and consultant obstetricians. Contacting and obtaining the feed back from the participants took more time and effort than expected, but it helped the participants to express what they really want from a postnatal discharge summary. Exploring a single aspect of a postnatal discharge summary opened the road to many other aspects. While reflecting, the researcher feels that working on a topic from an under investigated area with no previous studies may be beyond the level of a M.Sc. dissertation majorly due to the time constraints. After an in-depth exploration into the area of postnatal discharge summaries in Ireland, the researcher feels that the following is an apt quote.

"*The journey of thousand miles start with a step*" - Lao Tzu.

5 C.11 Summary

The research on development of a minimum data set for postnatal discharge summary is an eye opener for many under investigated areas in maternity care for achieving the goals of eHealth strategy in Ireland. This chapter discussed the need for a national data dictionary for Ireland and the need for data development in maternity care in align with SNOMED-CT. The study implications and recommendations are explained. The reflection explains the researcher’s feelings on the study process. The next chapter (6) describes the summary and conclusion of this research.

Chapter 6 Summary & Conclusion

6.1 Summary

The role and functions of a primary care team in providing maternity care in the community is well understood in literature but seldom investigated in their information requirement to provide continuity of care. The review of literature on postnatal discharge summaries indicates that it is an under developed research area. This exploration shows that, research is lacking not only in quality and content of a postnatal discharge summary, but also in the information requirement of the major care partners of the long time implemented maternity shared care system.

The main aim of this study is to develop a minimum data set for postnatal discharge summaries in Ireland and the main objectives were,

1. Finding frequently used information content in postnatal discharge summaries in Ireland.
2. Identifying the existing data sets available in Ireland for postnatal discharge summary.
3. Identifying the postnatal discharge summary related maternity data sets available in Data Dictionaries in Ireland
4. Checking whether the new discharge summary data sets are in agreement with SNOMED clinical terminologies.

To accomplish these aims and objectives, a mixed research methodology of sequential explanatory research design and the development of minimum data set methodology are used. There was four major phases for this study and a minimum data set development process also was used to harmonise the data sets. In phase 1, discharge summaries are collected from all the maternity hospitals in Ireland and a quantitative analysis is carried out to identify the existing data sets. In phase 2, a draft postnatal discharge summary is developed using the existing data set and related literature review. In phase 3, the draft discharge summary and a questionnaire is posted/e-mailed to the major stakeholders of the maternity care system including

PHNs (n=20), GPs (n=5), midwives (n=15), and consultant Obstetricians (n=10) and consultation feedback is obtained. In phase 4, the questionnaires is analysed and appropriate inclusions/exclusions were made in the draft. Harmonisation of the data set was done using Minimum data Set Development Process to finalise the minimum data sets for the postnatal discharge summary.

The analysis on the discharge summaries collected from the different maternity hospitals in Ireland shows that, majority of the handwritten discharge summaries followed a pattern of general discharge summaries and failed to include maternity specific data sets. A lack of uniformity in delivering quality information to the primary care team was prevalent. It is considered as a major concern as it questions the ability of health professionals in providing continuity of care in the community to mother and baby.

The newly developed minimum data set for postnatal discharge summary is included in the Appendix 2. These minimum data sets are classified under two separate headings, one for the mother and the other for the baby. The 10 headings included in this postnatal discharge summary includes demographics of mother, primary health care professionals details, admission and discharge details, previous obstetric history, general health history, antenatal clinical information, delivery clinical information, postnatal clinical information, baby demographic details and baby clinical details.

The sub-data sets used under these headings concur with the core set of outcome measures for maternity care. Also, the sub-data sets used under “antenatal, delivery, and postnatal clinical information” headings are similar to most of the National Perinatal Mortality and Morbidity Data sets. Therefore, it is obvious that this minimum data sets developed for the postnatal discharge summaries has the potential to support strategic planning by providing information on maternity health indicators, maternity care outcome measures, national perinatal mortality and morbidity statistics and national and international data comparisons.

It has been revealed that the information requirement varies among the participants depending on the role and function they have to perform in caring for both mother and baby postnatally. This study ranked the information requirements of PHNs as the highest among the 4 groups. This may be due to the multi faceted roles they are required to play in the community for the care and welfare of the mother and the baby

One of the challenges encountered during the study was; defining the data sets using the existing maternity data dictionary (NPRS Data Dictionary) in Ireland and there was a need to utilise the maternity data dictionaries from other countries. This study recognized the necessity for including the SNOMED-CT in the minimum data set development plan. This is a bottom down approach towards the attainment of using terminology standards in maternity care and thus to contribute to semantic interoperability.

It is evident from this research that standardisation of the discharge summary across the maternity care services in Ireland would be an obvious solution to tackle information inequalities. The needs for development of a national maternity data dictionary and a new maternity data set to pair with SNOMED-CT are also highlighted. It is also recommended to link the upcoming MN-CMS (Maternity and Neonatal Clinical Management System) with relevant community databases to minimise human error and maximise efficiency, in producing and disseminating a postnatal discharge summary in a timely and effective manner.

The main limitations of this study were,

- This study has relied on the existing data sets and various national and international guidelines, as there were no precedent studies in this area.
- Study samples only from Dublin are selected and therefore, may not be representative of all hospitals and primary care populations within Ireland. However, this study randomised the community care area to choose the primary care team to support the generalisation.
- The disproportionate sample sizes of the stakeholders also have an impact in the generalisation of the result of this study. Although this study attempted to obtain a representative sample, the noncompliance with returning the

questionnaire from some stakeholders minimally affected the over all representation.

6.2 Conclusion

The National Standard for Discharge summary Information (HIQA 2013) is a standard for the general discharge summaries from hospitals in Ireland, but is insufficient to cover the specialties like maternity care. This study addresses this gap by contributing to the development of a minimum data set for a postnatal discharge summary. The findings from this study are an appropriate fit for the purpose of contributing to the new national initiative of MN-CMS, which is currently under development in Ireland. Maternity care can benefit by transferring complete, consistent, understandable information across its services. The review on all the discharge summaries collected from the different maternity hospitals shows not only the deficiency in available data sets in Ireland but also the inconsistency of information transferred to the primary care team. Using this minimum data set for postnatal discharge summaries will meet the varied information requirement of the stakeholders in maternity care.

Lack of precedent studies in the development of a minimum data set for a postnatal discharge summary provided insight into the pre-requisite researches conducted, before developing a discharge summary for health specialties. It is possible that other specialties developing discharge summaries specific to their informational needs could benefit from this study. The minimum data set development methodology used in this study is specific to developing a minimum data set using an already existing data set. The results of this study shows that this is the best fitting methodology for developing a minimum data set using an already existing data set and future studies from any category could rely on.

The development of a minimum data set for a postnatal discharge summary identified shortfalls in connecting with eHealth Ireland Strategies. To implement reform programs in eHealth, we need efficient, integrated, and timely information with good information flow (eHealth strategy for Ireland 2013). This study developed a minimum data set for a postnatal discharge summary to aid standardisation and efficiency of information-flow across maternity care in Ireland. An assessment of information requirements of major stakeholders identified the communication gap in providing good integrated care delivery with primary care. The constraints faced with the Data Dictionary and SNOMED-CT during this study identifies the problems in achieving interoperability and information flow. Adapting and implementing the minimum data set for a postnatal discharge summary, derived using data definitions, constructed on SNOMED clinical terminologies, ensures relevant, reliable, and consistent patient information flow across maternity care in Ireland.

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Appendices

Appendix 1 Minimum Data Requirements for a Harmonized European Discharge Summary

Minimum Data Requirements for a harmonized European Discharge Summary

- Patient Details(Name, Date of Birth)
- Hospital Details (including ward and Department)
- Specialist `details(Name, contact details, preferably phone or e- mail)
- Primary Health care details(name and practice)
- Admission Details(Date, mode, presenting complaint)
- Clinical information
- Diagnosis (using ICD Codes)
- Operations, treatments, procedures
- Medication Information(using international non propieratory names)
- Discharge information (date,reason,discharge diagnosis, person signing the discharge summary)
- Follow up/future management

Additional categories relevant for a cross border care scenario:

➢ Social and psychosocial support for the patient, support for the carer ➢ Contact details for close relatives ➢ Patient and career concerns/information given to the patient

(*Adapted from:- Policy* Summary 14 - Cross Border Health Care In Europe by Footman K., Knai C., Glonti K.& Mckee M. page no :2

Appendix 2 Minimum data set for Postnatal Discharge Summary

The new minimum data set prepared from the postnatal discharge summary is given below. The data set agreed by the more than 75% of the participants are included in the minimum data sets. The below table includes the data items, definition, Optionality and SNOMED-CT name and concept ID.

The data sets are selected from the analysis result of all the discharge summaries collected from different maternity hospitals in Ireland. It is evident that the maternity data sets commonly in use in Ireland are not from data dictionary. or, it is clear that most of the maternity data sets currently used in Ireland, does not have a commonly agreed definition. This may be due to the lack of electronic health record in the maternity care. The upcoming MN-CMS will be able to solve this problem to an extent.

The data definitions for this discharge summary are identified using *National Perinatal Reporting System* (**NPRS**) data dictionary Ireland), **HIQA** (2013) *National standard for Discharge Summary Information*, *Maternity Information Matrix* (**MIM**) Data Dictionary (Australia), and *Maternity service Data Set* (**UK**). It is evident that NPRS–Ireland needs to include more data sets in order to cover the postnatal discharge summary. Moreover, these data definitions needs to be updated as per internationally used data definitions. For example, the data definition of mode of delivery is defined by MIM-Australia as "*The method of complete expulsion/extraction from its mother of a product of conception in a birth event* "and the same defined by NPRS as *"Method of delivery for this birth* ". The meaning is very clear with MIM definition. UK has tremendous input into the Maternity service Data Set (UK), still requires to include more data sets into maternity data set section.

The optionality column indicates the recommendation for the inclusion data. This is the participant's choice to decide the data items to be optional or mandatory depending on their information needs. The "mandatory" data elements are mandatory and cannot be completed without these data sets. The inclusions of “optional” data element are not mandatory and can be included as required for local purposes.

This study recognized the necessity for including the SNOMED-CT in the minimum data set development plan. This is a bottom down approach towards the attainment of using terminology standards in Maternity care and thus to contribute to semantic interoperability. Some of the terminologies used in this discharge summary either could not match with SNOMED clinical terminologies or related terminology was not present in the SNOMED-CT.

The discharge summary is described in two sections

1.Discharge summary of mother

2.Discaherge summary of baby

The references used for data definitions in this discharge summary are,

1. HIQA 2013- National standard for discharge summary information.

2. NPRS- National perinatal reporting system data dictionary

3. MIM- Maternity information matrix, National data dictionary, Australian institute of health and welfare.

4. UK-Maternity service data set HSCIC, UK.

Section 1. Discharge Summary of Mother

1.1 Demographic Details

No.	Data set	Definition and source of	Optionality	SNOWMED-CT

		definition		Name and Concept ID
1.	Name (Forename & Surname) (*HIQA 2013)	A patient’s first name or given name as per birth certificate. The second part of the name, which denotes their family or marital name.	Mandatory	Demographic History details (Observable entity) Concept ID: 703503000
2.	Address (HIQA 2013)	The particulars of the place used to correspond with the patients primary health care professional.	Mandatory	Patient address (Observable entity) Concept ID: 184097001
3.	Date Of birth (HIQA 2013)	Date of birth indicating the day, month, and year when the patient was born.	Mandatory	Date Of Birth (Observable entity) Concept ID: 184099003
4.	Health Identifier/Hospital Number (HIQA 2013).	A number of codes assigned to an individual to uniquely identify the individual within an organization.	Mandatory	Identification Number (Observable entity) Concept ID: 396278008
5.	Next of kin	The name, address, and phone number of the next of kin	Mandatory	Patient’s next of kin Concept ID: 184142008

6.	Discharge Destination Address (HIQA 2013).	The patient the patient was discharged to, if the patient as not discharged to the usual address.	Optional	Not available
7.	Contact Phone Number	The contact telephone number of the patient (No nationally agreed definition available).	Optional	Not available

*HIQA (2013)- National standard for Discharge summary Information

1.2 Primary Care Healthcare Professional Details

No.	Data set	Definition	Optionality	SNOWMED-CT
1.	Name of the Primary Care Professional (HIQA 2013).	First name and surname of the primary care professional.	Mandatory	Only related search available. Referral to primary care service (procedure) Concept ID: 703978000

2.	Phone Number	The contact phone number (No nationally agreed definition available).	Mandatory	Not available
3.	Address (HIQA 2013)	The particulars of the place used to correspond with the patients primary health care professional.	Mandatory	Not available

1.3 Admission and Discharge Details

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1.	Date of Admission (HIQA 2013).	The date at which the patient was admitted to the hospital ward	Mandatory	Date of Admission – temporal observable (Observable entity) Concept ID: 399423000
2.	Reason for admission	The diagnoses	Mandatory	Reason for

	(Diagnosis)(HIQA)	established after study to be chiefly responsible for occasioning an episode of admitted patient care and conditions or complaints either coexisting with the principal diagnosis or arising during the episode of admitted patient care.		Admission (record artefact) Concept ID: 886861000000108 ***This is a UK specific concept***
3.	Date of Discharge (NPRS)	The date the patient departed from the hospital.	Mandatory	Date of discharge (observable entity) Concept ID: 442864001
4.	Discharge method (HIQA 2013).	The circumstances under which a patient left hospital.	Mandatory	Not available
5.	Date of Death (HIQA 2013).	The date and t time the patient died	Mandatory where applicable	Date of Death (observable entity) Concept ID: 399753006

5.	Postmortem Flag (HIQA 2013)	A flag to indicate whether a postmortem is to be carried out.	Mandatory where applicable	Not available

1.4 Previous Obstetric History

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Parity (*[1]MIM)	Number of times the mother gave birth to a foetus with a gestational age of 24 weeks or more regardless the child born alive or still born	Mandatory	Parity (observable entity) Concept ID: 364325004
2	Date of birth of previous children (*[2]NPRS)	Infant's date of birth	Mandatory	Date Of Birth (Observable entity) Concept ID: 184099003
3	Weeks of gestation of previous children (NPRS)	It is measured from the first day of the last menstrual period (if not available it should be based on the best clinical estimate) and is expressed in completed days or weeks.	Mandatory	Fetal gestational Age (Observable entity) Concept ID: 412726003
4	Mode of delivery of previous	The method by which the baby is delivered in	Mandatory	Not present

	children (*[3]UK)	previous children		
5	Gender of previous children	Gender identity is a person’s sense of identification with either the male or female sex, as manifested in appearance, behaviour and other aspects of a person’s life.	Mandatory	Sex of baby (Observable entity) Concept ID: 268476009
6	Condition of the baby at birth	Outcome of previous pregnancies (MIM)	Mandatory	Not available
7	Complications	Obstetric diagnosis from previous pregnancies that may present a risk or complicating factor for the current episode	Mandatory	Other complications of labour and delivery (SHRIMP Australia) ID: 200158002

[1]MIM- Maternity Information Matrix

[2]NPRS – National Perinatal Reporting System

[3]UK – Maternity Service Data Set UK

1.5 General Health History

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Age (MIM)	Age in completed years of the women giving birth	Mandatory	Age (qualifier Value) Concept ID: 397669002
2	Allergy (HIQA)	Include information about all allergies known about the patient that may put the patient at risk. The allergen, reaction, date of reaction and source of information should be provided.	Mandatory	Allergic reaction (Disorder) Hypersensitivity reaction Concept ID: 419076005
3	Mental Health	Conditions, disease or illness present prior pregnancy or arising during pregnancy which are not directly attributable to the pregnancy but may affect care during or after pregnancy or outcome (MIM)	Mandatory	Mental Health (Qualifier value) Concept ID: 720821000000105
4	Substance abuse	Mothers use of other drugs in first trimester and month prior to birth. Drugs during pregnancy include none, nicotine/cigarettes, heroin, methadone, cocaine, marijuana, other, alcohol	Mandatory	Substance of abuse (substance Concept ID: 312417001

		(MIM).		
5	Smoking during pregnancy	Did he women smoke during pregnancy? (MIM)	Optional	Cigarette smoke (substance) **Concept ID:** 102408007 Tobacco smoke (substance) **Concept ID:** 102407002
6	Alcohol (MIM)	If the women has consumed alcohol during pregnancy then the number of standard drinks per day has to be specified	Optional	Alcohol intake ((Observable entity) Concept ID: 160573003
7	Maternal Serology	If the result reported in this field affects the management of the pregnancy, report the associated condition in medical conditions or pregnancy complications.	Optional – only if positive	Positive measurement finding (finding) Concept ID: 441773004
8.	Relevant previous medical, surgical, and family history	If the result reported in this field affects the management of the pregnancy, report the associated condition in medical conditions or	Mandatory – if relevant	

		pregnancy complications.		
8	Blood group (ABO & Rhesus Blood grouping)	An indication whether a person has or does not have rhesus factor on the surface of their red blood cells, using Rh system	Optional	Group and save (procedure) Name: Rhesus blood grouping Concept ID: 165745004, Blood group finding Concept ID: 900000000000207008
9	BMI	A standard for recording obesity statistics derived from maternal weight and height	Optional	Body Mass Index Centile Concept ID: 846911000000109
10	Relevant Psycho Social risk factors	Result of prenatal psychosocial risk factors- If the result reported in this field affects the management of the pregnancy. Women's current, or history of mental health illness.	Optional- If any concern raised	Antenatal care: Social risk (situation) Concept ID: 900000000000207008 Only in SHRIMP SNOMED-CT. Not present in NPEx Antenatal mental health – not present

				in SNOMED-CT

1.6 Antenatal Clinical Information

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Infections during pregnancy (MIM)	If there was an infection, specify the evidence of infection and organism.	Mandatory	**Name:** Infectious disease in mother complicating pregnancy, childbirth AND/OR puerperium (disorder) See more descriptions. **Concept ID:** 40609001
2	Antenatal Complications (MIM)	The presence of any antenatal complications during this pregnancy.	Mandatory	**Name:** Complication occurring during pregnancy (disorder) See more descriptions. **Concept ID:** 609496007
3	*Model Of Care (MIM)	Plan of mother in choosing a maternity care provider	Mandatory	Not present

*Antenatal care this pregnancy (NPRS) - Type of antenatal care received for this pregnancy

1.7 Delivery Clinical Information of Mother

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1.	Parity (MIM).	The total number of previous pregnancies experienced by the woman that have resulted in a live birth or a still birth	Mandatory	**Name:** Parity (observable entity) **Concept ID:** 364325004
2.	Gestation (NPRS)	Gestation is measured from the first day of the last normal menstrual period. Gestational age is expressed in completed days or completed weeks. Where the date of last normal menstrual period is not available, gestational age should be based on the best clinical estimate.	Mandatory	Fetal gestational Age (Observable entity) Name: Length of gestation at birth. Concept ID: 412726003
3	Type of birth (NPRS)	Identifies event as live birth or still birth	Mandatory	Findings of birth outcome (finding) Concept ID: 3950001
4	Mode of birth	The method of complete	Mandatory	Delivery procedure

	(MIM & NPRS)	expulsion/extraction from its mother of a product of conception in a birth event (MIM). Method of delivery for this birth (NPRS)		(Procedure) Concept ID: 236973005
5	Indication for mode of delivery (MIM)	Specification of reason for instrumental or caesarean section	Optional	Not present
6	Perinial Status (MIM)	If a laceration occurs and an episiotomy is performed, Both degree of laceration and episiotomy should be performed (MIM).	Mandatory	Not present
7	Placenta, cord and Membranes (MIM)	Indicate placenta was complete or other and whether the cord has three vessels.	Mandatory	Placental findings (findings) Concept ID: 289266008
8	Estimated blood loss (Not in dictionary)	Estimated loss of blood during labour and delivery	Mandatory	Quantity of maternal blood loss Name: Estimated maternal blood loss Concept ID: 409086003

9	Antibiotics in labour (MIM)	The mother received either one or more doses of either prophylactics or therapeutic antibiotic during labour and birth	Mandatory	Not present
10	Intra partum complication (MIM)	Complications occurred during labour and delivery	Mandatory	Complications occurred during labour and delivery Concept ID: 90000000000207008
11	Presentation at birth (MIM)	The presenting part of the foetus at birth	Optional	Presentation of foetus Concept ID: 271692001

1.8 Postnatal Clinical Information

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Perinial wound suture status (Not In Dictionary - NID)	Type of suture used	Optional	Not present
2	Abdominal wound Sutures status (NID)	Status of wound. Type of suture used and date of removal	Mandatory	Not present
3	Relevant investigation and results	Relevant assessment, investigation/observations undertaken on the mother	Mandatory	Investigation result (record artefact)

	(HIQA)	during inpatient stay		Concept ID: 24641000000107. **This is a UK specific concept**
4	Anti –D (NID)	Injection of Anti-D immunoglobulin to prevent sensitization to Rhesus positive blood	Mandatory	Anti-D immunoglobulin given. Concept ID: 170459006
5	Rubella (NPRS)	Immunity to Rubella: An affirmative answer should be recorded only where there is documented evidence of a rubella antibody test.	Mandatory	Findings of Rubella Status Concept ID: 365862000
6	Group B streptococcal (GBS) status (UK)	Presence of GBS infection during pregnancy or postnatal period		Not present
7	Postnatal Thromboprophylaxis (MIM)	Any puerperium thromboprophylaxis required following birth including pharmacological and non-pharmacological intervention (e.g.TEDs)	Mandatory	Anticoagulant prophylaxis (procedure) Concept ID: 421728001
8	Feeding comment (NID)	Comments on feeding method including problems and plan of care	Optional	**Related findings** Feeding problems in new born

				Concept ID: 72552008
9	Agencies involved (NID)	Agency involved in postnatal care	Mandatory	Liaising with agency (procedure) Concept ID: 312050005
10	Postnatal Problems (NID)	Problems encountered during postnatal period not written in postnatal complications	Mandatory	Maternal distress with postnatal problems Concept ID: 200102005
11	Postnatal complications (MIM)	Medical and obstetric complication of mother occurring during the postnatal period up to the time of separation from care	Mandatory	Complications of during pregnancy, childbirth /puerperium Concept ID: 90000000000207008
12	Blood transfusion (UK)	Blood transfusion required postnatal period	Mandatory	Transfusion of blood product. Concept ID: 116859006
13	Blood transfusion reaction (UK)	Include information about adverse events occurred during Blood transfusion	Optional	Blood transfusion reaction (Disorder) Concept ID: 82545002
14	Mental health (MIM)	Conditions, diseases or illness present prior to pregnancy or arising during pregnancy	Mandatory	Mental Health (Qualifier value) Concept ID:

		which may significantly affect pregnancy outcome and postnatal care		720821000000105
15	Medication at the time of discharge HIQA)	The medication the patient intended to take after they have been discharged from hospital	Mandatory	Not present
16	Discharged with baby (NID)	Indicates whether the baby discharged home with mother	Mandatory	Not present
17	Postnatal Follow up (NID)	The relevant Follow up specific to postnatal care	Mandatory	Not present
18	Other follow up (NID)	All medical and other follow up for mother	Mandatory	Post Discharge follow up Concept ID: 406151001
19	Discharge Method (HIQA)	The circumstances under which a patient left the hospital.	Optional	Not present
20	Healthcare professional postnatal Visit (NID).	The category of healthcare professional visiting mother during immediate postnatal period e.g.- PHN, Early transfer home programmed midwife, GP etc.	Optional	**Name:** Health visitor new birth visit. **Concept ID:** 755041000000102 ***This is a UK specific concept.***

				Name: Postnatal listening visits. **Concept ID:** 883501000 ***This is a UK specific concept.***
21	Copies to (HIQA)	A list of people to whom copies of the discharge summary sent	Optional	Not present
22	Discharged by (HIQA)	Surname and job title of the person completing the discharge summary	Optional	**Name:** Discharge by person (procedure) **Concept ID:** 307838002
23	*Date and time of discharge (HIQA)	The date and time the discharge summary was completed.	Mandatory	**Name:** Date of discharge See more descriptions. **Concept ID:** 442864001

*Date of discharge (NPRS) Mother’s Date of discharge from hospital

Section 2:Baby Discharge

1.Baby Demographics

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Surname of the baby	Include Surname of the mother as per birth certificate. (From recommendation from the participants)	Mandatory	Demographic History details (Observable entity) Concept ID: 703503000
2	Date of Birth (HIQA 2013)	Date of birth indicating the day, month, and year when the patient was born.	Mandatory	Date Of Birth (Observable entity) Concept ID: 184099003
3	Hospital Number (HIQA 2013).	A number of codes assigned to an individual to uniquely identify the individual within an organization	Mandatory	Identification Number (Observable entity) Concept ID: 396278008
4	Address (HIQA 2013)	The particulars of the place used to correspond with the patients primary health care professional.	Mandatory	Patient address (Observable entity) Concept ID: 184097001
5	Gender (HIQA)	Gender identity is a person’s sense of identification with either the male or female sex, as manifested in appearance,	Mandatory	Gender (observation entity) Concept ID: 263495000

		behaviour and other aspects of a person’s life.		
6	GP name and Address (HIQA 2013)	First name and surname of the GP. The particulars of the place used to correspond with the patients primary health care professional.	Mandatory	Only related search available. Referral to primary care service (procedure) Concept ID: 703978000
7	Date and time of Discharge (HIQA)	The date and time the discharge summary was completed.	Mandatory	**Name:** Date of discharge See more descriptions. **Concept ID:** 442864001

2.Baby Clinical

No.	Data set	Definition and source of definition	Optionality	SNOWMED-CT
1	Date and time of birth (NPRS)	Infant's day of birth and time of birth	Mandatory	Not present
2	SEX (NPRS)	Sex of Infant	Mandatory	Gender (observable entity) Concept ID: 263495000
3	Gestation	Gestation is measured from the	Mandatory	**Name:** Length of

	(NPRS)	first day of the last normal menstrual period. Gestational age is expressed in completed days or completed weeks. Where the date of last normal menstrual period is not available, gestational age should be based on the best clinical estimate. Gestational age is measured or estimated according to the best method available in each case.		gestation at birth **Concept ID:** 412726003
4	Type of Birth (NPRS) Birth status (MIM)	Method of delivery for this birth (NPRS) The status of the baby at birth (live birth, stillbirth (fetal death)- MIM	Mandatory	Name: Finding of birth outcome (finding). Concept ID: 302080006
5	Birth order (NPRS)	Order of birth in multiple birth episodes.	Optional	Order of Birth at delivery (observation) Concept ID: 382391000000106
6	Presentation (UK)	The method by which a baby is delivered	Optional	Presentation of foetus (observation entity)

7	Apgar Score (MIM)	The score is based on the five characteristics of heart rate, respiratory condition, muscle tone, reflexes and colour. The maximum or best score being 10. Numerical score to evaluate the baby's condition at 1, 5 and 10 minute after birth.	Mandatory	Findings of Apgar score (finding) Concept ID: 302083008 Concept ID: 271692001
8	Resuscitation at birth (MIM)	None, suction, oxygen therapy, IPPV bag and mask, IPPV intubation, external cardiac massage.	Mandatory	Resuscitation of neonate Concept ID: 386412000
9	Birth Weight (NPRS)	The first weight of the foetus or new born obtained after birth should be given. This weight should preferably be measured within the first hour of life before significant postnatal weight loss has occurred.	Mandatory	Birth weight finding. Concept ID: 47340003
10	Neonatal Unit Admission (MIM)	A baby separated from its mother for the purposes of receiving observation, special treatment, or intensive care.	Mandatory	Not present
11	Reason for	The reason for Neonatal unit	Mandatory	Not present

	neonatal Unit Admission NID)	admission		
12	Relevant Investigations and results (HIQA 2013)	Relevant assessment, investigation/observations undertaken on the mother during inpatient stay	Optional	Investigation result (record artifact) Concept ID: 24641000000107. **This is a UK specific concept**
13	Treatment Other than routine care (HIQA 2013)	The relevant treatments that the patient received during the inpatient stay. Can include medications given while an inpatient.	Optional	Not present
14	Congenital abnormalities (NPRS)	This categorisation indicates the main disease or condition in the infant.	Mandatory	Congenital malformation (disorder) Concept ID: 900000000000207008
15	Length (MIM)	The length of the baby at birth in centimeters. Measured to the nearest centimeter from the crown to the heel.	Optional	Finding of birth length (Finding) Concept ID: 302082003
16	Head	Head circumference of the baby at birth in centimeters, to	Mandatory	Birth Head Circumference

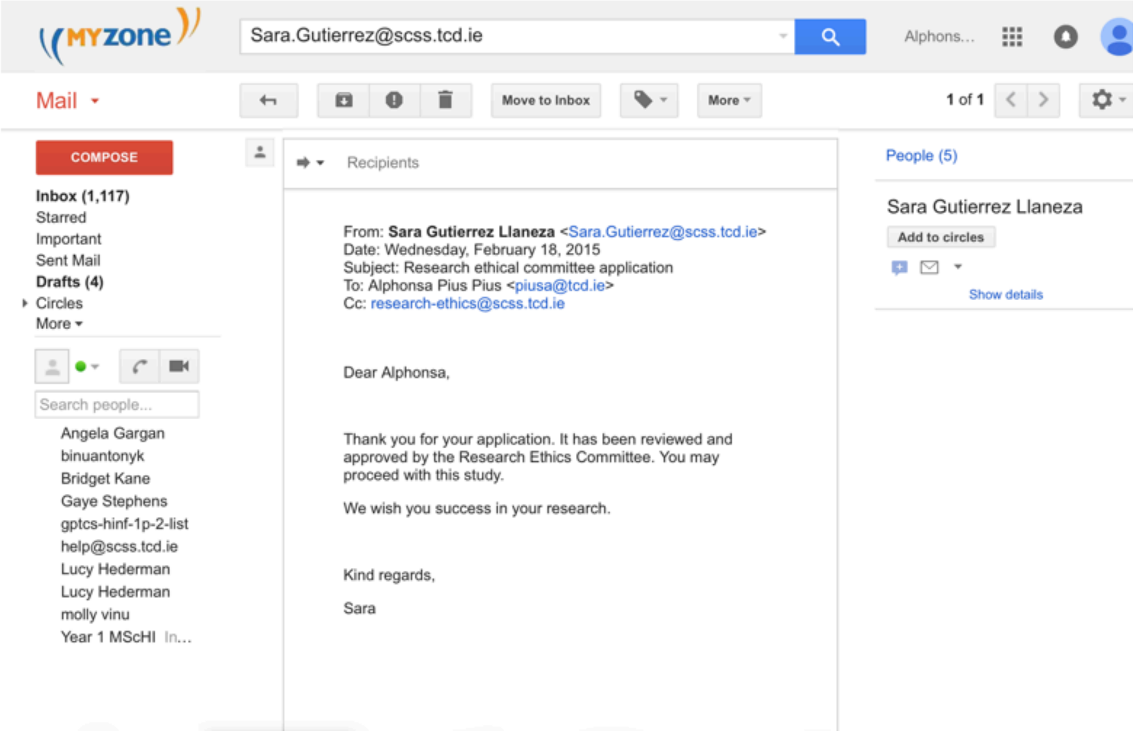
	circumference	the nearest one decimal point. WA: The measurement the nearest centimeter with the tape just above the eyebrows anteriorly and at the maximum point of the occiput posteriorly,		(observation entity) Concept ID: 169876006
17	Pertinent Clinical findings (HIQA). Newborn physical examination findings	Clinically significant information relating to the patient which the discharging health care professional wishes to convey to the primary care healthcare professional	Optional	Not present
18	Hip Examination (NID)	Clinically significant information relating to the hips of the baby which the discharging health care professional wishes to convey to the primary care healthcare professional	Mandatory	**Name:** Congenital dislocation of hip **Concept ID:** 48334007
19	Hip referral (NID)	Actions that are requested after hip examination of the newborn.	Mandatory	Not present

20	Neonatal Jaundice	Presence or absence of jaundice and actions taken	Optional	Neonatal Jaundice Concept ID: 387712008
21	Direct Coomb's test Result	Test result of Direct Coomb's test	Optional	Not Present
22	Feeding (UK)	Feeding status of a baby	Optional	Not Present
23	Feeding problem (MIM)	Problems identified with feeding	Optional	Feeding problem in neonate (Findings) Concept ID: 72552008
24	Discharge weight of baby (MIM)	The weight of the baby on discharge in grams.	Mandatory	Not Present
25	Newborn Hearing Screening test (MIM)	The day, month, and the year that the neonatal screening was performed.	Mandatory	Hearing Screening status (finding) Concept ID: 310240007 Neonatal audiological screening service Concept ID: 310009009
26	New Born	The day, month, and the year	Mandatory	New born blood spot

	Blood spot screening (NBS) date (MIM)	that the neonatal screening test is due or was performed.		screening Concept ID: 428447008
27	Discharge destination (HIQA 2013)	The patient was discharged to, if the patient as not discharged to the usual address.	Mandatory	Not available
28	Social Worker service involved	Agencies involved in the care of the baby	Mandatory	Medical Social Worker involved (finding) Concept ID: 183419004
29	Discharge follow up (NID)	All medical and other follow up for baby	Mandatory	Post Discharge follow up Concept ID: 406151001
30	Appointments	Date and time for all the arranged appointments.	Mandatory	Appointment Concept ID: 749001000000101
31	Discharged by (HIQA)	Surname and job title of the person completing the discharge summary	Optional	**Name:** Discharge by person (procedure) **Concept ID:** 307838002

Appendix 3 Research Ethics committee approval Letter, TCD

Research Ethics committee of the School of Computer Science and Statistics (SCSS) of Trinity College Dublin (Appendix 3)



From: **Sara Gutierrez Llaneza** <Sara.Gutierrez@scss.tcd.ie>
Date: Wednesday, February 18, 2015
Subject: Research ethical committee application
To: Alphonsa Pius Pius <piusa@tcd.ie>
Cc: research-ethics@scss.tcd.ie

Dear Alphonsa,

Thank you for your application. It has been reviewed and approved by the Research Ethics Committee. You may proceed with this study.

We wish you success in your research.

Kind regards,

Sara

Appendix 4 Research Ethics Committee Approval Letter, National Maternity Hospital, Dublin

An tOspidéal Náisiúnta Máithreachais
The National Maternity Hospital
Founded in 1894
Sráid Holles, Baile Átha Cliath 2 • Holles Street, Dublin 2.
Telephone: (01) 6373100. Fax: 6766623. Web: www.nmh.ie
Máistir/ Master: Dr. Rhona Mahony

9th February 2015

Ms. Alphonsa Pius
Clinical Midwife Manager
National Maternity Hospital
Holles Street
Dublin 2

Re: Development of minimum data set for postnatal discharge summary

Dear Alphonsa

This research project was approved by the Ethics Committee.

Kind Regards

Yours sincerely

Dr. John Murphy
Consultant Paediatrician
Chairman
Ethics Committee

Appendix 5 Participant's Consent Form

TRINITY COLLEGE, DUBLIN

Lead Researcher: Alphonsa Pius

Supervisor: Dr. Bridget Kane, Ph.D

Background Of Research:

Discharge summaries are vital communication tool between hospitals and primary care team. Studies shown that, low quality discharge summaries can principal reason for poor communication and causes negative consequences for patients (Kripalini et al 2007). Even though, HIQA (2013) developed a National Standard for discharge summary information, maternity care settings, needs specific requirement regarding the information they need to share with primary care team. This study is being conducted to develop a guideline minimum standard for postnatal discharge summaries to improve the quality of discharge summaries.

Procedures of this study:

This study intends to develop a minimum data set for postnatal discharge summaries.

- Initially a draft for minimum data set will be developed, after analyzing discharge summaries collected from different Maternity Hospitals in Ireland and related literature review.
- In second stage, this draft will be e-mailed to and Consultation feedback will be obtained from, Public Health Nurses, General Practitioners, midwives, and obstetricians. After the consultation feedback, appropriate inclusions/exclusions will be brought to the draft resulting in the development of a minimum data set.

The duration of this study is four months from February 2015 to 30th May 2015. There are no foreseeable risks to the participants in taking part in this study.

Publication:

Individual results may be aggregated anonymously and research reported on aggregate results.

Declaration:

- I am 18 years or older and am competent to provide consent.
- I have read, or had read to me, a document providing information about this research and this consent form. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction and understand the description of the research that is being provided to me.
- I agree that my data is used for scientific purposes and I have no objection that my data is published in scientific publications in a way that does not reveal my identity.
- I understand that if I make illicit activities known, these will be reported to appropriate authorities.
- I may also opt out of this research at any time, even if you have submitted your questionnaire you can still ask to have it removed.
- I freely and voluntarily agree to be part of this research study, though without prejudice to my legal and ethical rights.
- I understand that I may refuse to answer any question and that I may withdraw at any time without penalty.
- I understand that my participation is fully anonymous and that no personal details about me will be recorded.
- I have received a copy of this agreement.

Participants Name:

Participant’s signature:

Date:

Statement of investigator’s responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken, and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

Researcher’s contact details: piusa@tcd.ie

Investigator’s signature:

Date:

Appendix 6 Participant's Information Leaflet

You are being invited to take part in research study. Before you decide whether or not you wish to take part, you should read the information provided below carefully. You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. You should be 18 years old and should be competent to provide consent. You do not have to participate in this research if you do not wish to do so. Your participation is fully anonymous and that no personal details about you will be recorded. You may also opt out of this research at any time, even if you have submitted your questionnaire you can still ask to have it removed.

Study Title: *Development of minimum data set for postnatal Discharge summaries*

Researcher Name: Alphonsa Pius

Designation: Second year M.Sc. Health Informatics, Trinity College, Dublin

Research Supervisor Name : Dr. Bridget Kane PH.D, Trinity College, Dublin.

Introduction

This study is intended to develop minimum data set for postnatal discharge summary from maternity hospitals. In Ireland, HIQA developed a National Standard for discharge summary information. This document aims to be a generic data set and some clinical specialties such as maternity care settings, requires specific requirement regarding the information they need to share with primary care team. This study intended to improve the quality of discharge summaries by defining the content of high quality discharge summaries from maternity care settings.

What is this research project about?

This study is being conducted to develop a guideline minimum standard for postnatal discharge summaries in order to facilitate sharing of relevant information from Maternity Hospitals to Community care professionals.

Who is organizing and funding this study?

A Second Year M.Sc. Health Informatics TCD student is carrying out this research. This research is not being funded by any third party and will not yield any financial gain for the researcher.

How can you contribute?

As a part of the study the researcher seeks to get expert opinion from health professionals working in maternity care services to develop minimum data set for postnatal discharge summaries. The responses to the questionnaire are sought from Obstetricians, Midwives, Public Health nurses, and General Practitioners. You can contribute by agreeing to take part by reading the draft discharge summary and giving your expert opinion by answering the questionnaire.

What do you have to do?

If you agree to take part in this study, you will be asked to sign a consent form prior participation. You will be given a draft discharge summary to read and a questionnaire to complete. You will not be required to provide any personal data and all questionnaires will be anonymous. There will be no interviews or interruptions to your work and no further participation will be required once the questionnaire has been completed. The expected duration of the time is 20 to 30 minutes.

Who will be conducting the data collection?

The Health Informatics student who is a senior midwife, under the supervision of Dr. Bridget Kane from Trinity College (Dublin), will do the data collection.

What are the possible risks taking part in this research study?

There are no foreseeable risks to you in taking part in this study.

What are the benefits in taking part in this study?

While there are no immediate benefits to you, your participation will provide important information on discharge summaries in maternity services in Ireland. Other benefits are,

1. The minimum data set will improve the efficiency of discharge process, and assist the coders in ensuring high quality data for hospital inpatient enquiry system
2. Minimum data sets are the basis for electronic discharge summaries, which will lead to a more timely transmission of information between secondary/tertiary care and primary care and reduce the need for duplicate data entry.
3. National Benefit - The developed minimum data set from this study could be used as a national standard for postnatal discharge summaries in Ireland.

What measures will be taken to ensure confidentiality?

You will not be required to provide any personal data and all questionnaires will be anonymous.

What will happen after the data collection is completed?

The researcher will analyze the data in order to provide a descriptive understanding of the data. Anonymity will be preserved all through analysis, publication, and presentation of resulting data and findings.

How will be the information stored and used?

The information will be stored in digital form in a password-protected computer and as a written transcript in a locked filing cabinet in National Maternity Hospital**.**

How will be the information reported?

Once analysed, the information will be used in preparing a final thesis and will be submitted to a university (Trinity College- Dublin). A full report will be submitted to the National Maternity Hospital. A poster presentation will be prepared to disseminate the findings from this study.

Has the study been approved by an ethical Committee?

The study has been approved by the Ethical committee of Trinity College, Dublin and National Maternity Hospital, Holles Street, Dublin, Ireland.

Declaration of Conflicts of Interest

This study involves no conflicts of interest that would affect the participant's decision to take part or withdraw from the study at any time.

Is there provision for debriefing after participation for this study?

If the participants wish to obtain further information, pleas contact:

Alphonsa Pius: E – Mail: apius@tcd.ie

Appendix 7 Development of Minimum Data Set for Postnatal Discharge Summaries (Draft)

Questionnaire

Please find the survey questionnaire for developing a minimum data set for postnatal discharge summary. Each question is optional. Feel free to omit a response to any question. However, the researcher would be grateful if all questions are responded to. This questionnaire includes three sections.

Section 1 contains the postnatal *maternal discharge summary* with 8 subheadings as follows.

1. Demographic details
2. Primary health care professionals details
3. Admission and discharge details
4. Previous Obstetric History (Previous pregnancies -first to recent births)
5. General health history
6. Antenatal clinical information
7. Delivery clinical information
8. Neonatal information
9. Maternal Discharge

Section 2 comprises *Baby Discharge* with two subheadings.

1. Baby Demographics
2. Baby clinical

Section 3 is a questionnaire related to postnatal discharge summary

Section 1 Maternal Discharge Summary

A. *Demographic Details*

No	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional comments
1	Name (forename, Middle Name &Address)	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Address	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Date Of Birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Health Identifier/Hospital Number	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Discharge Destination Address	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Length Of Stay in current address	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
	Nationality	☐Agree	☐Mandatory ☐Optional	

7		☐Disagree	☐Conditional	
8	Next Of Kin	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (A) ***Demographic Details***, do you suggest any item that should be excluded or additional information that should be included?

B. ***Primary Care Health Care Professionals Details***

No.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item**.**	Additional comments
1	Name of the General Practitioner	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Address	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Phone Number	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

4	E-Mail	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Community care area	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (B), Primary Health Care Professionals Details Section, do you suggest any item that should be excluded or additional information that should be included?

C. Admission And Discharge Details

No.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item**.**	Additional Comments
1	Date of admission	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Source of Referral	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Method of admission	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Reason for admission	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

5	Date od Discharge	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Discharge method	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Date of death	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Post mortem flag	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (C), Admission And Discharge Details Section, do you suggest any item that should be excluded or additional information that should be included?

D. Previous Obstetric History (*Previous pregnancies -first to recent births****)***

NO.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
1	Parity	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Date of Birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
	Weeks of gestation	☐Agree	☐Mandatory ☐Optional	

3		☐Disagree	☐Conditional	
4	Type of birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Sex of the baby	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Condition of the baby	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Complications encountered during antenatal, natal and postnatal period	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (D), Previous Obstetric History Section, do you suggest any item that should be excluded or additional information that should be included?

E. General Health History

No.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
	Age	☐Agree	☐Mandatory ☐Optional	

1		☐Disagree	☐Conditional	
2	BMI	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Blood Group	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Antibodies	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Allergies	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Antenatal education	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Maternal Serology	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Diet	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
9	Smoking	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
10	Alcohol use	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
11	Substance use	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

12	On National Drug treatment program	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
13	Mental Health	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
14	Social Care	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
15	Interpreter service	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (E), general health history Section, do you suggest any item that should be excluded or additional information that should be included?

F. Antenatal Clinical Information

No.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments

1	EDD by scan	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Scan Report	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Model of care	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Parity	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Gestation	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Antenatal Complications	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Infections during Pregnancy	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Method of Induction	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (F), Antenatal Clinical Information Section, do you suggest any item that should be excluded or additional information that should be included?

G. Delivery Clinical Information

No.	Item for Discharge summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
1	Onset of Labour	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	ROM	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Amniotic Fluid status	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Intra partum Analgesia	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Antibiotics in Labour	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

G. Delivery Clinical Information continued……….

No.	Item for Discharge Summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
6	Monitoring in Labour	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

7	Type of Birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Perineum	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
9	Placenta and Membranes	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
10	Estimated blood loss	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
11	Intra partum complications	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (G), delivery clinical information Section, do you suggest any item that should be excluded or additional information that should be included?

H. Neonatal Information

No.	Item for Discharge Summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
1	Baby Hospital Number (Unique Identifier)	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Surname	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Date of birth and Time	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	SEX	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Gestation	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Type of Delivery	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Birth order	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Presentation	☐Agree	☐Mandatory ☐Optional	

		☐Disagree	☐Conditional	
9	Apgar Score	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
10	Resuscitation	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
11	Birth Weight	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
12	Vitamin K	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
13	Head to toe Examinations	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
14	Complications	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
15	Transferred to	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (H), neonatal information Section, do you suggest any item that should be excluded or additional information that should be included?

I. Maternal Discharge

No.	Item for Discharge Summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
1	Vital signs Blood pressure Temperature Pulse	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Uterus	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Perineum	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Abdominal Wound	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

5	Wound Suture	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Suture removed	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Postnatal problems	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Postnatal complication	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
9	Emotional Status	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
10	Mental Health	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
11	Breast	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
12	Feeding	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
13	Feeding comment	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
14	Lactation Support	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
	Anti D	☐Agree	☐Mandatory ☐Optional	

15		☐Disagree	☐Conditional	
16	Rubella Status	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
17	MMR given	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
18	Mode of discharge	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
19	Discharge destination	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
20	Medication at the time of discharge	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
21	Postnatal antithrombotic treatment	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
22	Relevant investigations	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
23	Blood transfusion	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
24	Any blood transfusion reaction	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
25	Discharged with baby	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

26	Postnatal Follow up	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
27	Other follow up	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
28	Agencies involved	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
29	Contraception	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
30	Cervical Smear	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
31	Discharge summary distribution	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
32	Date and time of dis charge	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
33	Discharged by	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
34	Additional comments	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (I), Maternal Discharge Section, do you suggest any item that should be excluded or additional information that should be included?

Section 2 Baby Discharge

BABY DISCHARGE

1.Baby Demographics

No.	Item for Discharge Summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item**.**	Additional Comments
1	Hospital Number	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Name	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Consultant paediatrician	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Date and time of birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

5	Date and time of discharge	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	GP name and address	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Gender	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Gestation at birth	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (1), Baby Demographics Section do you suggest any item that should be excluded or additional information that should be included?

2. Baby Clinical Details

No.	Item for Discharge Summary	Is this information to be included in the discharge summary	If you agree, please indicate the priority for this item.	Additional Comments
1	Type of Delivery	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
2	Birth order	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
3	Presentation	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
4	Apgar Score	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
5	Resuscitation	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
6	Outcome	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
7	Birth weight	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
8	Length	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
9	Head circumference	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

10	Neonatal Unit Admission	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
11	Reason for neonatal Unit Admission	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
12	Relevant Investigations and results	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
13	Treatment Other than routine care	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
14	Congenital abnormalities	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
15	Hips	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
16	Hip referral	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
17	BCG	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
18	Feeding	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
19	Feeding problem	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

20	Referral to Lactation support	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
21	Jaundice	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
22	Blood Group	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
23	Direct Coombs Test (DCT)	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
24	Discharge weight	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
25	Newborn Hearing Screen	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
26	Butler test	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
27	New Born Blood spot screening (NBS) date	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
28	Relevant Investigations and results	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
29	New Born Bloodspot screening (NBS) consent	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

30	NBS performed by	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
31	Discharge destination	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
32	Social Worker service involved	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
33	River Score/ Finnegan's scoring	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
34	Complications	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
35	Discharge follow up	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
36	Appointments	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
37	Discharged By	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	
38	Additional Comments	☐Agree ☐Disagree	☐Mandatory ☐Optional ☐Conditional	

With regard to section (2), Baby clinical details Section do you suggest any item that should be excluded or additional information that should be included?

Section 3 Questionnaire

1.How useful is it to have a standardized data set for postnatal clinical discharge summaries?

☐Extremely useful ☐Useful ☐Neutral ☐ Slightly useful ☐ Not at all useful

2.What are the advantages and disadvantages of standardized postnatal discharge data set in your professional view?

Ans:

3. Have all the appropriate **grouping** of data items as given in previous pages been included in this draft discharge summary? (See Summary Below)

Maternal Discharge	***Baby Discharge***
Demographic details Primary care health care professionals details	Baby Demographics

Admission and discharge details Previous Obstetric History (Previous pregnancies -first to recent births) General health history Antenatal clinical information Delivery clinical information Neonatal information Maternal Discharge	Baby clinical

Yes ☐ No ☐

Please comment

4.Which do you prefer?

1. Two separate discharge Summary for Mother and Baby ☐

2. Two separate but linked discharge Summaries ☐

3. Combined Discharge Summary for Mother and Baby ☐

4. Don’t Know ☐

5. Other ☐

Please Comment

5. How do you feel about the following statement?

"A single discharge Programme should be used across the Maternity Hospitals in Ireland."

Please score in a scale of 1 - 5?

Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
(1) ☐	(2) ☐	(3) ☐	(4) ☐	(5) ☐

6. Please add suggestions and amendments