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Exploring acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland: an interpretive description study.

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Exploring acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland:

An Interpretive Description Study.

Jo Lironi

MRes November 2021

Exploring acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland: An Interpretive Description Study.

Jo Lironi

This thesis submitted in partial fulfilment of the requirements of the Robert Gordon University for the degree of Master of Research.

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“Ordinary…is what you are used to. This may not seem ordinary to you now, but after a time it will. It will become ordinary”

Margaret Atwood

“Confidence begets confidence, and without confidence fruitful cooperation will not be possible.”

Albert Einstein

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Declaration

I declare that I produced the work presented in this thesis called "Exploring acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland: An Interpretive Description Study". No material in this thesis has been used in any other submission for an academic award.

Jo Lironi September 2021

Abbreviations used in the thesis

AAP	American Academy of Pediatrics
CSR	Cochrane Systematic Review
CASP	Critical Appraisal Skills Programme
DHI	Digital Health and Care Institute
GP	General Practitioner
HCPs	Healthcare professionals
KPMCP	Kaiser Permanente Medical Care Programme
LED	Light- Emitting Diode
MVP	Maternity Voices Partnership
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NICU	Neonatal Intensive Care Unit
PT	Phototherapy Treatment
PICO	Population, Intervention, Comparison, Outcome
POF	Poly Optical Fibres
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCT	Randomised Controlled Trial
RGU	Robert Gordon University
SBR	Serum Bilirubin
SERP	School of Nursing, Midwifery and Paramedic Practice Ethics Review Panel
SSC	Skin to Skin Contact
TcB	Transcutaneous Bilirubin
UK	United Kingdom
USA	United States of America

Abstract

Jo Lironi, Master of Research.

Exploring acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland: An Interpretive Description Study.

Background: Jaundice is a common condition in newborn infants turning skin colour yellow due to build-up of bilirubin. Internationally, jaundice continues to result in newborn infants' hospital admission, forcing separation of family units at the pivotal point for breastfeeding initiation and bonding.

Purpose: To explore with healthcare professionals' and parents' acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice in rural Scotland.

Design: A qualitative interview using Interpretive Description to accommodate various perspectives influencing acceptability and feasibility of a wearable device to facilitate home phototherapy treatment.

Methods: Participants were recruited via purposive sampling from one NHS board in Scotland. Semi- structured interviews were used with parental dyads (n= 4) and mothers (n= 6). Healthcare professionals (n= 9) were recruited onto two focus groups conducted in different geographical locations (an urban and regional hospital) in NHS Grampian. The Framework approach was used to thematically analyse the data. Miranda Fricker's concept of epistemic injustice, which proposes inequity due to unequal power dynamics between people or systems, provided a theoretical perspective to interpret key findings.

Findings: Although parents expressed desire for wearable phototherapy devices to facilitate breastfeeding and newborn infant's comfort, they primarily wanted home phototherapy treatment. As rather, study participants described a 'one size fit all' focus for newborn jaundice centred round quick reduction of serum bilirubin levels. Furthermore, healthcare professionals assumed parents agreed use of overhead phototherapy devices were worth the distress to mothers and newborn infants to effectively lower serum bilirubin levels and facilitate timely discharge home. Parents perceived postnatal care of newborn infants with jaundice to be paternalistic, which was interpreted by parents as healthcare professionals' lack of trust in their parental capabilities. Moreover, healthcare professionals did not trust their clinical judgement to assess and manage newborn jaundice due to fear they would be held clinically accountable for serum bilirubin levels not improving, which affected healthcare professionals’ ability to trust parental capabilities. As a result, the rural aspect of the study became inconsequential to the acceptability and feasibility of a wearable device to facilitate home phototherapy treatment for newborn jaundice.

Conclusion: Parents were willing to compromise on size, functions, and usability of phototherapy devices to facilitate home phototherapy treatment in the short term. However, epistemic injustice towards parents and midwives impacted shared decision making within care teams obstructing acceptability and feasibility of home PT, and a wearable device to facilitate home PT.

CHAPTER ONE: INTRODUCTION

1.0 Introduction

Firstly, this chapter will outline the structure of the thesis. After which, background information regarding the study will be provided to illustrate the subject and aim of the thesis. Furthermore, the researcher will present their position in the research to clarify their personal perspective.

1.1 Thesis outline

Structured into five chapters, the first introduces the research study. Thereafter, a systematic integrative literature review will be presented in chapter two. The third chapter describes methodology and methods employed for the study. Following this, chapter four will present study findings, before discussing main themes derived from research data in chapter five. This fifth and final chapter will consider study strengths and limitations, as well as recommendations for practice and research. After concluding chapter five, the thesis will end with a researcher's reflection on the study.

1.2 Background to study

Jaundice is a common condition in newborn infants, turning their skin colour yellow due to build-up of broken-down red blood cells from the liver called bilirubin (Malwade and Jardine 2014). Approximately 60% of term and 80% of preterm newborn infants develop jaundice within one week of life (National Institute for Healthcare and Excellence (NICE) 2016). When left untreated, jaundice can result in long term brain dysfunction (Michaelides 2017a). Jaundice is a common condition treated with phototherapy in response to excess bilirubin levels in blood. Phototherapy treatment (PT) is an artificial light source, and first line treatment for over 80% of newborn infants with jaundice, resulting in hospital admission lasting on average two days in otherwise healthy term newborn infants (Battersby et al. 2017). Subsequently, newborn infants are separated from mother and/or family for hospital PT treatment, which potentially impacts breastfeeding and bonding (Battersby et al. 2017).

Supporting maternal-infant bonding is beneficial to maximise breastfeeding initiation and continuation (Renfrew 2016). Establishing breastfeeding is important in order to avoid dehydration in newborn infants which is a risk factor for jaundice (Mcintyre 2020). Furthermore, bonding and breastfeeding promotes newborn infants' brain development (McNabb 2017), potentially assisting evolution into more empathetic societies (Grille 2015). Based on a 2015 systematic review and meta- analysis about brain development with breastfeeding (Horta, Loret de Mola and Victora 2015), Rollins et al. (2016) determined the economic potential associated with not breastfeeding impacts the global economy at an estimated loss of 302 billion United States Dollar per year.

Additionally, numerous health benefits from breastfeeding for mothers and newborn infants, include: reduced risk of infections in newborn infants; reduced risk of childhood leukaemia by 19%; and prevention of 20,000 deaths annually from breast cancer (Dodds 2016, World Health Organisation (WHO) 2017). Although rates of exclusive breastfeeding have increased globally, rates have remained low in most western or high-income countries (Dodds 2016). Consequently, measures to support breastfeeding need to extend beyond individual women into wider society (Rollins et al. 2016).

For this reason, collaboration between healthcare professionals (HCPs) and parents is needed to revolutionise healthcare services (Renfrew 2016). Home PT could support bonding and breastfeeding by keeping mothers and newborn infants with families (Malwade and Jardine 2014). Therefore, exploring methods to facilitate home PT is desirable. However, national evidence-based guidelines in the United Kingdom (UK) recommending management for newborn jaundice do not mention home PT (NICE 2016). In contrast, the American Academy of Pediatrics (2004) recognised home PT almost 20 years ago. Nevertheless, a Cochrane Systematic Review of randomised controlled trials (RCTs) and quasi RCTs that compared term newborn infants who received home PT to hospital PT did not find any studies meeting their inclusion criteria (Malwade and Jardine 2014). However, this thesis includes a systematic integrative review which does not solely rely on RCTs to establish what is known about home PT.

Currently, overhead or fibreoptic devices (see appendix 1 figure 1.1 to 1.4) can deliver PT. They can be powered by conventional light sources (fluorescent lamps tubes or bulbs) or light-emitting diode (LED). However, overhead devices (see appendix 1 figure 1.1) are more commonly used (Chowdhury, Hussey and Shortland 2007) to provide PT, regardless of whether powered by conventional or LED light sources. During PT, newborn infants lie naked in cots or incubators under the device and wear an eye patch for protection against lights (see appendix 1 figure 1.1). Consequently, PT using overhead devices carries side effects, namely: heat loss; fluid loss; and separation of mother and infant affecting breastfeeding and bonding (Chowdhury, Hussey and Shortland 2007). Although, PT using overhead devices can be delivered on maternity wards with newborn infants at their mother's bedside.

However, depending on the National Health Service (NHS) Board's local pathway of care it can involve admission to Neonatal Intensive Care Units (NICUs) or children's wards (Chowdhury, Hussey and Shortland 2007, Mirza, Turner and Hansen 2017), further interfering with the newly established family unit. Bearing in mind approximately 20% of Scotland's population reside in remote and rural areas (Scottish Government 2015), some families must travel over 100 miles (Van Woerden 2016) for PT. This means the separation of rural families to access PT for newborn jaundice could disproportionately isolate parents.

Alternatively, fibreoptic devices (see appendix 1 figures 1.2 to 1.4) are compact and easy to use (Mills and Tudehope 2001) thus, potentially enabling home PT, and facilitating breastfeeding and bonding (Malwade and Jardine 2014, Føreland, Rosenberg and Johannessen 2016). They were developed in the 1990s to provide effective PT for newborn jaundice, whilst reducing side effects associated with overhead devices (heat loss, fluid loss and separation of mother and infant). The devices include a fibreoptic pad that transmits light from a source via optical fibres, and a covering for the pad which is disposable (see appendix 1 figures 1.2 to 1.4). When they were initially developed, they were powered by a conventional light source (Tudehope 1995). However, a Cochrane Systematic Review including 24 high quality RCTs or quasi RCTs (Mills and Tudehope 2001) found PT using a conventional light source with overhead devices more effective at reducing serum bilirubin (SBR) levels in term newborn infants than fibreoptic devices, therefore potentially influencing HCPs' decision to use overhead devices to deliver PT.

Furthermore, since the Cochrane Systematic Review (CSR) by Mills and Tudehope (2001) PT using LEDs has been introduced. Compared to phototherapy devices using conventional fluorescent lamps tubes or bulbs, LEDs require less power and produce less heat providing portability and endurance (Kumar, Chawla and Deorari 2011). As a result, they could be a safe source of light for home PT. Moreover, a CSR (Kumar, Chawla and Deorari 2011) including six RCTs of moderate to good quality found PT via overhead devices powered by LEDs to be comparatively successful at reducing SBR levels as PT using a conventional light source. Although PT using LEDs has existed since the turn of the 21st century (Kumar, Chawla and Deorari 2011), technological developments in phototherapy devices such as battery-operated flexible mattresses (Jimenez, Vilcahuaman, et al. 2016), support further research into its potential use for home PT.

Additionally, computer science has produced smaller but more complex technology that can be worn (Junata and Tong 2018). For example, wearable technology aimed at extremely premature infants in a NICU setting has been developed to remote real time monitor neonatal vital signs (Chen et al. 2010, Di Rienzo et al. 2005). Moreover, wearable technology is portable and not limited to static environments (Junata and Tong 2018). Smart textiles are developments in wearable technology integrating functioning technology into clothing (Junata and Tong 2018). Therefore, designing wearable technology for newborn infants' comfort and access for breastfeeding, whilst integrating a functioning LED light source able to perform PT, could facilitate home PT whilst supporting bonding and breastfeeding (see appendix 1 figure 1.5). Although lowering infants' serum bilirubin (SBR) levels is the primary objective of PT for newborn jaundice (National Institute for Healthcare and Excellence (NICE) 2013, Abraham et al. 2015), there is potential for maximising outcomes beyond lowering SBR levels to include breastfeeding and bonding (Francis and Byford 2011).

1.3 Study rationale

In short, hospital admission for PT due to newborn jaundice disrupts newly established family units at the pivotal point for bonding and breastfeeding initiation, and potentially isolates rural families from their support network.

Additionally, developments in LED powered phototherapy devices, and wearable technology suggests technological ability to create a wearable phototherapy device. As a result, the current study aims to explore use of wearable phototherapy devices to facilitate home PT in rural settings, and potentially identify alternative outcome measures of PT for newborn jaundice, such as breastfeeding and bonding.

1.4 Locating oneself in the study (Coffey 1999)

Primarily I identify as a midwife. Having spent almost a decade working clinically it is the role I am most familiar with. Since moving into academia, I have adapted to the role of midwifery educator. However, it is a role I have an inner sense of conflict towards. Midwifery involves practical skills I no longer maintain in clinical settings. Being in education challenges my concept of what it means to be a midwife.

At times I feel I am masquerading as a midwife because I am teaching a role I no longer practice clinically. Visiting students and colleagues in clinical areas as a practice education lecturer has not mitigated my feelings of estrangement between midwifery clinical practice and education. Although a dichotomy between practice and theory prevails in midwifery, research has potential to bridge the division.

For example, as an educator I feel alienated from clinical midwives because 'educator' implies expertise in a role I no longer practice clinically. Clinical midwives are the experts of clinical midwifery. In contrast, as a researcher I feel more akin to clinical midwives because by understanding aspects of practice I can support colleagues and help to inform improvements in care. Whilst working as a midwife in the NHS my ability to make a difference felt challenged by women, by colleagues and the system of care. To be more precise, I consider there to be cultural issues in midwifery individual midwives do not aim to perpetuate (Lironi 2017), such as emphasis on hospital-based skills. However, my experience suggests there is a process of socialisation during midwifery training and after registering as a newly qualified midwife that potentially inhibits systemic change. Alternatively, research can offer potential collaboration with clinical colleagues to support transformation in healthcare and this has underpinned my approach to this study.

For half of my clinical career, I was a rotational midwife in obstetric units and the remainder was spent as an integrated midwife in a rural maternity unit in Scotland. This study is a consequence of my clinical experience as a midwife, although time has allowed me to reflect on the experience.

In the rural maternity unit where I worked, we had consultant obstetricians but no paediatricians or neonatologists. As a result, newborn infants requiring specialised care were collected by the national transport team and taken to the closest neonatal unit with available cots. On one occasion a couple left to meet their newborn infant on arrival at the neonatal unit. However, their newborn infant did not arrive at the neonatal unit and the parents watched their newborn infant die over video conferencing in the arms of the grandparents. In the aftermath of the newborn infant's death the entire community grieved and with grief came the need for blame. Although midwives in the community were held in esteem, it felt like we were demonised overnight. Consequently, the community was polarised into those supporting the midwifery unit and those against the midwifery unit promoting 'dichotomous thinking' resulting in the distortion of truth (Sherwin 1988). Although the newborn infant did not die because of newborn jaundice, the experience is intrinsic to this study. The family, midwives and wider community are still living through that reality. On reflection I think I have felt guilt about leaving the local community and moving into a new area of midwifery and onto a new chapter of my life.

I appreciate I would have been too emotionally involved in the geographical area for this study to be based within the NHS Board where I worked. In other words, I have never worked as a clinical midwife within the NHS Board in which this study is set. Although there will be similarities between the clinical areas, this separation has provided me objectivity alongside my clinical experience which has afforded me the ability to empathise with HCPs which supports communication.

In addition, I started my master’s in research almost two years after becoming a midwifery educator. Time has allowed me to transition from a clinical midwife and adopt a new role and identity as a midwife. In this study I transition into a researcher. As such, I will continue to reflect upon my role as a researcher and as a midwife to remain separate from the study participants. However, the greater challenge is distancing myself from identifying with the experience of living and working rurally as opposed to the role of the midwife.

From my experience, there was inequity in the distribution of healthcare resources in Scotland culminating in people from rural locations travelling long distances to access maternity and neonatal services (Lironi 2017). Since newborn infants with jaundice under PT only require temperature checks and monitoring of serum bilirubin levels, I perceived home PT as a possible service improvement. As a result, I chose to consider newborn jaundice in this study because it is a common condition which separates families for PT. However, if treated in an appropriate manner it is not life threatening. Consequently, this study has the potential to inform strategies to help families from rural areas to remain together during PT for jaundice. Furthermore, I regarded home PT to offer benefits to HCPs because it could reduce hospital admissions. Moreover, I considered a wearable phototherapy device could facilitate home PT.

However, the study was likely to have a greater impact on me because I was going to explore potential service improvements to a common episode of care. For instance, this study highlights a common episode of postnatal and neonatal care (PT for newborn jaundice) that could be transformed to keep families together. At the outset I accepted families and HCPs might be disinterested in a wearable device to facilitate home PT. Regardless, I explored their understanding and experience of PT for newborn jaundice. In short, time has afforded distance to heal from my experience in rural healthcare. Furthermore, it has allowed me to consider my relationship to the study and develop self-awareness. Continuing to reflect upon my situation gives me the ability to pursue this research study.

1.5 Summary

To conclude this first chapter of the thesis, newborn jaundice is a common condition in newborn infants. Furthermore, phototherapy is first line treatment for newborn jaundice which is routinely delivered in hospital. Although PT can be delivered at the maternal bedside, hospital PT can create division within families, particularly for families living rurally. Moreover, the process of PT separates newborn infants from mothers (see appendix 1 figures 1.1 to 1.2). As a result, hospital PT potentially obstructs family bonding and establishment of breastfeeding. Although, lowering infants serum bilirubin (SBR) levels is the primary objective of PT for newborn jaundice (Abraham et al. 2015, National Institute for Healthcare and Excellence (NICE) 2013), there is potential for maximising outcomes beyond lowering SBR levels (Francis and Byford 2011). In the next chapter of this thesis, findings of the systematic integrative literature review will be presented. The aim of the integrative literature review was to determine use of wearable phototherapy devices in facilitating home PT, though synthesising the evidence base related to home PT and wearable phototherapy for treatment of newborn jaundice. The intention was to minimise disruption to families from hospital admission, in support of bonding and breastfeeding.

CHAPTER TWO: LITERATURE REVIEW

2.0 Introduction

This chapter presents the systematic integrative literature review and details of the systematic process used to identify and appraise the current research base. To recap, jaundice is a common condition in newborn infants turning skin colour yellow due to a build-up of bilirubin. Phototherapy is first line treatment for over 80% of newborn infants with jaundice. Lowering newborn infants' serum bilirubin (SBR) levels is the primary objective of phototherapy treatment (PT). Internationally, jaundice continues to be a common reason for newborn infant hospital admission, forcing separation of families to facilitate treatment at the pivotal point for breastfeeding initiation and bonding. The purpose of this systematic integrative review was to determine use of wearable devices in facilitating home PT in rural settings and explore parents and healthcare professionals (HCPs) experience of home PT. Therefore, synthesising the evidence base related to wearable and home PT for newborn jaundice.

Firstly, this chapter states the research questions forming the basis of the review, before explaining the review design which followed an integrative review procedure. Findings report the use and experience of home PT. Furthermore, findings revealed types of phototherapy devices used at home, and the impact of support and technology to facilitate home PT. Significance of the review findings will be discussed prior to acknowledging study strengths, limitations, and areas for further research. In addition, this chapter will present recommendations for practice. Finally, the systematic integrated literature review concludes, and the chapter summarised.

2.1 Research questions

The following questions formed the basis of the review:

1. What is the use of home and wearable PT for newborn jaundice in rural settings?
2. What is the experience of parents and healthcare professionals in caring for newborn infants receiving home PT for newborn jaundice?

2.2 Research design

Integrative review methods were chosen for not solely relying on RCTs. Therefore, the review was able to synthesise evidence from qualitative, quantitative, and mixed methods studies irrespective of research design to address relevance to practice of a wearable device to facilitate home PT. Conducting this review involved: identifying the problem; searching the literature base; extraction and evaluation of journal articles (see appendix 2); data analysis; and synthesis and presentation of findings (Cooper 1982, Whittemore and Knafl 2005). Following integrative review procedure (Cooper 1982, Whittemore and Knafl 2005) appraisal tools (see appendix 3) were used from Critical Appraisal Skills Programme (CASP) to evaluate the literature. The methods of this review are reported in consistence with PRISMA guidance for systematic reviews (Page et al. 2021), enhancing study's quality and rigour (Bryman 2016). The study protocol has been published by PROSPERO (Lironi, Grant and Kennedy 2019), registration number: CRD42019157824 (see appendix 4).

2.3 Identifying the problem

The search strategy tool of PICO (Population, Intervention, Comparison and Outcome) was employed to exercise a comprehensive search of the literature base. Key search terms developed by PICO are presented in table 2 section 2.4 (Rees 2016, Methley et al. 2014).

2.4 Table 2. Search strategy

Key Search Terms
Search strategy tool
• Population (mother* OR famil* OR parent*) (remote OR rural OR isolat*) (newborn OR neonat* OR baby OR infant) (hospital* AND risk*)
• Intervention (PT AND hospital) (remote OR rural OR isolate*) (newborn OR neonat* OR baby OR infant*) (staff* OR nurs*)
• Comparison (PT AND wearable*) (stress OR cop* OR stress reduction OR stress management) AND Breastfeed* (Bond* AND attach*)
• Outcome (PercePTion* OR view* OR experience*)
Databases
• CINAHL; Medline; Scopus; and Web of Science
Searched
• Title; abstract and keyword

Alternative search strategy tools to PICO have been identified as generating lower number of search hits, resulting in potentially missing relevant articles (Methley et al. 2014). Journal articles employing quantitative, qualitative, and mixed methods irrespective of research design were included. There was no limitation placed on geographical origins of journal articles. Peer reviewed journal articles published in English between 1st January 2000 to 10th May 2021 are included in the search. The timescale for this review started at the turn of the century because it was identified as a period when light- emitting diode (LED) PT began to be used commonly (Kumar, Chawla and Deorari 2011). Moreover, technological developments in phototherapy devices utilising LED PT, such as battery-operated flexible mattresses (Jimenez, Vilcahuaman, et al. 2016) support research into LED PT for use at home (Snook 2017). Additionally, it ensured contemporary journal articles related to use of a wearable device in facilitating home PT.

2.5 Searching the literature base

The systematic search strategy involved four databases (see table 2 section 2.4), chosen after discussions with Robert Gordon University's (RGU) liaison librarian and review team, because they were judged to yield relevant studies. An ancestry search of reference lists was performed on journal articles included in the review, though generated no new articles.

2.6 Table 3. Inclusion/ exclusion criteria

Inclusion / exclusion criteria
Inclusion criteria
Types of studies:
• Primary qualitative studies
• Primary quantitative studies
• Mixed methods studies
Types of participants:
• Midwives
• Neonatologists
• Newborn infants with jaundice
• Nurses
• Parents
Studies must:
• Relate to and be able to answer the research questions.
• Be published from 1st January 2000 to May 10th, 2021.
Exclusion criteria
• Non- peer reviewed research studies.
• Published in a language other than English.
• Systematic reviews, pilot studies, discussion papers, editorials, conference papers, opinion papers and thesis.

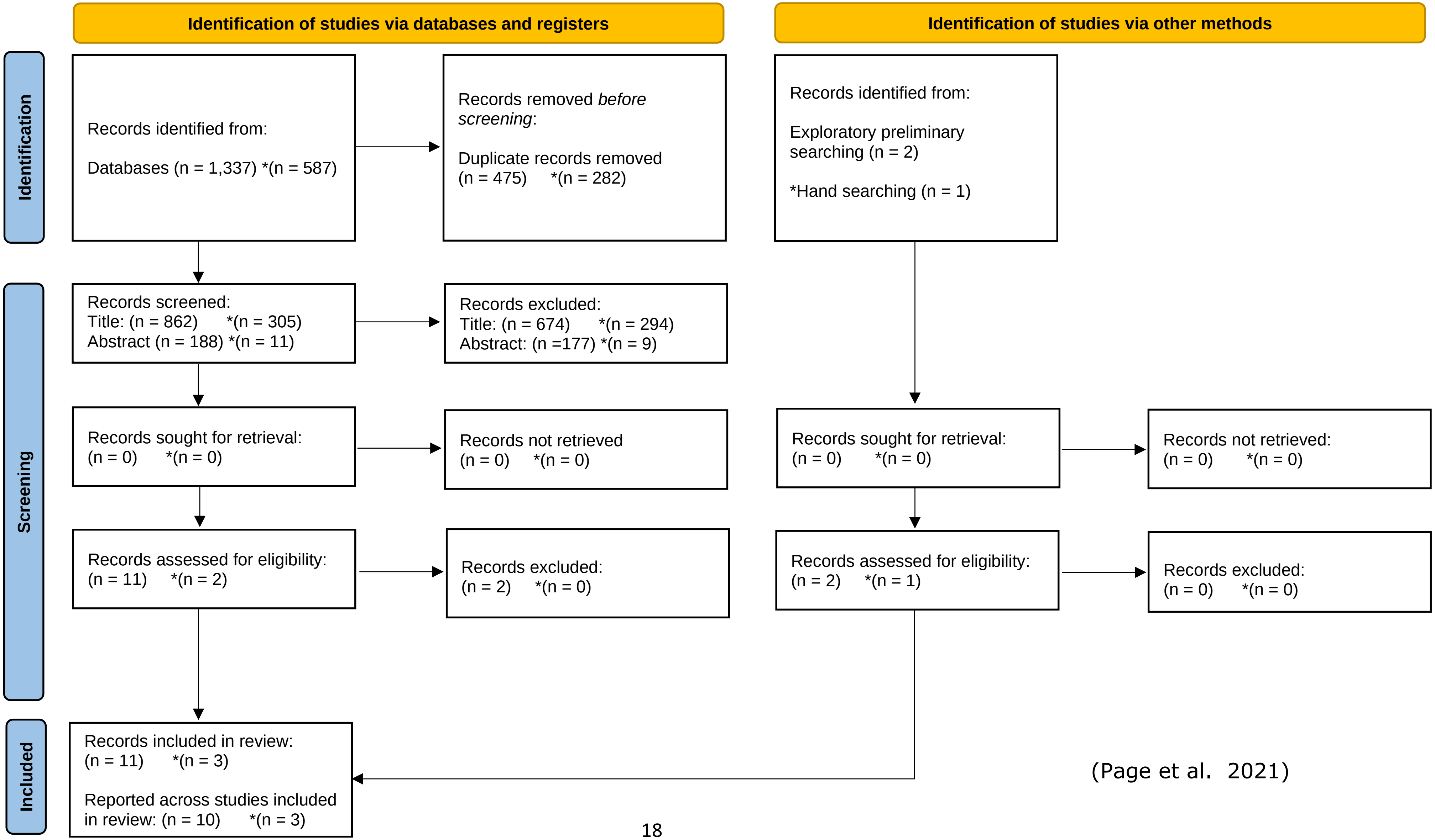
2.7 Extraction and evaluation of data

This search strategy resulted in 13 studies reported over 14 records for full- text assessment (see table 4 in appendix 5, and figure 2 section 2.8), because one RCT produced two journal articles (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019). When reading the journal articles the researcher made extensive notes which were used to assist extraction of data into categories and codes. This involved a template (see appendix 2) developed by the research team to extract data from each journal article, and collate results and findings related to the research questions forming the basis of this review (Lucas et al. 2007).

Details regarding study design and methodology were extracted and assessed for quality and rigour using the appropriate checklist developed by CASP (2021). CASP checklists (2021) provided a systematic approach to appraise trustworthiness of articles identified through the study selection process. Each study included in this review has been summarised, with study methods identified, and critical appraisal performed and is presented in table 4 (see appendix 5).

Quality of studies included in the review varied, however: the previous chapter identified up until 2014 there had been a paucity of studies comparing home and hospital PT for newborn infants with jaundice. Since then, results from RCTs have been published (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019, Pettersson et al. 2021). Furthermore, qualitative research (NICE 2013) exploring mothers’ and healthcare professionals’ (HCPs) experience with newborn jaundice and home PT should be considered prior to developing complex interventions (Medical Research Council (MRC) 2008), such as a wearable device to facilitate home PT. Consequently, the research team agreed no studies be excluded from this review based on quality. Two of the studies included were part of service evaluations, one quantitative (Noureldein et al. 2021) and one qualitative study (Walls et al. 2004). Most studies included in this review were moderate to low quality, however: two high quality and well conducted RCTs with transferable findings are included (Sardari, Mohammadizadeh and Namnabati 2019, Pettersson et al. 2021) (see appendix 5).

2.8 Figure 2. PRISMA diagram



(Page et al. 2021)

2.9 Data analysis

Journal articles were analysed thematically to facilitate use of heterogenous studies and potentially generate further research hypotheses (Lucas et al. 2007). In addition, quality and limitations of studies included in the review have been clearly identified (by the process described in section 2.7) and presented in table 4 (appendix 5), acknowledging significance of methodological rigour. The researcher categorised information identified from the journal articles into codes. Following coding, themes identified in each study were synthesised into final themes, involving an iterative process with the data and research team (Lucas et al. 2007). An audit trail was maintained, and the research team worked with and refined the themes until consensus was achieved.

2.10 Findings

The search strategy from February 28th, 2019 yielded 1, 337 records and are presented in PRISMA format (Page et al. 2021) in figure 2 (section 2.8). Duplicates were removed (n= 475) then titles screened for relevance by the researcher, reducing the number of identified records to 188. Subsequently, three members of the research team separately screened titles and abstracts of records identified, excluding 177 (see table 3 section 2.6 for inclusion and exclusion criteria). Although 11 records were identified for full- text assessment, two were excluded due to full- text unavailability in English (Khatami and Soltani 2007, Uslu et al. 2012). A further two records (Walls et al. 2004, Adlina et al. 2007) were identified through exploratory preliminary reading and screened by the research team for full- text assessment. Consequently, the initial search strategy yielded 11 records from 10 studies to be included in this review.

A search update[1] was performed on May 31st, 2021 yielding 587 records and are presented in PRISMA format (Page et al. 2021) in figure two (see section 2.8). Duplicates were removed (n= 282) then titles screened for relevance by the researcher, reducing the number of identified records to 11. Subsequently, three members of the research team separately screened titles and abstracts of records identified through the search update excluding nine, resulting in two records for full- text assessment. A further record (Chang and Waite 2020) was

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[1] Identified by asterisk in figure two.

found through hand searching and screened by the research team for full- text assessment.

As a result, a total of 13 studies reported across 14 records were included in this review. One RCT produced two records, both included in the review. Literature originated from four continents, which included: The Middle East (n= 2); Asia (n= 1); Europe (n= 5); and North America (n= 6). There were ten quantitative studies (reported over 11 journal articles) found and included in this review, including: two RCTs (Sardari, Mohammadizadeh and Namnabati 2019, Pettersson et al. 2021, Namnabati, Mohammadizadeh and Sardari 2019); three retrospective studies (Escobar et al. 2005, Chang and Waite 2020, Adlina et al. 2007); and two observational studies (Bhutani et al. 2006, Noureldein et al. 2021). In short, quantitative studies focused on management of newborn jaundice with reference to provision of home PT (Escobar et al. 2005, Bhutani et al. 2006, Chowdhury, Hussey and Shortland 2007, Chang and Waite 2020, Noureldein et al. 2021), and effectiveness of home PT (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007, Pettersson et al. 2021, Namnabati, Mohammadizadeh and Sardari 2019). Additionally, one tested yarn thickness, weave pattern and yarn density to create a light emitting fabric (Quandt et al. 2017), and one used a survey to identify the model of postnatal care most likely to reduce hospital admissions for newborn jaundice (Goulet et al. 2007). Three qualitative studies exploring maternal experience of home PT were identified and included in this review (Brethauer and Carey 2010, Hannon, Willis and Scrimshaw 2001, Walls et al. 2004).

Four themes were identified to determine the use of a wearable device in facilitating home PT. These themes included: use of home PT; PT devices used at home; experience with home PT; and support and technology.

2.10.1 Use of home phototherapy treatment (PT)

The first theme determined use of home PT (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019, Chowdhury, Hussey and Shortland 2007, Bhutani et al. 2006, Adlina et al. 2007, Walls et al. 2004, Noureldein et al. 2021), and management of newborn jaundice which impacted rates, and trauma, (Brethauer and Carey 2010) of readmission to hospital (Escobar et al. 2005, Goulet et al. 2007, Chang and Waite 2020, Pettersson et al. 2021).

Across the UK, 13% of Neonatal Intensive Care Units (NICUs) (n= 160) were identified by lead paediatricians as being able to provide home PT, though it did not state how many offered and delivered home PT (Chowdhury, Hussey and Shortland 2007). Similarly, over a ten- year period in the United States of America (USA) 15% of newborn infants (n= 31, 059) received home PT (Bhutani et al. 2006). During this period paediatricians did not promote use of home PT, for reasons not stated (Bhutani et al. 2006). However, two recent studies (Chang and Waite 2020, Pettersson et al. 2021) revealed paediatricians only supported parents they ‘trusted’ with home PT, suggesting it was not offered to everyone clinically eligible. The criteria on which they assessed parents as trustworthy were not identified.

Similarly, despite paediatricians not recommending home PT over concerns with lack of training for parents, it was reportedly common in Iran, although these authors did not state the incidence of home PT nationally (Namnabati, Mohammadizadeh and Sardari 2019, Sardari, Mohammadizadeh and Namnabati 2019).

Alternatively, 98% of families (n= 1297) using home PT in the Klang Valley, Malaysia were referred by paediatricians (Adlina et al. 2007). High costs for hospital treatment due to private healthcare may have impacted referral rates for home PT, and uptake by parents (Adlina et al. 2007).

In Scotland, a regional home PT programme was developed and assessed (Walls et al. 2004). Home PT was accepted by 78.5% of parents offered it (n=28), proving to be popular with parents when available. Likewise, feedback about a regional programme in England affirmed home PT’s popularity stating (if required again) 98% of parents included in the study (n= 100) would opt for home over hospital PT (Noureldein et al. 2021).

Moreover, in the USA 34.3% of readmissions to hospital for newborn infants (n= 33,276) of all gestations was due to jaundice, making it the most common reason (Escobar et al. 2005). Readmission to hospital for jaundice was significantly increased from units not providing home PT ($p<0.0001$) for newborn infants equal to or greater than 34 weeks gestation at birth (Escobar et al. 2005). In support of this, the retrospective study from the USA of newborn infants born at 35 weeks gestation who had home PT (n= 1324) found 2% (n= 25) required hospital readmission (Chang and Waite 2020). Similarly, 4% (n= 3) of healthy term newborn infants (n= 147) allocated to home PT (n= 78) in the Swedish RCT comparing hospital and home PT required readmission to hospital (Pettersson et al. 2021). Likewise, the model of postnatal care in Quebec to offer home PT (n= 201) had no readmissions to hospital for newborn jaundice (Goulet et al. 2007).

However, readmission to hospital after home PT could be low because only 28% of Chang and Waite's (2020) cohort (n= 376) had bilirubin levels equal to or over American Academy of Paediatrics (AAP) (2004) criteria recommending hospital PT. Although 95% (n= 140) of participants included by Pettersson et al. (2021) met AAP (2004) criteria for hospital PT, of which 4% were readmitted to hospital.

Therefore, availability of home PT avoided readmission to hospital for jaundice in USA, Canada, and Sweden (Escobar et al. 2005, Goulet et al. 2007, Chang and Waite 2020, Pettersson et al. 2021). Furthermore, home PT could prevent maternal trauma of newborn readmission to hospital (Brethauer and Carey 2010). Although it is unclear why, home PT was not widely supported by lead paediatricians (Chowdhury, Hussey and Shortland 2007, Bhutani et al. 2006, Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019). Studies included in this review evidence home PT practiced sporadically in six countries across four continents, and suggest it was offered at paediatricians' discretion.

2.10.2 Phototherapy devices used at home

In addition to determining impact of paediatric practice on use of home PT, findings in this review identified phototherapy devices and their capability to treat newborn jaundice at home (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007, Walls et al. 2004, Chowdhury, Hussey and Shortland

2007, Quandt et al. 2017, Chang and Waite 2020, Pettersson et al. 2021, Noureldein et al. 2021).

The clinical trial of newborn infants with jaundice (n= 64) (Sardari, Mohammadizadeh and Namnabati 2019) using overhead phototherapy devices (see table one figure 1.1), concluded no significant difference in reduction of SBR levels (p>0.05) between hospital (n= 32) and home (n= 32) PT. There was no significant difference in duration of PT for both groups (p>0.05), with mean duration of PT being two days (Sardari, Mohammadizadeh and Namnabati 2019). Additionally, treatment failure between home (n= 32) and hospital (n= 32) PT was insignificant (Fishers test p= 0.246) (Sardari, Mohammadizadeh and Namnabati 2019). These findings were supported by other studies (Namnabati, Mohammadizadeh and Sardari 2019, Adlina et al. 2007). Although PT using an overhead device is cumbersome, it effectively treated newborn jaundice at home.

Alternatively, fibreoptic phototherapy devices (see figure 1.2 to 1.4) being compact, easy to use (Chowdhury, Hussey and Shortland 2007, Adlina et al. 2007), and could keep mother and newborn infants together (Adlina et al. 2007) were determined capable of facilitating home PT. However, fibreoptic devices required a layer of fabric covering the light source, potentially leading to discomfort and temperature change due to "low water vapour diffusion" and rigidity (Quandt et al. 2017, p4318).

This review found four examples of fibreoptic devices (see figure 1.2 to 1.4) used at home (Walls et al. 2004, Chang and Waite 2020, Pettersson et al. 2021, Noureldein et al. 2021). Treatment lasted on average 47.3 hours (Walls et al. 2004) using the biliblanket device (n= 22), mirroring duration of PT recorded in the RCT (n= 64) using an overhead phototherapy device (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019). Similarly, average treatment length using a bilibed device (Chang and Waite 2020) was 53 hours. In support of this, Pettersson et al. (2021) found no significant difference (p= 0.461) between duration of home (n= 78) and hospital PT (n= 69) using a bilisoft device. In contrast, Noureldein et al. (2021) found duration of home PT using a bilicocoon device was longer than hospital PT using an overhead device (p= 0.0001). However, compared to hospital PT lasting 26 (+/- 9) hours the mean duration of stay in hospital lasted 51(+/- 19) hours, equating 2.1 days of inpatient bed use which could be released using home PT (Noureldein et al. 2021). Consequently, from their baseline data and expenditure Noureldein et al. (2021) determined home PT as efficient, though they did not perform economic analyses. In support of this, hospital PT was calculated three times more expensive than home PT by Chang and Waite (2020), though duration of PT was shorter in hospital than home.

This review has not found evidence to date of a wearable phototherapy device to facilitate home PT. However, it has found PT using overhead and fibreoptic devices to capably treat newborn jaundice at home (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007, Namnabati, Mohammadizadeh and Sardari 2019, Walls et al. 2004, Chang and Waite 2020, Pettersson et al. 2021, Noureldein et al. 2021).

2.10.3 Experience with home phototherapy treatment (PT)

Experience of home PT comprised the third theme of this review. This theme connected to previous themes because it considered the impact of PT on the family’s experience of newborn jaundice.

Although not exclusively about home PT, mothers (n= 47) disclosed feeling guilty and distressed about separation from their newborn infant for PT (Hannon, Willis and Scrimshaw 2001). Furthermore, mothers (n= 6) felt it impacted their ability to bond and breastfeed their newborn infant (Brethauer and Carey 2010). Additionally, mothers (n= 6) specified that overhead and biliblanket phototherapy devices (see appendix 1 figure 1.1 and 1.3) impacted their ability to bond with their newborn infant (Brethauer and Carey 2010). Nevertheless, parents (n= 22) were satisfied with home PT using the biliblanket device and preferred it to hospital PT (Walls et al. 2004). Likewise, parents (n= 95) were positive about home PT using the bilicocoon device, preferring it to hospital PT (Noureldein et al. 2021).

However, Walls et al (2004) found a 9% poor compliance rate. Interfering grandmothers advocating 'traditional' methods of treatment (not specified), and against PT were identified as reasons for treatment failure (Adlina et al. 2007). Yet, unsettled newborn infants (n= 64) were the most common complication using an overhead device, though not significantly different between home (n= 32) and hospital (n= 32) ($p>0.05$) (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007). Therefore, poor compliance with PT may be influenced by family members and unsettled newborn infants (Walls et al. 2004, Adlina et al. 2007, Sardari, Mohammadizadeh and Namnabati 2019), rather than locality of treatment.

Although mothers (n= 47) reported preference over being at home and not separated from newborn infants, others felt pressure from responsibility to monitor newborn infants (Hannon, Willis and Scrimshaw 2001). Likewise, Noureldein et al. (2021) stated some parents felt anxious caring for newborn infants at home without continuous supervision from HCP. Goulet et al (2007) attempted to identify the model of postnatal care that augmented maternal satisfaction (n= 1,096) and preparation for discharge home. Although not exclusively about home PT, the mixed ambulatory model of care (n= 201) was the only model to offer home PT (Goulet et al. 2007). Yet, mothers reported feeling unprepared for discharge home, hospital stay was too short, and less awareness of who to contact regarding unwell newborn infants after discharge home (Goulet et al. 2007). Therefore, mothers were potentially uncomfortable with home PT under the mixed ambulatory model of care, which meant they received care at hospital as outpatients, not inpatients.

On the other hand, parents determined two of the most common advantages of home PT was being at home and surrounded by family (Noureldein et al. 2021). In support of this, one RCT (n=64) explored the effect of home (n= 32) and hospital (n=32) PT on maternal stress levels using an overhead device and found it significantly lower ($p<0.05$) with home PT (Namnabati, Mohammadizadeh and Sardari 2019). In contrast to the mixed ambulatory model of care in Quebec (Goulet et al. 2007), the researcher provided training to parents at home which could be repeated at parental request.

Although this review found overhead and fibreoptic phototherapy devices to impact mothers' ability to bond with newborn infants (Brethauer and Carey 2010), home PT was found to significantly reduce maternal stress levels (Namnabati, Mohammadizadeh and Sardari 2019). Furthermore, parents expressed satisfaction and preference for home PT, identifying home environments and closeness of family as advantageous (Walls et al. 2004, Noureldein et al. 2021). However, parents inconclusively sanctioned home PT (Hannon, Willis and Scrimshaw 2001, Goulet et al. 2007, Namnabati, Mohammadizadeh and Sardari 2019). In other words, support at home to facilitate PT could favourably impact maternal experience and stress levels.

2.10.4 Support and technology

The final theme identified was support and technology, which connected the other themes by demonstrating the potential impact of maternal support and wearable phototherapy devices on the use and experience of home PT.

This review found some mothers felt pressurised caring for newborn infants with home PT (Hannon, Willis and Scrimshaw 2001, Brethauer and Carey 2010, Goulet et al. 2007). However, support at home from midwives may alleviate maternal pressure. Community- based models of postnatal care (n= 679) reported higher levels of maternal satisfaction rates, and better preparation for discharge home than mixed hospital- based (n= 216), and mixed- ambulatory (n= 201) models of postnatal care (Goulet et al. 2007). However, the mixed-ambulatory model provided home PT and had no readmissions to hospital for newborn jaundice (Goulet et al. 2007). Goulet et al. (2007) concluded improved integration of home PT and community services could potentially impact mothers and newborn infants.

Certainly, this review found some evidence of home PT with high satisfaction rates (Walls et al. 2004) and reduced maternal stress levels (Namnabati, Mohammadizadeh and Sardari 2019) when support was provided to parents. Each parent received a nursing care session lasting approximately 60 minutes and more sessions were arranged at parental request (Namnabati, Mohammadizadeh and Sardari 2019). Likewise, on average the first postnatal midwife visit involving home PT lasted approximately 60 minutes (Walls et al. 2004).

Nevertheless, mothers (n= 6) specified overhead and biliblanket phototherapy devices negatively impacted bonding with newborn infants (Brethauer and Carey 2010). However, this review found the creation of a flexible light emitting fabric using LEDs (see appendix 1 figure 1.5) could be made into a sleepsuit (see appendix 1 figure 1.5) to potentially treat newborn jaundice at home (Quandt et al. 2017). The fabric was demonstrated to be washable, breathable, and comfortable for newborn infants, potentially supporting mothers with newborn infants to support breastfeeding and bonding (Quandt et al. 2017). However, effectiveness at treating newborn jaundice needs to be assessed before a sleep-suit made from flexible light emitting fabric could feasibly facilitate home PT using LED light source.

Developing a wearable device integrating LED PT could support breastfeeding and bonding, and effectively treat newborn jaundice at home (Quandt et al. 2017), potentially impacting paediatricians to consider home PT. Providing mothers and families with midwifery postnatal home support could facilitate home PT using a wearable device (Namnabati, Mohammadizadeh and Sardari 2019, Walls et al. 2004), and prevent readmission to hospital for jaundice (Goulet et al. 2007, Escobar et al. 2005), avoiding a traumatising event for mothers (Brethauer and Carey 2010).

2.11 Discussion

Using a systematic approach to address the review questions, four themes were identified to determine the use of a wearable device in facilitating home PT. Subsequently these themes uncovered barriers and facilitators to using a wearable device for home PT.

This review discovered examples of overhead (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007) and fibreoptic phototherapy devices (Walls et al. 2004, Chang and Waite 2020, Pettersson et al. 2021, Noureldein et al. 2021) used to effectively treat newborn jaundice at home. Furthermore, reduced maternal stress levels were found using home PT (Namnabati, Mohammadizadeh and Sardari 2019), which could prevent maternal trauma of newborn infant's readmission to hospital for PT (Brethauer and Carey 2010). Moreover, this review found hospital readmission rates for jaundice reduced with home PT provision (Escobar et al. 2005, Goulet et al. 2007). Additionally, home PT was considered more economically efficient than hospital PT, even with increased duration of PT (Chang and Waite 2020, Noureldein et al. 2021).

In contrast, there was a noticeable gap in literature included in the review between 2010 to 2019. The reason for this has not been identified, however: national evidence- based guidelines regarding management of newborn jaundice were not published in the UK until 2010 (NICE 2016), and did not mention the practice of home PT. Although evidence- based guidelines from the USA (American Academy of Pediatrics (AAP) 2004) refer to home PT and provide advice on eligibility for home PT, it is unclear: how many newborn infants could be eligible; whether home PT would be offered by paediatricians; and the cost effectiveness of home PT. Therefore, potentially home PT was not considered a research area of interest, and was not widely supported by lead paediatricians (Bhutani et al. 2006, Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019). In 2011 (Kumar, Chawla and Deorari 2011), PT using LEDs was found to be as effective as PT using a conventional light source. Therefore, this review suggests exploring PT using LEDs for home use, and decision- making for PT to determine reasons some parents are offered home PT but not others.

Although paediatricians were concerned with lack of parental training (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019), with additional training from researchers mothers were less stressed (Namnabati, Mohammadizadeh and Sardari 2019). Additionally, with support at home from HCPs parents reported satisfaction with home PT (Walls et al. 2004, Noureldein et al. 2021). Furthermore, treatment failure between home and hospital PT was statistically insignificant (Sardari, Mohammadizadeh and Namnabati 2019, Namnabati, Mohammadizadeh and Sardari 2019, Adlina et al. 2007, Chang and Waite 2020, Pettersson et al. 2021).

Although PT using an overhead device is cumbersome, this review has demonstrated it effectively treated newborn jaundice at home (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007). Nevertheless, unsettled newborn infants (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007) and interference from grandmothers advocating alternative treatment methods were common complications when using an overhead device (Adlina et al. 2007). Therefore, rather than location treatment failure using an overhead device could be influenced by family members and comforting newborn infants, resulting in discontinuation of treatment.

These reasons for treatment failure using an overhead device to facilitate home PT (Sardari, Mohammadizadeh and Namnabati 2019, Adlina et al. 2007) could be applied to fibreoptic devices (Walls et al. 2004, Chang and Waite 2020, Pettersson et al. 2021). PT was found to impact bonding and breastfeeding (Hannon, Willis and Scrimshaw 2001, Brethauer and Carey 2010) regardless of whether it was delivered via overhead or fibreoptic devices (Brethauer and Carey 2010). Furthermore, fibreoptic devices reported as rigid, potentially affect newborn infant's thermoregulation and comfort (Quandt et al. 2017). However, the recent creation of flexible light emitting fabric could be made into sleep-suits to facilitate home PT (Quandt et al. 2017). Potentially supporting bonding and breastfeeding (Quandt et al. 2017), this creation could support newborn infant's comfort, impacting compliance with PT treatment. However, further understanding of decision- making for, and compliance with, PT would be beneficial to establish whether a wearable phototherapy device would be promoted by HCPs and used by families.

2.12 Strengths, limitations, and areas for further research

Strengths of this review involved following a structured process to source heterogenous research studies, evaluate quality and including research studies from four continents.

Nevertheless, limitations included exclusion of two research studies published in languages other than English (Khatami and Soltani 2007, Uslu et al. 2012).

Additionally, limited papers were found exclusively about home PT. The qualitative studies from the USA (Hannon, Willis and Scrimshaw 2001, Brethauer and Carey 2010) included home and hospital PT. Although data could be extracted about home PT, it was difficult to distinguish maternal experiences about home PT specifically from PT in general. Moreover, it was unclear whether home PT occurred in rural or urban settings in all studies except two, which identified urban provision for home PT (Goulet et al. 2007, Chang and Waite 2020). Therefore, transferability of findings from this review may be limited by lack of clarity over geographical setting for home PT, and subsequently access to healthcare support. Additionally, different healthcare models from those free at point of entry could limit transferability of findings. Furthermore, variations in research methodologies and methods could limit generalisation of findings.

Although two high quality and well conducted RCTs with transferable findings demonstrated effectiveness of home PT (Sardari, Mohammadizadeh and Namnabati 2019, Pettersson et al. 2021), most studies included in this review were moderate to low quality. Only three qualitative studies exploring maternal experience of home PT were identified and included in this review, two of which involved hospital and home PT (making it difficult to differentiate home from hospital PT) and one was a service evaluation. Therefore, this review has identified areas for further research, including exploring parents' experience with home PT for newborn jaundice; exploring impact of postnatal midwifery home support in rural areas on satisfaction and compliance with home PT for newborn jaundice; examining HCPs decision- making in offering home PT and selecting the phototherapy device to use to treat newborn jaundice; and exploring HCPs and parents' acceptability of a wearable device to facilitate home PT.

2.13 Recommendations for practice

Although there are limitations to this review, the findings have been able to determine use of wearable devices in facilitating home PT. As a result, the findings have implications for maternity and neonatal practice, highlighting the importance of postnatal support. Additionally, development in wearable phototherapy technology could support breastfeeding and bonding, facilitating home PT for newborn jaundice whilst keeping newborn infants with mothers and families. The recommendations from this review are:

1. Consider mothers in management plans for newborn jaundice.
2. Provide option of home PT for newborn jaundice.
3. Healthcare services to value postnatal midwifery home support for mothers and newborn infants.
4. Increase use of technology to humanise healthcare.

2.14 Conclusion

This review was able to evidence capabilities of home PT for treating newborn jaundice and demonstrate its use in six countries across four continents. However, it did not uncover much evidence linked to rural: therefore, conclusions are based on a range of settings. Furthermore, it identifies midwifery postnatal home support as potentially impacting maternal satisfaction with home PT. Additionally, the availability of home PT was found to reduce rates of readmission to hospital for newborn jaundice. As a result, home PT could reduce hospital admissions during the coronavirus pandemic and afterwards. Moreover, it could avoid maternal trauma of newborn readmission to hospital. Nevertheless, home PT for newborn jaundice has not been widely supported by lead paediatricians. Though reasons for this have been speculated, they have not been confirmed. This review has been able to determine there is currently no wearable device used to facilitate home PT. However, recent creation of light-emitting fabric could be used to facilitate home PT in the future, potentially preventing admissions to hospital and keeping mothers with newborn infants. This would thereby facilitate effective treatment of newborn jaundice at home by lowering SBR levels whilst supporting breastfeeding and bonding. As a result, healthcare services could potentially be improved to maximise family health outcomes.

2.15 Summary

This review determined no wearable device was currently used to facilitate home PT, although: the recent creation of light- emitting fabric could be used as a wearable device to facilitate home PT in the future. Consequently, minimising maternal trauma from hospitalisation by keeping families together at home to support bonding and breastfeeding. On the other hand, this review found home PT was not widely supported by paediatricians. Therefore, further research with HCPs and parents is necessary to explore whether a wearable phototherapy device would be wanted and used to facilitate home PT in rural settings for newborn jaundice.

CHAPTER THREE: METHODOLOGY AND METHODS

3.0 Introduction

In this chapter, Interpretative Description as the chosen research methodology will be explained and justified. In addition, data collection methods will be described. Moreover, recruitment of study participants, sample size, study setting, and ethical considerations will be discussed. Furthermore, the framework for data analysis will be explained before considering study limitations and determining the study's trustworthiness.

3.1 Research aim

The aim of this research was to explore with healthcare professionals (HCPs) and parents the acceptability and feasibility of a wearable device to facilitate home phototherapy treatment (PT) for newborn jaundice in rural Scotland.

3.2 Research objectives

1. Understand parents' experiences of PT for newborn jaundice who self-identified as living rurally.
2. Explain HCPs' experience of providing PT to newborn infants with jaundice.
3. Explore parents' and HCPs' perspectives towards home PT for newborn jaundice in rural Scotland.
4. Explore with parents and HCPs the concept of a wearable device to identify potential barriers and facilitators for it enabling home PT in rural Scotland.

3.3 Qualitative methodology and study design

The integrative literature review did not find much evidence linked to rural settings and no evidence of a wearable device currently used to facilitate home PT. However, the recent creation of light- emitting fabric could be used as a wearable device to facilitate home PT rurally in the future. The reason for employing qualitative methodology was to explore parents' and HCPs' thoughts and feelings about a wearable device to facilitate home PT in rural Scotland before investing in developing a complex intervention (Medical Research Council (MRC) 2008), such as a wearable phototherapy device. Therefore, qualitative methodology was chosen to determine acceptability and feasibility of a wearable device in facilitating home PT in rural Scotland for this exploratory study.

In contrast, quantitative methodology begins with a theoretical position and the research is conducted to deduce whether the hypothesis is correct (Bryman 2016). Consequently, a positivist epistemological position accepting methods of studying the natural sciences for the social sciences was rejected (Bryman 2016). Therefore, this study is situated within an interpretive epistemological position because it seeks to understand social interactions through recognising the diversity between people (Bryman 2016). Moreover, this study purports a constructivist ontological position (Bryman 2016). For instance, people create the social phenomena being studied through continual interaction (Bryman 2016). As a result, there is not one absolute truth because the researcher can only present their version of the current social reality (Bryman 2016).

The research design used for this study was Interpretive Description, which provided an analytical framework to guide initial decisions in study design (Thorne, Reimer Kirkham and MacDonald-Emes 1997). The purpose of Interpretive Description was to create a cohesive description of the study phenomena acknowledging isolated deviations whilst capturing common themes (Thorne, Kirkham and O'Flynn-Magee 2004). Due to its dependence on interpretation, it does not claim to produce absolute truths, but rather findings that have been socially constructed by the researcher (Thorne, Kirkham and O'Flynn-Magee 2004). Locating the researcher within the study (Coffey 1999) was to acknowledge the impact from the researcher’s midwifery experience, both clinically and academically (see section 1.4). As a result, Interpretative Description regarded clinical knowledge and insight (Thorne, Kirkham and O'Flynn-Magee 2004) as beneficial to scaffold the study design (Hunt 2009).

Although Ethnography would reveal through observation how parents and HCPs experienced PT for newborn jaundice (Thorne 2016), it could struggle to explore perspectives of a wearable phototherapy device. Additionally, an Ethnographic study would have been time consuming and challenging to complete within the timeframe of a part- time master’s in research postgraduate degree.

Initially Grounded Theory appeared an appropriate study design to employ since it recognised truth as indeterminate because knowledge is socially constructed (Oliver 2012). However, the strict rules (particularly around theoretical sampling and data analysis) were considered too rigid for the necessary exploration this study entailed. Furthermore, Grounded Theory focused on new theory generation whereas Interpretative Description was pragmatic and aimed to transform practice through action (Oliver 2012) rather than theorising (Hunt 2009).

Additionally, although Phenomenology aims to understand the essence of human experience (Thorne 2016), the focus on individuals overlooked group dynamics. For example, the impact of parents’ shared experience of PT, and the influence of care teams, on acceptability and feasibility of a wearable device for home PT in rural Scotland (Thorne 2016).

In contrast, Interpretative Description was found to consider various perspectives (for example, parents and HCPs) that could influence acceptability and feasibility of a wearable device to facilitate home PT in rural Scotland (Olufemi-Yusuf et al. 2018). Although, study findings for Interpretative Description can diverge from initial research objectives (Thorne, Kirkham and O'Flynn-Magee 2004), the rationale for such divergence needs justified (Thorne, Kirkham and O'Flynn-Magee 2004). Furthermore, Interpretative Description acknowledged numerous components in clinical practice could influence acceptability and feasibility between individuals, and members of the multi-disciplinary team (Olufemi-Yusuf et al. 2018). For this reason, Interpretative Description as a pragmatic approach was chosen with the aim to generate knowledge relevant for clinical practice (Olufemi-Yusuf et al. 2018).

3.4 Sample, recruitment and setting: Parents

Purposive sampling (Hunt 2009) was employed in one NHS board in Scotland to recruit parents (16 years of age and over) who self- identified as living rurally and had a newborn infant within the last five years that received PT for jaundice. Although newborn jaundice is a common condition (Malwade and Jardine 2014), the pool of parents eligible was potentially reduced due to the rural context of the study. Therefore, parents with experience of PT for newborn jaundice within the last five years in NHS Grampian were targeted to facilitate recruitment and trustworthiness of the study (Bryman 2016). The five- year limit minimised time since parents had experience with PT. This was desirable because the study involved parents remembering experiences and discussing thoughts about how they felt. Furthermore, five years allowed for diversity of family size.

Parents were asked to self- identify as living rurally to understand the impact of distance from HCPs and healthcare services (Dixon-Woods et al. 2006) on their acceptability or feasibility of a wearable device to facilitate home PT. Both parents were provided the opportunity to share their thoughts. This was to assist identification of potential barriers and facilitators to a wearable device to deliver home PT. In other words, understanding interactions between parents and how they made care decisions for their newborn infant was considered worthwhile to determine feasibility of a wearable device to deliver home PT in rural Scotland.

Parents were recruited through an open advert on social media via Twitter which was reviewed by Grampian Maternity Voices Partnership (MVP). Grampian MVP is an independent group consisting of service users and NHS members of staff. They aim for quality assurance of maternity services and recommend quality improvements. The researcher communicated with Grampian MVP as a method of patient and public involvement in the study. Grampian MVP provided feedback that maternity service users were more likely to participate in studies when they could identify with the researcher. Therefore, two adverts were created (see appendix 6), one which clearly stated the area for research with eligibility criteria, and another which included a short bio of the researcher and their photograph, as suggested by Grampian MVP. The decision was made to release the first advert without the bio and picture in December 2019. This was shared by Grampian MVP on their social media platforms. To encourage more interest in the study the second advert with the bio and picture was planned for release on social media in January 2020.

Caldicott approval was obtained (see appendix 7) in case there was an inadequate response from parents to participate in the study via the advertisement on social media. In such an event, the Neonatal Nurse manager agreed to identify and screen a sample of 30 newborn infants that received PT for jaundice within the last five years living at a rural postcode address. As a result, the Neonatal Intensive Care Unit would send the parents a letter (see appendix 8) or email (see appendix 9) with an invitation to participate in the study and an information sheet (see appendix 10). The research team would not have had details or knew who they were unless the parents choose to contact them.

However, 25 women responded to the first advert: therefore, subsequent adverts were neither required nor shared on social media. To clarify, the research team only had parents' details once they expressed interest in the study. In the end, four parent couples (consisting of a mother and father[2]) and six individual mothers met the eligibility criteria (see section 3.5 table 5) and were recruited onto the study. More in-depth exploration of parents' perspectives and experience of newborn jaundice was considered necessary to inform development of service provision (Thorne 2016).

3.5 Table 5. Study eligibility criteria

Study eligibility criteria

Inclusion criteria	Exclusion criteria
Parents over the age of 16 years	Current patients
Parents self- identify as living rurally	Parents under the age of 16 years
Parent to a newborn infant within the last five years that required phototherapy treatment for jaundice	Experience of having a newborn infant with jaundice is over five years ago
Midwives, neonatal nurses, health visitors, children's nurses.	Parents do not identify as living rurally
Paediatricians, neonatologists, general practitioners	Unable to speak, read, understand English proficiently

3.6 Sample recruitment and setting: Healthcare professionals (HCPs)

The researcher aimed to recruit midwives, health visitors, neonatal nurses, children's nurses, paediatricians, neonatologists and general practitioners (GPs) to participate in the study through purposive sampling: because, they either had relevant clinical knowledge and experience of PT (Bryman 2016); or in rural areas they could be involved in care of newborn infants during home PT (Van Woerden 2016). Consequently, the researcher asked senior management within

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[2] The terms woman/ mother and father are used throughout this thesis because the study participants identified as such. Likewise, the thesis will use the term breastfeeding (Dodgson 2019) because it was the term used by study participants.

NHS Grampian to distribute an email including study invitation (appendix 11) to HCPs (on behalf of the researcher) and information sheet (see appendix 12). The research team only had HCPs' details once they expressed interest in the study. The research team aimed for a variety of HCPs in each focus group to explore acceptability of a wearable device to deliver home PT. Although planning to recruit up to eight study participants for three focus groups, work activity and staffing levels impeded recruitment of HCPs. Unfortunately, one paediatrician would not consent to inclusion in the study explaining apprehension about their views being made public and perceived radical. In addition, one paediatrician could not attend the scheduled focus group due to an emergency, and one GP could not participate due to their workload.

3.7 Table 6. Study participants characteristics: Healthcare professionals

Healthcare professional (HCP)	Role	Base in hospital	Participant in first or second focus group
Amelia	Senior charge midwife	Maternity unit	First
Brenda	Midwife, neonatal trained	Maternity unit	First
Caitlin	Midwife, neonatal trained	Maternity unit	First
Daisy	Senior charge midwife	Maternity unit	First
Elaine	Senior charge midwife	Maternity ward	Second
Fern	Community midwife	City team	Second
Grainne	Bank midwife	Varied locations in hospital and community	Second
Hilda	Bank midwife	Varied locations in hospital	Second
Irene	Neonatal nurse	Neonatal intensive care unit	Second

From the 15 HCPs that responded to the email invitation, nine HCPs were recruited onto the study, which consisted of: eight midwives; and one neonatal nurse (see section 3.7 table 6). Focus groups were conducted in different geographical locations (an urban and regional hospital- see section 3.8 table 7) to capture responses from HCPs throughout NHS Grampian and enhance confirmability of the data collected (Bryman 2016).

3.8 Table 7. Study site characteristics

Regional district general hospital in Scotland	Large, specialised urban hospital in Scotland
Temporary service model of Women and Children's services since March 2018, resulting in no paediatric services over night.	Includes a Children's Hospital and Maternity Hospital, which has a Neonatal Intensive Care Unit.
The main hospital for neonatal transfers is over 60 minutes away on a major road.	Main unit for maternity and neonatal transfers from two rural general hospitals, two stand-alone midwifery led units, one alongside midwifery led unit, and one regional district general hospital.

3.9 Data collection methods: Parents

Parents were offered the option to be interviewed individually or together. The semi- structured interviews (see appendix 13) were digital voice recorded on a password protected audio recorder and conducted face-to-face, in the participants' home and at a time convenient to them (Bryman 2016). Parents were interviewed for approximately one hour and asked about their experience caring for newborn infants during PT and the impact it had on families. They were also asked about their perceptions and acceptability of a wearable device to deliver home PT in rural Scotland. Furthermore, the visual aid and baby clothes were taken to interviews as stimulus material of potential wearable PT devices (see appendix 14).

The benefit of interviewing parental dyads (n= 4) was exploring both parents' experiences and perspectives (Thorne 2016) of living rurally with a jaundiced newborn infant to inform the understanding of home PT using a wearable device. Although both parents present could have affected how each responded, it was arguably a more accurate reflection of the couple's dynamic which could impact acceptability of home PT (Thorne 2016). For instance, their relationship and how they make decisions together could affect how both parents feel about caring for newborn infants with home PT using a wearable device. Providing opportunities for parents to be interviewed together could have been perceived by parents as having control over the situation. As a result, parents may have felt more relaxed and willing to share their thoughts and feelings about experiences. However, it was still valuable to hear from one parent. Consequently, the study included individual interviews with mothers (n= 6), as the primary care giver, if preferred by the study participants.

The use of semi- structured interviews provided flexibility so different perspectives could be explored (Bryman 2016). In contrast, unstructured interviews would have been unsuitable due to lack of focus for this study with a limited timespan (Bryman 2016). Regardless, using interviews facilitated intimacy without being overtly observational (Thorne 2016). However, an inherent weakness to interviews was the study participants could retain secrecy (Thorne 2016). Another challenge was the language used by study participants. Instead of using language to precisely capture their feelings and perceptions it could have been easy for language from popular culture to infiltrate conversation and dilute the meaning (Thorne 2016). In this situation the researcher reflected upon current culture within society (Thorne 2016).

3.10 Data collection methods: Healthcare professionals (HCPs)

For HCPs use of focus groups was preferred to facilitate exploration into how they felt about a wearable device for home PT (Bryman 2016). Since HCPs work in multi-disciplinary teams focus groups were considered favourable for revealing the influence of individual study participants on group acceptability of a wearable device to facilitate home PT. For instance, patterns of behaviour might become apparent within the group which could influence barriers and facilitators to wearable home PT (Thorne 2016). Although, there is a skill to conducting focus groups to facilitate equal participation and avoid individual dominance (Thorne 2016). Lack of control over the focus group is not necessarily a negative of the method: however, determining how much control to relinquish to the group was discussed by the research team (Bryman 2016).

However, extenuating circumstances (for instance workload and staffing levels) prevented HCPs' participation in focus groups. Although the researcher had ethical approval, the coronavirus pandemic obstructed the use of individual face to face interviews with HCPs to ensure their participation in this study. Consequently, two focus groups were organised to explore experiences of PT and thoughts about a wearable device to facilitate home PT in rural Scotland (Bryman 2016). As a result of the smaller size of focus groups they were easy to manage. Moreover, study participants appeared more comfortable in the intimate environment to disagree with each other and promote diversity of opinion within the group (Bryman 2016). Both focus groups followed a topic guide (see appendix 15) and lasted approximately one hour. As was done with parental interviews, focus groups were digital voice recorded on a password protected audio recorder. Likewise, the visual aid and baby clothes were provided as stimulus material for exploring wearable phototherapy devices (see appendix 14).

To conclude the section about data collection methods, this study employed two methods of data collection, namely: semi- structured interviews for parents; and focus groups for HCPs. Concurrent data collection and analysis occurred between December 2019 and February 2020 (Thorne 2016). Using two different methods established confidence in the data collected regarding acceptability and feasibility of a wearable device to facilitate home PT in rural Scotland. Therefore, trustworthiness of the study was supported in relation to credibility of the findings (Hunt 2009).

3.11 Data analysis

This study explored parents' and HCPs' experience of PT for newborn jaundice, and their thoughts on a wearable device to facilitate home PT in rural Scotland. Therefore, thematic analysis was considered an appropriate method to understand the entire data set (Braun and Clarke 2006) and look for commonalities (Kiger and Varpio 2020). Furthermore, it is a flexible method of qualitative data analysis that is not usually used to generate new theory (Kiger and Varpio 2020). As a result, thematic analysis was an applicable method of data analysis for an Interpretive Description study design (Kiger and Varpio 2020). In addition, the analytical process for thematic analysis was clearly presented in the literature making it a pragmatic choice to use (Kiger and Varpio 2020). Framework was the systematic approach (Hackett and Strickland 2018) used to thematically analyse the data in this study (Gale et al. 2013). Although it was time-consuming (Gale et al. 2013), it added trustworthiness to findings because a clear audit trail was maintained from the start (Hackett and Strickland 2018).

There were seven stages for data analysis the researcher followed (Gale et al. 2013). The first stage involved a word for word transcription (Gale et al. 2013) of interviews (n= 10) and focus groups (n=2). The decision was made to use a professional transcriber (contracted to RGU) due to the time constraints involved in a part-time Master of Research postgraduate degree. Nevertheless, the researcher concurrently analysed and collected data by listening to audio recordings and taking notes before proceeding with further interviews or focus group, contributing to the subsequent method of data collection (Thorne 2016). In addition, the researcher was immersed in the data (Gale et al. 2013) checking transcriptions. This involved listening to audio recordings whilst following transcriptions word for word and correcting mistakes along the way.

Stage two involved familiarisation with the data (Gale et al. 2013). During this stage the researcher repeatedly listened to audio recordings and read transcriptions. Furthermore, the researcher took notes of initial thoughts and feelings about recordings. For example, the researcher noted that HCPs appeared to consider parents challenging or non-compliant as opposed to needing more information when parents asked questions about routine care pathways. The researcher reflected on how care should evolve from the first point of contact in pregnancy to support the transition of women into mothers. However, paternalistic care appeared to impact parents' understanding of their experience of newborn jaundice. Moreover, the notes produced during listening to audio recordings were collated with the researcher's journal notes that were developed during interviews and focus groups (appendix 16).

After familiarisation with the data, the researcher applied open codes (Thorne 2016) to transcriptions for stage three of data analysis (Gale et al. 2013). During this stage the researcher and the principal supervisor independently coded the first interview and focus group (Gale et al. 2013). This initial coding (see appendix 17) used paper and pens to start to organise the data into groups that might be related (Thorne 2016). For example, parents' experience of newborn jaundice, breastfeeding, and the postnatal ward environment emerged as open codes which could be grouped into parents' current experience of phototherapy treatment.

Once the first couple of transcripts had been coded the principal supervisor and researcher met to discuss the codes that had been generated, for stage four of data analysis (Gale et al. 2013). The researcher grouped the codes into categories which became the initial analytic framework (see appendix 18), though it was not finalised until the last interview (Gale et al. 2013).

Then the analytic framework was applied (Gale et al. 2013) to the transcripts using NVivo 12, which was the data management software used to manage and organise the data into categories and codes (Bergin 2011). Although stage five was time consuming because the researcher had to become familiar with NVivo due to inexperience, it was beneficial to be able to retrieve data easily (Gale et al. 2013). Furthermore, the researcher received one day of training which introduced the functions of NVivo. In addition, NVivo was available for research students to use at Robert Gordon University (RGU) making it a practical choice.

NVivo was useful for stage six of the data analysis process because it allowed the researcher to manage thoughts (Bergin 2011), and summarise data in a matrix (appendix 19) to facilitate thorough analysis by case and code (Gale et al. 2013). During this stage the researcher was immersed in the data, reading transcripts, and listening to audio recordings. Furthermore, ideas and initial interpretations were annotated on transcripts then developed further in memos. For example, mothers identified partners and family members as their immediate support network. This initial interpretation was developed further in memos considering the philosophy of postnatal care.

The final stage of the data analysis process involved interpreting the data (Gale et al. 2013). This was an iterative process across the entire data set allowed the researcher to immerse in the data leading to a more accurate understanding of study participants' experiences and perceptions (Hackett and Strickland 2018). Themes were generated by identifying patterns through querying and comparing data categories within and between each case (Gale et al. 2013). As a result, thematic charts (see appendix 20) were constructed, mapping main themes and subthemes (Hackett and Strickland 2018). The names of which were discussed with the research team to ensure they reflected the study participant's experiences and perceptions, adding to the study's trustworthiness (Hackett and

Strickland 2018). For instance, one subtheme addressed the environmental impact of hospitalisation on mothers. After discussion within the research team a quote from Jayne (one of the mothers who participated in the study) was used to name the subtheme. Jayne described hospital postnatal wards as *"…like a prison. It was a prison for me",* thereby revealing metaphorically, the environmental impact of hospitalisation on mother's autonomy and control.

3.12 Ethics

This research study was funded by the Digital Health and Care Institute (DHI). The researcher was accountable to their employer, funder, the public, and professional body as a registered midwife to maintain safe services. Although the researcher is a practice education lecturer (and had been involved with NHS staff training) the researcher has not worked as a clinical midwife within the NHS Board in which the study was set. The School of Nursing, Midwifery and Paramedic Practice Ethics Review Panel at RGU approved the research study (see appendix 21). Since the study involved NHS employees and parents of former inpatients, ethical approval from NHS Research Ethics Committee (see appendix 22) and NHS Grampian Research and Development Office was required and granted (see appendix 23).

Participation in the study was voluntary, and participants were free to withdraw at any point, but none did. Parents over 16 years of age were recruited because they were assumed in law to have the ability to make decisions about their care (*Adults with Incapacity Act* 2000). This study (being part of the researcher's Master of Research) did not have funding to enlist translation services. Therefore, people who might not have adequately understood written information or verbal explanations in English or have special communication needs were excluded from the study and this is a limitation.

To support transparency, an information sheet was developed that provided additional information in clear and plain language about the proposed device. Informed consent was obtained by asking each participant to sign the consent form (see appendix 24) after they read the information sheet attached to their invitation email and had time to ask questions. In the information sheet it was identified for potential study participants that there may be opportunities to share the findings at a conference through a presentation about the study or through publications in journals (see appendix 10 and 12).

The focus groups and interviews were recorded using a password protected digital audio recorder. The data included experiences, thoughts, and feelings the participants shared about caring for a newborn infant with jaundice and their opinions about a wearable device to provide home PT. Measures were taken to ensure study participants' privacy (Bryman 2016). For example, confidential information like names, emails and contact details were stored in a password protected personal computer file separate from the data so the connection could not be traced and was not shared (*General Data Protection Regulation (GDPR)* 2018). Data from interviews and focus groups was downloaded as soon as possible afterwards to be stored to the R: Drive on RGU's secure server and deleted from the digital device (Robert Gordon University (RGU)2018). The research team consisting of three people had access to participants' personal data because the researcher was a student being supported through the process by two academic supervisors.

A secure password protected file sharing site was used to share audio files with a professional transcriber contracted to RGU (*General Data Protection Regulation (GDPR)* 2018). Study participants were given a pseudonym so once the recording had been transcribed all identifiable references were removed from the transcription (*General Data Protection Regulation (GDPR)* 2018).

Data will be stored in a password protected computer for no longer than ten years as per RGU policy (Robert Gordon University (RGU) 2016) after which it will be destroyed as per RGU policies (Robert Gordon University (RGU)2018, Robert Gordon University (RGU) 2016). However, confidential information like names, emails and contact details will be disposed of when they are no longer needed as per Caldicott Principles in NHS Code of Confidentiality. RGU's long term arrangements for storage of research data is being followed because RGU is the researcher's sponsor.

The potential risks involved for the research participants was the process of sharing experiences in the interview and focus group that may be unsettling or upsetting if they have been negative or traumatic. They sacrificed approximately one hour of their time that could have been spent at work or on other activities. During the interviews and focus groups the researcher had information about local counselling and support services to share with the participants should they required it, which they did not.

NVivo was the data management software created to support the Framework approach used in this study. Data were uploaded to NVivo which protects confidentiality as stated in their QSR Cloud Services Agreement. Using NVivo software to analyse data meant data could be managed quickly whilst maintaining the quality of the analysis process. The Framework management tool leaves a documented audited trail which increases the dependability of the findings. Supervision meetings with the researcher’s academic supervisors meant the study was being continuously monitored. As a student the researcher met yearly with the School's research degree coordinator to ensure the study progressed in a timely and orderly manner. Additionally, the Graduate School at RGU monitored study progress. In conclusion, study documentation was maintained should the study be audited by the regional NHS Research and Development department.

3.13 Epistemic injustice

Interpretation of key findings will be discussed using Fricker’s (2007) concept of epistemic injustice. Epistemic injustice refers to inequity due to unequal power dynamics between people or systems (Fricker 2007). Deriving from these data, therefore inductive in nature (Bryman 2016), epistemic injustice helped prioritise findings and scrutinise them from different perspectives making connections and ultimately to tie everything together. Therefore, the theory was used at an advanced stage of analysis to construct the discussion and assist interpretation of findings.

Fricker (2007) proposed two key types of epistemic injustice, namely: testimonial injustice; and hermeneutical injustice. Testimonial injustice occurs between individuals and was determined by Fricker (2007) to take place when a person’s knowledge was valued over another due to prejudicial stereotypes. In contrast, hermeneutical injustice refers to structural discrimination (Fricker 2007). This is discrimination caused by those in power collectively controlling knowledge and understanding (Fricker 2007).

Several studies illustrate marginalisation of patients (Blease, Carel and Geraghty 2017, Kidd and Carel 2017) or women (Freeman 2015, Villarmea and Kelly 2020) during healthcare encounters. However, they focus on patients or women and do not consider healthcare professional’s perspectives. Although Hutchison (2020) revealed epistemic injustice imposed by male surgeons towards female surgeons in Australia, Hutchison (2020) does not consider the perspective of patients.

In contrast, this study explored interactions between mothers, parents, and healthcare professionals in NHS maternity services during PT for newborn jaundice. The downside is epistemic injustice can be subtle and unconsciously perpetuated, therefore difficult to expose (Fricker 2007). However, the current study included data from parents and HCPs which when inspected through the lens of epistemic injustice suggests a coherent picture of parental and midwifery marginalisation in NHS maternity services.

3.14 Summary

To conclude, qualitative methodology using semi- structured interviews and focus groups methods for data collection were employed to explore with parents and HCPs, acceptability, and feasibility of a wearable device to facilitate home PT in rural Scotland. The Framework approach was employed to analyse thematically data in this Interpretive Description study. In chapter four, the findings from semi- structured interviews and focus groups will be presented.

CHAPTER FOUR: FINDINGS

4.0 Introduction

Chapter four will present the study's findings from two focus groups (with nine healthcare professionals) and ten interviews (with 14 parents) conducted between December 2019 and February 2020.

4.1 Participants

The study participants are recognised by pseudonyms, and P for parent or HCP for healthcare professional. HCPs are allocated numbers to identify the focus group they participated in. For example, Annie. P refers to a parent who participated in this study and was allocated the pseudonym Annie, similarly: Fern. HCP-2 refers to a healthcare professional who participated in the second focus group and was allocated the pseudonym Fern. Where both parents have been interviewed, they have been counted as a singular unit. For example, when presenting data of parents included in the study (n= 3) refers to three separate parent interviews, which may include one or both parents. However, when presenting data from mothers and fathers specifically their accounts were presented separately. To clarify, six of the ten interviews were with only mothers and four included both parents (mother and father). A summary of study participants' characteristics is displayed in table 8 and 9 (see section 4.4.1(i) and 4.4.4(i) respectively), whilst table 10 in section 4.4.4(ii) illustrates study site characteristics.

4.2 Figure 3. Mind map summary of the themes and subthemes from thematic analysis.

4.3 Themes and subthemes

Two main themes generated from the data are: current limitations to the phototherapy treatment experience; and considering an alternative experience of phototherapy treatment. These themes are used as main headings to organise findings into two sections. Each section consists of a brief introduction describing the theme and presents subthemes which use anonymised quotes from study participants to evidence data analysis. In addition, a mind map (see section 4.2 figure 3) is provided to visually summarise findings.

4.4 Current limitations to the phototherapy treatment experience

An important finding was parents' dissatisfaction with phototherapy treatment (PT) for newborn jaundice. Therefore, this theme explored the participants experience of current PT. Sub-themes generated were: 'one size fit all' focus for newborn jaundice; *"It was like a prison. It was a prison for me"*; *"I think that would've helped me, mentally, having, having them home"*; midwives lack of trust in assessing newborn jaundice and parental capabilities; and parents' awareness of mistrust. Participants described a 'one size fit all' focus for newborn jaundice centred round reducing serum bilirubin (SBR) levels as quickly as possible. Parents described lack of autonomy as primary carer for newborn infants during their hospital postnatal stay which mothers perceived as detrimental to holistic health. Midwives lacked trust in their assessment of newborn jaundice, and parents' capabilities as primary carer with home PT using a wearable device. Additionally, parents expressed awareness of HCP's lack of trust in their capabilities which they perceived to limit choices and perpetuate paternalistic care.

4.4.1'One size fit all' focus for newborn jaundice

The first subtheme presents participants description of 'one size fit all' focus for newborn jaundice. Parents (n= 10) included in the study described care centred round biomedical measurements (such as reducing SBR levels as quickly as possible). Furthermore, they described prioritisation of biomedical measurements ahead of parental instincts to hold and comfort newborn infants. For instance, parents were not routinely involved in obtaining SBR levels by providing support and comfort to newborn infants during the invasive procedure. Care plans were perceived as 'one size fit all', with little or no tailoring to family circumstances. For example, an overhead phototherapy device (see appendix 1 figure 1.1) was routinely used because it most effectively reduced SBR levels. Treatment could have been facilitated by alternative phototherapy devices accommodating newborn infant's comfort, such as: a phototherapy device lit from underneath the newborn infant accommodating blankets for warmth and comfort (see appendix 1 figure 1.2). This resulted in lack of options for parents regarding care plans for newborn jaundice.

"…I felt like I was being controversial or awkward by saying that I, by saying that I didn't want to give her formula and that I wanted to go home, you know, which, things were, which were quite basic to me and felt very instinctive but, because it didn't necessarily correlate with what was on their chart, or their guidelines, or their protocol." (Grace. P)

Having a 'one size fit all' focus on newborn jaundice meant parental instinct was viewed as interfering with hospital guidelines. For instance, artificially feeding Grace's newborn infant would increase baby's weight quicker to correspond with hospital guidelines but would affect establishment of breastfeeding. Likewise, though overhead phototherapy devices most effectively lower SBR levels (Mills and Tudehope 2001, Kumar, Chawla and Deorari 2011), newborn infants can be unsettled using them (Føreland, Rosenberg and Johannessen 2016). Parents (n= 3) described feeling viewed by HCPs as unreasonable when they asked for flexibility to PT plans to accommodate caring for newborn infant how they wanted. Care focussed on reducing SBR levels to treat newborn jaundice meant HCPs (n= 8) did not advocate breastfeeding, bonding, and maternal mental health (as presented within sections 4.4.1, 4.4.2 and 4.4.3 respectively). In other words, empathic care was overshadowed by focussing on biomedical measurements.

Furthermore, when parents proposed using alternative phototherapy devices to accommodate newborn infant's comfort, HCPs (n= 4) determined parents as not understanding it would impede lowering SBR levels: as opposed to parents making informed choices regarding PT. Therefore, HCPs assumed they knew best. On the other hand, HCPs (n=5) recognised parents were upset with unsettled newborn infants during PT.

"Trying to educate them [parents] that this is the best thing for your baby and the quickest way to get your baby home, can be difficult… cause for us, phototherapy's very normal, in a sense. It's not, in most cases that serious but, for some parents, they find it, like a horrific thought, they get really upset by it." (Daisy. HCP-1)

In contrast, when parents (n= 2) challenged PT plans parents perceived HCPs assumed they wanted to lower SBR levels as quickly as possible, however: this was not reflected in data gathered from parents.

[Dave]...cause the nurse came in...oh, you don't need to hold them, I goes, she'll nae settle otherwise, just with heat off my body, so this came around a couple of times but then I'd obviously seen online that you got another version of light where the baby could lie on it [see appendix 1 figure 1.2] and said, oh, I goes, is there not another type of light you can get, again, genuinely wasn't being awkward or nothing but, I was just wondering, oh, there is but this is the better one for giving more light…"

"[Isobel] They told us that one [see appendix 1 figure 1.1] was more effective at like, it reversed the kind of effects of the jaundice quicker so, you know, we understood why they wanted to keep her on that one…. The one with lights from underneath [see appendix 1 figure 1.2] …. Yeah, it was definitely a lot better than the other one, although obviously we knew that then it meant that, that the, it would maybe work less quickly."

[Dave] It would take longer" (Isobel and Dave. P)

Moreover, Irene (neonatal nurse) explained parents were not routinely offered PT options, such as: alternative phototherapy devices to accommodate newborn infant's comfort.

"They don't get any choice...no, and, they don't have, I never seen a discussion or had a discussion with parents regarding what device we're using, yeah." (Irene. HCP-2)

Therefore, overhead phototherapy devices were routinely used because they most effectively reduced SBR levels. Consequently, PT was performed as 'one size fit all', with little or no tailoring to family circumstances. Although paediatricians (as lead professional) were recruited onto the study, hospital activity prevented their inclusion on the day of focus groups, and coronavirus prohibited inclusion in the study via interviews. Additionally, one paediatrician declined to consent for inclusion in the study due to unease over repercussions from perceived radical opinions about current management of newborn jaundice (which is related to section 4.4.4). As a result, from data collected it is inconclusive if paediatricians perceived discussions to take place between them and parents regarding the type of phototherapy device to use.

In addition, an issue raised by most parents and in both focus groups with HCPs regarded monitoring serum bilirubin (SBR) levels during home PT in rural Scotland using a wearable device. On the whole HCPs (n= 6) were concerned who would obtain SBR levels, and distances for transportation from home to hospital laboratory for processing SBR levels to guide PT (see section 4.4.1(i) table 8). However, this focussed on hospital practices rather than adapting processes to enhance family centred care.

Alternatively, most parents (n= 6) reported they would have considered travelling into hospital for SBR levels to facilitate home PT using a wearable device, although: this could interrupt PT.

"I wouldn't have cared, if someone had said to me, you need to drive five hours every day." (Jayne. P)

Therefore, individualising care plans would require parents' involvement in decision-making.

4.4.1(i) Table 8. Study participants characteristics: Parents

Parent(s)	Number of children	Birth order for newborn jaundice	Time since experience	Approximate distance from home during hospital admission for phototherapy treatment	Reason for self-identifying as living rurally	Urban rural classification (Scottish Government 2020b)
Annie	2	2nd	9 months	70 miles	Change in service model of local Women and Children's services	Accessible town
Bridgit	1		3 years	8 miles	Lack of local activities	Accessible town
Cat	2	1st	3 years	14 miles	No local amenities	Accessible rural
Diane and Chris	2	Both	5 months	18 miles	Countryside characteristics	Accessible rural
Erin and Frank	1		2 years	3 miles *	Change in service model of local Women and Children's services	Urban area
Fiona	1		6 months	13 miles	Inconvenient access to Women and Children's services	Accessible town
Grace	1		9 months	39 miles	No local amenities	Accessible rural
Hannah	2	1st	3 years	26 miles	No local amenities	Accessible rural
Isobel and Dave	1		3 months	12 miles	No local amenities	Remote rural
Jayne and Pete	1		2 months	30 miles	No local amenities	Accessible rural

*Erin and Frank had their child three months before the local model of Women and Children's services changed, which would have resulted in a transfer of over 60 minutes for phototherapy treatment.

Furthermore, fathers (n= 3) described exclusion from hospital postnatal care which hindered supporting partners (as primary carer) care for newborn infants. Separating newly established family units for hospital PT detached siblings as well as newborn infants from parents, impacting bonding as a family.

"…that was the hardest part I think, driving all the way home knowing that, you know, cause I left you [Diane] and you were in tears, cause you were so tired, and I think driving away, all the way home, leaving you in the state you were in…it was heart breaking, certainly….[Our first child] as well, you could tell [our first child] was frustrated because, you know, mummy's home and then she's gone again and, and [our first child], [our first child's sibling's] home, and gone again. So, yeah, it was a tough time certainly." (Chris. P)

Although partners could stay overnight on maternity wards (supporting family centred care), in most instances it was unrealistic, due to distance from hospital from living rurally, (see section 4.4.1(i) Table 8) impacting caring responsibilities for children and pets, or work commitments such as farming.

In support of this, some parents (n= 3) lived over thirty miles from hospital (see section, 4.4.1(i) table 8) where mothers and newborn infants stayed for PT making daily visitation onerous for family members. HCPs were not necessarily aware of families' situation and did not individualise care planning to accommodate family circumstances.

"…my husband had to drive home at half ten at night, after being out the door at half five in the morning and stuff so, it was dangerous, him on the roads then as well." (Annie. P)

Moreover, all parents that participated self-identified as living rurally. However, some parents (n= 4) lived in areas classified an accessible town or urban area (see section 4.4.1(i) table 8). Of these parents, two experienced periods of no car ownership resulting in reliance on friends and family to access healthcare. The remaining two parents lived in areas where the local hospital temporarily changed service meaning no paediatric cover overnight.

"Erm, I think it's because we are quite far from, I think if [our child] got sick in the middle of the night, I know we could, we could go to [the local hospital], then we'd be transferred to [the large specialised hospital] or [alternative hospital], which is quite, well, we both drive, which is fine, erm, but, for a lot of the community, that's [an identifiable] community, a lot of them don't drive and could be here by themselves, cause their husbands could be away, which I think a lot of people find quite scary, erm, not that anything's happened, that I know of anyway, but, erm, yeah, I think it's because the major hospitals now are quite far away." (Erin. P)

Therefore, some parents included in the study (n= 4) identified as living rurally because they perceived isolation from healthcare services. As a result, parents (n= 3) described generalised vulnerability which encroached on their independence, affecting confidence and feelings of security. Likewise, feeling vulnerable when isolated from support was echoed by community midwives (which will be discussed in section 4.4.4).

To conclude section 4.4.1, parents included in the study described care centred round biomedical measurements (such as reducing SBR levels as quickly as possible). Furthermore, hospital initiatives to promote family centred care (such as facilitating partners overnight on maternity wards) was impractical for some families due to distance from hospital with living rurally. As a result, newly established family units were often separated at the pivotal point for bonding to facilitate hospital PT. Furthermore, some parents identified as living rurally because they perceived isolation from healthcare services which created feelings of generalised vulnerability. In addition, using overhead phototherapy devices to treat newborn jaundice was recognised by HCPs to most effectively lower SBR levels below treatment thresholds. Consequently, parents and newborn infants could be promptly discharged home. Although parents wanted discharged home with newborn infants, they did not want newborns infant unsettled during PT. On the whole, newborn infants were unsettled under overhead phototherapy devices. In other words, parents may have chosen (if offered) alternative phototherapy devices slower to reduce SBR levels if newborn infants were more settled using them. In contrast, HCPs viewed the impact of current PT on parents and newborn infants as a means to justify quickly lowering SBR levels, enabling discontinuation of PT and discharge home.

4.4.2 *"It was like a prison. It was a prison for me"* (Jayne. P).

Parents (n= 8) included in this study described lack of control over hospital postnatal stays. Mothers (n= 5) elaborated how staying in hospital post birth impinged upon freedom of movement, and choice regarding care.

"I kind of felt imprisoned in the room…" (Isobel. P).
"I felt like we were held hostage in the hospital…" (Grace. P).

Although all mothers included in this study identified as primary carer for newborn infants in hospital, they perceived not being involved with decision making and care plans. In support of this, Irene (neonatal nurse) disclosed parents were not routinely involved in decision making regarding type of phototherapy device to use (as presented in section 4.4.1). Likewise, most parents did not perceive sharing care with HCP. Consequently, mothers (n= 2) described postnatal care in hospital as happening ‘to them’ not ‘with them’. In contrast, some mothers perceived care during antenatal and intrapartum periods as shared between them and HCP.

"So, it's a huge shock cause you're given, they're really good with you through the whole birthing and they'll talk you through everything, you know, we have to do this because of X, Y, Z, is this okay, can I check this, can I do that, you have all that and it's wonderful and then nothing. It was, yeah, it, it got to me… [The postnatal period] Is just as important...it's a huge, huge difference, yeah, it's just like you're, I don't want to say kicked to the kerb but...verging on, yeah." (Jayne. P)

Furthermore, mothers (n= 5) described their immediate environment on hospital maternity wards as cramped with little privacy. Mothers (n= 3) felt vulnerable in unfamiliar environments with no control over who could enter bedside areas.

"I found it really difficult being in hospital and, you know, kind of feeling trapped there…obviously by the time you've got the these lights in with you and you're already stuck between two curtains and you always feel like people are encroaching on either side..." (Cat. P)

Lack of control over their immediate environment affected instinctive behaviours to recover after birth. For instance, mothers (n= 3) reported maternity wards as noisy which disturbed sleep and impinged upon recovery post birth.

"…it just wasn't peaceful cause they slammed, all the doors were slammed and they were always emptying the kitchen through the night and things like that, so I didn't feel like I was getting much sleep, and I think that probably affected me getting better quickly as well." (Isobel, parent)

Moreover, lack of space and use of curtains between bedside areas infringed upon mothers (n= 3) privacy. As a result, Hannah felt insecure breastfeeding her newborn infant.

"…when you're new to breastfeeding, you tend to not have any clothes on, you know, top half, yeah, erm, and doing that when you've got sort of people in out, you've got the curtains closed, fine, but everyone can hear everything, you know, and it's just, it's quite a, it's quite a public arena to be, erm, to be learning to do that...when you just want to be in your bed...in your environment…" (Hannah. P)

In addition, mothers perceived (n= 3) PT to interrupt time for bonding with newborn infants during breastfeeds. They recounted feeling disconcerted breastfeeding or cuddling their newborn infant because it was time away from PT. Consequently, breastfeeding became functional and bonding with their newborn infant was forfeited to ensure PT could be recommenced as quickly as possible.

"It [phototherapy treatment] did make it harder because, with my first one, I loved the closeness and cuddles and, like, cause the blanket round yous and stuff like that but, obviously this one, it was quite a separation, feed, and then down, it was no closeness in it at all. It was like, feed, get down." (Annie. P)

Overall, mothers lacked autonomy and control over postnatal care and surroundings on maternity wards in hospital. For this reason, mothers felt vulnerable and insecure in hospital. As a result, ability to breastfeed their newborn infant, and recover from birth was obstructed by hospital environments.

4.4.3 *"I think that would've helped me, mentally, having, having them home"* (Diane. P)

During hospital PT mothers were primary carers for newborn infants. Of the mothers that participated in this study, half (n=5) considered home PT using a wearable device would positively impact maternal mental health. Furthermore, mothers and newborn infants have a symbiotic relationship. Therefore, preserving the mother- infant unit would be advantageous to newborn infants' health (through breastfeeding) and wellbeing (through bonding and attachment). In contrast, parents described focus on biomedical measurements for newborn jaundice during hospital PT (as addressed in section 4.4.1), which eclipsed families' holistic health.

"I just really strongly felt that my milk, my mental health, my, you know, kind of wellbeing, my recovery was not, no longer being aided by being in hospital…" (Grace. P)

Consequently, parents' perceived home a more nurturing environment to support mothers care for newborn infants postnatally.

All parents included in the study commented on ward activity and staff shortages. Maternity wards were noisy which hindered mothers' ability to sleep, and busy which interfered with support available to mothers from healthcare professionals (HCP).

"[First child] would not settle under the lights so I had to sit with a finger in [first child's] mouth, to try and get [my first child] to settle, which meant I wasn't sleeping, which, I think, started off my postnatal depression, because I hadn't slept for a week..." (Diane. P)

Consequently, mothers struggled caring by themselves for unsettled newborn infants during PT which reduced opportunities for sleep and self- care. Although partners could stay overnight on maternity wards to assist in newborn infant's care this was often unrealistic (as described in section 4.4.1). Similarly, ward activity and staff shortages could impact time available for HCP to discuss care options, such as: manoeuvring overhead devices to facilitate skin to skin contact (SSC) between mothers and newborn infants to provide comfort; or using alternative phototherapy devices to settle newborn infants.

In other words, parents aspired for more autonomy in their role as providers of care (to their newborn infant) and recipients of care. For instance, parents identified (in section 4.4.1) people they would choose to support them care for newborn infants during PT, which was primarily close family members and not HCP. Likewise, home PT using a wearable device was regarded an opportunity for parents to have choice and autonomy.

"…it [home PT using a wearable device] at least gives you the freedom of choice, which I think would be, most people would be happy with." (Fiona. P)

Therefore, home PT using a wearable device was considered beneficial because mothers could be at home which they perceived as conducive to breastfeeding and bonding as a family unit (see section 4.4.2). In addition, mothers would be surrounded by their chosen support network to facilitate time for sleep and self-care whenever they desired. As a result, home PT using a wearable device was perceived by mothers as beneficial to their mental health.

4.4.4 Midwives' lack of trust in assessing newborn jaundice and parental capabilities

Midwives (n= 4) lacked trust in their clinical assessment of newborn jaundice, which involved examining: yellowness of skin and sclera; newborn infant's tone and energy; and their fluid intake and output. For example, Fern (see section 4.4.4(i) table 9) explained during postnatal home visits midwives referred jaundiced newborn infants into hospital for serum bilirubin (SBR) levels and paediatric review to guide PT.

4.4.4(i) Table 9. Study participants characteristics: Healthcare professionals

Healthcare professional (HCP)	Role	Base in hospital	Participant in first or second focus group
Amelia	Senior charge midwife	Maternity unit	First
Brenda	Midwife, neonatal trained	Maternity unit	First
Caitlin	Midwife, neonatal trained	Maternity unit	First
Daisy	Senior charge midwife	Maternity unit	First
Elaine	Senior charge midwife	Maternity ward	Second
Fern	Community midwife	City team	Second
Grainne	Bank midwife	Varied locations in hospital and community	Second
Hilda	Bank midwife	Varied locations in hospital	Second
Irene	Neonatal nurse	Neonatal intensive care unit	Second

Community midwives relied upon clinical judgement to assess newborn jaundice because they did not have transcutaneous bilirubin meters (TcB). However, community midwives (n= 2) felt their assessment was questioned by midwifery colleagues in hospital during referrals because their clinical judgement was not trusted. The second focus group revealed HCPs were unaware community midwives did not have TcBs, which could explain questioning during referrals. However, Elaine (a hospital midwife, see section 4.4.4(i) table 9) divulged her clinical judgement was 'questioned' by midwifery colleagues. Therefore, lack of trust in midwives' clinical assessment of newborn jaundice existed amongst midwives. In addition, Fern perceived hospital activity to potentially influence prioritising care of families in hospital over those at home.

"[Fern]…that's the worry I think, for sending for babies back in, cause I feel like we don't get trusted, sometimes our judgement's not the, does it really need to come back in, so…. but there is sometimes, you know...
[Grainne] We're questioned…
[Fern] I think when it happens it's more, maybe you're phoning and the wards are chocker that day...and they're kind of, do you really need to send this baby in…you're by yourself out there...you know, and it's your judgement that, we don't have TCs [transcutaneous bilirubin meter], we can't...you know, it's just our eyes and our judgement that's sending them in…" (HCP-2).

Furthermore, Fern felt vulnerable relying on clinical assessment of newborn jaundice working in community. Moreover, she described feeling isolated in community from HCPs when referring newborn infants to hospital. However, only two midwives who participated worked in community so caution should be observed to avoid over emphasising this point.

To be more precise, midwives did not trust their assessment of newborn jaundice regardless of working in community or hospital. In hospital they obtained transcutaneous bilirubin meter (TcB) readings to assess newborn jaundice prior to serum bilirubin (SBR) levels to avoid unnecessary invasive procedures. Participants in the second focus group had an open discussion about potential use of TcBs in community to support midwives' assessment of newborn jaundice. Consequently, providing opportunity for midwives and a neonatal nurse working in various areas of maternity services to share experiences. In contrast, the first focus group included midwives from the same area, namely: the regional district general hospital's maternity unit (see section 4.4.4(i) table 9 and 4.4.4(ii) table 10).

4.4.4(ii) Table 10. Study site characteristics

Regional district general hospital in Scotland	Large specialised hospital in Scotland
Temporary service model of Women and Children's services since March 2018, resulting in no paediatric services over night.	Includes a Children's Hospital and Maternity Hospital, which has a Neonatal Intensive Care Unit.
The main hospital for neonatal transfers is over 60 minutes away on a major road.	Main unit for maternity and neonatal transfers from two rural general hospitals, two stand-alone midwifery led units, one alongside midwifery led unit, and one regional district general hospital.

However due to potential false negative readings, participants in the second focus group (n=3) did not trust TcBs either. Nevertheless, hospital midwives (n= 2) trusted TcBs over their clinical assessment of newborn jaundice. This highlighted lack of confidence in midwives' clinical assessment of newborn jaundice. As a result, professional responsibility as autonomous practitioners to escalate concerns (based on their clinical judgement) and request SBR levels or paediatric review was impacted.

"I'm worried about the TC [transcutaneous bilirubin meter] machines, like I really don't like them….We've had so many, like so many incidences, in the last years or so, maybe year and half, where the TCs have been fine and they've said, you don't need to do anything else but, we've known that baby's like orange...or whatever and done SBRs and it's like, exchange level and they've been so wrong…I don't think they work…And then like you're, you're just, you think, well, the machine must be right, my instinct, probably not right...the machine, you know, that must be okay." (Elaine. HCP-2)

Consequently, midwives feared relying on clinical judgement in case they misdiagnosed or mistreated newborn jaundice. In other words, they feared a failure to reduce SBR levels in a timely manner. This fear resulted from uncertainty regarding professional accountability, and sharing responsibility as a care team, which included: midwives; parents; and paediatricians.

Therefore, midwives (n= 6) from both study sites (see section 4.4.4(ii) table 10) depicted lack of professional identity caring for families experiencing newborn jaundice. As a result, midwives relinquished decision making responsibilities to paediatricians.

"…we make contact with the paediatrician on call for that day and just say, this is baby X, Y, Z, and they will let us know what the plan is after that." (Hilda. HCP-2)

"…Otherwise, they [the paediatrician] give us instruction…." (Brenda. HCP-1)
"We provide the care but, they [paediatrician]...we're led by them, erm...they're responsible, their responsibility." (Caitlin. HCP-1)

Consequently, midwives' professional identity as autonomous practitioners with ability to share care with paediatricians was affected. Midwives in this study responded to instructions from paediatricians rather than making clinical decisions about care. Furthermore, midwives (n= 4) did not trust parents as primary carers with home PT using a wearable device and feared midwives would be clinically accountable for SBR levels not improving. This involved midwives working in community or from the regional district general hospital which did not have paediatric services overnight. Therefore, without paediatricians on hand midwives felt vulnerable and isolated from support.

Although HCPs (n= 8) were aware of negative impact to families and newborn infants with hospital PT (such as, bonding and comfort), midwives (n= 4) did not trust parents would comply with home PT. They questioned whether parents would remember to recommence PT after breaks for infant feeding, nappy change, or comfort.

"[Amelia] And you'd have to be very sure of the parents, that they are going to keep the lights on.
[Brenda] Yeah, and how reliable they're going to be to do it all." (HCP-1)

Midwives lacked confidence supporting families share decision making as members of a care team. It is worth disclosing that two participants in the first focus group left discussions mid- way through due to ward activity. Therefore, the influence not trusting parents as primary carers could have on HCPs' acceptability for home PT using a wearable device could be under reported.

Midwives' (n= 4) lack of trust in parents to perform home PT using a wearable device influenced eligibility criteria. For example, Fern (community midwife) proposed eligibility criteria extending beyond clinical factors (including gestation, severity of newborn jaundice, dehydration, and weight loss) to include social factors, however: study participants could not specify social factors they judged to be relevant.

"I think, yeah, the healthy, and, as well, the social side of things...as well, looking at the, is it appropriate for them...you know, it's hard not to be, sound like, the, the parents are capable of having this responsibility in their home, you know, yes, clearly could be, they're responsible enough to have a new born baby but, are they responsible enough to do this kind of care..." (Fern. HCP- 2)

This sentiment about social factors determining eligibility for home PT was echoed in the first focus group. They discussed community midwives as having developed better relationships with parents than hospital midwives. Therefore, community midwives were seen as able to assess parents as trustworthy for home PT.

"So, you would probably go on your community midwife by that as well...they would be pretty, especially with the best start team, they'll be very sure of their parents, they would have a good relationship already with them, so they would...be able to advise you whether they thought that would be...feasible or not. Or, if there was a reason for it not, a categorically to be a no." (Amelia. HCP-1)

In other words, development of 'best start' teams were seen as beneficial to relationships between parents and midwives. In 'best start' teams midwives carry a caseload of women providing continuity of carer throughout antenatal, intrapartum, and postnatal care. This was perceived by HCPs (n= 2) as giving midwives knowledge to judge whether there were reasons to prevent offering home PT to parents.

In brief, midwives feared relying on their clinical judgement in case they misdiagnosed or mistreated newborn jaundice (by failing to reduce SBR levels quickly). Furthermore, midwives relinquished decision making responsibilities to paediatricians, responding to their instructions rather than sharing clinical decisions. Apart from this, community midwives described feeling vulnerable when isolated from hospital support. Moreover, midwives lacked confidence supporting families to share decision making as members of a care team. In addition, midwives did not trust parents as primary carers with home PT using a wearable device and feared midwives would be clinically accountable for SBR levels not improving.

4.4.5 Parents' awareness of mistrust

Mothers (n= 3) described care from midwives in hospital as overwhelming and not beneficial. As a result, empathic care was overshadowed by structured processes and routine (as discussed in section 4.4.1). Mothers interpreted this type of 'care' as a consequence of midwives' fear of missing abnormal signs developing in mothers and newborn infants, which could result in litigation due to negligence.

"…in hospital, it was too much for me. I was getting overwhelmed by the, the amount of people that would come and check and, it was just, it felt like was literally never ending…It being forced upon me. Yeah, like I think the health visitor comes too often but, I understand why she has to. Erm, because of the negligence and you've got to cover your backs…" (Jayne. P)

Furthermore, parents (n= 2) explained they received care from multitudes of HCP making the experience feel impersonal. Moreover, parents (n= 3) did not describe care as individualised. As a result, individual capabilities and needs were not considered. In other words, parents did not view care as shared between them and HCPs. Consequently, parents (n= 3) perceived support to care for newborn infants as paternalistic which restricted choices regarding and control over their infants' care.

Although parents (n= 5) recognised postnatal vulnerability, they did not equate it with incapacity to share care with HCPs. Likewise, parents did not consider themselves unable to make decisions regarding newborn infants’ care. In contrast, parents (n= 3) described wanting HCPs to have more confidence in parental capabilities, and making decisions regarding newborn infants’ care. In addition, they required HCPs’ to consider parents individual circumstances (such as family support) when care planning. Therefore, parents yearned for HCPs to contemplate their social circumstances when planning care.

“Yeah, I don't know, maybe a bit more confidence in new parents, erm, you know, I've talked about not feeling empowered but, I just felt like a lot of it happened to us, erm, and were, you know, I was definitely in the most vulnerable state I've been in my life but…we'd had that support from family as well as being kind of capable in ourselves so, maybe a bit more confidence really.” (Grace. P)

Furthermore, parents included in the study self- identified as living rurally. Distance to hospital from home was isolating for some mothers in hospital. Consequently, parents included in this study perceived more support at home than hospital to care for their newborn infant. For example, at home partners and close family members would be available to share care of newborn infants, such as: assist with infant feeding; comfort; and change nappies. Additionally, partners and close family members could provide emotional support to mothers and time for rest or self- care (which was discussed in section 4.4.3).

“With my mum and dad so close and [Chris] at home as well, that I would've always had someone at my beck and call…I think I would've had more support at home.” (Diane. P)

In contrast, for parents included in this study mothers were primary carers for newborn infants in hospital and carried this burden alone (see section 4.4.3). Although HCPs were available for support during hospital PT all parents included in this study were sensitive to ward activity and staff shortages. As a result, parents were reluctant to seek support from HCPs because they assumed somebody else needed assistance more. Whereas parents expressed feeling comfortable asking partners and close family members for support caring for newborn infants.

To conclude this first theme, mothers described structured processes and routine care provided in hospital as not for their benefit. Care was perceived as defensive resulting from HCPs fear of missing abnormal signs developing in mothers and newborn infants. In addition, parents perceived HCPs as not trusting parent's capabilities to assess their own (and newborn infants') health and wellbeing. Moreover, distance between rural homes and hospital were isolating for some mothers whilst in hospital. This meant some parents included in the study perceived more support to care for newborn infants at home than hospital. However, parents sensed HCPs were not confident in family's capabilities to share care of newborn infants at home. Therefore, parents perceived hospital postnatal care as paternalistic restricting parental choice regarding (and control over) their newborn infant's care.

4.5 Considering an alternative experience of phototherapy treatment

Although parents were dissatisfied with current phototherapy treatment (PT) they considered an alternative experience of PT through ideas for service improvement. Therefore, this second theme explored parents' and healthcare professionals' (HCP) perspectives of alternative phototherapy devices and delivery of PT. Additionally, the theme illuminated using technology to facilitate trust between HCPs and parents, as well as support for home PT. As such, sub-themes generated were: parents guiding service improvement for PT; and use of technology to facilitate trust and support home PT.

4.5.1 Parents guiding service improvement of phototherapy treatment

All parents wanted the option of home PT. Likewise, all parents expressed a desire for phototherapy devices to facilitate breastfeeding and newborn infant's comfort. However, most parents (n= 9) would compromise on the useability, size, and functionality of phototherapy devices to enable home PT in the short term.

"Something home related… I think a home version of a phototherapy suite is definitely a brilliant idea, or they're going with textiles obviously I think it's going to take quite a bit of time and funding, that aspect, so I think a, a home version, if they can come up with something like that would be definitely beneficial for parents..." (Frank. P)

Furthermore, all parents described wanting some flexibility with PT that satisfied individual needs. For example, during hospital PT parents (n= 8) felt confined (see section 4.4.2) and wanted to leave bedsides whilst continuing PT. Likewise, parents (n= 5) desired mobility between rooms with a phototherapy device during home PT. Moreover, parents (n= 3) aspired for flexibility of movement to extend beyond boundaries at home. Although a wearable phototherapy device could satisfy their requests parents were realistic about available healthcare resources. Consequently, parents had simple suggestions to improve current phototherapy devices to provide flexibility of movement and freedom of choice (which featured in section 4.4.2 and 4.4.3) in the short term.

"You just need a battery back up on the lights, that way you could wheel them about." (Dave. P)

Additionally, all parents included in the study were interested in tele- medicine to support home PT in Scotland using a wearable device. To be precise, parents did not consider in person support from HCPs as necessary for the entire episode of care involving home PT using a wearable device. However, parents (n= 2) identified out of hours support to be required, although it was not regarding PT per se but in relation to breastfeeding. This could be due to the relationship between newborn jaundice and poor infant feeding.

"it's the 7 til 11, that cluster feeding, where, just at the end of your tether, it's the evening you need support more, I would say." (Bridgit. P)

Likewise, midwives (n= 1) recognised demand from parents for out of hours breastfeeding support because parents were currently accessing maternity triage service for breastfeeding support. Maternity triage service is staffed 24 hours a day for pregnancy and labour advice.

"So, I work in TR [maternity triage] sometimes so a lot of postnatal women do phone just for, sometimes just breastfeeding advice and things like that, overnight, because they can't wait, you know, sometimes it's later in the day before they see their midwife so, yeah, having, maybe having somebody available to, to speak to really." (Grainne. HCP-2)

Furthermore, HCPs in the second focus group discussed 'Best Start' teams' use of video calls for breastfeeding support at home which will be discussed in section 4.5.2.

In summary, parents desired the option of home PT with a wearable device. In addition, parents requested a degree of flexibility with PT to address families' needs. Moreover, parents yearned for phototherapy devices to facilitate breastfeeding and newborn infant's comfort, however: most would compromise on the useability, size, and functionality of phototherapy devices to enable home PT in the short term. Additionally, parents expressed interest using tele-medicine to facilitate out of hours breastfeeding support. In support of this, midwives revealed parents currently accessed maternity triage for breastfeeding advice.

4.5.2 Use of technology to facilitate trust and support home phototherapy treatment

HCPs participating in the first focus group raised concerns about newborn infants' maintaining temperature during home PT. For example, overhead phototherapy devices routinely used in hospital (as presented in section 4.4.1) involved newborn infants lying naked in a cot to receive maximum coverage of PT (see appendix 1 figure 1.1). Therefore, HCPs (n= 7) liked a wearable phototherapy device to facilitate home PT because it could maintain newborn infants' temperature. As explained in section 4.4.4, two participants in the first focus group left mid- way through discussions due to ward activity. Therefore, value of a wearable phototherapy device for HCP's acceptability of home PT could be under reported. Nevertheless, the remaining HCPs in the first focus group discussed potential features of a wearable phototherapy device.

"…long sleeves, long legs, for maximum [coverage]…the more the better… have a hat made of it as well then cause then it could help with coverage as well...erm, and have feet on the suit, the more coverage the better…" (Caitlin. HCP-1)

Furthermore, during both focus groups the researcher enquired about a removable front panel to the wearable phototherapy device. This meant skin to skin contact (kangaroo care) between mothers and newborn infants could be facilitated throughout PT to support breastfeeding and bonding. Therefore, encouraging

HCPs (n= 7) a wearable phototherapy device could facilitate PT whilst protecting the mother- infant unit.

"Yeah, definitely, cause I mean, kangaroo care's so important." (Caitlin. HCP-1)

Additionally, in section 4.4.4 HCPs expressed doubt parents would comply with home PT. However, a wearable phototherapy device with removable front panel was perceived advantageous by allowing parents to comfort newborn infants whilst continuing PT.

Likewise, parents recognised benefits to a wearable phototherapy device facilitating skin to skin contact with newborn infants whilst continuing PT. For instance, mothers (n= 5) determined a removable front panel could assist with breastfeeding and bonding. As a result, they correlated a removable front panel to a wearable phototherapy device with supporting emotional wellbeing and mental health (which was explored in section 4.4.3).

"...that would've been great, just anything that facilitates skin to skin, cause it just solves so much and really helps with a lot of the emotions and bonding and, erm, you know, issues in milk as well, you know, just helping my milk come in." (Grace. P)

Furthermore, parents (n= 3) identified home PT to potentially impact treatment compliance because they perceived HCPs as unable to monitor duration of PT like they did on the maternity ward. However, parents (n= 2) suggested using technology to measure duration of PT themselves, which could be remotely monitored by HCPs.

"I suppose something as well, I'm just thinking about the functionality, erm, something that would link into your phone, sort of like working out, or maybe even a little app, you know for seeing how many minutes, hours, or whatever they've been under the lights, or in the lights… cause you're on your phone anyway…Erm, cause, yeah, you're sitting down feeding all the time." (Hannah. P)

Moreover, HCPs (n= 5) included in the study acknowledged ability to remotely monitor duration of PT would reassure compliance with PT. Additionally, enabling remote access by HCPs in hospital to monitor duration of PT could influence parental compliance with PT.

"[Amelia] Yeah, I suppose you could put in a feature to monitor it [duration of PT].

[Caitlin] Yeah, that would work." (HCP-1)

Likewise, parents (n= 5) were interested in technology to monitor newborn infants' temperature at home during PT using a wearable device. Therefore, parents suggested sensors to monitor newborn infants' temperature. In contrast, all parents included in the study felt competent as primary carers to monitor newborn infants' temperature during home PT with a wearable device using thermometers. One parent suggested using thermometers supplied in Scottish Government's Baby Box scheme to monitor and document newborn infants' temperature in a journal shared with HCPs. However, this would rely on HCPs trusting parents' capabilities to monitor newborn infants' temperature, accurately document it, and inform HCPs of abnormal results (related to section 4.4.4).

In contrast, HCPs (n= 4) in the second focus group discussed remote real time monitoring of newborn infants' temperature linked to online medical notes so paediatricians could oversee results. Therefore, HCPs envisioned technology facilitating trust between them and parents to support home PT in rural Scotland using a wearable device.

"[Grainne] Like a wee Fitbit kind of...
[Hilda] That would work.
[Elaine] I suppose if like, ideal, ideal world...that all that information then magically appeared on Badger [online maternity portal]…in the hospital, that people can keep an eye on things and...
[Irene] And part of their [paediatricians] role would be to, to go through the…the results from the home." (HCP-2)

On the other hand, technology to remote real time monitor newborn infants' temperature linked to online medical notes could be perceived as surveillance at home opposed to facilitating trust. Additionally, conversation revealed HCPs considered paediatricians to make decisions instead of sharing care and responsibility as a team.

Apart from this, the second focus group had an open discussion about the local 'best start' team using video calls to provide breastfeeding support. This was received well within the focus group and viewed as facilitating out of hours support for home PT.

[Fern]...cause I think that's what they're doing with Best Start, you know, you've got iPhone, they're doing facetime... giving support like breastfeeding support…
[Irene] Yeah, so there was still support out of hours...but it wasn't direct face to face, it was on, yeah…
[Elaine] Yeah, I think it'd be quite good.
[Irene] That would work.
[Hilda] Definitely (HCP- 2).

Participants (n= 2) in the first focus group agreed tele- med could provide support for home PT using a wearable device, however: they raised a question they could not answer, which was who would be answering the calls.

In addition, parents suggested online resources for information regarding working phototherapy equipment during home PT using a wearable device. Therefore, they could easily (and repeatedly) access information from mobile phones at their convenience.

"I guess if there was some digital kind of, maybe videos that you maybe watch on YouTube or whatever, you know, how to, how to...how to use these things or, you know, just sort of, erm, that sort of thing, actually, would probably be, erm, that would be useful, yeah, you could watch in the middle of the night."
(Hannah. P)

In short, all parents included in the study were interested in accessing a variety of information and support that did not necessarily involve 'in person' contact with (but was endorsed by) HCPs.

4.6 Summary

This chapter presented two themes generated from data collected from two focus groups with nine HCPs and ten interviews with 14 parents: current limitations to the phototherapy treatment experience; and considering an alternative experience of phototherapy treatment (PT). Study participants described a 'one size fit all' focus for newborn jaundice centred round quick reduction of serum bilirubin (SBR) levels. HCPs justified this approach resulting in discontinuation of PT enabling families' discharge home. However, HCPs assumed parents agreed use of overhead phototherapy devices were worth the distress to mothers and newborn infants to effectively lower SBR levels and facilitate timely discharge home. In contrast, parents reported prioritising reduction of SBR levels over parental instincts jeopardised breastfeeding, bonding and maternal mental health. As a result, parents described lack of autonomy over care in hospital. This meant ability to care instinctively for newborn infants and recover from birth was impacted by hospital stay.

As a result, parents perceived lack of autonomy during hospital PT. Moreover, parents considered care received in hospital as paternalistic. Consequently, parents interpreted this as HCPs lack of trust in parental capabilities. However, HCPs did not trust their clinical judgement to assess and manage newborn jaundice. As a result, midwives feared they would be held clinically accountable for SBR levels not improving. Therefore, HCPs lacked trust in their assessment of newborn jaundice because of fear. This fear resulted from perceived professional responsibility as autonomous practitioners, as opposed to sharing responsibility as members of a care team (including parents). In addition, it affected ability to trust parental capabilities. For this reason, the rural aspect of the study became inconsequential to acceptability and feasibility of a wearable device to facilitate home PT for newborn jaundice.

However, parents perceived home PT using a wearable device as control over their care. Although parents expressed desire for phototherapy devices to facilitate breastfeeding and newborn infant's comfort, they primarily wanted home PT. Therefore, study participants explored capabilities of technology to facilitate trust and support home PT. HCPs and parents were receptive to technology monitoring duration of PT and providing breastfeeding support at home. Although challenges with monitoring SBR levels were recognised, supporting parents to guide PT would avoid a 'one size fit all' focus for newborn jaundice.

CHAPTER FIVE: DISCUSSION

5.0 Introduction

The aim of this research was to explore (with parents and HCPs) the acceptability and feasibility of a wearable device to facilitate home PT in rural Scotland. Perceived trustworthiness of medical knowledge and quantifiable measurements over parental instincts and midwifery clinical judgement were key findings found to hinder feasibility of a wearable device to facilitate home PT. Apart from this, midwives in the current study perceived a wearable phototherapy device to influence positively acceptability of home PT. However, the rural aspect of the study became inconsequential to acceptability and feasibility of a wearable device to facilitate home PT. Furthermore, parents were willing to compromise on size, functions, and usability of a phototherapy device to facilitate home PT in the short term. In this last chapter, interpretation of key findings will be discussed within the context of the existing body of literature using Fricker's (2007) concept of epistemic injustice (see section 3.13). In short, epistemic injustice refers to inequity due to unequal power dynamics between people or systems (Fricker 2007). There are two sections to the discussion with headings replicating key types of epistemic injustice, namely: testimonial injustice; and hermeneutical injustice. Each section consists of a definition and brief introduction. Finally, study strengths and limitations will be addressed, followed by recommendations for practice and research, a conclusion, and personal reflection on my journey.

5.1 Testimonial injustice

The current study claims credibility of medical knowledge involved identity prejudice, reflecting what Fricker (2007) referred to as testimonial injustice. For example, Fricker (2007) determined testimonial injustice to take place when a person's knowledge was valued over another due to prejudicial stereotypes. This study demonstrated parents were disadvantaged due to positive prejudice towards medicalised knowledge focused on reducing serum bilirubin (SBR) levels as quickly as possible. Consequently, parents sharing decision making with the care team was hindered due to credibility of medical knowledge over parental values and instincts, potentially impeding feasibility of a wearable device to facilitate home PT.

The current study disclosed midwives did not trust some parents with home PT using a wearable device due to identity prejudice towards some parents stereotyped as untrustworthy, reflecting Fricker's (2007) identity prejudice in stereotyping. Similarly, Dykes (2005, p246) found midwives made judgements culminating in "stereotyping of women". Set in two maternity units in England, Dykes' (2005) critical ethnographic study used participant observations and focus groups to gather data from 61 postnatal women and 39 midwives. The present study suggests inequity of access to a wearable device facilitating home PT could derive from HCPs not trusting some parents due to identity prejudice towards parents. In support of this, Chang and Waite (2020) admitted a limitation to their retrospective cohort study of 1,324 newborn infants in the USA was that HCPs trust influenced parent's inclusion. Although Chang and Waite (2020) determined home PT treated newborn jaundice effectively, they recognised the cohort consisted of parents HCPs trusted with following care plans for home PT. Likewise, Walls et al (2004) acknowledged two newborn infants met criteria excluding them from the home PT programme in Scotland but were included at paediatrician's discretion, demonstrating superiority of medical opinion. In other words, it was unclear why healthcare professionals (such as paediatricians) trusted some parents and not others to follow care plans for home PT (Chang and Waite 2020, Walls et al. 2004).

This study suggests identity prejudice towards parents could result in negative stereotypes diminishing parents' credibility and rendering them incapable to make care decisions. In support of this, Sudia- Robinson and Freeman's (2000) case study of a 25 week gestation first born child in the USA used descriptive design to interview the parent couple and their health and social care team, consisting of: two of the child's neonatal intensive care unit (NICU) nurses; one neonatologist; one paediatrician; and one social worker. The findings demonstrated lack of shared decision making with parents, specifically involving critical and 'daily- stage decision making' (Sudia- Robinson and Freeman 2000). Sudia- Robinson and Freeman (2000) described 'critical- stage decisions' as major decisions, such as ventilatory transition. 'Daily- stage decision making' referred to routine care planning (Sudia- Robinson and Freeman 2000). However, through frequency of experience extraordinary events become ordinary and routine (Atwood 1985). Therefore, lack of shared decision making with parents could be due to the health and social care team perceiving care performed as routine and not requiring shared decision making (Sudia- Robinson and Freeman 2000). It is worth noting Sudia- Robinson and Freeman's (2000) study occurred before family integrated care was introduced into NICUs, which locates families central to newborn infant care (Patel et al. 2018). Sudia- Robinson and Freeman (2000, p147) found "missed opportunities" to participate in 'daily- stage decision making' were key issues raised by parents, causing parents stress and anxiety through not valuing parental knowledge during decision making.

Similarly, maternity services promote family centred philosophy of care: however, from this current study and supported by Franck et al. (2019) it is unclear how families are integrated into care plans for newborn infants as primary carers. For instance, mothers included in the present study felt they alone carried the burden of primary carer in hospital, which contrasts with the philosophy of midwifery care: working 'with woman' (Bradfield et al. 2019). In other words, this philosophy entails working in partnership with women to protect their rights and encourage maternal self-confidence (International Confederation of Midwives (ICM) 2018). Contrary to midwives being 'with woman' (Bradfield et al. 2019), mothers expressed awareness midwives lacked confidence in their parental capabilities.

Echoing Fricker's (2007) concept of epistemic harm, mothers disclosed hospital PT impacted their mental health, ability to breastfeed and bond as a family. Although, mothers in this study felt their opinion was valued more in pregnancy and birth compared to postnatal care. On the other hand, mothers in this present study may have experienced "illusion of…empowerment" during pregnancy and birth (Bennett 2011, p154). In other words, mothers choose from options provided by HCPs during pregnancy and birth. Therefore, knowledge can be a tool to control women. Similarly, Freeman (2015) claimed paternalised care combined with overuse of some technologies (ultrasound scans for example) perpetuated HCPs' power and control over women during pregnancy and birth by distancing women from their bodies. However, mothers in the present study perceived no options for care of newborn infants with jaundice out with hospital admission.

In the same way, HCPs in the present study revealed parental exclusion from discussions about care plans for newborn infants' PT meaning parents' values neither guided nor individualised care, potentially explaining why parents embraced participating in this study exploring ways to protect the mother- infant relationship and improve families' experience of a common episode in postnatal care, namely: PT for newborn jaundice. This was demonstrated by 25 mothers from rural settings responding to the first advert during recruitment (see section 3.4).

Fricker (2007) determined open conversation to be necessary for construction of one's identity. In other words, dialogue forms one's thoughts and opinion shaping identity. Ostracising women from discussions and shared decision making during the immediate postnatal period could hinder transition into 'mother'. On the other hand, this period is short lived so will not prevent the "formation of their identity" (Fricker 2007, 54) as a mother. However, Leah-Warren, McCarthy and Corcoran (2012) demonstrated a significant relationship between maternal parental self- efficacy and maternal mental health ($p<0.001$). Leah- Warren, McCarthy and Corcoran (2012) found support from family (not HCPs) affirmed maternal mental health and significantly reinforced parental self-efficacy at six weeks postnatal for first time mothers. Therefore, this study claims a wearable device to facilitate home PT (or PT designed for home use) could benefit women's transition to motherhood because partners and family would be available to care for the mother- infant dyad.

To conclude section 5.1, the current study claims parents' disadvantage could hinder feasibility of a wearable device to facilitate home PT due to testimonial injustice impeding shared decision making within the care team (including parents and HCPs). Due to identity prejudice towards some parents stereotyped as untrustworthy by midwives, this study claims potential for inequity of access to home PT, and a wearable device facilitating home PT. Therefore, this study suggests credibility of medical knowledge involves identity prejudice towards parents, reflecting what Fricker (2007) referred to as testimonial injustice.

5.2 Hermeneutical injustice

Hermeneutical injustice is not imposed by individuals but refers to structural discrimination (Fricker 2007). In other words, it is discrimination caused by those in power collectively controlling knowledge and understanding (Fricker 2007). As applied to this study's context, dominance of medicalised care within maternity services of the National Health Service (NHS) has structured "collective social understandings" (Fricker 2007, p147) of newborn jaundice around quantifiable measurements, such as: serum bilirubin (SBR) levels to guide PT; transcutaneous bilirubin meter (TcB) readings to assess newborn jaundice; and kilograms measuring newborn infant's weight to determine effective breastfeeding. Validating trustworthiness of medicalised care using quantifiable measurements, compared to midwifery clinical judgement or parental instinct is apparent. Therefore, justifying medicalised care of newborn infants with jaundice by valuing quantifiable measurements more than other aspects of care, such as: maternal mental health; bonding; and breastfeeding. This section will discuss hermeneutical injustice and what it means for acceptability and feasibility of home PT (irrespective of device because parents in the current study primarily wanted home PT), and a wearable device to facilitate home PT.

Hermeneutical injustice is difficult to expose because it appears restrictedly in areas, referred to by Fricker (2007, p152) as "hermeneutical hotspots". However, this study suggests care of newborn infants with jaundice is such a 'hotspot' in which midwives appear powerless, prohibiting shared decision making within care teams. The present study suggests dominance of medicalised care involves structural identity prejudice towards midwifery care diminishing midwives' credibility, reflecting what Fricker (2007) referred to as hermeneutical marginalisation. In other words, discrimination caused by those in power collectively controlling knowledge and understanding (Fricker 2007). For instance, midwives in the current study indicated apprehension at not using transcutaneous bilimeters (TcBs) or challenging TcB readings, despite TcB readings occasionally conflicting with midwifery clinical judgement.

In other words, midwives in this study designated greater credibility to TcBs, potentially being reassured by false negative readings instead of trusting their clinical judgement. Unfortunately, the findings of this study did not illuminate why midwives feared trusting their clinical judgement. However, midwives included in Hunter's study (2003, p243) spoke of "an atmosphere of surveillance" at obstetric hospitals in New Zealand, culminating in fear of judgement. Similarly, Scamell (2016) described NHS maternity services operating within a culture based on clinical governance, which standardises and audits care to ensure safety, and to withstand scrutiny (Scamell 2016). However, Scamell (2016, p17) claimed midwives felt "singled out and blamed" because of clinical governances' "tendency towards culpability". Likewise, Hunter (2003) explained midwives not using technology available was interpreted as defiant and affiliated with unsafe practice. Supporting this study's claim midwives perceive quantifiable measurements as collectively valued more than their clinical judgement. This is the case even though focus on quantifiable measurements potentially leads to unsafe practice, which ironically clinical governance aims to avoid. In other words, potentially due to fear of being perceived as defiant and unskilled (Hunter 2003) leading to scrutiny and blame from clinical governance (Scamell 2016), midwives are reassured by false negative TcB readings instead of trusting their clinical judgement: because TcB readings are collectively valued more by NHS maternity services to assess newborn jaundice than midwifery clinical judgement. As a result, the present study claims hermeneutical marginalisation of midwifery care suppresses evolution of midwives' professional identity, leading to midwives not trusting their clinical judgement.

Consequently, restraining midwives' advocacy role to challenge care plans for newborn jaundice, hindering a holistic approach centred on the symbiotic relationship between mothers and newborn infants emerged (which will be explored later in this section). In contrast, midwives in the current study identified their role to be 'with woman' (Bradfield et al. 2019), recognising parents found PT 'horrific'. Yet they did not challenge current approaches to delivery of PT. This study claims hermeneutical marginalisation of midwifery care resulted in midwives' loss of confidence inhibiting courage (Fricker 2007) to challenge colleagues and care plans. This reflects what Fricker (2007) referred to as epistemic harm. As a result, midwives took instruction from paediatricians without challenging care plans.

Therefore, this study claims midwives accepted overhead hospital PT due to dominance of medicalised care involving hermeneutical marginalisation (Fricker 2007) of midwifery care in NHS maternity services. Thereby, hindering midwives supporting breaks from PT to facilitate bonding and breastfeeding, whilst conserving maternal mental health. Breaks from continuous PT lasting 30 minutes to provide comfort and accommodate infant feeding, changing nappies and cuddles are recommended (National Institute for Healthcare and Excellence (NICE) 2016). In fact, national guidance (NICE 2016) recognises intermittent PT as effective for newborn infants from 37 weeks gestation with SBR levels requiring low grade PT. Furthermore, national guidance (NICE 2016) advised breaks from PT to be arranged using clinical judgement which the current study revealed midwives did not trust. In contrast, family integrated care (implemented in NICUs) locates families as central to newborn infant care (Patel et al. 2018), emulating the model of newborn care proposed by Levin (1994). Levin (1994, p39) maintained adherence of symbiosis between mothers and newborn infants for one month through "psychological and biological umbilicus". Part of this involved keeping mothers and newborn infants physically connected (Levin 1994). Therefore, incorporating the philosophy of family integrated care into care of newborn infants with jaundice to support the delivery of PT around the maternal infant dyad could minimise their separation.

Similarly, midwives perceived a wearable device to facilitate home PT to reinforce the position in current policy of: keeping families together (Scottish Government 2011); and making decisions in partnership with families (Scottish Government 2016); so families remain at the centre of care (Scottish Government 2017a). Even so, midwives in the current study were concerned who would obtain SBR levels, and distances for transportation from rural homes to hospital laboratories for processing SBR levels to guide home PT using a wearable device. Consequently, they were focussing on biomedical measurements instead of holistic care. However, midwives feared blame from jaundice not improving, and medical knowledge has structured “collective social understandings” (Fricker 2007, p147) about newborn jaundice around SBR levels. This suggests that if a wearable phototherapy device was proven to effectively reduce SBR levels, midwives may be more likely to promote it’s usage than home PT. This could also be perceived as “a paternalistic trend within medicine” to maintain power over mothers (Freeman 2015, p45). In other words, midwives will support home PT when a wearable device is created to facilitate continuous PT whilst feeding or comforting infants, therefore minimising interruptions from PT to reduce SBR levels quickly. Consequently, medical technology determines the option of home PT for parents. This implies that the ability to humanise PT (by facilitating maternal- infant bonding and breastfeeding) relies upon medical technology instead of people in care teams. A reliance on medical technology could be interpreted as disempowering women (Freeman 2015), parents and midwives.

Likewise, this study suggests mothers could not challenge hospital PT due to “unequal relations of power” (Fricker 2007, p152). Fricker (2007, p152) describes “women’s…unequal hermeneutical participation” as a “background condition of hermeneutical injustice”. For example, mothers in the current study disclosed distress at using overhead phototherapy devices. Yet, alternative devices were not offered to improve maternal and newborn infant experience of PT. Referring to Fricker’s (2007) concept of hermeneutical injustice, mothers’ disadvantaged position thwarted her understanding of the experience, obstructing ability to challenge and transform her experience of PT. On hindsight, focus groups with mothers would have been beneficial for them to feel less isolated by sharing experiences and form a collective understanding of PT to challenge the dominant medicalised focus on SBR levels. In the same way, women’s understanding of postnatal experiences came from historically sharing their thoughts and feelings collectively resulting in recognition of postnatal depression (Fricker 2007). Other studies have discussed women’s epistemic injustice during pregnancy and labour resulting in unequal power dynamics between HCPs and women (Freeman 2015) impacting shared decision making (Villarmea and Kelly 2020).

Although gender is part of it, this current study claims hermeneutical injustice in NHS maternity services transcends gender. For example, fathers included in this study were middle class white men. However, their opinion was excluded by midwives because they were not HCPs. Even when fathers had valuable knowledge related to PT through their trade it was deemed implausible by HCPs. Therefore, parents with newborn infants receiving PT can be "doubly wronged" by structural prejudice and identity prejudice (Fricker 2007, p159). For example, medical superiority within NHS maternity services organises care of newborn jaundice around biomedical measurements. Additionally, identity prejudice towards women stereotyped as emotional and irrational (Fricker 2007) could render maternal knowledge about newborn infants unreliable. Likewise, identity prejudice towards some parents stereotyped as untrustworthy could exclude them from home PT with a wearable device.

Yet, midwives in the present study recognised the benefit of a wearable device in promoting maternal- infant bonding, facilitating home PT and keeping families together. It is worth reiterating data collection occurred before lockdown from coronavirus. As such, midwives since the pandemic would likely perceive more benefits, such as reduction to hospital admissions for PT. To recap, approximately 60% of term and 80% of preterm newborn infants develop jaundice within their first week of life (National Institute for Healthcare and Excellence (NICE) 2016). With over 80% requiring PT as first line treatment, hospital admission lasts on average two days in otherwise healthy term newborn infants (Battersby et al. 2017). Therefore, home PT in the UK could reduce newborn hospital readmission and length of stay for PT, as evidenced elsewhere (Escobar et al. 2005, Goulet et al. 2007, Chang and Waite 2020, Pettersson et al. 2021).

However, this study suggests midwives experience hermeneutical injustice in NHS maternity services, restraining their advocacy role and hindering feasibility for home PT due to the dominance of medicalised care. Although, midwives in the current study perceived a wearable phototherapy device to positively influence acceptability of home PT if it was proven to reduce SBR levels because it could minimise interruptions from PT to feed and comfort infants. It is worth acknowledging most midwives are women which could explain midwives' "unequal hermeneutical participation" as a "background condition of hermeneutical injustice" (Fricker 2007, p152). In other words, identity prejudice towards women

(Fricker 2007) could stereotype midwives as emotional and irrational obstructing participation in shared decision making within care teams. Midwifery care, perceived historically as a women's role (Donnison and Macdonald 2017), could be collectively valued less than medicalised care within NHS maternity services. This thereby minimises midwives' influence on shared decision making within care teams. As a result, midwives (as well as parents) could be "doubly wronged" by structural prejudice and identity prejudice (Fricker 2007, p159). In support of this, Hutchison (2020) considered the subtlety of epistemic injustice in Australia impacting upon female surgeons' careers.

Furthermore, the current study revealed "unequal relations of power" (Fricker 2007, p152) between midwives. Community midwives in the present study relied upon clinical judgement to assess newborn jaundice instead of transcutaneous bilimeters (TcBs). Perceiving their assessment of newborn jaundice inferior to hospital midwives because the dominance of medicalised care increased credibility of TcB readings. As a result, community midwives lost confidence in their clinical judgement. This study suggests community midwifery is a subculture within midwifery due to hermeneutical injustice (Fricker 2007) because using holistic informed midwifery clinical judgement could be perceived careless (Hunter 2003) and unwholesome (Donnison and Macdonald 2017). Moreover, the current study suggested hospital midwives might prioritise inpatients when community midwives refer newborn infants to hospital. Combined with community midwives' reduced credibility due to hermeneutical injustice this could pose problems for home PT using a wearable device, namely: home PT is out of sight for hospital HCPs, therefore out of mind; and it is questionable whether concerns raised by parents or community midwives would be taken seriously. Additionally, creation of a wearable phototherapy device will be costly. Using a wearable device to facilitate home PT could maximise outcomes for parents and newborn infants with jaundice beyond lowering SBR levels (Francis and Byford 2011) to include breastfeeding, bonding, and maternal mental health: however, whether it would be cost effective has yet to be explored.

Parents were willing to compromise on size, functions, and usability of a phototherapy device to facilitate home PT in the short term. Consequently, home PT appeared more important for parents than the concept of a wearable device to deliver PT. Furthermore, studies about home PT (Walls et al. 2004, Jackson et al. 2000, Sardari, Mohammadizadeh and Namnabati 2019, Pettersson et al. 2021, Adlina et al. 2007, Noureldein et al. 2021) suggest parents were comfortable using currently available phototherapy devices (including overhead, biliblanket, and bilicocoon) in their home. All parents in the current study described wanting some flexibility of movement with PT. Although a wearable phototherapy device could provide flexibility of movement, so could a battery pack on an overhead phototherapy device (as suggested by one parent in this study who was an electrician) or alternative devices. Moreover, adapting phototherapy devices for homes could be explored by co-designing with parents, HCPs and product designers (Lironi et al. 2019), for instance PT delivered overhead via household furniture, such as a living room lamp (Lironi et al. 2019). Equally, overhead devices could be redesigned for contemporary postnatal wards, improving current experience of hospital PT. Therefore, parents in the current study imagined an alternative experience of PT (in hospital and home) that need not involve creating a wearable device.

For this reason, the present study challenges the dominant medicalised understanding of newborn jaundice focused on SBR levels with a holistic approach centred on the symbiotic relationship between mothers and newborn infants. For example, breastfeeding support is important because breastfeeding prevents dehydration (a risk factor for newborn jaundice) and subsequent deterioration of newborn jaundice (Mcintyre 2020). Additionally, increased fluid loss is a side effect of overhead PT (Michaelides 2017b), emphasising gravitas of breastfeeding, and potential advantage to wearable phototherapy devices. This study argues hospital admission for breastfeeding support metaphorically gives HCPs power and control over women (Freeman 2015) by medicalising infant feeding. In other words, hospital admission for breastfeeding support implies HCP's knowledge about breastfeeding is more valuable than mothers.

Furthermore, the current study found mothers perceived home- based breastfeeding support to augment home PT using a wearable device. It is worth noting mothers expressed interest in virtual home- based breastfeeding support when data collection occurred before lockdown from coronavirus. Since then, mothers have used virtual postnatal support at home implying more likelihood of uptake from mothers and midwives. Although, research is required to determine how successful it has been. However, breastfeeding support at home from HCPs may alleviate maternal pressure and facilitate home PT with a wearable device. In support of this, the home phototherapy pilot study for newborn infants (n=32) by Jackson et al. (2000), found most phone calls to their 24-hour support line was regarding breastfeeding although, 56% of parents included in their pilot study did not require support (Jackson et al. 2000). Therefore, out of hours breastfeeding support to augment home PT using a wearable device may not be as onerous for HCPs as they might assume.

Additionally, this study claims facilitating home- based breastfeeding support to augment home PT using a wearable device symbolically shifts power from medicalised to holistic care and from hospital to home. Given that breastfeeding relies upon interaction between hormones it seems reasonable to conclude environments are important to facilitate breastfeeding. Mothers in the current study expressed a yearning for their own home comforts yet described being trapped in hospital which impacted breastfeeding experience. In support of this, Flacking and Dykes (2013) demonstrated the significance of space and place on encouraging parent- infant relationships and attunement during breastfeeding (Flacking and Dykes 2013). In contrast, mothers in the current study described breastfeeding as a task performed quickly so newborn infants could return to PT. Consequently, time for mothers' attunement to newborn infants during breastfeeding was sacrificed for PT: therefore, interrupting formation of their relationship. Furthermore, supporting maternal-infant bonding is beneficial to maximise breastfeeding initiation and continuation (Renfrew 2016). Home PT using a wearable device could facilitate breastfeeding whilst continuing PT and preventing disruption to mothers' attunement to newborn infants.

As a result, mothers in the present study perceived home PT using a wearable device as beneficial to their mental health, breastfeeding journey, and bonding with newborn infants. Flacking and Dykes (2013) explained interruption to mother- infant relationships as impacting maternal self-worth and parental self-efficacy. As discussed in section 5.1, Leah- Warren, McCarthy and Corcoran (2012) demonstrated a significant relationship between maternal parental self- efficacy and maternal mental health ($p<0.001$). Finding, support from family to significantly reinforce parental self- efficacy (Leah- Warren, McCarthy, and Corcoran 2012), therefore: supporting home PT using a wearable device because partners and family could care for mothers and newborn infants whilst protecting the mother- infant dyad. Consequently, supporting maternal-infant bonding to maximise breastfeeding (Renfrew 2016) and prevent deterioration of newborn jaundice whilst positively influencing mothers' mental health, and experience of PT. Therefore, these findings, challenge the dominant medicalised understanding of newborn jaundice focused on SBR levels with a holistic approach centred on the symbiotic relationship between mothers and newborn infants.

In contrast, this study claims midwives accepted overhead hospital PT due to positive prejudice towards medicalised knowledge focused on reducing SBR levels as quickly as possible, potentially impacting midwives' confidence to advocate flexibility to care plans based on or deviated from newborn jaundice national guidance (NICE 2016). This included: breaks from continuous PT; intermittent PT; and home PT using a wearable device. Moreover, Fricker (2007) claims epistemic loss of confidence negatively impacts knowledge retention and acquisition. As a result, midwives could benefit from regular education and training in postnatal care to gain (and retain) knowledge to ensure confidence caring for newborn infants with jaundice. However, unless NHS maternity services respect medical and midwifery knowledge and expertise, midwives are unlikely to feel confident using their skills and advocating parents' choices, fearing blame for jaundice not improving. In other words, "confidence begets confidence, and without confidence fruitful cooperation will not be possible" (Nathan and Norden 1981, p71).

To conclude section 5.2, the current study challenges the dominant medicalised understanding of newborn jaundice focused on SBR levels with a holistic approach centred on the symbiotic relationship between mothers and newborn infants. Therefore, the holistic approach symbolically shifts power from medicalised to holistic care and from hospital to home. However, credibility of medicalised care within NHS maternity services has led to hermeneutical injustice towards parents and midwifery care. Thus, leading to midwives' loss of confidence from fear of blame for newborn jaundice not improving. In addition, credibility of quantifiable measurements has created a subculture of community midwifery which is further subjected to hermeneutical injustice (Fricker 2007) due to hospital reliance on medical technologies (Freeman 2015). Resulting in midwives' lacking trust in each other and parental capabilities, obstructing home PT using a wearable device.

5.3 Study strengths and limitations

There were strengths and limitations to the current study that should be addressed. A key strength of this study was its exploration into wearable technology to facilitate home PT in rural Scotland. Furthermore, exploring an alternative pathway to a common episode in postnatal care (such as a wearable device to facilitate home PT for newborn jaundice) was meaningful to parents. This was demonstrated by 25 mothers from rural settings responding to the first advert during the recruitment stage.

Another strength of the study was the use of Fricker's (2007) epistemic injustice to discuss study findings in this Master of Research project. Although a rich data set, the study findings were unexpected and moved beyond the stated aim of exploring the use of wearable technology to provide home PT in rural Scotland. For instance, parents described willingness to compromise on size, functions, and usability of phototherapy devices to facilitate home phototherapy treatment in the short term. Furthermore, the rural aspect of the study became insignificant to acceptability and feasibility of a wearable device to facilitate home PT. As a result, the researcher demonstrated openness and receptivity to the study participants' perspectives. However, the researcher struggled to prioritise the findings and make connections to tie the findings together. Epistemic injustice assisted in scrutinising the findings from different perspectives. As a result, use of epistemic injustice derived from the data set, which is a strength of this study.

Furthermore, using Interpretative Description was a pragmatic approach to generate knowledge relevant for clinical practice. Apart from this, the study included HCPs from two different settings who had varied clinical experience of newborn jaundice across primary, secondary, and tertiary care. Along with the flexible structure to the focus groups, this facilitated sharing of experiences and development of thought amongst HCPs.

On the other hand, there were limitations to the study, such as difficulty recruiting HCPs due to hospital activity and staff shortages. The researcher obtained ethical approval to interview midwives, health visitors, neonatal nurses, children's nurses, paediatricians, neonatologists, and GPs to assist recruitment. Although paediatricians and GPs responded to the advert, they were not included in the study due to workload or fear of sharing their opinion. In addition, the coronavirus pandemic resulted in increased workloads for HCPs impeding recruitment of HCPs. As a result, the sample size of HCPs was smaller than hoped and, other than one neonatal nurse, consisted of midwives. Overall, the small sample size resulted from limited timeframe (due to being a masters research project) impacting recruitment. Similarly, parents unable to speak, read, or understand English proficiently were excluded from the study because of financial restrictions preventing hiring of interpreters.

However, some of the study's strengths could also be interpreted as limitations. For example, recruiting parents with experience of PT within the last five years meant that parents with more than one child were included. Therefore, some had experience of PT with their first child, second child or both children. On the other hand, it meant a gap in the experience for some parents that could have affected them recalling the event. Similarly, interviewing parents protected confidentiality and may have encouraged open conversation. However, focus groups would have allowed sharing experiences amongst peers, which may have been beneficial to parents for processing their postnatal experience.

5.4 Recommendations for practice

- Provision of home PT with 24- hour support telephone line and suitable monitoring of newborn jaundice.
- Regular midwifery education and updates on newborn jaundice including use of phototherapy devices to deliver treatment; and equipment to monitor newborn jaundice.
- Document care plan for newborn jaundice in maternal and newborn online record, to include discussion of phototherapy device to use and regularity of breaks from PT.
- Consider using an internet- based decision aid incorporated into online medical records to assist information sharing and shared decision making.
- Out of hours home based breastfeeding support (whether facilitated in person or virtually by HCP) to avoid hospital admission for infant feeding support.
- Integrate partners and families into routine care of women and newborn infants with jaundice. In other words, for postnatal care to incorporate a family integrated women centred philosophy of care.

5.5 Recommendations for research

- Explore parents' and HCPs' experience of newborn jaundice and PT during the coronavirus pandemic. Given the move to online support during the pandemic it would be useful to learn what has worked.
- Co- production research to explore adaptions to phototherapy devices designed for home use.
- Co- production research to explore adaptations to phototherapy devices designed for hospital use. To support flexibility of movement and the mother- infant dyad.
- Investigate textiles to ascertain translucency for permitting PT using an overhead device.
- Participatory research to explore parents' and HCPs' experience using digital platforms available for maternity services during the coronavirus pandemic to evaluate their use and adapt technology to support home PT.
- Explore non-invasive methods to monitor bilirubin levels to guide PT.

5.6 Conclusion

The present study challenges the dominant medicalised understanding of newborn jaundice focused on SBR levels with a holistic approach centred on the symbiotic relationship between mothers and newborn infants. Therefore, supporting home PT using a wearable device to let partners and families care for mothers and newborn infants and protect the mother- infant dyad is important. Consequently, supporting maternal-infant bonding to maximise breastfeeding (Renfrew 2016) and prevent deterioration of newborn jaundice whilst positively influencing mothers' experience of PT, and mental health.

However, the current study claims parents and midwives could be "doubly wronged" by hermeneutical and testimonial prejudice (Fricker 2007, p159) impeding use of a wearable device to facilitate home PT in rural Scotland. Although these epistemic injustices may appear minor or be unconscious their cumulative impact requires attention (Hutchison 2020).

This study claims positive prejudice towards medicalised care in NHS maternity services means midwifery clinical judgement is deemed less credible due to structural identity prejudice towards midwifery care. As a result, midwives rely on TcBs for assessing newborn jaundice or overhead devices (which quickly reduce SBR levels) for PT. Midwives hermeneutical marginalisation leads to loss of confidence inhibiting courage (Fricker 2007) to challenge medical colleagues and care plans suppressing evolution of midwives' professional identity, consequently impacting shared decision making within care teams. Therefore, midwives comply with medicalised care plans taking instruction from paediatricians.

Furthermore, this study argues community midwifery may be a subculture within midwifery subjected to hermeneutical injustice (Fricker 2007) because using holistic informed clinical judgement is potentially considered careless by hospital- based midwifery colleagues. This creates doubt whether concerns raised by community midwives visiting families using a wearable device to facilitate home PT in rural Scotland would be trusted by hospital colleagues.

Similarly, identity prejudice towards parents rendered parental knowledge as unreliable. Fueling uncertainty concerns raised to HCPs by parents with home PT using a wearable device would be trusted. Additionally, data from the current study suggested postnatal care for newborn jaundice focussed on hospital inpatients to the detriment of families at home. Therefore, safety of home PT using a wearable device could relate more to relationships between HCPs and parents rather than the type of phototherapy device used at home or the rural setting. As a result, the rural aspect of the study became insignificant to acceptability and feasibility of a wearable device to facilitate home PT.

Furthermore, the current study exposed identity prejudice towards parents (stereotyping some as untrustworthy) could result in inequity for access to a wearable device facilitating home PT. Parents' testimonial and hermeneutical injustice excludes participation in open exchange of information with HCPs, impacting shared decision making. As a result, use of a wearable device to facilitate home PT in rural Scotland is impeded.

In contrast, parents were willing to compromise on size, functions, and usability of a phototherapy device to facilitate home PT in the short term. However, epistemic injustice towards parents and midwives could obstruct the practice of home PT. Although midwives perceived a wearable device to facilitate home PT, parents were comfortable with the prospect of home PT using currently available phototherapy devices.

Therefore, a holistic approach for newborn jaundice centred on the symbiotic relationship between mothers and newborn infants requires NHS maternity services to value holistic family integrated care. In doing so, NHS maternity services would recognise and respect parental, midwifery, and medical knowledge. For it is only through trusting each other, structurally and individually, a wearable device facilitating home PT would be used effectively and to the benefit of the relationship between mothers, families and newborn infants.

5.7 Researcher's reflections

When I started my master's in research in September 2018, I had planned to have it completed by September 2020. The reason for this was that September is the start of the new academic year and the modules in which I lead and am a member of commence in September. Furthermore, 2020 was when the RGU Midwifery team planned to apply for NMC course approval. Additionally, a new curriculum was to be designed to commence in September 2021. Therefore, the academic year of 2020 was always going to be a busy year.

However, the coronavirus pandemic resulted in lockdown in March 2020 and the timeline for completion of my studies changed due to increased workload. Although I had planned to try and recruit more HCPs onto the study, I was lucky to complete my data collection the end of February 2020. Moreover, the pandemic coincided with my data analysis which impacted my ability to prioritise it. Apart from this, I struggled using NVivo for data analysis and had problems with internet connectivity. However, I was determined to persevere with NVivo and learn how to use the digital tool effectively.

Overall, it’s hard to quantify the skills that I have gained during the course of my studies because there are so many. On a practical level, I have learnt how to search and critically appraise literature. Additionally, applying for a scholarship from the Digital Health and Care Institute (DHI) meant that I learnt about writing proposals for funding. As a result of funding through the DHI scholarship I was able to attend workshops to learn skills for conducting qualitative interviews, focus groups, data analysis, and writing up the findings to my research. Moreover, obtaining NHS ethical approval, developing the documentation involved for the process, and becoming competent using NVivo was a steep learning curve for me.

On a personal level, I developed patience and perseverance. Although I never questioned my commitment to the study, I was frustrated with my workload as a midwifery lecturer because I felt it was taking time away from my study. However, I learned to adapt to this. For example, as stage two lead and stage two practice education lecturer I had to develop another module and alternative assessment for stage two students. This was so stage two students who did not opt into an extended placement were eligible for progression into stage three. Consequently, it was a considerable increase to my workload which was demoralizing because I felt the workload was never ending.

On the other hand, it made me think outside the box and use my research study in ways I might not have done. For instance, the alternative assessment I developed was a service improvement proposal. Furthermore, the module sessions associated with the assessment ranged from change behaviour theory, patient and public involvement, and workshops to generate ideas. On completion of the module, I selected three student service improvement proposals to share with midwifery managers in the clinical area. As a result, the midwifery managers are interested in using these proposals in the clinical area to improve local services. Additionally, I co-authored an article with the three students whose proposals I selected, and it has been published in a midwifery journal (Stanhope et al. 2021). Apart from this, midwifery managers are interested to collaborate with students in the new curriculum and to align an assessment with an area in practice for potential service improvement.

Furthermore, I delivered a session about newborn jaundice for our current stage two students which was well received. This session was facilitated historically by neonatal nurses. However, I developed the material which gave me an opportunity to discuss phototherapy devices, home PT and intermittent PT to support bonding and breastfeeding.

To conclude, at times I felt I was reading and writing five times what was required for a master’s in research thesis. However, nothing went to waste. I have used my knowledge gained through my studies to facilitate classes in four separate modules across the three stages, excluding the module and assessment I had to develop due to the coronavirus pandemic. To be more precise, I have facilitated sessions on service improvement (including workshops for generating ideas), qualitative research, and newborn jaundice. However, my favourite has been sessions regarding service improvement and generating ideas because it gives students space to reflect, think, then consider whether we could provide care differently. As a result, it has bridged a gap between practice and theory through collaboration with student midwives and midwifery managers who will have the opportunity in the clinical area to transform the future of midwifery care.

REFERENCES

Adults with Incapacity Act 2000.

General Data Protection Regulation (GDPR) 2018.

ABRAHAM, C. et al., 2015. Designing interventions to change health related behaviour. In: D.A. RICHARDS and H.I. RAHM, eds. *Complex Interventions in Health: An Overview of Research Methods.* London: Taylor and Francis Group. pp. 103-110

ADLINA, S. et al., 2007. Use of home phototherapy for neonatal jaundice. *Malaysian Journal of Public Health Medicine,* 7(2), pp. 49-52

AMERICAN ACADEMY OF PEDIATRICS (AAP), 2004. Management of hyperbilirubinemia in the newborn infant 35 weeks or more weeks gestation. *Pediatrics,* 114(1), pp. 297-316

ATWOOD, M., 1985. *The Handmaid's Tale.* UK: Penguin Random House.

BATTERSBY, C. et al., 2017. Term admissions to neonatal units in England: a role for transitional care? A retrospective cohort study. *Bmj Open,* 7(5), pp. e016050-DOI:10.1136/bmjopen-2017-016050

BENNETT, P.N., 2011. Satellite dialysis nursing: technology, caring and power.(Report). *Journal of advanced nursing,* 67(1), pp. 149

BERGIN, M., 2011. NVivo 8 and consistency in data analysis: reflecting on the use of a qualitative data analysis program.(Nurse Researcher)(Report). *Nurse Researcher,* 18(3), pp. 6

BHUTANI, V.K., DONN, S.M. and JOHNSON, L.H., 2005. Risk management of severe neonatal hyperbilirubinemia to prevent kernicterus. *Clinics in perinatology,* 32(1), pp. 125-139

BHUTANI, V.K. et al., 2006. A systems approach for neonatal hyperbilirubinemia in term and near-term newborns. *JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing,* 35(4), pp. 444-455

BLEASE, C., CAREL, H. and GERAGHTY, K., 2017. Epistemic injustice in healthcare encounters: evidence from chronic fatigue syndrome. *Journal of medical ethics; J Med Ethics,* 43(8), pp. 549-557

BRADFIELD, Z. et al., 2019. Midwives' perceptions of being 'with woman': a phenomenological study. *BMC pregnancy and childbirth; BMC Pregnancy Childbirth,* 19(1), pp. 363-363

BRAUN, V. and CLARKE, V., 2006. Using thematic analysis in psychology. *Qualitative research in psychology,* 3(2), pp. 77-101

BRETHAUER, M. and CAREY, L., 2010. Maternal Experience with Neonatal Jaundice. *MCN, The American Journal of Maternal/Child Nursing,* 35(1), pp. 15-16

BRYMAN, A., 2016. *Social Research Methods.* 5th ed. Oxford: Oxford University Press.

CHANG, P.W. and WAITE, W.M., 2020. Evaluation of Home Phototherapy for Neonatal Hyperbilirubinemia. *The Journal of pediatrics; J Pediatr,* 220, pp. 80-85

CHEN, W. et al., 2010. Design of an integrated sensor platform for vital sign monitoring of newborn infants at neonatal intensive care unit. *Journal of Healthcare Engineering,* 1(4), pp. 535-554

CHOWDHURY, A.D., HUSSEY, M.H. and SHORTLAND, D.B., 2007. Critical overview of the management of neonatal jaundice in the UK. *Public Health,* 121, pp. 137-143

COFFEY, A., 1999. *The Ethnographic Self: Fieldwork and the Representation of Identity.* London: Sage.

COOPER, H.M., 1982. Scientific guidelines for conducting integrative research reviews. *Review of Educational Research,* 52(2), pp. 291-302

CRITICAL APPRAISAL SKILLS PROGRAMME (CASP), 2021. *Checklists.* [online] Oxford: CASP. Available from: https://casp-uk.net/casp-tools-checklists/ [Accessed 07/15 2021]

DI RIENZO, M. et al., 2005. MagIC System: a New Textile-Based Wearable Device for Biological Signal Monitoring. Applicability in Daily Life and Clinical Setting. *Conference proceedings : ...Annual International Conference of the IEEE Engineering in Medicine and Biology Society.IEEE Engineering in Medicine and Biology Society.Annual Conference,* 7, pp. 7167

DIXON-WOODS, M. et al., 2006. Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC medical research methodology,* 6, pp. 35

DODDS, R., 2016. The Lancet Series on Breastfeeding. *MIDIRS Midwifery Digest,* 26(2), pp. 237-240

DODGSON, J., 2019. Non- conforming: Aren't we all in one way or Another? *Journal of Human Lactation,* 35(2), pp. 212-213

DONNISON, J. and MACDONALD, S., 2017. A hisory of the midwifery profession in the United Kingdom. In: S. MACDONALD and G. JOHNSON, eds. *Mayes' Midwifery.* 15th ed. Edinburgh: Elsevier. pp. 24-48

DYKES, F., 2005. A critical ethnographic study of encounters between midwives and breast-feeding women in postnatal wards in England. *Midwifery; Midwifery,* 21(3), pp. 241-252

ESCOBAR, G.J. et al., 2005. Rehospitalisation after birth hospitalisation: Patterns among infants of all gestations. *Archives of Disease in Childhood,* 90(2), pp. 125-131

FLACKING, R. and DYKES, F., 2013. 'Being in a womb' or 'playing musical chairs': the impact of place and space on infant feeding in NICUs. *BMC pregnancy and childbirth; BMC Pregnancy Childbirth,* 13(1), pp. 179-179

FØRELAND, A.M., ROSENBERG, L. and JOHANNESSEN, B., 2016. Nurses' experiences using conventional overhead phototherapy versus fibreoptic blankets for the treatment of neonatal hyperbilirubinemia. *Journal of Neonatal Nursing,* 22(3), pp. 108-114

FRANCIS, J. and BYFORD, S., 2011. *SCIE's approach to economic evaluation in social care.* UK: SCIE.

FRANCK, L.S. et al., 2019. Comparison of family centered care with family integrated care and mobile technology (mFICare) on preterm infant and family outcomes: a multi-site quasi-experimental clinical trial protocol. *BMC pediatrics; BMC Pediatr,* 19(1), pp. 469-469

FREEMAN, L., 2015. Confronting diminished epistemic privilege and epistemic injustice in pregnancy by challenging a "panoptics of the womb". *The Journal of medicine and philosophy; J Med Philos,* 40(1), pp. 44-68

FRICKER, M., 2007. *Epistemic Injustice: Power and the Ethics of Knowing.* Oxford: Oxford University Press.

GALE, N.K. et al., 2013. Using the framework method for the analysis of qualitative data in multi-disciplinary health research.(Report). *BMC Medical Research Methodology,* 13(1),

GE HEALTHCARE, 2021. *Bilisoft 2.0 phototherapy system: A revolution in blue light phototherapy.* [online] UK: GE Healthcare. Available from: https://www.gehealthcare.co.uk/products/maternal-infant-care/phototherapy/bilisoft-2-phototherapy-system [Accessed 03/26 2021]

GOULET, L. et al., 2007. Preparation for discharge, maternal satisfaction, and newborn readmission for jaundice: Comparing postpartum models of care. *Birth,* 34(2), pp. 131-139

GRILLE, R., 2015. *UNICEF UK baby friendly initiative conference: Robin grille on neuro social evolution.* [online] UK: Baby Friendly Initiative UK. Available from: https://www.youtube.com/watch?v=Iw-o4Ypt6hs [Accessed 06/11 2020]

HACKETT, A. and STRICKLAND, K., 2018. Using the framework approach to analyse qualitative data: a worked example. *Nurse researcher; Nurse Res,* 26(2), pp. 8-13

HANNON, P.R., WILLIS, S.K. and SCRIMSHAW, S.C., 2001. Persistence of maternal concerns surrounding neonatal jaundice: An exploratory study. *Archives of Pediatrics and Adolescent Medicine,* 155(12), pp. 1357-1363

HORTA, B.L., LORET DE MOLA, C. and VICTORA, C.G., 2015. Breastfeeding and intelligence: a systematic review and meta-analysis. *Acta Paediatrica; Acta Paediatr,* 104, pp. 14-19

HUNT, M.R., 2009. Strengths and Challenges in the Use of Interpretive Description: Reflections Arising From a Study of the Moral Experience of Health Professionals in Humanitarian Work. *Qualitative health research; Qual Health Res,* 19(9), pp. 1284-1292

HUNTER, M., 2003. Autonomy, clnical freedom and responsibility. In: M. KIRKHAM, ed. *Birth Centres: A Social Model for Maternity Care.* England: Elsevier. pp. 239-248

HUTCHISON, K., 2020. Four types of gender bias affecting women surgeons and their cumulative impact. *Journal of medical ethics; J Med Ethics,* 46(4), pp. 236-241

INDIAMART, 2021. *Biophoton bili blanket phototherapy system.* [online] Delhi: IndiaMart. Available from: https://www.indiamart.com/proddetail/bili-blanket-phototherapy-system-8853606197.html [Accessed 03/26 2021]

INTERNATIONAL CONFEDERATION OF MIDWIVES (ICM), 2018. *Philosophy and model of midwifery care.* [online] The Netherlands: ICM. Available from: https://www.internationalmidwives.org/assets/files/definitions-files/2018/06/eng-philosophy-and-model-of-midwifery-care.pdf [Accessed 07/06 2021]

JACKSON, C.L. et al., 2000. Home phototherapy for neonatal jaundice -- technology and teamwork meeting consumer and service need. *Australian Health Review,* 23(2), pp. 162-168

JIMENEZ, L., VILCAHUAMAN, L. and GALDOS, J., 2016. Development and thermal assessment of a blue light emitting diode phototherapy device for neonatal jaundice treatment in Kangaroo mother care. *IEEE Healthcare innovation Point-of-Care Technologies Conference (HI-POCT).* November 2016. DOI: 10.1109/HIC.2016.7797691: IEEE. pp. 37-41

JUNATA, M. and TONG, R., 2018. Chapter 1. Wearable technology in medicine and healthcare: Introduction. ID: 319092. In: R. TONG, ed. *Wearable Technology in Medicine and Health Care.* London: Academic Press. pp. 1-5

KHATAMI, F. and SOLTANI, M., 2007. Home phototherapy; an alternative method for treatment of jaundice in healthy-term newborns. *Iranian Journal of Pediatrics,* 17, pp. 193-198

KIDD, I.J. and CAREL, H., 2017. Epistemic Injustice and Illness. *Journal of applied philosophy; J Appl Philos,* 34(2), pp. 172-190

KIGER, M.E. and VARPIO, L., 2020. Thematic analysis of qualitative data: AMEE Guide No. 131. *Medical teacher; Med Teach,* 42(8), pp. 846-854

KUMAR, P., CHAWLA, D. and DEORARI, A., 2011. Light-emitting diode phototherapy for unconjugated hyperbilirubinaemia in neonates. *Cochrane Database of Systematic Reviews,* (12), pp. CD007969-DOI:10.1002/14651858

LALSSTOCK, 2021. *The baby lies under an ultraviolet light with jaundice.* [online] California: Adobe Stock. Available from: https://stock.adobe.com/uk/images/the-baby-lies-under-an-ultraviolet-lamp-with-jaundice/261715624 [Accessed 03/26 2021]

LEAHY-WARREN, P., MCCARTHY, G. and CORCORAN, P., 2012. First-time mothers: social support, maternal parental self-efficacy and postnatal depression. *Journal of Clinical Nursing; J Clin Nurs,* 21(3), pp. 388-397

LEVIN, A., 1994. The Mother- Infant Unit at Tallinn Children's Hospital, Estonia: A Truly Baby- Friendly Unit. *Birth,* 21(1), pp. 39-44

LIRONI, J., 2017. A changing model of rural care. *The Practising Midwife,* 20(5), pp. 27-28 29

LIRONI, J. et al., 2019. *Meeting about wearable phototherapy treatment at Duncan of Jordanstone College of Art and Design.* Notes from a meeting ed.

LIRONI, J., GRANT, A. and KENNEDY, C., 2019. Exploring the facilitators and barriers of a wearable device to treat newborn jaundice at home: protocol for an integrative review. *PROSPERO.* [online] Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019157824 [Accessed 15/06/2020]

LUCAS, P.J. et al., 2007. Worked examples of alternative methods for the synthesis of qualitative and quantitative research in systematic reviews. *BMC Medical Research Methodology,* 7

MALWADE, U.S. and JARDINE, L.A., 2014. Home- versus hospital-based phototherapy for the treatment of non-haemolytic jaundice in infants at more than 37 weeks' gestation. *Cochrane Database of Systematic Reviews,* (6), pp. CD010212.-DOI: 10.1002/14651858

MCINTYRE, J., 2020. Significant Problems in the Newborn. In: J. MARSHALL and M. AND RAYNOR, eds. *Myles Textbook for Midwives.* 17th ed. Edinburgh: Elsevier. pp. 917-964

MCNABB, M., 2017. Physiology changes from late pregnancy until the onset of lactation: from nesting to suckling- lactation and parent- infant attachment. In: S. MACDONALD and G. JOHNSON, eds. *Mayes' Midwifery.* 15th ed. Edinburgh: Elsevier. pp. 562--585

MEDICAL EXPO, 2021. *Infant phototherapy lamp: Bilicocoon.* [online] Marseille: Virtual Expo Group. Available from:

https://www.medicalexpo.com/prod/neomedlight-sas/product-120913-843597.html [Accessed 07/13 2021]

MEDICAL RESEARCH COUNCIL (MRC), 2008. Developing and evaluating complex interventions. [online] Available from: www.mrc.ac.uk/complexinterventionsguidance

METHLEY, A.M. et al., 2014. PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews. *BMC Health Services Research,* 14(1),

MICHAELIDES, S., 2017a. Aiming for a seamless service for the baby with jaundice. *MIDIRS Midwifery Digest,* 27(2), pp. 237-243

MICHAELIDES, S., 2017b. Neonatal Jaundice. In: S. MACDONALD and G. JOHNSON, eds. *Mayes' Midwifery.* 15th ed. Edinburgh: Elsevier. pp. 828-845

MILLS, J.F. and TUDEHOPE, D., 2001. Fibreoptic phototherapy for neonatal jaundice. *The Cochrane Database of Systematic Reviews,* (1), pp. CD002060.-DOI: 10.1002/14651858

MIRZA, M., TURNER, S. and HANSEN, R., 2017. Acute admissions for neonatal jaundice screens- time for a rethink? . *BMJ Archives of Disease in Childhood,* 102, pp. A77

NAMNABATI, M., MOHAMMADIZADEH, M. and SARDARI, S., 2019. The effect of home-based phototherapy on parental stress in mothers of infants with neonatal jaundice. *Journal of Neonatal Nursing,* 25(1), pp. 37-40

NATHAN, O. and NORDEN, H., eds. 1981. *Einstein on Peace.* New York: Avenal Books.

NATIONAL INSTITUTE FOR HEALTHCARE AND EXCELLENCE (NICE), 2013. *Guide to the method of technology appraisal.* UK: NICE.

NATIONAL INSTITUTE FOR HEALTHCARE AND EXCELLENCE (NICE), 2016. *Jaundice in newborn babies under 28 days.* London: NICE.

NEOMEDLIGHT, 2017. *Revolutionary phototherapy system for newborns now available from CMS.* [online] France: NeoMedLight. Available from: https://www.neomedlight.com/2017/03/23/revolutionary-phototherapy-system-for-newborns-now-available-from-cms/ [Accessed 07/13 2021]

NOURELDEIN, M. et al., 2021. Home phototherapy for neonatal jaundice in the UK: a single-centre retrospective service evaluation and parental survey. *BMJ paediatrics open,* 5(1), pp. e001027-e001027

OLIVER, C., 2012. The Relationship Between Symbolic Interactionism and Interpretive Description. *Qualitative health research,* 22(3), pp. 409-415

OLUFEMI-YUSUF, D. et al., 2018. "Being in Control of My Asthma Myself" Patient Experience of Asthma Management: A Qualitative Interpretive Description. *Pharmacy; Pharmacy (Basel),* 6(4), pp. 121

PAGE, M.J. et al., 2021. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Online),* 372

PATEL, N. et al., 2018. Family Integrated Care: changing the culture in the neonatal unit. *Archives of Disease in Childhood,* 103(5), pp. 415

PETTERSSON, M. et al., 2021. Home phototherapy for hyperbilirubinemia in term neonates-an unblinded multicentre randomized controlled trial. *European journal of pediatrics; Eur J Pediatr,*

PHOTOBANK, 2021. *Phototherapy for newborn.* [online] California: Adobe 2021. Available from: https://stock.adobe.com/uk/images/phototherapy-for-newborn/29878405 [Accessed 03/26 2021]

QUANDT, B.M. et al., 2017. POF-yarn weaves: Controlling the light outcoupling of wearable phototherapy devices. *Biomedical Optics Express,* 8(10), pp. 4316-4330

RATTANAPRON, 2021. *Illustration of phototherapy lamp use for jaundice newborn in the hospital.* [online] California: Adobe Stock. Available from: https://stock.adobe.com/uk/images/illustration-of-phototherapy-lamp-use-for-jaundice-newborn-in-the-hospital/412718663 [Accessed 03/26 2021]

REES, C., 2016. *Rapid research methods for nurses, midwives, and health professionals.* Chichester, West Sussex: Wiley Blackwell.

RENFREW, M., 2016. Breastfeeding in the 21st century. *The Lancet,* 387(10033), pp. 2089

RESNICK, J., 2021. *Newborn baby with jaundice getting ultra violet phototherapy treatment.* [online] California: Adobe Stock. Available from: https://stock.adobe.com/uk/images/newborn-baby-with-jaundice-getting-ulta-violet-phototherepy-treatment/143179458 [Accessed 03/26 2021]

ROBERT GORDON UNIVERSITY (RGU), 2016. *Master retention schedule (MaRS). 2. research.* [online] Aberdeen: RGU. Available from: https://you.rgu.ac.uk/org/ig/SiteAssets/Pages/MasterRetentionScedule/2.%20Research%202016%20(188%20Kb).pdf [Accessed March 23rd 2019]

ROBERT GORDON UNIVERSITY (RGU), 2018. *Information Governance Policy.*

ROLLINS, N.C. et al., 2016. Why invest, and what it will take to improve breastfeeding practices? *The Lancet,* 387(10017), pp. 491-504

SARDARI, S., MOHAMMADIZADEH, M. and NAMNABATI, M., 2019. Efficacy of home phototherapy in neonatal jaundice. *Journal of Comprehensive Pediatrics,* 10(1), pp. DOI:105812-82630

SCAMELL, M., 2016. The fear factor of risk – clinical governance and midwifery talk and practice in the UK. *Midwifery; Midwifery,* 38, pp. 14-20

SCOTTISH GOVERNMENT, 2011. *Improving Maternal and Infant Nutrition: A framework for Action.* Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2015. *Rural Scotland Key Facts 2015.* Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2016. *A National Clinical Strategy for Scotland.* Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2017a. *The Best Start: A Five- Year Forward Plan For Maternity and Neonatal Care in Scotland.* Edinburgh: Scottish Government.

SCOTTISH GOVERNMENT, 2020b. *Scottish government urban rural classification.* [online] Edinburgh: Socttish Government. Available from: https://www2.gov.scot/urbanrural [Accessed October/ 24 2020]

SHERWIN, S., 1988. Philosophical methodology and feminist methodology: are they compatible? In: L. CODE, S. MULLET and C. OVERALL, eds. *Feminist Perspectives: Philosophical Essays on Method and Morals.* London: University of Toronto Press. pp. 13-14-27

SIX, A., 2017. *Illuminated pyjamas treat newborns.* [online] Switzerland: Empa. Available from: https://www.empa.ch/web/s604/photonic-textiles-for-newborns [Accessed 10/31 2018]

SNOOK, J., 2017. Is home phototherapy in the term neonate with physiological jaundice a feasible practice? A systematic literature review. *Journal of Neonatal Nursing,* 23(1), pp. 28-39

STANHOPE, J. et al., 2021. Lockdown 1.0- A Different Opportunity. *The Student Midwife,* 4(3), pp. 29-32

SUDIA- ROBINSON, T. and FREEMAN, S.B., 2000. Communication patterns and decision making among parents and health care providers in the neonatal intensive care unit : A case study. *Heart & lung; Heart Lung,* 29(2), pp. 143-148

THORNE, 2016. *Interpretive Description: Qualitative Research for Applied Practice.* 2nd ed. London: Routledge.

THORNE, REIMER KIRKHAM, S. and MACDONALD-EMES, J., 1997. Interpretive description : A noncategorical qualitative alternative for developing nursing knowledge. *Research in nursing & health; Res Nurs Health,* 20(2), pp. 169-177

THORNE, KIRKHAM, S.R. and O'FLYNN-MAGEE, K., 2004. The Analytic Challenge in Interpretive Description. *International Journal of Qualitative Methods,* 3(1), pp. 1-11

TOMSICKOVA, 2021. *Young mother breastfeeding her newborn baby boy.* [online] California: Adobe Stock. Available from: https://stock.adobe.com/uk/images/young-mother-breastfeeding-her-newborn-baby-boy/202822760 [Accessed 03/26 2021]

TUDEHOPE, D., 1995. Fibreoptic versus conventional phototherapy for treatment of neonatal jaundice. *Paediatric Child Health,* 31, pp. 6-7

USLU, S. et al., 2012. Effect of maternal education for neonatal jaundice and breastfeeding with early follow-up visits of newborn on rehospitalization due to hyperbilirubinemia. *Nobel Medicus,* 8(2), pp. 16-21

VAN WOERDEN, H., 2016. *The Safe Provision of Maternal and Neonatal Services at Caithness General Hospital: A Public Health Review.* Inverness: NHS.

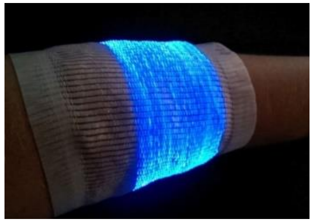
VILLARMEA, S. and KELLY, B., 2020. Barriers to establishing shared decision-making in childbirth: Unveiling epistemic stereotypes about women in labour. *Journal of evaluation in clinical practice; J Eval Clin Pract,* 26(2), pp. 515-519

WALLS, M. et al., 2004. Home phototherapy: a feasible, safe and acceptable practice. *Journal of Neonatal Nursing,* 10(3), pp. 92-94

WHITTEMORE, R. and KNAFL, K., 2005. The integrative review: updated methodology. *Journal of advanced nursing,* 52(5), pp. 546-553

WORLD HEALTH ORGANISATION (WHO), 2017. *Protecting, promoting and support breastfeeding in facilities providing maternity and newborn services.* Geneva: WHO.

Appendix 1: Figures of phototherapy devices

Figure	**1.1**	**1.2**	**1.3**	**1.4**	**1.5**
Device	Overhead	Fibreoptic [similar to Bili boat]	Fibreoptic [similar to Bili blanket]	Fibreoptic [pad made of woven fabric and optical fibres]	Wearable: Poly optical fibres
light source	Conventional or light emitting diode (LED)	Conventional or LED	Conventional or LED	LED	LED
Image of device	 (Rattanapron 2021)	 (Resnick 2021)	 (GE Healthcare 2021)	 (Medical Expo 2021)	 (Six 2017)
Device in use	 (Photobank 2021)	 (Lalsstock 2021)	 (IndiaMart 2021)	 (NeoMedLight 2017)	 (Tomsickova 2021)

Appendix 2: Example of data extraction

SECTION 1: FULL-TEXT SCREENING

Reviewer's initial:

Initial assessment: Does the paper explore one or more of the following areas?

☐Yes ☐ No

☐ Yes ☐ No

☐ Yes ☐ No

Overall Assessment:

Primary Qualitative study	☐Yes ☐ No
Primary Quantitative study	☐Yes ☐ No
Mixed method study	☐Yes ☐ No

FINAL DECISION:

Include paper	☐Yes ☐ No

IF EXCLUDING PAPER, GIVE REASONS BELOW AND DO NOT PROCEED ANY FURTHER

Reasons for exclusion (e.g. Commentary, opinion, discussion or review paper, not empirical study):____

SECTION 2: QUALITY APPRAISAL

Assessment of primary qualitative study:

Aim of study clear and justified	☐Yes	☐Not Clear	☐No
Sampling strategy described and justified	☐Yes	☐Not Clear	☐No
Fieldwork well described and appropriately conducted	☐Yes	☐Not Clear	☐No
Clearly described/theoretically justified data analysis	☐Yes	☐Not Clear	☐No
Good discussion which support conclusions	☐Yes	☐Not Clear	☐No

Comments:

Assessment of primary quantitative study

Randomisation method	☐Yes	☐Not Clear	☐No
Blinded assessment	☐Yes	☐Not Clear	☐No
Attrition rate stated	☐Yes	☐Not Clear	☐No

Primary outcome identified ☐Yes ☐Not Clear ☐No

Sample size stated ☐Yes ☐Not Clear ☐No

Individual effect size stated ☐Yes ☐Not Clear ☐No

Heterogeneity assessed ☐Yes ☐Not Clear ☐No

Publication bias ☐Yes ☐Not Clear ☐No

Were limitations accounted for in the analysis? ☐Yes ☐Not Clear ☐No

Were the findings clearly reported? ☐Yes ☐Not Clear ☐No

Was there an attempt to synthesise the findings? ☐Yes ☐Not Clear ☐No

Were recommendations made for policy or practice? ☐Yes ☐Not Clear ☐No

Was a need for further research identified? ☐Yes ☐Not Clear ☐No

Comments:____

Quality of study (refer to the hierarchy of evidence, SIGN grading system 2012)

See link for decision: https://www.sign.ac.uk/assets/sign_grading_system_1999_2012.pdf

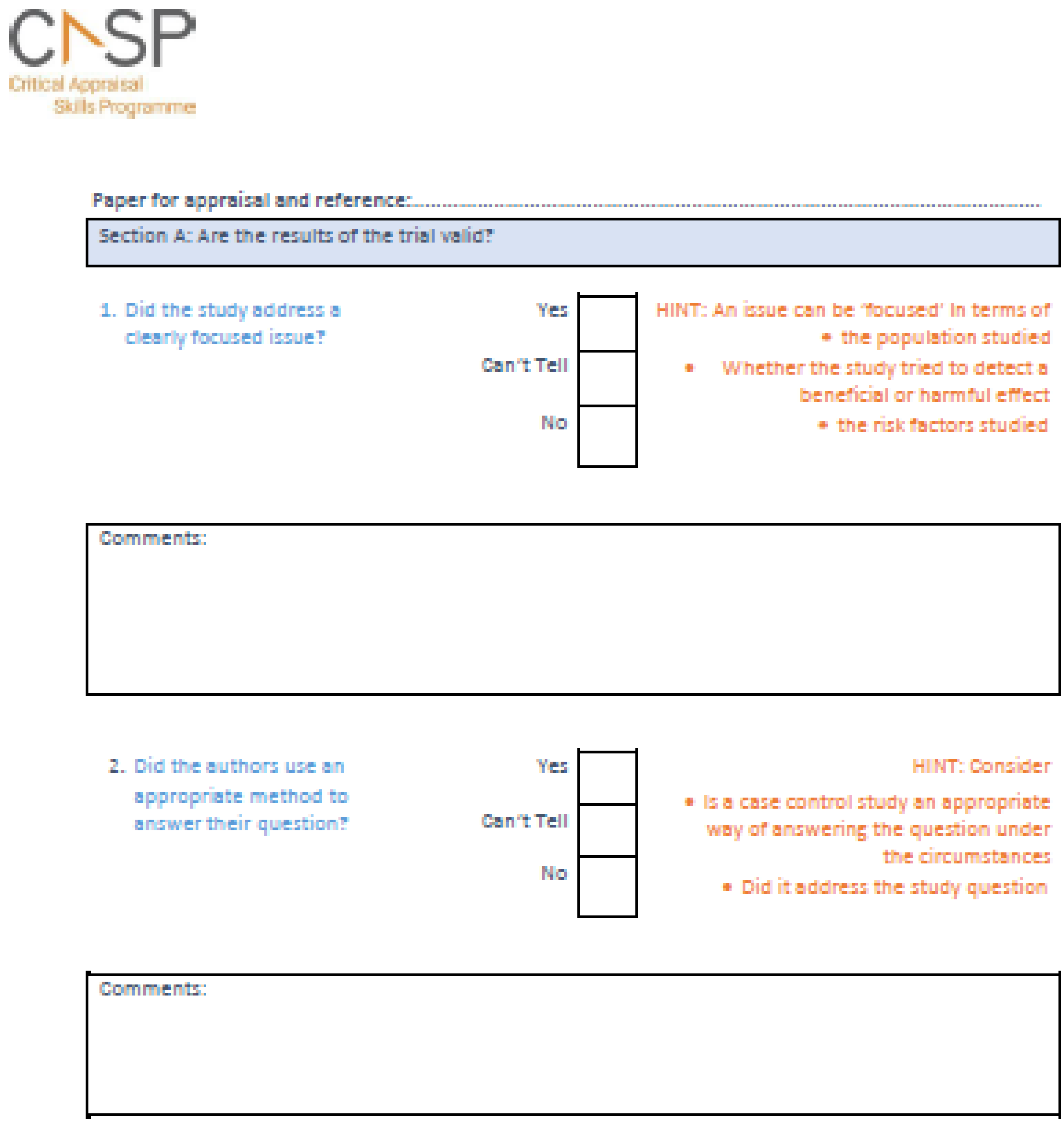
Level of evidence:

PROCEED TO DATA EXTRACTION

SECTION 3: DATA EXTRACTION TEMPLATE

Date of data extraction:		
Article details:	Author/year	
	Country	
	Title number and title of article	
	Journal name	
Study focus and methods:	Aim(s)	
	Research question(s)	
	Design	
	Data collection methods	
	Sample characteristics	
	Data analysis methods	
Ethical approval identified		☐Yes ☐ No
Description of intervention		
Results/ Findings		
Other relevant result/findings (not identified above)		
Key message(s)		
Additional comments/notes		

Appendix 3: Example of CASP appraisal tool



Paper for appraisal and reference:……………………………………………………………………………

Section A: Are the results of the trial valid?

1. Did the study address a clearly focused issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: An issue can be 'focused' in terms of
- the population studied
- Whether the study tried to detect a beneficial or harmful effect
- the risk factors studied

Comments:

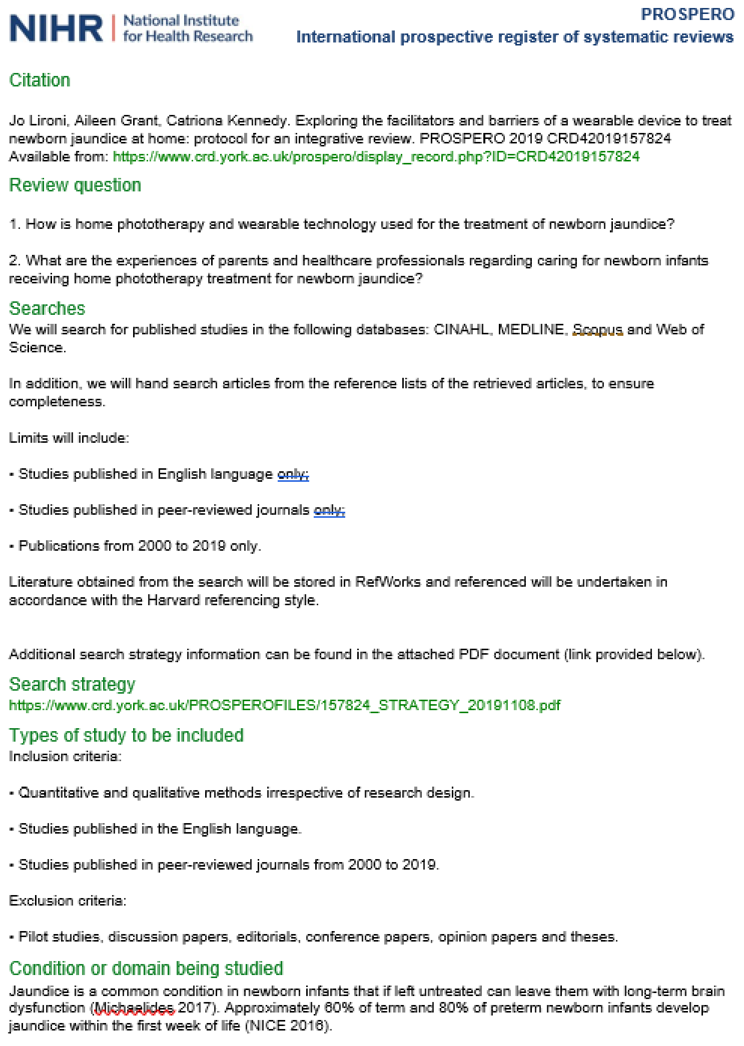
2. Did the authors use an appropriate method to answer their question?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- Is a case control study an appropriate way of answering the question under the circumstances
- Did it address the study question

Comments:

Appendix 4: PPROSPERO protocol



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PROSPERO
International prospective register of systematic reviews

Citation

Jo Lironi, Aileen Grant, Catriona Kennedy. Exploring the facilitators and barriers of a wearable device to treat newborn jaundice at home: protocol for an integrative review. PROSPERO 2019 CRD42019157824 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019157824

Review question

1. How is home phototherapy and wearable technology used for the treatment of newborn jaundice?

2. What are the experiences of parents and healthcare professionals regarding caring for newborn infants receiving home phototherapy treatment for newborn jaundice?

Searches

We will search for published studies in the following databases: CINAHL, MEDLINE, Scopus and Web of Science.

In addition, we will hand search articles from the reference lists of the retrieved articles, to ensure completeness.

Limits will include:

- Studies published in English language only;

- Studies published in peer-reviewed journals only;

- Publications from 2000 to 2019 only.

Literature obtained from the search will be stored in RefWorks and referenced will be undertaken in accordance with the Harvard referencing style.

Additional search strategy information can be found in the attached PDF document (link provided below).

Search strategy

https://www.crd.york.ac.uk/PROSPEROFILES/157824_STRATEGY_20191108.pdf

Types of study to be included

Inclusion criteria:

- Quantitative and qualitative methods irrespective of research design.

- Studies published in the English language.

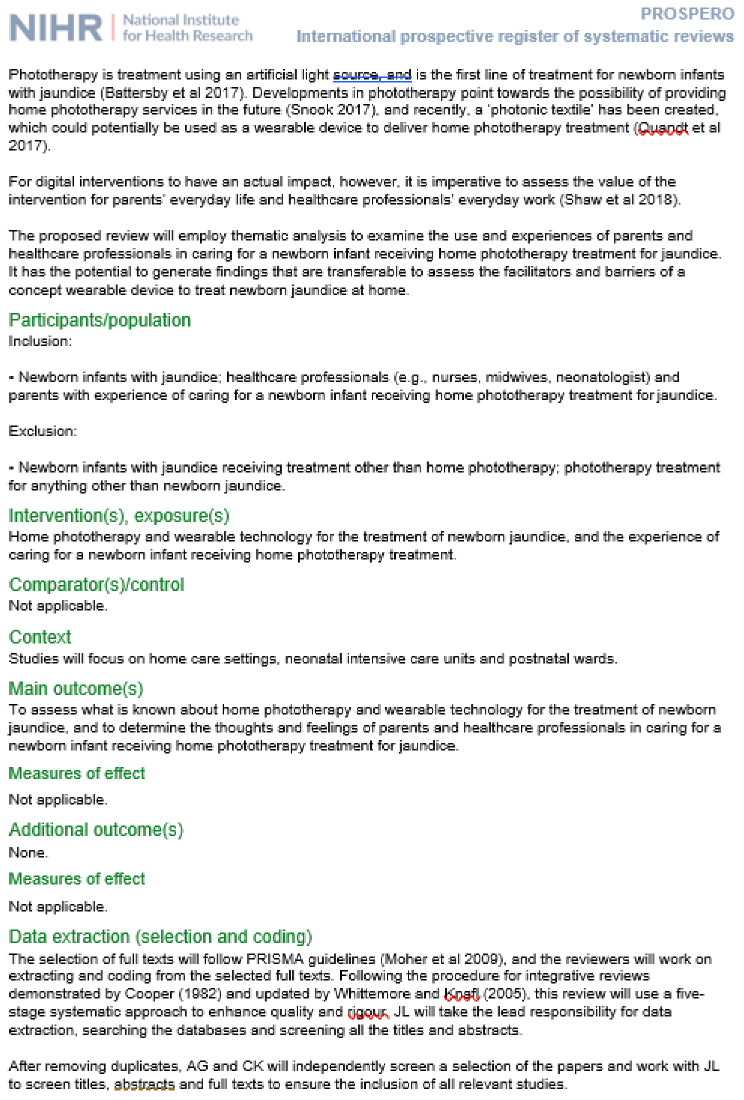
- Studies published in peer-reviewed journals from 2000 to 2019.

Exclusion criteria:

- Pilot studies, discussion papers, editorials, conference papers, opinion papers and theses.

Condition or domain being studied

Jaundice is a common condition in newborn infants that if left untreated can leave them with long-term brain dysfunction (Michaelides 2017). Approximately 60% of term and 80% of preterm newborn infants develop jaundice within the first week of life (NICE 2016).



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Phototherapy is treatment using an artificial light source, and is the first line of treatment for newborn infants with jaundice (Battersby et al 2017). Developments in phototherapy point towards the possibility of providing home phototherapy services in the future (Snook 2017), and recently, a 'photonic textile' has been created, which could potentially be used as a wearable device to deliver home phototherapy treatment (Quandt et al 2017).

For digital interventions to have an actual impact, however, it is imperative to assess the value of the intervention for parents' everyday life and healthcare professionals' everyday work (Shaw et al 2018).

The proposed review will employ thematic analysis to examine the use and experiences of parents and healthcare professionals in caring for a newborn infant receiving home phototherapy treatment for jaundice. It has the potential to generate findings that are transferable to assess the facilitators and barriers of a concept wearable device to treat newborn jaundice at home.

Participants/population

Inclusion:

- Newborn infants with jaundice; healthcare professionals (e.g., nurses, midwives, neonatologist) and parents with experience of caring for a newborn infant receiving home phototherapy treatment for jaundice.

Exclusion:

- Newborn infants with jaundice receiving treatment other than home phototherapy; phototherapy treatment for anything other than newborn jaundice.

Intervention(s), exposure(s)

Home phototherapy and wearable technology for the treatment of newborn jaundice, and the experience of caring for a newborn infant receiving home phototherapy treatment.

Comparator(s)/control

Not applicable.

Context

Studies will focus on home care settings, neonatal intensive care units and postnatal wards.

Main outcome(s)

To assess what is known about home phototherapy and wearable technology for the treatment of newborn jaundice, and to determine the thoughts and feelings of parents and healthcare professionals in caring for a newborn infant receiving home phototherapy treatment for jaundice.

Measures of effect

Not applicable.

Additional outcome(s)

None.

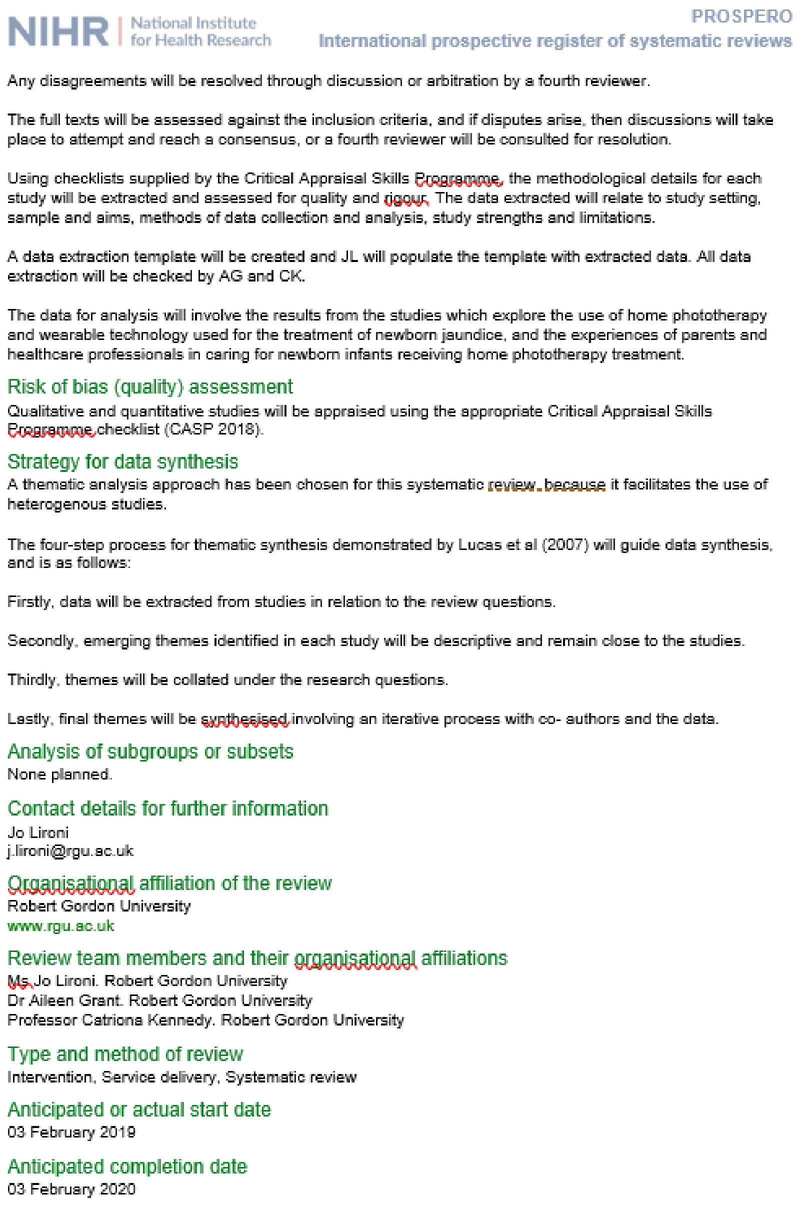
Measures of effect

Not applicable.

Data extraction (selection and coding)

The selection of full texts will follow PRISMA guidelines (Moher et al 2009), and the reviewers will work on extracting and coding from the selected full texts. Following the procedure for integrative reviews demonstrated by Cooper (1982) and updated by Whittemore and Knafl (2005), this review will use a five-stage systematic approach to enhance quality and rigour. JL will take the lead responsibility for data extraction, searching the databases and screening all the titles and abstracts.

After removing duplicates, AG and CK will independently screen a selection of the papers and work with JL to screen titles, abstracts and full texts to ensure the inclusion of all relevant studies.



Any disagreements will be resolved through discussion or arbitration by a fourth reviewer.

The full texts will be assessed against the inclusion criteria, and if disputes arise, then discussions will take place to attempt and reach a consensus, or a fourth reviewer will be consulted for resolution.

Using checklists supplied by the Critical Appraisal Skills Programme, the methodological details for each study will be extracted and assessed for quality and rigour. The data extracted will relate to study setting, sample and aims, methods of data collection and analysis, study strengths and limitations.

A data extraction template will be created and JL will populate the template with extracted data. All data extraction will be checked by AG and CK.

The data for analysis will involve the results from the studies which explore the use of home phototherapy and wearable technology used for the treatment of newborn jaundice, and the experiences of parents and healthcare professionals in caring for newborn infants receiving home phototherapy treatment.

Risk of bias (quality) assessment

Qualitative and quantitative studies will be appraised using the appropriate Critical Appraisal Skills Programme checklist (CASP 2018).

Strategy for data synthesis

A thematic analysis approach has been chosen for this systematic review, because it facilitates the use of heterogenous studies.

The four-step process for thematic synthesis demonstrated by Lucas et al (2007) will guide data synthesis, and is as follows:

Firstly, data will be extracted from studies in relation to the review questions.

Secondly, emerging themes identified in each study will be descriptive and remain close to the studies.

Thirdly, themes will be collated under the research questions.

Lastly, final themes will be synthesised involving an iterative process with co- authors and the data.

Analysis of subgroups or subsets

None planned.

Contact details for further information

Jo Lironi
j.lironi@rgu.ac.uk

Organisational affiliation of the review

Robert Gordon University
www.rgu.ac.uk

Review team members and their organisational affiliations

Ms Jo Lironi. Robert Gordon University
Dr Aileen Grant. Robert Gordon University
Professor Catriona Kennedy. Robert Gordon University

Type and method of review

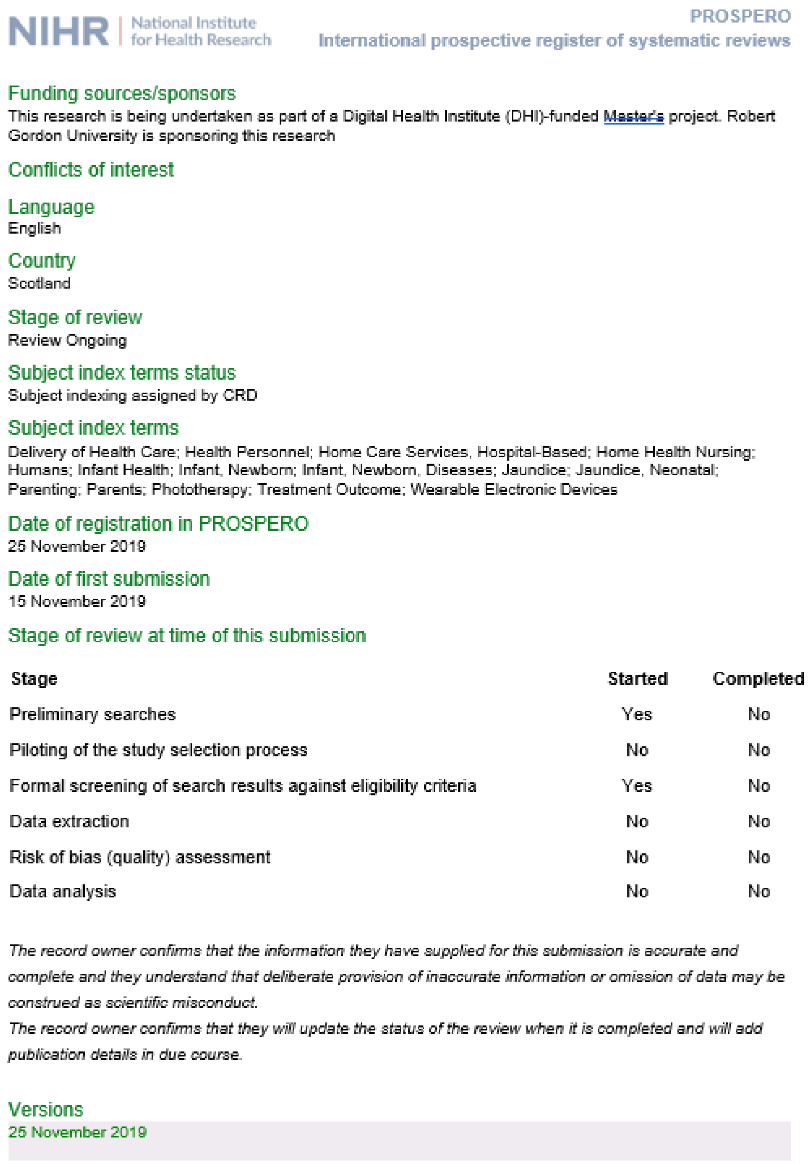
Intervention, Service delivery, Systematic review

Anticipated or actual start date

03 February 2019

Anticipated completion date

03 February 2020



Funding sources/sponsors

This research is being undertaken as part of a Digital Health Institute (DHI)-funded Master's project. Robert Gordon University is sponsoring this research

Conflicts of interest

Language

English

Country

Scotland

Stage of review

Review Ongoing

Subject index terms status

Subject indexing assigned by CRD

Subject index terms

Delivery of Health Care; Health Personnel; Home Care Services, Hospital-Based; Home Health Nursing; Humans; Infant Health; Infant, Newborn; Infant, Newborn, Diseases; Jaundice; Jaundice, Neonatal; Parenting; Parents; Phototherapy; Treatment Outcome; Wearable Electronic Devices

Date of registration in PROSPERO

25 November 2019

Date of first submission

15 November 2019

Stage of review at time of this submission

Stage	Started	Completed
Preliminary searches	Yes	No
Piloting of the study selection process	No	No
Formal screening of search results against eligibility criteria	Yes	No
Data extraction	No	No
Risk of bias (quality) assessment	No	No
Data analysis	No	No

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.

The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

25 November 2019

Appendix 5: Table 4. Summary of studies included in literature review

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Namnabati, Mohammadizadeh and Sardari (2019) Iran	Explore effect of home and hospital PT treatment on stress levels of mothers with newborn infants receiving PT treatment for jaundice.	Quantitative study. Clinical Trial with jaundiced newborn infants (n= 64) referred to health centres of Isfahan in 2017. Randomly divided into two groups: Control- hospital PT (n=32) Experimental- home PT (n=32) Training checklist, demographic characteristics, and questionnaire completed at two stages. Data entered SPSS 21 software and analysed using descriptive statistics and inferential statistical tests.	Randomised control trial. States that home PT is common practise in Iran, though provides no figures to support statement. Physicians in some areas reluctant to recommend home PT. Not clear if both groups received continued support from researcher, which could affect validity of study.	Maternal stress significantly lower using home PT group ($p<0.05$). Home PT can be considered a suitable treatment for newborn jaundice and reduce maternal stress levels.	Clearly defined issue and assignment of full term, healthy newborn infants to groups was randomised. Demographics not significantly different between both groups. There was significant treatment effect and significant outcomes demonstrating home PT effectively reduced SBR and maternal stress levels. Participants all accounted for at the conclusion and applicable to local population. Treatment was not blinded; and it is not clear if both groups received the same amount of support from the researcher, which raises questions over validity of findings.
Sardari, Mohammadizadeh and Namnabati (2019) Iran	Investigate effectiveness of home PT on treatment duration; bilirubin level; treatment failure and side effects.	Same study as above. Demographic questionnaire and checklist to determine duration of treatment, frequency of treatment, mean bilirubin and PT complications. Data collected for statistical analysis.	Researchers faced problems convincing people to cooperate because home PT is not the officially accepted pathway for treatment of newborn jaundice. Does not define data analysis other than statistical.	No significant difference in the most common complication of restlessness between both groups (p>0/05). No significant difference in treatment failure between groups, Fishers test ($p=0.246$). No significant difference in bilirubin reduction between both groups ($p>0.05$). No significant difference in duration of treatment between the groups ($p>0.05$). Mean duration of two days.	Clearly defined issue and assignment of full term, healthy newborn infants to groups was randomised. Demographics not significantly different between both groups, with both groups being treated equally. Participants all accounted for at the conclusion and applicable to local population. Treatment was not blinded. There was significant treatment effect and significant outcomes. Could be applied to local region.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Quandt et al. (2017) Switzerland	To produce a flexible light emitting fabric that does not require post processing or extra fabric covering the light source. Consideration given to comfort and commercial capabilities- exploring friction, breathability and wash ability.	Quantitative study. Testing of yarn thickness, weave pattern and yarn density to create a light emitting fabric. Thin POF woven to create homogenous light emissions to the infant's skin by 'bend out coupling'- light reflected within the fabric. Several weaves of pattern were produced in a semi-automatic loom to investigate weft yarn density. Weaves subjected to same tests.	Explores more parameters in textile production and structure of weave pattern than previous studies exploring POFs. Produced so that LEDs can be connected at both sides which facilitates equal light source across the fabric.	A flexible light emitting fabric that does not require post processing or an extra layer of fabric covering the light source. Breathable and washable, therefore potential commercial capabilities. The fabric can be made in small sections. Suitable for less severe cases of neonatal jaundice. Wavelength would need to be increased for intensive PT.	Clearly defined issue. Appropriate comparison to reference standard. Structure of weave remained the same when investigating weft yarn density. Sufficient detail provided on weaves and tests performed. Identified population this could be applicable to- namely full term, healthy newborn infants with jaundice.
Goulet et al. (2007) Quebec, Canada	Identify model of postnatal care most likely to prepare mothers for discharge, reduce newborn hospital admission for jaundice, and enhance maternal satisfaction.	Quantitative epidemiological study. Epidemiological survey via telephone one month after birth. Four regions used in Quebec with three different models of care involving mothers (n= 1,096). Both urban and rural settings included. Data analysed using SPSS 11.0 Windows (32). Logistic regression analyses to control potential confounding effects.	Cases reported on basis of visual assessment or TcB reading. Sometimes blood test. SBR would have confirmed or denied jaundice. Potential memory bias. Good sample size. Includes rural and urban settings. Regions selected in collaboration with Quebec Ministry of Health and Social Service. Limitation of bias with recognition of potential confounding effects. Telephone survey conducted by the Centre for Research on Public Opinion.	Home PT was offered in the mixed ambulatory care model (n=201), which covered an urban area. Of this population, 10.1% received home PT, and the most home visits. There was no readmission for jaundice using this model. Regions with community- based models (n= 679) reported higher levels of satisfaction and better preparation for discharge home.	Clearly defined issue using appropriate method and recruitment. Represents 80% of all births in each region. Good comparison of rural and urban settings, making it potentially applicable to local region. Findings fit with Escobar et al. (2005) and Namnabati, Mohammadizadeh and Sardari (2019). Cannot tell if confounding factors in design and/ or analysis have been considered.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Adlina et al. (2007) Malaysia	Identify sociodemographic data of the population that used home PT, and the effect the treatment has on SBR.	Quantitative study. Retrospective study of families (n=1,297) that consented to home PT treatment for their newborn infant. Set in the Klang Valley which includes: Petaling Jaya; Kuala Lumpur; Shah Alam; and Klang. All cases of home PT from May 2003 to December 2006 included. Tool used to collect data was a survey.	No explanation of data analysis methods. Good sample size. No details about the setting. Don't know whether they are urban or rural areas. No discussion about confounding effects and potential bias. Private healthcare so high cost of hospital treatments. May have impacted who had home PT. Verbal conversations found parents decided on home PT on grounds of cost- would be good to explore further using qualitative methods. Does not discuss data analysis methods.	Good reduction in bilirubin levels with correct usage of equipment. Motivation of parents identified as important for continuation of treatment. 98% referral by paediatricians and 2% initiated by parents. Two reasons for treatment failure: crying newborn infants; and interfering grandmothers.	Clearly defined issue using appropriate recruitment method. Cannot tell if exposure accurately measured to minimise bias. Confounding factors not identified. Follow up complete and long enough. Private healthcare system so referral rate not applicable to local region. However, reason given for treatment failure could be applicable to local region.
Escobar et al. (2005) USA	To analyse newborn infant's readmission to hospital.	Quantitative study. Retrospective study of delivery services at seven KPMCP from October 1998 to March 2000. Live infants of all gestations included (n= 33, 276). KPMCP hospital databases and information systems, include data on: admission, readmission, clinical, laboratory, out-patient, inpatient and out of plan (to determine ones lost at follow- up). Statistical Analyses Software used.	Good sample size. However, variation between centres cannot be explored using these methods. Demonstrates impact of home PT on a population. Bivariate comparisons of potential predictors were performed. KPMCP resembles NHS, physicians are salaried and capitated healthcare, therefore paid per patient not treatment.	Significant variation in use and follow up care in home PT. Data suggests that home PT may be commenced earlier than for readmission ($p=0.0052$). Concluded that short term readmission rates were affected by the availability of home PT and follow up care. Significant difference ($p<0.0001$). Jaundice only was the most common reason for readmission (34.3%).	Clearly defined issue using appropriate recruitment method. Exposure and outcome accurately measured to minimise bias. Authors identified confounding factors, and took them into account in design and analysis. Follow- up was long enough and complete. Results were precise and could potentially be applied to the local population. Jaundice has been demonstrated to be common cause for readmission in other studies (Battersby et al. 2017). This study has shown the impact of home PT on a population basis.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Bhutani et al. (2006) USA	To implement a family centred systems approach to manage newborn jaundice for safer outcomes.	Quantitative observational study. Semi- private urban maternity hospital. Between 1990 to 2000 there were 41,961 live births, of which healthy term or near-term newborn infants discharged home included (n= 31,059). An organised institutional systems-based guideline worked as framework for management of neonatal jaundice. Nurses obtain TcB reading, universal SBR at newborn screening test and targeted follow- up for at risk groups. SBR post discharge as per the newly developed hour- specific bilirubin nomogram.	Does not define data analysis methods. Home PT limited to few practitioners who cared for less than 15% of the study population. Precise data for home PT administration not available.	No effort to promote home PT, and behaviour of paediatricians over the 10-year period appeared unchanged.	Clearly defined issue using appropriate recruitment method. Exposure and outcome accurately measured to minimise bias. Authors identified confounding factors and follow- up was long enough and complete. Implication for practice in relation to risk assessment and decision making, though no precise data for home PT. Therefore, cannot be applied to local population. Fits with other studies supporting a systems approach to reduce adverse events (Bhutani, Donn and Johnson 2005).
Chowdhury, Hussey and Shortland (2007) UK	To determine management of newborn jaundice in the UK and if they are evidence based.	Quantitative study. Questionnaire survey with Lead paediatricians from NICU in the UK (n=160). No discussion about data analysis methods.	Prior to national guidance from NICE. Only 13% of units could provide home PT. The survey question was 'Can you provide PT treatment at home?' Could be misleading.	Management of jaundice in UK was not standardised and often did not follow evidence-based research. Only 21 units (13%) in the UK could provide home PT.	Clearly defined issue using appropriate recruitment method. Cannot tell if exposure accurately measured to minimise bias. Confounding factors not identified. Follow up complete and long enough. Fits with other studies, demonstrating lack of home PT provision and use of new PT equipment (Bhutani et al. 2006). Small sample size that does not explore decision- making for PT equipment used.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Hannon, Willis and Scrimshaw (2001) USA.	To explore mothers' perceptions regarding newborn jaundice; to identify factors influencing these; and to explore maternal recommendations for improved interactions with healthcare staff.	Qualitative study. Ethnographic interviews using grounded theory. Purposive sampling. Spanish and English-speaking mothers (n=47). University and community hospitals. Analysis: ATLAS.ti. Iterative process. Codes with inclusion and exclusion criteria were developed representing themes from the interviews.	Mainly Latina population. Modest sample size. Three trained female ethnographers conducted the in-depth interviews in Spanish or English (two were in the research team). University and community hospitals. Interview guide used to prompt conversation. Audiotaped and transcribed using bilingual transcribers. Detailed attrition rate. Team meetings to discuss data analysis and coding. Unclear how many newborn infants received home PT. Minimal differentiation made between hospital and home. It is more about jaundice than PT.	Mother as well as baby needs to be cared for. Mixed emotions regarding home PT: Some preferred not being separated from baby; others felt pressurised. Communication was important. Almost all mothers discussed feelings of guilt and distress over separation for PT and blood tests: impact breastfeeding, bond, touch their baby. Perceived jaundice as serious. Medical views described jaundice as normal, though not consistent with management of jaundice.	Clear aim identified and qualitative methodology was appropriate. Study design and recruitment method was appropriate. Data collected in a manner to address the aim. Ethical implications were addressed and analysis was rigorous. A clear statement of findings was provided. However, cannot tell if the relationship between researcher and participants had been considered.
Brethauer and Carey (2010) USA	Describe the lived experiences of mothers with an infant that had jaundice.	Qualitative study. Descriptive phenomenological. Interviews via telephone. Two midwestern hospitals in USA (n=6). Five interviews conducted via telephone and one interview conducted face to face. Streubert's 10 procedural steps for qualitative data collection and analysis. Concurrent data collection and analysis.	Small sample size. Interviews audiotaped and transcribed by researcher. Half of study participants used home PT. Does not particularly differentiate between home and hospital PT.	Physical, emotional and learning needs of mother rarely met. Readmission and SBR described as a 'horrendous ordeal'. Reduced bonding time with newborn infants reported with use of overhead and biliblanket phototherapy device. First time mothers more likely to stay quiet and mothers with experience more likely to take an active role on management plans.	Clear aim identified and qualitative methodology was appropriate. Study design and recruitment method was appropriate. Data collected in a manner to address the aim. A clear statement of findings was provided. However, cannot tell if the relationship between researcher and participants had been considered. Cannot tell whether ethical implications have been fully considered, and no reference made to informed consent.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Walls et al. (2004) Tayside, UK	First assessment of home PT programme in UK.	Qualitative study as part of service evaluation. Semi-structured telephone questionnaire. Daily logbook completed by parents and community midwives. 22 families, out of 28 families offered, receive home PT treatment. Supported by community midwife visit.	Ethical approval and consent not obtained because treatment being offered not 'novel'. Does not discuss data analysis.	All parents satisfied and preferred home PT to inpatient stay. 78.5% parents offered home PT accepted it. 45% of mothers that accepted it were primiparous. 36% of newborn infants included developed jaundice at home and had all their treatment at home. On average, PT treatment started on day 5.5 and lasted 47.3 hours. Reduces length of hospital stay for some mother.	Clear aim not identified, therefore unable to determine if methodology appropriate. The journal article does not discuss methodology. Recruitment appeared appropriate though eligibility was not strictly adhered to. The data was not collected in a way that fully assessed the programme. The relationship between researcher and participants has not appeared to be considered. Ethical implications have not been considered. Data analysis was not rigorous and there is no clear statement of findings. However, it is the first assessment of home PT in the UK.
Chang and Waite (2020) USA	To define home PT and assess risk factors for hospital readmission or requirement of another course of PT.	Quantitative retrospective study of 1324 newborn infants born at 35 weeks gestation and over who had home PT between September 2015 to February 2017. Study participants lived in an urban area and were recruited from one hospital site. Statistical analyses performed using Stata version 14.2.	Good sample size. Families had daily breastfeeding support and SBR levels obtained by a paediatric nurse at home. Families were trusted by clinicians to follow PT plan. Furthermore, clinicians were comfortable treating the study participants with home PT. However, only 28% were above AAP threshold for PT. Similarly, in the study by Goulet et al (2007) one model of care used PT prophylactically.	3% (n=42) infants required hospitalisation or a second course of PT. Commencing home PT at or above PT threshold was a risk factor for hospitalisation or another course of PT ($p<.001$). 25 infants admitted to hospital, of which 15 had rising SBR levels. Reason for rise in SBR levels for 15 infants was non-compliance due to unsettled infants (n=3), parental request (n=3), other clinical concerns unrelated to jaundice (n=6), and power cut (n=1). Charges for hospital PT was 3x higher than home PT in 2014.	Clearly defined issue using appropriate recruitment method. Exposure and outcome accurately measured to minimise bias. Authors identified confounding factors and took them into account in design and analysis. Follow-up was long enough and complete. Results were precise and could potentially be applied to the local population. This study has shown the impact of home PT on a population basis.

Author, Year, Country	Aims	Design, methods, sample, setting	Strengths and limitations	Findings	Critical appraisal
Pettersson et al. (2021) Sweden.	To assess safety and feasibility of home PT.	Quantitative study. Clinical trial with sample of jaundiced newborn infants (n= 147). Randomly allocated into two groups: control- hospital PT (n= 69); intervention- home PT (n= 78). Recruitment from one university hospital and five regional hospitals in Sweden. A logbook was kept at each hospital to allow analysis of families that did not want to participate or were excluded. Compare efficacy of home and hospital PT on SBR levels using a Bilisoft device. Determine home PT failure by recording the number resulting in hospital admission.	Moderate sample size. Although both groups treated equally, the participants allocated to home PT received further information regarding use of the Bilisoft system at home and contact details. The study did not define the distances involved for excluding parents from eligibility, but parent had to be able to return to hospital daily for check-ups. Also, they used several different light sources that might change the results. The study provided strict information and followed protocol. There was 24/7 telephone support for parents. Eligible parents were considered capable to perform PT, however: the study does not determine how they assessed parents as capable.	4% of home PT were changed to hospital PT due to lack of PT at home. This was due to misunderstanding (n=1), unsettled infants during PT (n=1), and insufficient duration of PT (n=1). Three parents decided not to continue with home PT due to the distance from home to hospital for daily check- ups, concerns about temperature at home, and pressure of being primary care giver. When performed effectively there were no cases of SBR levels at dangerous levels using home PT. No significant difference between groups for length of stay. No significant difference in weight gain.	Clearly defined issue and assignment of newborn infants over 36 weeks gestation to groups was randomised. Both groups being treated equally. Participants all accounted for at the conclusion and applicable to local population. Treatment was not blinded. There was significant treatment effect and significant outcomes. Could be applied to local region.
Noureldein et al. (2021) UK.	To report Birmingham Heartlands Hospital neonatal community outreach team's (NCOT) experience of home PT and discuss its effectiveness. Additional outcomes measured included parental satisfaction and duration of PT.	Quantitative retrospective observational study as part of a service evaluation. Included 100 newborn infants using a Bili cocoon device at home. Data collected between April 2018 and September 2020. Included 50 newborn infants (as a control) using an overhead device. Data collected between January 2019 and September 2020. The NCOT cover an area that has approximately 18,000 births a year. Statistical Analyses Software used.	Although a small sample size it is the largest cohort of home PT for newborn jaundice in the UK. Limitations include equipment issues at home; parents satisfaction collected via a survey. Strengths include information about hospital and home PT, such as: parents' positive feedback about home PT; longer duration of treatment with home PT; average length of hospital PT 51 hours; potentially able to save 2.1 bed days per newborn infant. However, economic analysis not performed.	52% of infants with home PT started treatment at home. Whereas 48% started PT in hospital and continued it at home. Similar decline in SBR level between hospital and home PT. Duration of PT was longer at home ($p= 0.0001$). 66% of infants with home PT had data measuring duration of PT via the phototherapy device. Potentially over estimated duration of home PT, which was significantly longer ($p<0.0001$).	Clearly defined issue using appropriate. Recruitment appeared appropriate though survey inefficient to explore parental experience of home PT. Exposure and outcome accurately measured to minimise bias. Authors identified confounding factors and took them into account in design and analysis. Follow-up was long enough and complete. Results for effectiveness of PT and duration of PT were precise and could potentially be applied to the local population.

Appendix 6: Study adverts

First advert for study

DIGITAL HEALTH & CARE INSTITUTE

RGU ROBERT GORDON UNIVERSITY ABERDEEN

JAUNDICE IN NEWBORNS

Important research is being conducted looking at developing a new device that could provide treatment at home

This research is being undertaken as part of a DHI funded Master project

We are looking for people who have had a baby within the last 5 years that received phototherapy treatment for jaundice to share their experiences and insights.

What's Involved:

A conversation with a researcher about your perspectives towards phototherapy for the treatment of newborn jaundice delivered at home and of a wearable phototherapy device.

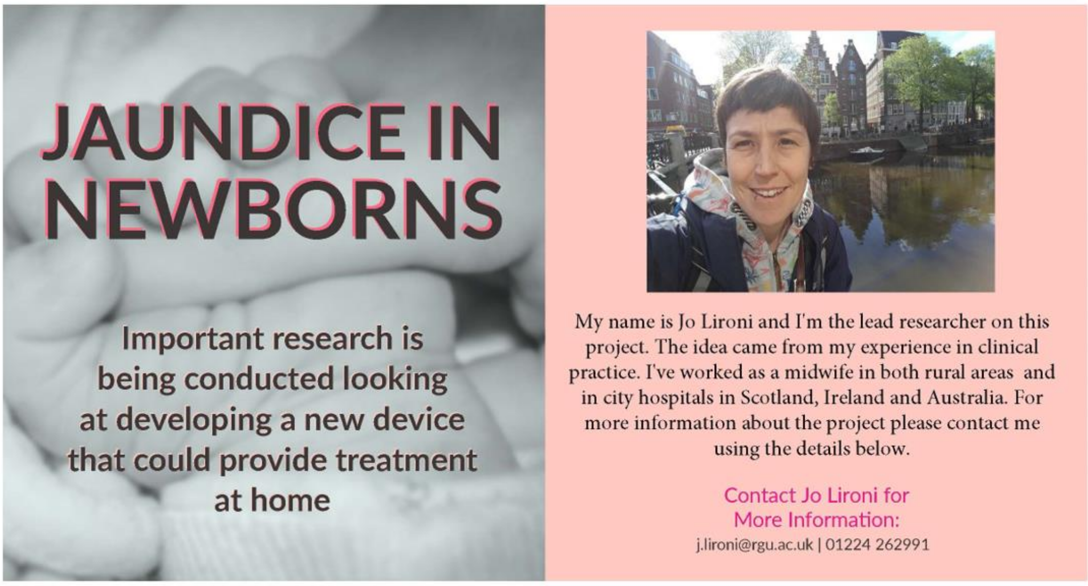
Who We Are Looking For:

16+ years old | Fluent in English | Live in Rural Location

Contact Jo Lironi for More Information:

j.lironi@rgu.ac.uk | 01224 262991

Second advert for study



JAUNDICE IN NEWBORNS

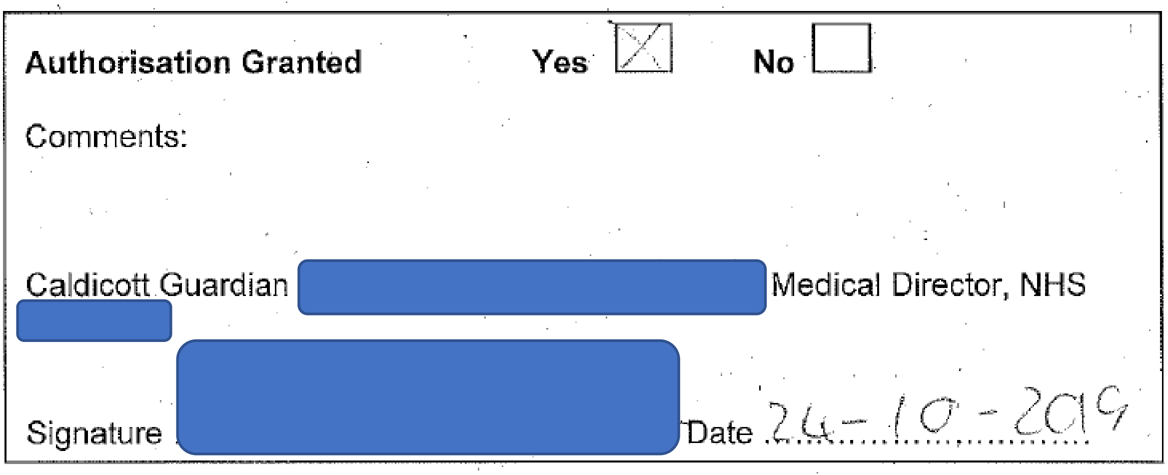
Important research is being conducted looking at developing a new device that could provide treatment at home

My name is Jo Lironi and I'm the lead researcher on this project. The idea came from my experience in clinical practice. I've worked as a midwife in both rural areas and in city hospitals in Scotland, Ireland and Australia. For more information about the project please contact me using the details below.

Contact Jo Lironi for More Information:

j.lironi@rgu.ac.uk | 01224 262991

Appendix 7: Caldicott approval



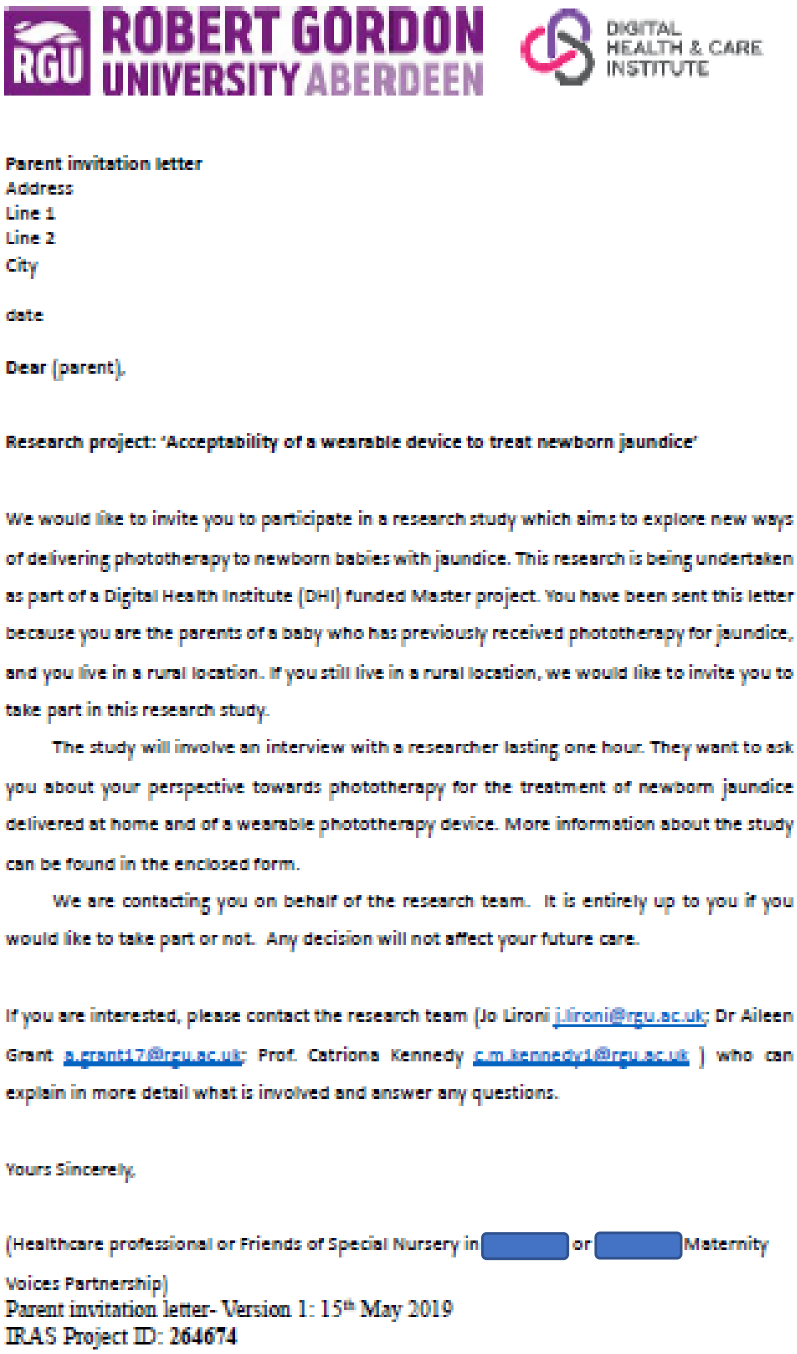
Authorisation Granted **Yes** ☒ **No** ☐

Comments:

Caldicott Guardian [redacted] Medical Director, NHS [redacted]

Signature [redacted] Date 24-10-2019

Appendix 8: Parent invitation letter



ROBERT GORDON UNIVERSITY ABERDEEN

DIGITAL HEALTH & CARE INSTITUTE

Parent invitation letter
Address
Line 1
Line 2
City

date

Dear (parent),

Research project: 'Acceptability of a wearable device to treat newborn jaundice'

We would like to invite you to participate in a research study which aims to explore new ways of delivering phototherapy to newborn babies with jaundice. This research is being undertaken as part of a Digital Health Institute (DHI) funded Master project. You have been sent this letter because you are the parents of a baby who has previously received phototherapy for jaundice, and you live in a rural location. If you still live in a rural location, we would like to invite you to take part in this research study.

The study will involve an interview with a researcher lasting one hour. They want to ask you about your perspective towards phototherapy for the treatment of newborn jaundice delivered at home and of a wearable phototherapy device. More information about the study can be found in the enclosed form.

We are contacting you on behalf of the research team. It is entirely up to you if you would like to take part or not. Any decision will not affect your future care.

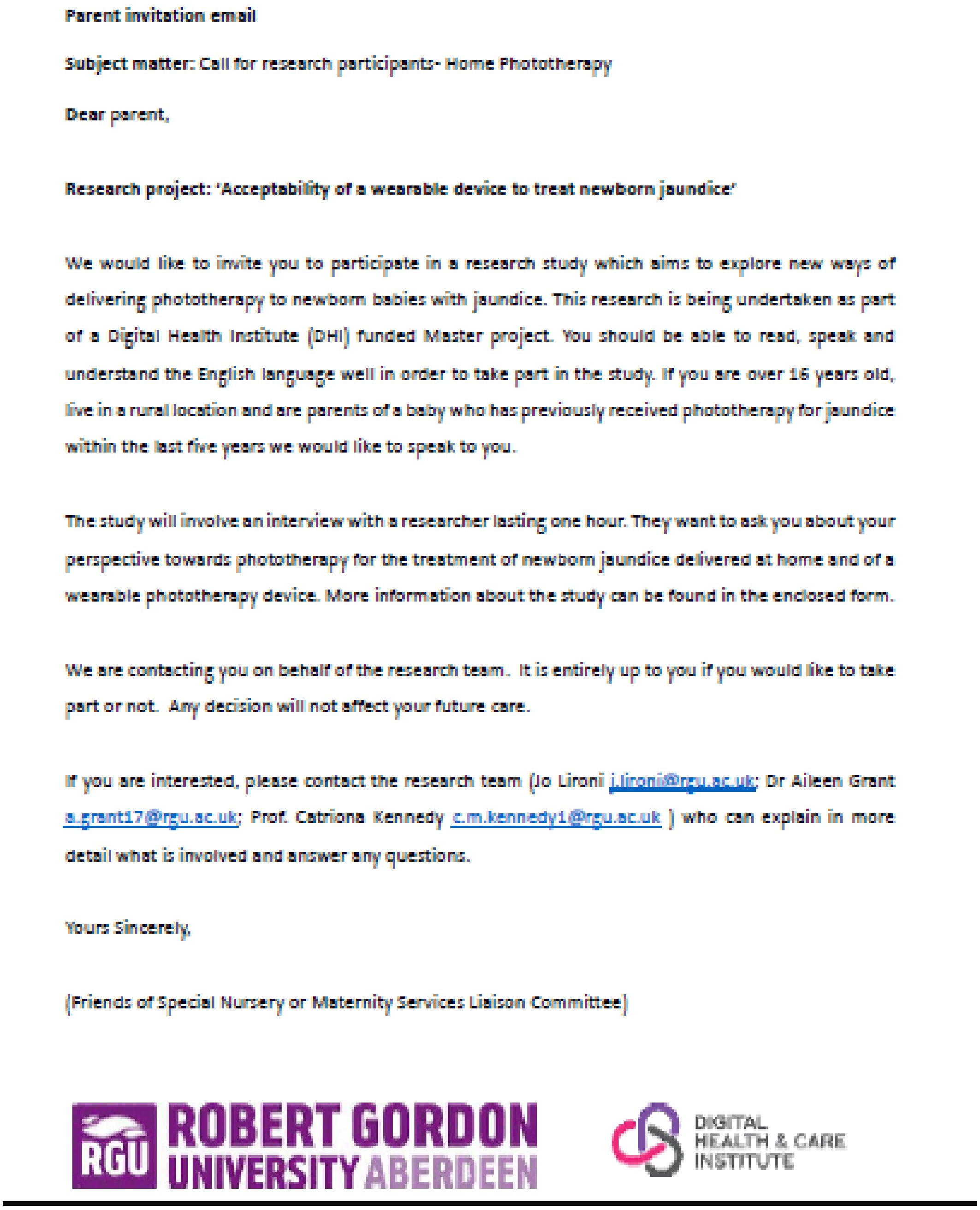
If you are interested, please contact the research team (Jo Lironi j.lironi@rgu.ac.uk; Dr Aileen Grant a.grant17@rgu.ac.uk; Prof. Catriona Kennedy c.m.kennedy1@rgu.ac.uk) who can explain in more detail what is involved and answer any questions.

Yours Sincerely,

(Healthcare professional or Friends of Special Nursery in [redacted] or [redacted] Maternity Voices Partnership)

Parent invitation letter- Version 1: 15th May 2019
IRAS Project ID: 264674

Appendix 9: Parent invitation email



Parent invitation email

Subject matter: Call for research participants- Home Phototherapy

Dear parent,

Research project: 'Acceptability of a wearable device to treat newborn jaundice'

We would like to invite you to participate in a research study which aims to explore new ways of delivering phototherapy to newborn babies with jaundice. This research is being undertaken as part of a Digital Health Institute (DHI) funded Master project. You should be able to read, speak and understand the English language well in order to take part in the study. If you are over 16 years old, live in a rural location and are parents of a baby who has previously received phototherapy for jaundice within the last five years we would like to speak to you.

The study will involve an interview with a researcher lasting one hour. They want to ask you about your perspective towards phototherapy for the treatment of newborn jaundice delivered at home and of a wearable phototherapy device. More information about the study can be found in the enclosed form.

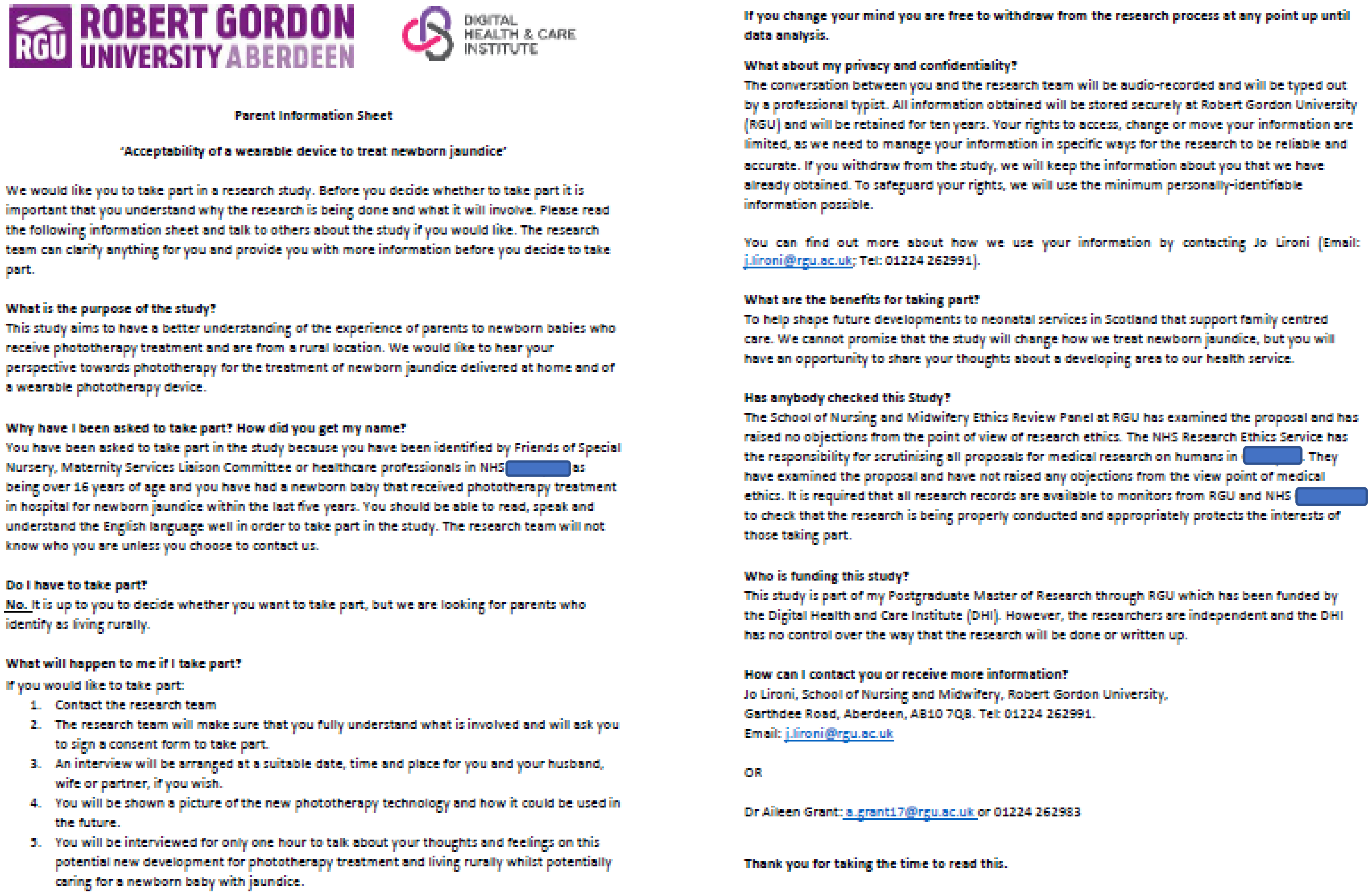
We are contacting you on behalf of the research team. It is entirely up to you if you would like to take part or not. Any decision will not affect your future care.

If you are interested, please contact the research team (Jo Lironi j.lironi@rgu.ac.uk; Dr Aileen Grant a.grant17@rgu.ac.uk; Prof. Catriona Kennedy c.m.kennedy1@rgu.ac.uk) who can explain in more detail what is involved and answer any questions.

Yours Sincerely,

(Friends of Special Nursery or Maternity Services Liaison Committee)

Appendix 10: Parent information sheet



ROBERT GORDON UNIVERSITY ABERDEEN

DIGITAL HEALTH & CARE INSTITUTE

Parent Information Sheet

'Acceptability of a wearable device to treat newborn jaundice'

We would like you to take part in a research study. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please read the following information sheet and talk to others about the study if you would like. The research team can clarify anything for you and provide you with more information before you decide to take part.

What is the purpose of the study?
This study aims to have a better understanding of the experience of parents to newborn babies who receive phototherapy treatment and are from a rural location. We would like to hear your perspective towards phototherapy for the treatment of newborn jaundice delivered at home and of a wearable phototherapy device.

Why have I been asked to take part? How did you get my name?
You have been asked to take part in the study because you have been identified by Friends of Special Nursery, Maternity Services Liaison Committee or healthcare professionals in NHS [redacted] as being over 16 years of age and you have had a newborn baby that received phototherapy treatment in hospital for newborn jaundice within the last five years. You should be able to read, speak and understand the English language well in order to take part in the study. The research team will not know who you are unless you choose to contact us.

Do I have to take part?
No. It is up to you to decide whether you want to take part, but we are looking for parents who identify as living rurally.

What will happen to me if I take part?
If you would like to take part:

1. Contact the research team
2. The research team will make sure that you fully understand what is involved and will ask you to sign a consent form to take part.
3. An interview will be arranged at a suitable date, time and place for you and your husband, wife or partner, if you wish.
4. You will be shown a picture of the new phototherapy technology and how it could be used in the future.
5. You will be interviewed for only one hour to talk about your thoughts and feelings on this potential new development for phototherapy treatment and living rurally whilst potentially caring for a newborn baby with jaundice.

If you change your mind you are free to withdraw from the research process at any point up until data analysis.

What about my privacy and confidentiality?
The conversation between you and the research team will be audio-recorded and will be typed out by a professional typist. All information obtained will be stored securely at Robert Gordon University (RGU) and will be retained for ten years. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Jo Lironi (Email: j.lironi@rgu.ac.uk; Tel: 01224 262991).

What are the benefits for taking part?
To help shape future developments to neonatal services in Scotland that support family centred care. We cannot promise that the study will change how we treat newborn jaundice, but you will have an opportunity to share your thoughts about a developing area to our health service.

Has anybody checked this Study?
The School of Nursing and Midwifery Ethics Review Panel at RGU has examined the proposal and has raised no objections from the point of view of research ethics. The NHS Research Ethics Service has the responsibility for scrutinising all proposals for medical research on humans in [redacted]. They have examined the proposal and have not raised any objections from the view point of medical ethics. It is required that all research records are available to monitors from RGU and NHS [redacted] to check that the research is being properly conducted and appropriately protects the interests of those taking part.

Who is funding this study?
This study is part of my Postgraduate Master of Research through RGU which has been funded by the Digital Health and Care Institute (DHI). However, the researchers are independent and the DHI has no control over the way that the research will be done or written up.

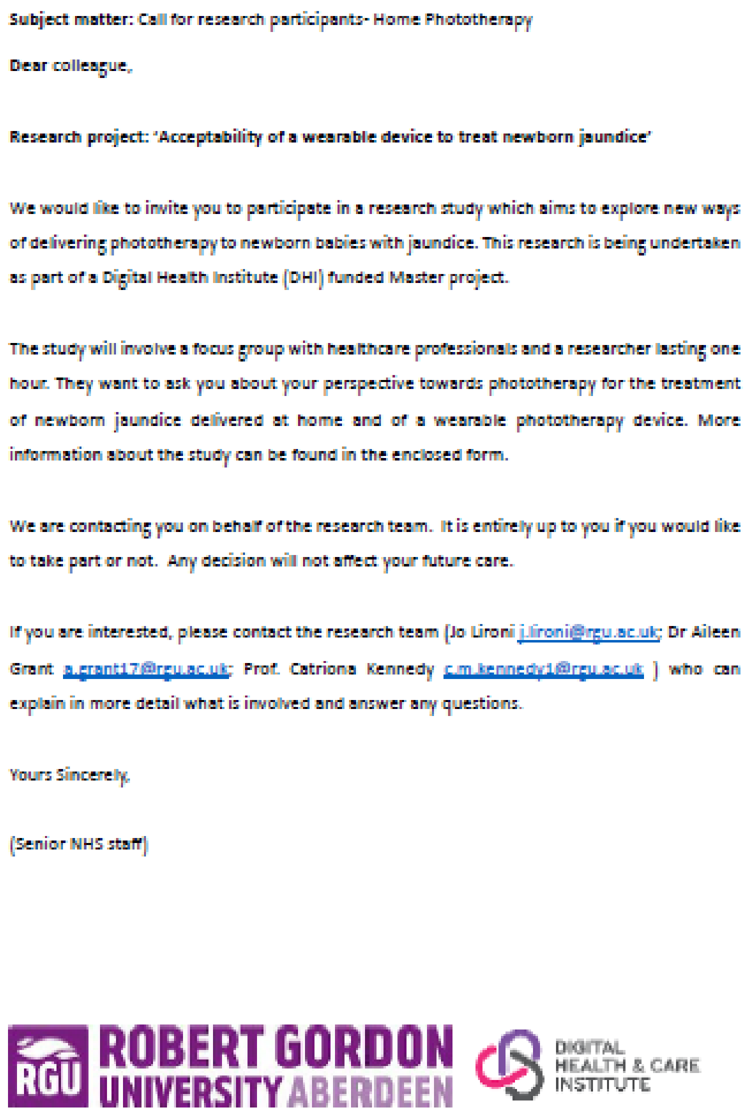
How can I contact you or receive more information?
Jo Lironi, School of Nursing and Midwifery, Robert Gordon University,
Garthdee Road, Aberdeen, AB10 7QB. Tel: 01224 262991.
Email: j.lironi@rgu.ac.uk

OR

Dr Aileen Grant: a.grant17@rgu.ac.uk or 01224 262983

Thank you for taking the time to read this.

Appendix 11: Healthcare professional invitation email



Subject matter: Call for research participants- Home Phototherapy

Dear colleague,

Research project: 'Acceptability of a wearable device to treat newborn jaundice'

We would like to invite you to participate in a research study which aims to explore new ways of delivering phototherapy to newborn babies with jaundice. This research is being undertaken as part of a Digital Health Institute (DHI) funded Master project.

The study will involve a focus group with healthcare professionals and a researcher lasting one hour. They want to ask you about your perspective towards phototherapy for the treatment of newborn jaundice delivered at home and of a wearable phototherapy device. More information about the study can be found in the enclosed form.

We are contacting you on behalf of the research team. It is entirely up to you if you would like to take part or not. Any decision will not affect your future care.

If you are interested, please contact the research team (Jo Lironi j.lironi@rgu.ac.uk; Dr Aileen Grant a.grant17@rgu.ac.uk; Prof. Catriona Kennedy c.m.kennedy1@rgu.ac.uk) who can explain in more detail what is involved and answer any questions.

Yours Sincerely,

(Senior NHS staff)

Appendix 12: Healthcare professional information sheet

RGU ROBERT GORDON UNIVERSITY ABERDEEN

DIGITAL HEALTH & CARE INSTITUTE

Healthcare professionals' information sheet

'Acceptability of a wearable device to treat newborn jaundice'

We would like you to take part in a research study. Before you decide whether to take part it is important that you understand why the research is being done and what it will involve. Please read the following information sheet and talk to others about the study if you would like. The research team can clarify anything for you and provide you with more information before you decide to take part.

What is the purpose of the study?
This study aims to understand parents' and healthcare professionals' perspectives of the acceptability of a wearable neonatal device to enable home monitoring and treatment of jaundice for newborn infants from a rural setting.

Why have I been asked to take part? How did you get my name?
You have been asked to take part in the study because if there were a home phototherapy service for newborn infants you could potentially be involved in their care. Senior staff in NHS [redacted] have sent you an invitation to the research study and an information sheet. The research team will not know who you are unless you choose to contact the team.

Do I have to take part?
No. It is up to you to decide whether you want to take part, but we are looking for NHS [redacted] healthcare professionals involved in caring for newborn infants.

What will happen to me if I take part?
If you would like to take part:

1. Contact the research team
2. The research team will make sure that you fully understand what is involved and will ask you to sign a consent form to take part.
3. A focus group will be arranged at a suitable date, time and place for you and the other participants.
4. You will be shown a picture of the new phototherapy technology and how it could be used in the future.
5. The focus group will involve only one hour of your time to talk about your thoughts and feelings on this potential new development for phototherapy treatment and its potential for a home phototherapy service in rural locations.

If you change your mind you are free to withdraw from the research process at any point up until data analysis.

What about my privacy and confidentiality?
The conversation between you and the research team will be audio-recorded and will be typed out by a professional typist contracted to Robert Gordon University (RGU). All information obtained will be stored securely at RGU and will be retained for ten years. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting Jo Lironi (Email: j.lironi@rgu.ac.uk; Tel: 01224 262991).

What are the benefits for taking part?
To help shape future developments to neonatal services in Scotland that support family centred care. Collaborate with colleagues and discuss alternatives to our services that could potentially reduce inpatient numbers. We cannot promise that the study will change how we treat newborn jaundice, but you will have an opportunity to share your thoughts about a developing area to our health service.

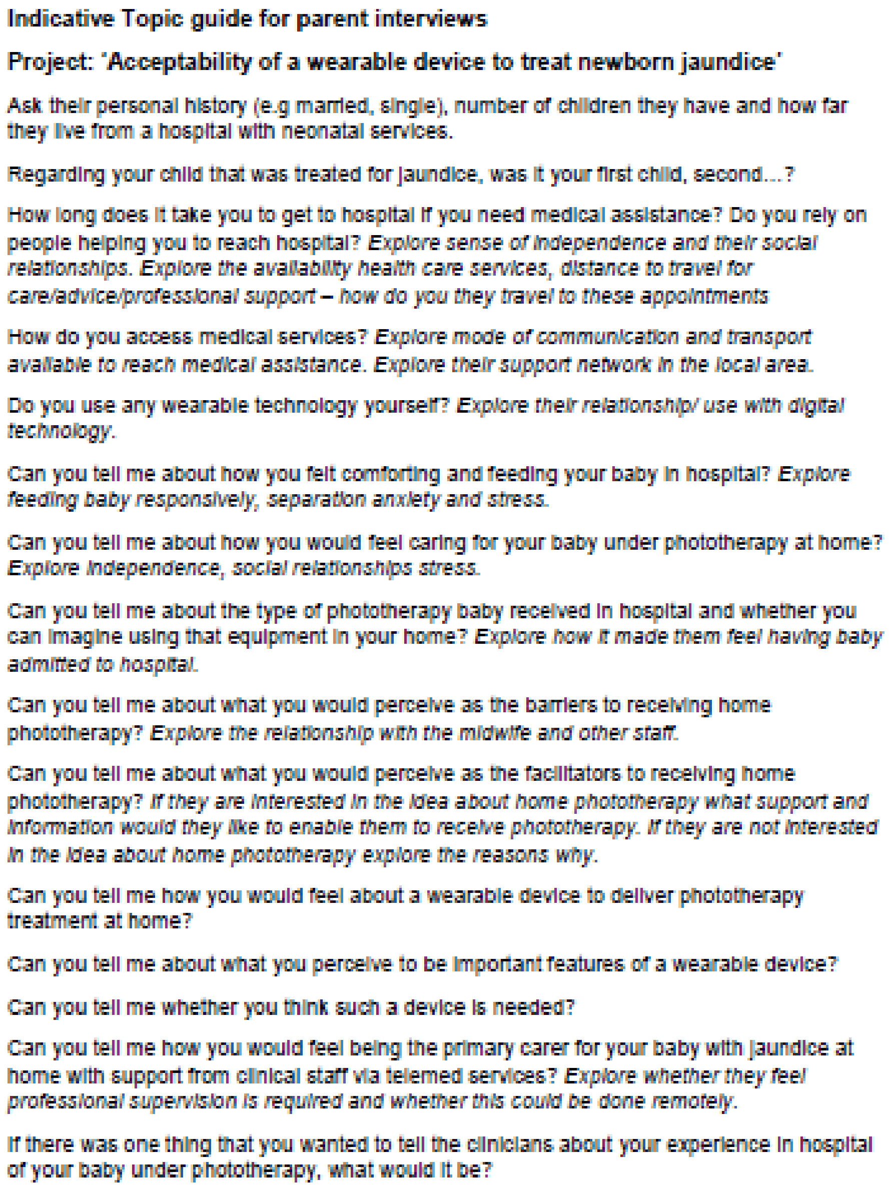
Has anybody checked this Study?
The School of Nursing and Midwifery Ethics Review Panel at RGU has examined the proposal and has raised no objections from the point of view of research ethics. The NHS Research Ethics Service has the responsibility for scrutinising all proposals for medical research on humans in Grampian. They have examined the proposal and have not raised any objections from the view point of medical ethics. It is required that all research records are available to monitors from RGU and NHS [redacted] to check that the research is being properly conducted and appropriately protects the interests of those taking part.

Who is funding this study?
This study is part of Jo's Postgraduate Master of Research through RGU which has been funded by the Digital Health and Care Institute (DHI). However, the researchers are independent and the DHI has no control over the way that the research will be done or written up.

How can I contact you or receive more information?
Jo Lironi, School of Nursing and Midwifery, Robert Gordon University,
Garthdee Road, Aberdeen, AB10 7QB. Tel: 01224 262991.
Email: j.lironi@rgu.ac.uk
OR
Dr Aileen Grant: a.grant17@rgu.ac.uk or 01224 262983

Thank you for taking the time to read this.

Appendix 13: Indicative topic guide for parent interviews



Indicative Topic guide for parent interviews

Project: 'Acceptability of a wearable device to treat newborn jaundice'

Ask their personal history (e.g married, single), number of children they have and how far they live from a hospital with neonatal services.

Regarding your child that was treated for jaundice, was it your first child, second…?

How long does it take you to get to hospital if you need medical assistance? Do you rely on people helping you to reach hospital? *Explore sense of independence and their social relationships. Explore the availability health care services, distance to travel for care/advice/professional support – how do you they travel to these appointments*

How do you access medical services? *Explore mode of communication and transport available to reach medical assistance. Explore their support network in the local area.*

Do you use any wearable technology yourself? *Explore their relationship/ use with digital technology.*

Can you tell me about how you felt comforting and feeding your baby in hospital? *Explore feeding baby responsively, separation anxiety and stress.*

Can you tell me about how you would feel caring for your baby under phototherapy at home? *Explore independence, social relationships stress.*

Can you tell me about the type of phototherapy baby received in hospital and whether you can imagine using that equipment in your home? *Explore how it made them feel having baby admitted to hospital.*

Can you tell me about what you would perceive as the barriers to receiving home phototherapy? *Explore the relationship with the midwife and other staff.*

Can you tell me about what you would perceive as the facilitators to receiving home phototherapy? *If they are interested in the idea about home phototherapy what support and information would they like to enable them to receive phototherapy. If they are not interested in the idea about home phototherapy explore the reasons why.*

Can you tell me how you would feel about a wearable device to deliver phototherapy treatment at home?

Can you tell me about what you perceive to be important features of a wearable device?

Can you tell me whether you think such a device is needed?

Can you tell me how you would feel being the primary carer for your baby with jaundice at home with support from clinical staff via telemed services? *Explore whether they feel professional supervision is required and whether this could be done remotely.*

If there was one thing that you wanted to tell the clinicians about your experience in hospital of your baby under phototherapy, what would it be?

Appendix 14: Visual aid

Current Phototherapy treatment, and the future of phototherapy treatment proposed with ‘photonic textiles’.

Current:

(SIX 2017)

Future:

(Tomsickova 2021)

Image of the photonic textile

which is washable and breathable

→

(SIX 2017)

Appendix 15: Indicative topic guide for focus groups

[redacted] focus group indicative topic guide

Project: 'Acceptability of a wearable device to treat newborn jaundice'

Participants will be asked to talk about:

- **Experiences of caring for a baby receiving phototherapy treatment**
    - Parents and family
    - Observations

- **Perspectives of a wearable phototherapy device**
    - Safety
    - Transition or family centred care
    - Features needed

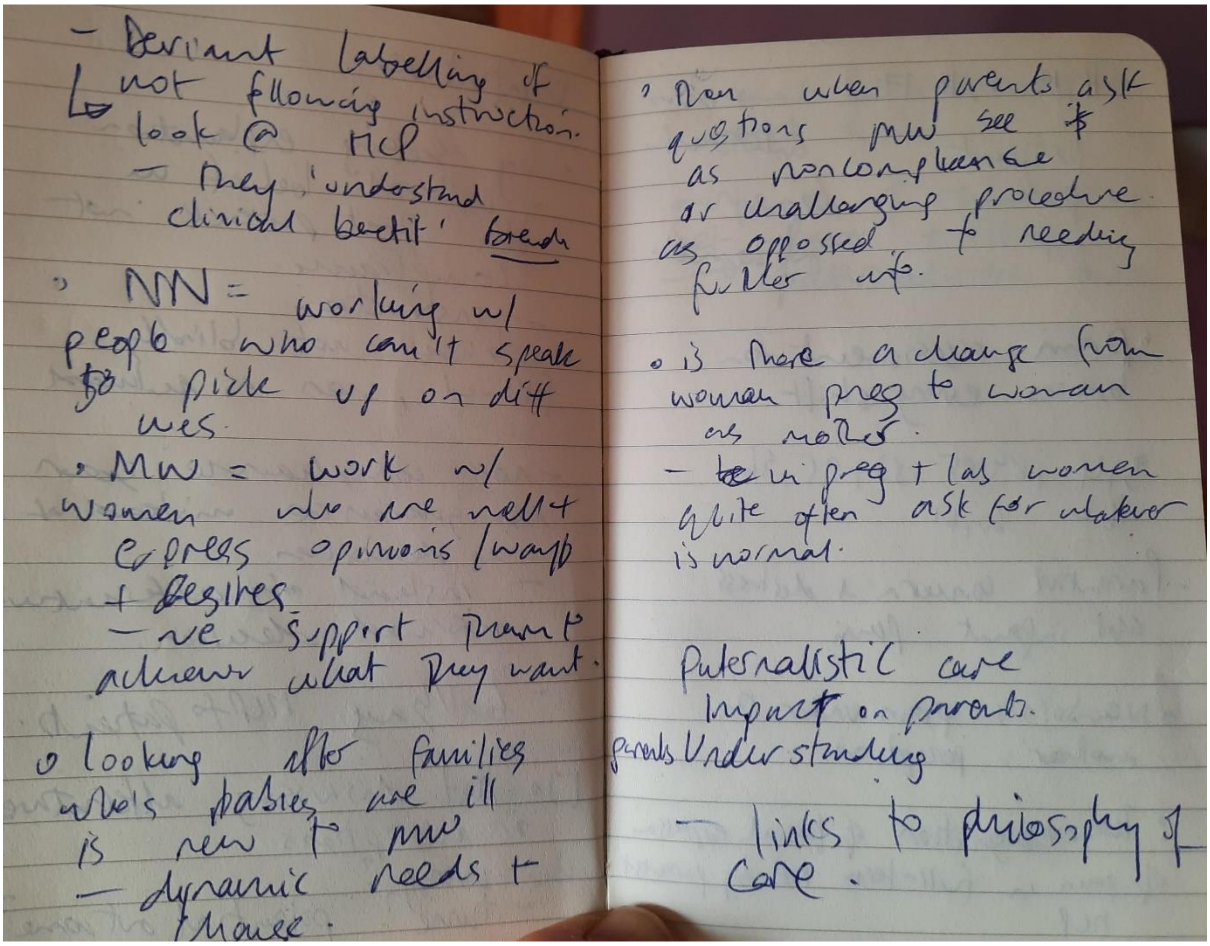
- **Expectations of parents**
    - Baby care

- **Perspectives of home phototherapy**
    - Process
    - Support and information required

- **Training and resources**
    - Is there a role for telemed?
    - Capacity
    - Education and training needs for professionals and parents

Appendix 16: Reflective journal

04/12/19 in Annie's home



— Deviant labelling of
↳ not following instruction.
look @ HCP
— they 'understand clinical benefit' breach

• NN = working w/ people who can't speak so pick up on diff cues.

• MW = work w/ women who are well + express opinions / wants + desires
— we support them to achieve what they want.

• looking after families who's babies are ill is new to mw
— dynamic needs + change.

• Then when parents ask questions MW see it as noncompliance or challenging procedure as opposed to needing further info.

• is there a change from woman preg to woman as mother.
— ~~to~~ in preg + lab women quite often ask for whatever is normal.

Paternalistic care
Impact on parents.
parents Understanding
— links to philosophy of care.

- Interview took place with Annie's 9-month-old child present. She is the child that had jaundice and is the experience that Annie is talking about.

- Misunderstanding or confusion at points:
Missed diagnosed gestational diabetes which she links to newborn jaundice. PET which she links to newborn jaundice. Relationship between fitbit and diagnosing PET.

- often uses the word horrible.

- Child was diagnosed jaundiced within 24hours which sounds like ABO incompatibility. However, there does not seem to be any acknowledgement or recognition of this.

- Distance between home and main hospital appears to be the main issue.

- When Annie was asked about the features of the wearable phototherapy device, she said that the colours or images on the material was not important. However, the fact she identifies these things makes me wonder whether it is more important to her than she realises.

Makes me think about the telephone conversation I had with Sarah Taylor about the aesthetics.

- *"Yeah, yeah, but if the doctors, like my midwives and that, they were lovely, they were great that, and, great support but, er, but I don't feel like, they want to be able to help you..."*

HCP want to be able to help you but they can't. Why? Sense of their hands are tied and it is out with their control. Does this bring up notions of trust again? - Between health board and staff at the coal face.
Also, acknowledgment they can offer emotional support or even BE with you but not physical/ practical support or care. Interesting idea to explore.

- *It really felt, made me feel horrible, like, I wasn't getting the bond with her cause even after birth, I passed out for two hours so I didn't even get that and two hours later she was taken away from me...*

Care is something that happens to you. Paternal care.

"I didn't get to see her"
Paternal care again. Not being 'allowed' again.

- *"It was like, I would set alarms, cause obviously you had to feed every four hours to make sure you flushed the jaundice out their systems, in a way. So, I would set alarms and make sure that I was feeding every four hours but, she was always up wanting a feed before that so, it was fine but, you could do that at home and not have the interruptions and everything like this, and doctors wanting to come in and check. Then, one midwife wouldn't tell the next midwife cause they were so busy so, of course, you would have two coming in within the hour and, if you'd got them settled down or, you'd just gone for a nap or something, it was like, you wouldn't have that at home."*

Why don't we trust parents to feed their newborn infants? Is it because if they are inpatient, we have to be seen as doing something?

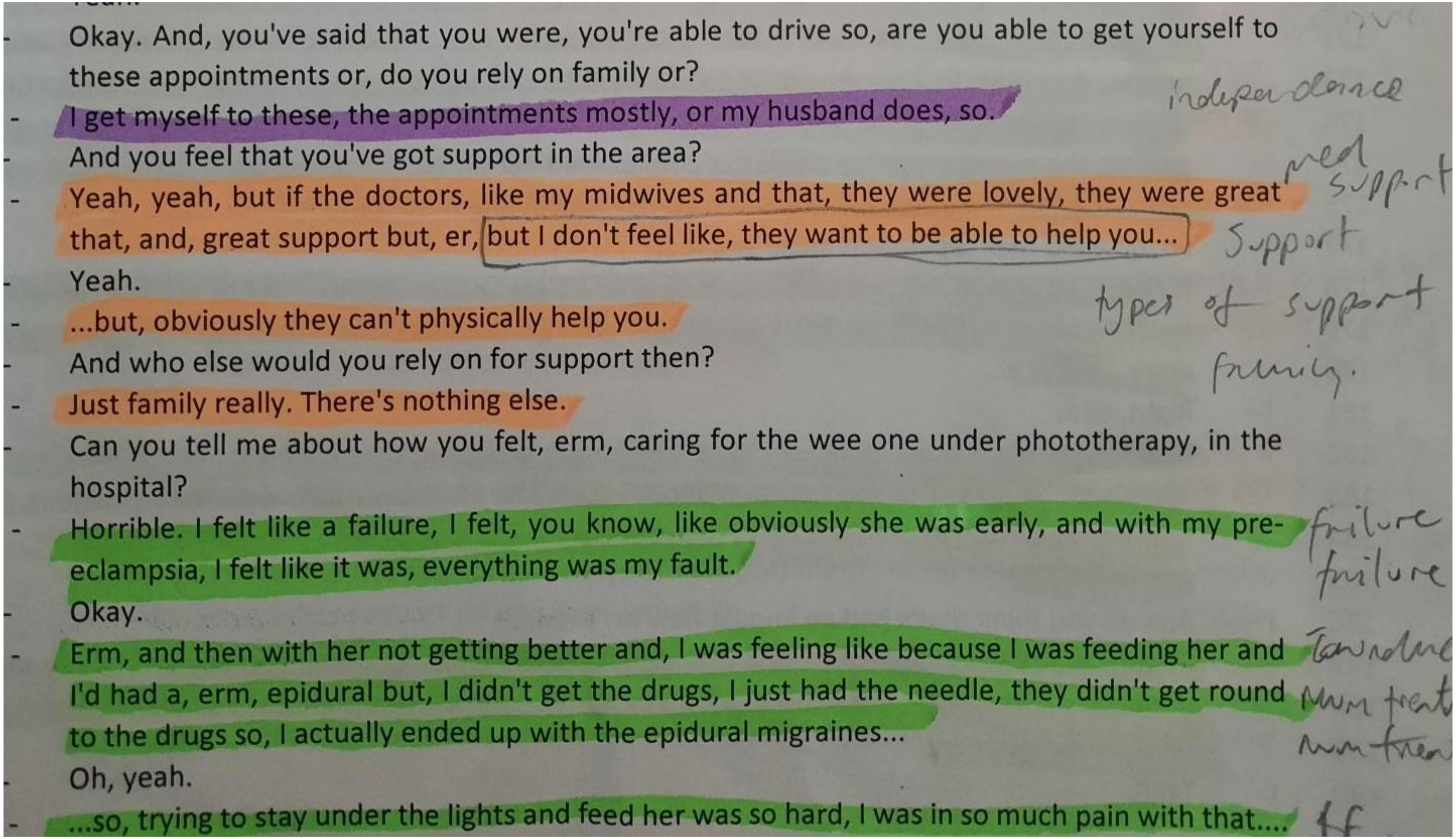
- *"You do things in your own time, bath them when you want to bath them."*

Independence and trust with home PT.

- *"But, yeah, erm, but no, literally just that, with the phototherapy thing on the inside or stitched into it, that..."*

Link to article by Quandt et al (2017). Would she actually want an extra layer of covering for aesthetics?? Contradicts Quandt's position.

Appendix 17: Example of initial coding



- Okay. And, you've said that you were, you're able to drive so, are you able to get yourself to these appointments or, do you rely on family or?
- I get myself to these, the appointments mostly, or my husband does, so.
- And you feel that you've got support in the area?
- Yeah, yeah, but if the doctors, like my midwives and that, they were lovely, they were great that, and, great support but, er, but I don't feel like, they want to be able to help you...
- Yeah.
- ...but, obviously they can't physically help you.
- And who else would you rely on for support then?
- Just family really. There's nothing else.
- Can you tell me about how you felt, erm, caring for the wee one under phototherapy, in the hospital?
- Horrible. I felt like a failure, I felt, you know, like obviously she was early, and with my pre-eclampsia, I felt like it was, everything was my fault.
- Okay.
- Erm, and then with her not getting better and, I was feeling like because I was feeling her and I'd had a, erm, epidural but, I didn't get the drugs, I just had the needle, they didn't get round to the drugs so, I actually ended up with the epidural migraines...
- Oh, yeah.
- ...so, trying to stay under the lights and feed her was so hard, I was in so much pain with that....

independence

med support

Support

types of support

family.

failure

failure

Jaundice

Mum treat

Mum trea

ff

A - Because of the way of the [redacted] hospital is. There's no help there, there's basically no ward there. You, if your baby's ill, it's [redacted]...

I - Okay.

A - ...so that's like an hour and a half's drive at the best of times, erm, and if you don't drive then that's just a nightmare, thankfully we do but, still, if you've got other kids then it's, physically impossible for your partners to be travelling every single day just to come and visit you. So, you're left on your half the time.

I - Yeah, so you can you expand on that? Cause you said there's no help there, what, what do they have, what?

A - **Assessment,** basically.

I - Okay. For when you're pregnant or for the children?

A - Children, as well. Children and when you're a pregnant, **it's just assessment** in a way...

I - Okay.

A - ...you're, if you have a **100% healthy pregnancy and no risks** whatsoever, then, yes, you can give birth there and **you get the help** but, as soon as your baby's ill and needing anything at all, it's straight down to [redacted]. So, even with phototherapy, I asked if she could be transferred but, [redacted] doesn't do phototherapy so, they couldn't do it.

I - Okay. That's interesting. So, normally then, how would you access medical treatment normally?

A - With [redacted] or the doctors first, erm, we have a few times up the [redacted] Hospital and I've been told, well, this is why, that, if her, she took a bad reaction to her jabs and I was told if she didn't have her temperature down within half an hour I was **having to go down to** [redacted] **cause the ward was closing**.

Jo Lironi (snm)
Rural identity- Impact of change in local HC service. Vulnerability.

Lironi Jo
Distance. Isolation. Not fair.

Jo Lironi (snm)
Access healthcare- local services for monitoring and assessment.

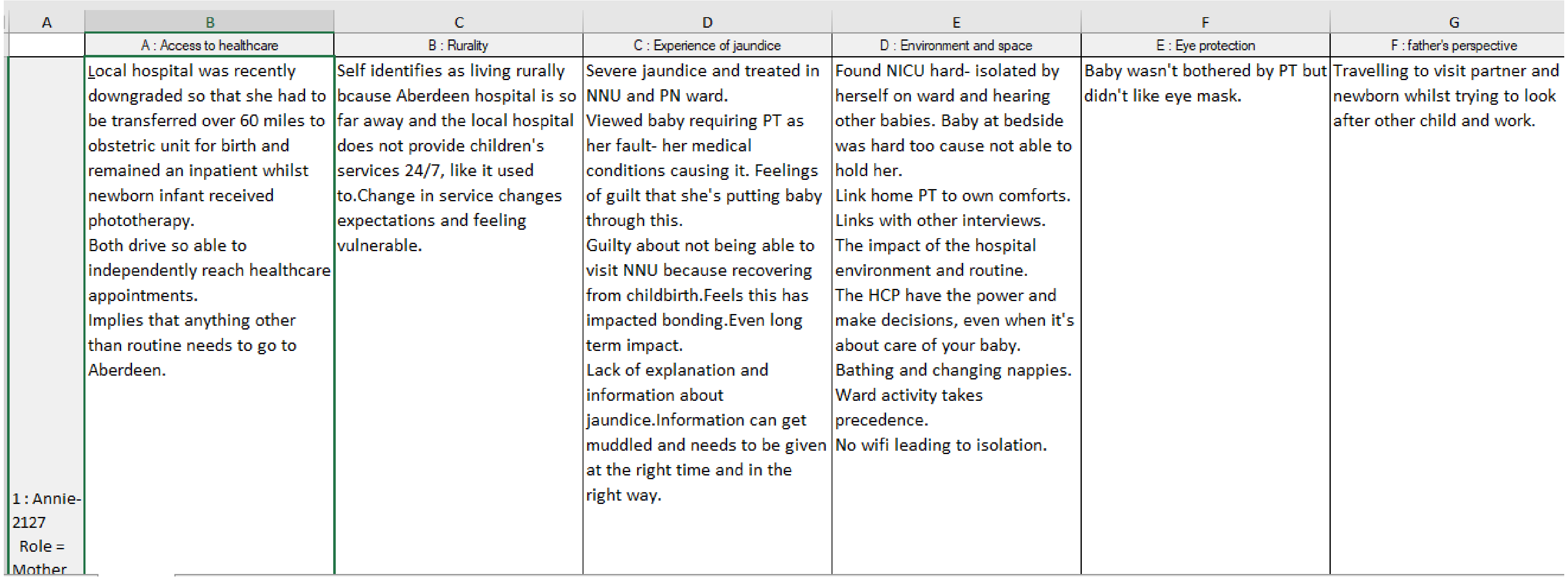
Lironi Jo
Eligibility for local HC services. Equity.

Lironi Jo
Referral pathway

Appendix 18. Example of initial analytical framework

Name	Description
Access to healthcare	Ways in which mothers/ parents access healthcare: GPs/ GDocs/ community hospitals/ car. Highlights whether people access healthcare independently or rely on other people. Links to rurality.
Rurality	Reason people identify as rural: need a car to reach a shop; no neighbours; no street lights; change in healthcare services leaves them feeling more vulnerable, isolated and distance to access certain services; one car family meaning they feel stranded at home with lack of activities in local area. This impacts access to healthcare. For HCP- people living further than 30minutes by car would impact ability to monitor jaundice at home. It's the monitoring of jaundice more than PT treatment that concerned them.
Experience of jaundice	Initially most of the data came under experience of jaundice so I looked for sub codes, leaving issues with information and explanations given for jaundice to this code. Information and explanations were impacted by ward activity. Mothers/ parents felt like a burden on staff. Staff did describe them as blocking beds. Family integrated care vs paternalism. Brings up informed choice and decision making. Shared care and working in partnership with women are strategies in midwifery care, that aren't necessarily seen in a practical sense.
Environment and space	Impact of the hospital environment on mother. This impacts maternal stress and mental health. Also, impact of the equipment on the space available in hospital. This impacts staff anxiety, logistics of sharing, storing and charging equipment.
Eye protection	Some mothers are more affected than others but they all mention a dislike for eye protection because it creates a barrier for them to connect with their newborn infant. Also, perceived as impacting newborn's comfort.

Appendix 19: Example of framework matrix

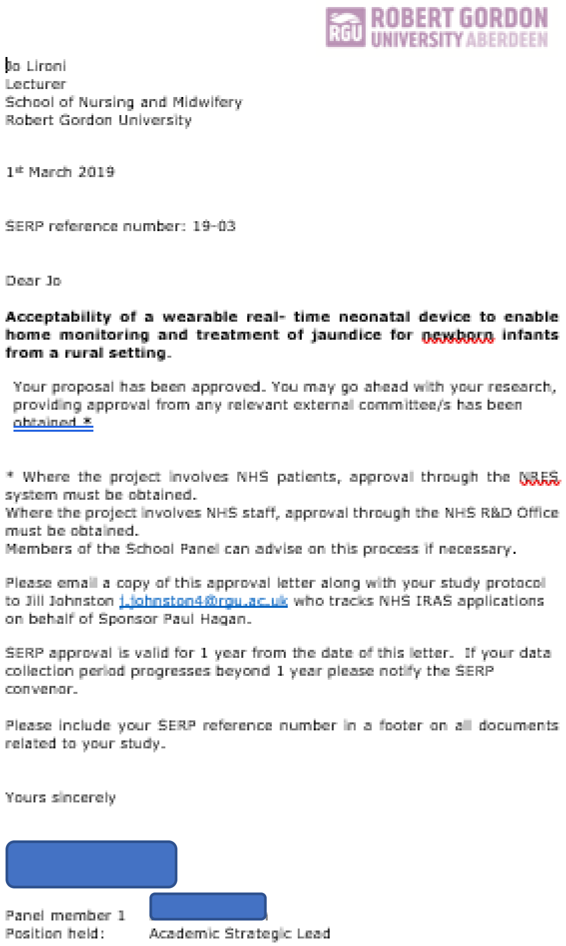


A	B	C	D	E	F	G
	A : Access to healthcare	B : Rurality	C : Experience of jaundice	D : Environment and space	E : Eye protection	F : father's perspective
1 : Annie-2127 Role = Mother	Local hospital was recently downgraded so that she had to be transferred over 60 miles to obstetric unit for birth and remained an inpatient whilst newborn infant received phototherapy. Both drive so able to independently reach healthcare appointments. Implies that anything other than routine needs to go to Aberdeen.	Self identifies as living rurally bcause Aberdeen hospital is so far away and the local hospital does not provide children's services 24/7, like it used to.Change in service changes expectations and feeling vulnerable.	Severe jaundice and treated in NNU and PN ward. Viewed baby requiring PT as her fault- her medical conditions causing it. Feelings of guilt that she's putting baby through this. Guilty about not being able to visit NNU because recovering from childbirth.Feels this has impacted bonding.Even long term impact. Lack of explanation and information about jaundice.Information can get muddled and needs to be given at the right time and in the right way.	Found NICU hard- isolated by herself on ward and hearing other babies. Baby at bedside was hard too cause not able to hold her. Link home PT to own comforts. Links with other interviews. The impact of the hospital environment and routine. The HCP have the power and make decisions, even when it's about care of your baby. Bathing and changing nappies. Ward activity takes precedence. No wifi leading to isolation.	Baby wasn't bothered by PT but didn't like eye mask.	Travelling to visit partner and newborn whilst trying to look after other child and work.

Appendix 20. Example of thematic chart

Data Extract	Initial codes	Sub theme	Main theme
"it was a while of that before someone said, why don't you put her on your chest and try her under the lights, again, another thing, had I known, she could've just been put on my chest straight away" (Bridgit, mother). *"There was no room at all, I had all these gifts round about me for [Bethany], I felt very claustrophobic…"* (Bridgit, mother). *"confined space"* (Bridgit, mother).	Environment and space Experience of jaundice Monitoring jaundice Instincts Psychological impact Support Infant feeding	*"It was like a prison. It was a prison for me."*	Current limitations to the PT experience
"when I got admitted, they didn't run through where anything was or anything so, I ended up like buzzing, saying I needed the bedding changed for her and they were like, no, that's not our job at all, you go and do it yourself, I was like, oh, I didn't know that..." (Fiona, mother).			
"…I felt like I was, always having to ask for things and, you know how pressured the staff are, and it's really difficult when you just want to be able to get on and do things and, you know, yeah, be independent..." (cat, mother). *"Aye, just the lack of space, the lack of privacy, erm, I think I felt a bit like a burden as well..".* (Cat, mother). *"I found it really difficult being in hospital and, you know, kind of feeling trapped there…obviously by the time you've got the these lights in with you and you're already stuck between two curtains and you always feel like people are encroaching on either side…"* (Cat, mother)			

Appendix 21: SERP approval letter



Jo Lironi
Lecturer
School of Nursing and Midwifery
Robert Gordon University

1st March 2019

SERP reference number: 19-03

Dear Jo

Acceptability of a wearable real- time neonatal device to enable home monitoring and treatment of jaundice for newborn infants from a rural setting.

Your proposal has been approved. You may go ahead with your research, providing approval from any relevant external committee/s has been obtained.*

* Where the project involves NHS patients, approval through the NRES system must be obtained.
Where the project involves NHS staff, approval through the NHS R&D Office must be obtained.
Members of the School Panel can advise on this process if necessary.

Please email a copy of this approval letter along with your study protocol to Jill Johnston j.johnston4@rgu.ac.uk who tracks NHS IRAS applications on behalf of Sponsor Paul Hagan.

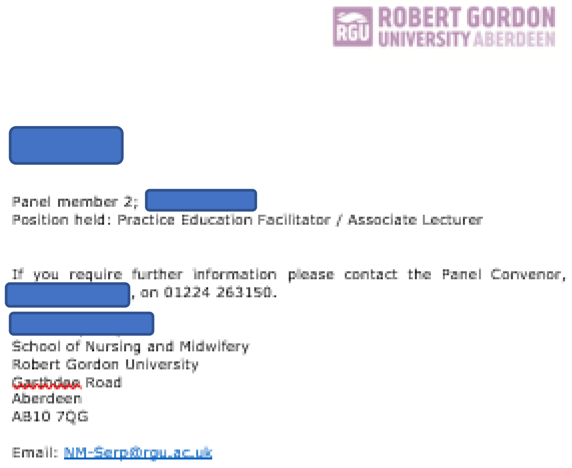
SERP approval is valid for 1 year from the date of this letter. If your data collection period progresses beyond 1 year please notify the SERP convenor.

Please include your SERP reference number in a footer on all documents related to your study.

Yours sincerely

[redacted]

Panel member 1 [redacted]
Position held: Academic Strategic Lead



[redacted]

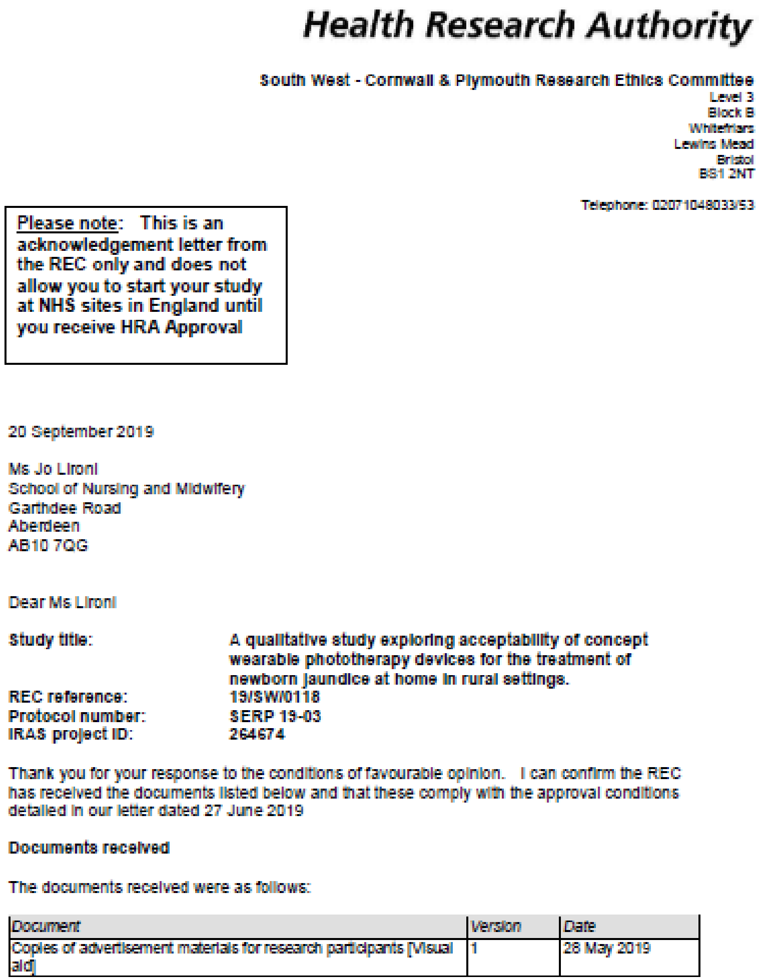
Panel member 2; [redacted]
Position held: Practice Education Facilitator / Associate Lecturer

If you require further information please contact the Panel Convenor, [redacted], on 01224 263150.

[redacted]
School of Nursing and Midwifery
Robert Gordon University
Garthdee Road
Aberdeen
AB10 7QG

Email: NM-Serp@rgu.ac.uk

Appendix 22: Research Ethics Committee approval



Health Research Authority

South West - Cornwall & Plymouth Research Ethics Committee
Level 3
Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048033/53

Please note: **This is an acknowledgement letter from the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

20 September 2019

Ms Jo Lironi
School of Nursing and Midwifery
Garthdee Road
Aberdeen
AB10 7QG

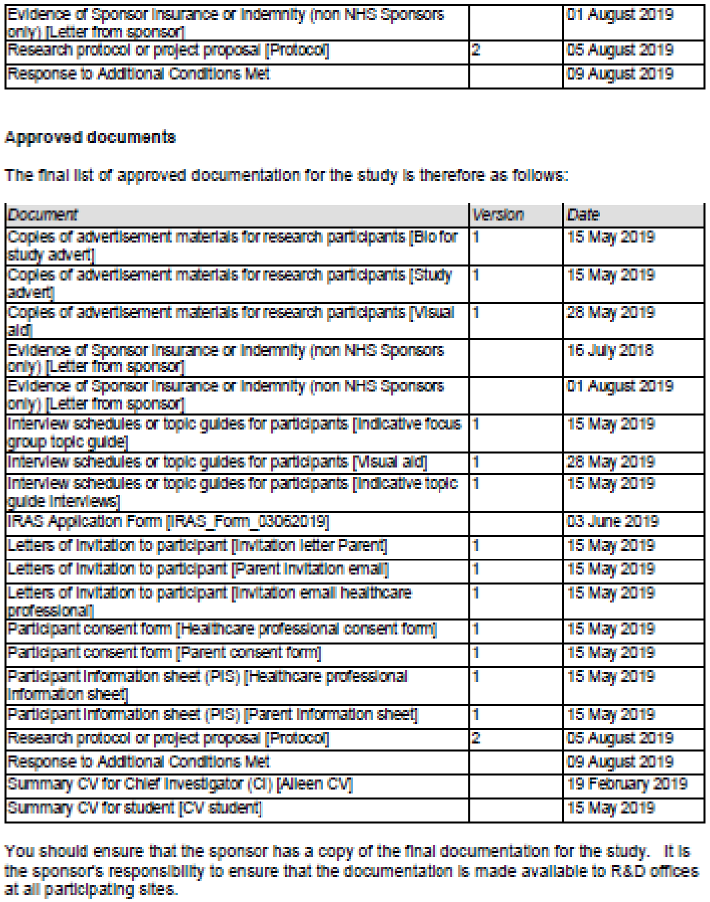
Dear Ms Lironi

Study title: **A qualitative study exploring acceptability of concept wearable phototherapy devices for the treatment of newborn jaundice at home in rural settings.**
REC reference: **19/SW/0118**
Protocol number: **SERP 19-03**
IRAS project ID: **264674**

Thank you for your response to the conditions of favourable opinion. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 27 June 2019

Documents received

The documents received were as follows:



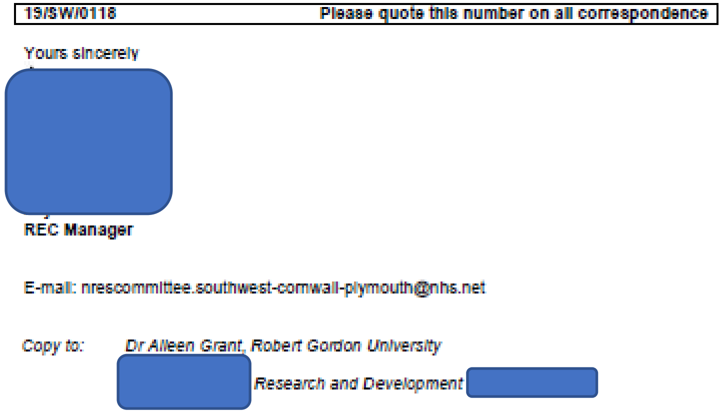
Document	*Version*	*Date*
Copies of advertisement materials for research participants [Visual aid]	1	28 May 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from sponsor]		01 August 2019
Research protocol or project proposal [Protocol]	2	05 August 2019
Response to Additional Conditions Met		09 August 2019

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
Copies of advertisement materials for research participants [Bio for study advert]	1	15 May 2019
Copies of advertisement materials for research participants [Study advert]	1	15 May 2019
Copies of advertisement materials for research participants [Visual aid]	1	28 May 2019
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from sponsor]		16 July 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Letter from sponsor]		01 August 2019
Interview schedules or topic guides for participants [Indicative focus group topic guide]	1	15 May 2019
Interview schedules or topic guides for participants [Visual aid]	1	28 May 2019
Interview schedules or topic guides for participants [Indicative topic guide interviews]	1	15 May 2019
IRAS Application Form [IRAS_Form_03062019]		03 June 2019
Letters of invitation to participant [Invitation letter Parent]	1	15 May 2019
Letters of invitation to participant [Parent invitation email]	1	15 May 2019
Letters of invitation to participant [Invitation email healthcare professional]	1	15 May 2019
Participant consent form [Healthcare professional consent form]	1	15 May 2019
Participant consent form [Parent consent form]	1	15 May 2019
Participant information sheet (PIS) [Healthcare professional information sheet]	1	15 May 2019
Participant information sheet (PIS) [Parent information sheet]	1	15 May 2019
Research protocol or project proposal [Protocol]	2	05 August 2019
Response to Additional Conditions Met		09 August 2019
Summary CV for Chief Investigator (CI) [Aileen CV]		19 February 2019
Summary CV for student [CV student]		15 May 2019

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.



19/SW/0118 **Please quote this number on all correspondence**

Yours sincerely

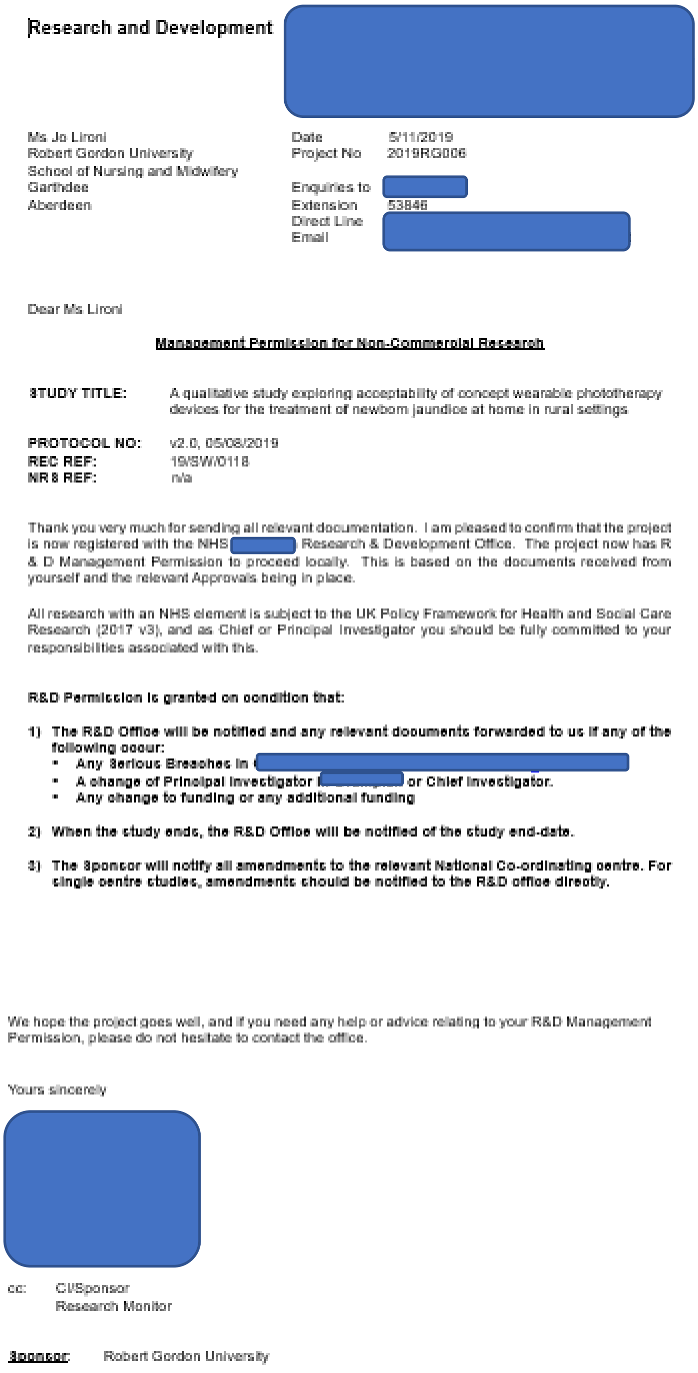
[redacted]

REC Manager

E-mail: nrescommittee.southwest-cornwall-plymouth@nhs.net

Copy to: *Dr Aileen Grant, Robert Gordon University*
[redacted] *Research and Development* [redacted]

Appendix 23: NHS Research and Development approval



Research and Development [redacted]

Ms Jo Lironi
Robert Gordon University
School of Nursing and Midwifery
Garthdee
Aberdeen

Date 5/11/2019
Project No 2019RG006

Enquiries to [redacted]
Extension 53846
Direct Line
Email [redacted]

Dear Ms Lironi

Management Permission for Non-Commercial Research

STUDY TITLE: A qualitative study exploring acceptability of concept wearable phototherapy devices for the treatment of newborn jaundice at home in rural settings

PROTOCOL NO: v2.0, 05/08/2019
REC REF: 19/SW/0118
NRS REF: n/a

Thank you very much for sending all relevant documentation. I am pleased to confirm that the project is now registered with the NHS [redacted] Research & Development Office. The project now has R & D Management Permission to proceed locally. This is based on the documents received from yourself and the relevant Approvals being in place.

All research with an NHS element is subject to the UK Policy Framework for Health and Social Care Research (2017 v3), and as Chief or Principal Investigator you should be fully committed to your responsibilities associated with this.

R&D Permission is granted on condition that:

1) The R&D Office will be notified and any relevant documents forwarded to us if any of the following occur:
  - **Any Serious Breaches in** [redacted]
  - **A change of Principal Investigator** [redacted] **or Chief Investigator.**
  - **Any change to funding or any additional funding**

2) When the study ends, the R&D Office will be notified of the study end-date.

3) The Sponsor will notify all amendments to the relevant National Co-ordinating centre. For single centre studies, amendments should be notified to the R&D office directly.

We hope the project goes well, and if you need any help or advice relating to your R&D Management Permission, please do not hesitate to contact the office.

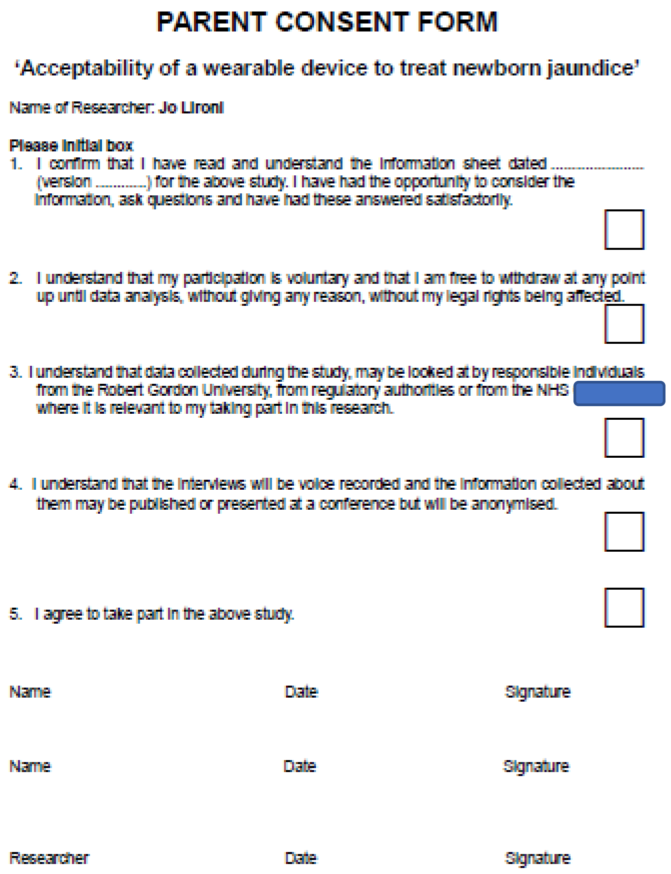
Yours sincerely

[redacted]

cc: CI/Sponsor
Research Monitor

Sponsor: Robert Gordon University

Appendix 24: Consent forms



PARENT CONSENT FORM

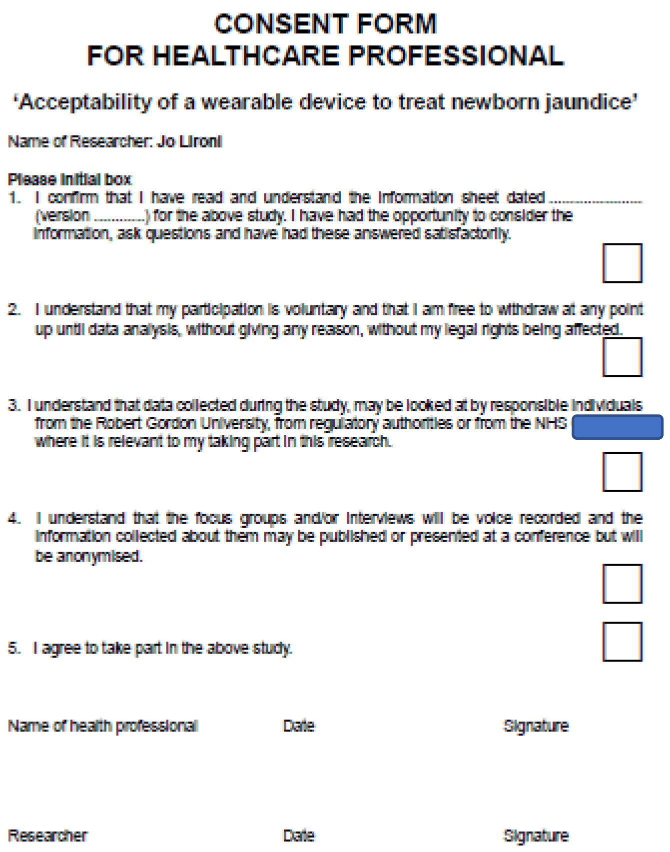
'Acceptability of a wearable device to treat newborn jaundice'

Name of Researcher: **Jo Lironi**

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any point up until data analysis, without giving any reason, without my legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by responsible individuals from the Robert Gordon University, from regulatory authorities or from the NHS [redacted] where it is relevant to my taking part in this research. ☐
4. I understand that the interviews will be voice recorded and the information collected about them may be published or presented at a conference but will be anonymised. ☐
5. I agree to take part in the above study. ☐

Name	Date	Signature
Name	Date	Signature
Researcher	Date	Signature



CONSENT FORM
FOR HEALTHCARE PROFESSIONAL

'Acceptability of a wearable device to treat newborn jaundice'

Name of Researcher: **Jo Lironi**

Please initial box

1. I confirm that I have read and understand the information sheet dated .... (version ....) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any point up until data analysis, without giving any reason, without my legal rights being affected. ☐
3. I understand that data collected during the study, may be looked at by responsible individuals from the Robert Gordon University, from regulatory authorities or from the NHS [redacted] where it is relevant to my taking part in this research. ☐
4. I understand that the focus groups and/or interviews will be voice recorded and the information collected about them may be published or presented at a conference but will be anonymised. ☐
5. I agree to take part in the above study. ☐

Name of health professional	Date	Signature
Researcher	Date	Signature