Helping parents 'keep in touch' with their babies in the neonatal unit: Evaluation of the *mylittleone* digital solution

Susan Kerr, Caroline King, Rhona Hogg, Kerri McPherson, Janet Hanley, Maggie Brierton and Sean Ainsworth

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DHI aims to create an open community where industry will collaborate and work together with academia, health, care and social partners effectively on innovation opportunities which will create social and economic benefits in Scotland.

The DHI draws together expertise across medicine, design, business and informatics to create innovative and transformational solutions to health and social care delivery through its Explore, Experience, Exploit approach. Through these activities the organisation builds capability and expertise in Digital Health and Care and embeds innovations and new ways of working through an engaged and integrated approach to ensure sustainable innovation and provide economic stimulation and growth.

DHI was involved in the *mylittleone* project by providing professional services and support, funding and facilitating collaboration among the project collaborators (i.e. the DHI, Integrated Care 24, NHS Fife, Glasgow Caledonian University).

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Integrated Care 24

Integrated Care 24 (IC24) is a 'not for profit' social enterprise, providing high quality care to over 6 million patients. IC24 was approached by the DHI in March 2014 who asked if the organisation would be interested in being part of this exciting innovation. Following consultation with staff in NHS Fife, the IC24 Development Team, led by David Brown, Director of Information Communication & Technology, developed *mylittleone*, which was successfully implemented following a very tight 20-week design period, in November 2014 (first pilot phase). Training for the health professionals working in the neonatal unit was provided by IC24 and continuous IT support has subsequently been provided, as required. IC24 considers it a privilege to have been able to provide the concept and technology which has enabled mothers to have contact with their baby/babies via the real time streamed images when they are physically separated from them.

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NHS Fife

NHS Fife is one of the fourteen regional health boards in NHS Scotland. The Health Board provides a wide range of services to patients across the region including neonatal services. The provision of person-centred care is a core objective.

The *mylittleone* digital solution was implemented and evaluated in a level 3 unit in NHS Fife which provides neonatal intensive care.

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Glasgow Caledonian University

Glasgow Caledonian University's (GCU) commitment to the Common Good is realised in its applied research which addresses three major societal challenges, enabling communities in the UK and internationally to build Inclusive Societies and live Healthy Lives in Sustainable Environments.

The Parenting and Family Support Research Group, in the University's Institute for Applied Health Research, has a particular focus on intervention research and supporting the transfer of evidence-based parenting and family support interventions into practice. The group's primary aim is to prevent social, emotional, behavioural and health problems in children and young people by enhancing the skills, knowledge and confidence of parents and by addressing family risk factors known to contribute to adverse outcomes.

GCU was commissioned, by the Digital Health & Care Institute, to undertake an independent evaluation of the *mylittleone* digital solution. The evaluation ran over a 20-month period, terminating in December 2015. Findings from the evaluation are presented in this Final Report.

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1. Acknowledgments

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Finally, and most importantly, we would like to thank the study participants; the mums, dads and professionals who shared their views and experiences.

2   Report summary

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Setting the scene

One in every eight infants requires some form of care in a neonatal unit. While the survival and long-term prospects of infants are enhanced by admission, the enforced separation of the mother and baby may have psychological consequences for both. In this report we present findings from an evaluation of a new digital solution designed to help parents 'keep in touch' with their infants when they are physically separated from them. Currently deployed in a neonatal unit in NHS Fife, the intervention, *mylittleone*, involves cameras being placed over incubators which transmit real-time images of each baby wirelessly to a coupled tablet device kept by the mother in the post-natal care environment. The study sought to explore parents' and professionals' views of the technology and make recommendations for its future development, deployment and evaluation.

What did we do?

In Phase 1 interviews were conducted with 33 parents and 21 professionals. In Phase 2 a systematic review of the literature was undertaken to identify valid and reliable questionnaires for potential use in a future trial to assess the clinical effectiveness of the technology. In Phase 3 parents were consulted on the acceptability of the questionnaires identified in Phase 2.

What did we find?

Phase 1: The majority of the parents and professionals believed *mylittleone* was an important advancement in the provision of neonatal care. Narratives focused on enhanced feelings of closeness and responsiveness towards the baby, physical and emotional well-being and inclusion of the wider family and friends. In contrast, while acknowledging some benefits in its use, a small number of parents believed *mylittlone* had increased their anxiety levels and so their preference was not to use it. Staff working in the neonatal unit discussed the occasional impact of the technology on their workload and care priorities.

Phase 2: Following the screening process, 34 papers met the criteria for inclusion in the review. Assessment of the methodological quality of the papers, and the measurement properties and feasibility and acceptability of the questionnaires, resulted eight being taken forward to Phase 3.

Phase 3: Consultation with parents resulted in the selection of four questionnaires for use in a future trial: the Mother-to-Infant Bonding Scale; the Perceived Stress Scale; the Edinburgh Postnatal Depression Scale; and, the Warwick-Edinburgh Mental Well-being Scale.

Recommendations

The current qualitative evaluation provides sufficient support to recommend use of *mylittleone* in other neonatal units in Scotland and to consider extending its use to the home environment. A key issue is that mothers of babies receiving care in a neonatal unit may be discharged weeks or months in advance of their baby and, while they will visit their baby regularly, long periods of separation are inevitable.

The effectiveness of *mylittleone* in encouraging bonding and in addressing various indicators of post-natal adjustment (e.g. stress, wellbeing) should now be assessed in a clinical trial.

3 Background – setting the scene
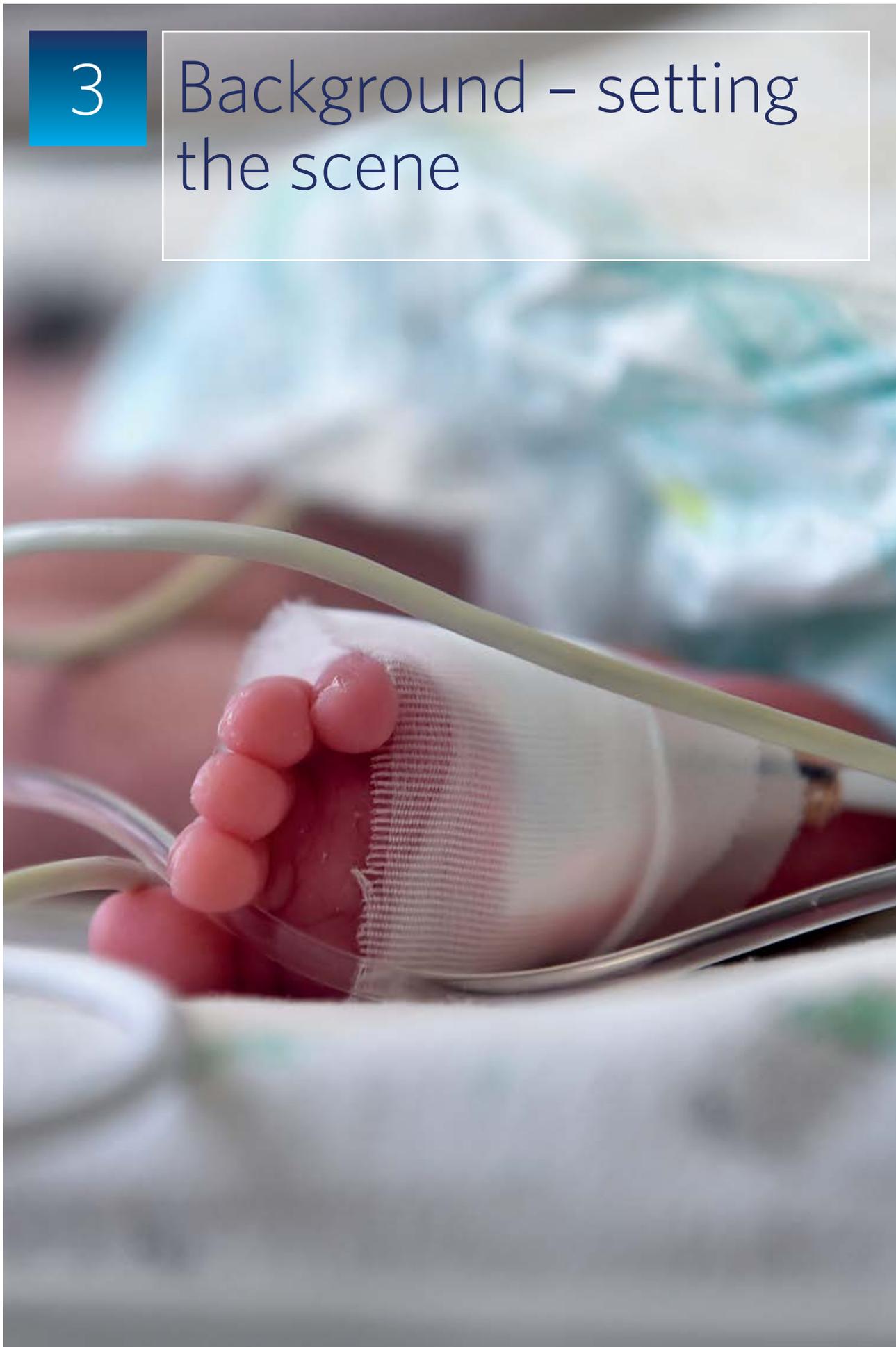
There are approximately 57,000 babies born in Scotland every year (NROS, 2015). Most pregnancies result in the birth of a healthy baby (or healthy babies); however, complications during pregnancy, childbirth or in the postnatal period may mean that the baby has additional healthcare needs. These babies are admitted to neonatal units (sometimes called Special Care Baby Units) (BAPM, 2010). One in every eight infants requires admission to a neonatal unit, with the most common reasons being low birth weight in full-term babies and premature births (RCPCH, 2015). The proportion of babies admitted as a result of premature birth has increased in Scotland in recent years, with one in every five admitted babies born more than six weeks early (ISD, 2015). There is a direct relationship between how premature a baby is and the length of time they will spend in a neonatal unit; babies born more than 15 weeks early are likely to be admitted for 100 days or longer (Manktelow et al., 2010).

The survival and long-term prospects of high-risk infants are enhanced by admission to a neonatal unit; however, the enforced separation of the mother and baby can have psychological consequences for both (Obeidat et al, 2009). Reduced opportunities for early bonding may lead to decreased levels of maternal responsiveness and sensitivity (Aagaard & Hall, 2008; Flacking et al., 2012). Also, concern for the immediate and long-term health and development of the baby has been shown to result in higher levels of stress, anxiety and depression in mothers, all of which may persist after the baby has been discharged (Borghini et al., 2006; Flacking et al., 2012). Importantly, the psychological well-being of mothers is known to influence early parent-child interactions and can impact the social, emotional and behavioural development of children in the short and longer term (Flacking et al., 2012).

A range of interventions designed to promote physical and emotional closeness between parents and their babies has been developed for use in neonatal units. These interventions include: kangaroo care, which facilitates skin to skin contact; infant massage, designed to promote parent-child interaction; and, diaries written by staff on behalf of babies, which parents can access online (Feldman et al. 2002; Ferber et al. 2005; Freer et al. 2005). However, while these interventions have been shown to be useful, further research is required to develop and evaluate interventions to help parents 'keep in touch' with their infants in circumstances where they are physically separated from them (Flacking et al., 2012). In this report findings are presented from an evaluation of a new digital solution designed to address this need.

A collaboration was facilitated by the Digital Health & Care Institute among Integrated Care 24, NHS Fife and Glasgow Caledonian University to develop and evaluate the digital solution. The solution, named *mylittleone*, involves Internet Protocol (IP) cameras being placed over incubators in the neonatal care unit which wirelessly transmit real-time footage of each baby to coupled tablet devices at the mother's bedside when they are in the post-natal care environment. While currently confined to the hospital setting, it is anticipated that, in the future, it will be possible to transmit the video footage to family homes when, for example, mothers have been discharged and their babies remain in hospital. The development of *mylittleone* aligns with recommendations in the Quality Framework for Neonatal Care in Scotland, where the development of e-health/digital solutions to enhance care delivery is encouraged (Scottish Government, 2013).

The aim of this study was to explore the use of the *mylittleone* technology and make recommendations for its future development and use in neonatal units. In addition, information was gathered to inform the design of a future trial to assess the effectiveness of the technology in promoting outcomes such as bonding and wellbeing and reducing levels of stress, anxiety and depression in mothers.

To address the study aims, we sought to do the following:

a) Explore parents' and professionals' views and experiences of the *mylittleone* technology

b) Identify factors that appeared to have influenced the views and experiences of the parents and professionals

c) Identify appropriate outcome measures/instruments to evaluate the effectiveness of the *mylittleone* technology in a future research trial

d) Seek parents' views on the acceptability of the outcome measures/instruments identified

The section that follows discusses the methods used to address the above study objectives.

4 Methods - what did we do?

The study was undertaken in three phases; each is discussed below.

Phase 1 – exploring parents' and professionals' views of the *mylittleone* technology

Using a qualitative approach, the first phase of the study sought to address Objectives a) and b) (see p11).

Participants were recruited from the only neonatal unit in the UK currently using the *mylittleone* technology, which is in NHS Fife in Scotland. When recruiting parents, we sought to ensure diversity in terms of age, family size, socio-economic status, the medical condition of the baby and the length of stay/ anticipated length of stay in the neonatal unit. This was done to ensure the views expressed were from a range of parents likely to be similar to those who might use the technology in the future. Our aim was to recruit 30 parents, including a small number of fathers. When recruiting the professionals we sought to recruit members of the multi-disciplinary team who care for babies and their parents in neonatal and post-natal care settings (e.g. neonatal nurses, midwives, doctors) and also professionals responsible for the deployment of the technology (i.e. IT/e-health professionals). We anticipated that the different roles may have influenced the professionals' experiences and subsequent views of the *mylittleone* technology. Our aim was to recruit 20-24 professionals.

The parents took part in individual or paired semi-structured interviews. Paired interviews were undertaken when both the mother and father had been recruited. The professionals participated in individual, paired or small group semi-structured interviews, depending on their availability and preference. Interview guides were used to facilitate the interview process and to ensure similar issues were addressed across the participant groups (see Appendix 1 and 2).

The audio-recorded interviews were transcribed verbatim and checked for accuracy. Names and any identifying features were removed prior to the analysis. The data were analysed thematically using the process described by Braun & Clarke (2006). The step-by-step process involved coding, building categories and the generation of themes. When presenting the findings we have integrated the accounts from the parents and professionals, where appropriate. Similarities and differences in the views and experiences of the participant groups are highlighted. The analysis was undertaken by the project researcher, Dr Caroline King, with input from members of the research team with qualitative expertise, to ensure rigour in the process.

Phase 2 – identifying instruments to evaluate the effectiveness of *mylittleone* in a future trial

The second phase of the study was undertaken to address Objective c) (see p11). A systematic review of the literature was undertaken to identify instruments used to assess parameters identified in Phase 1 as important outcomes to be measured in a future research trial. These outcomes included maternal bonding and a range of psychological indicators of post-natal adjustment (i.e. well-being, stress, anxiety, depression). Work was undertaken to evaluate the reliability and validity of the instruments identified and to assess the feasibility and acceptability of using them in a future study (i.e. considering their ease of administration and completion).

Peer-reviewed literature was identified through searches of the academic databases Medline, CINAHL, PsycINFO and the Cochrane Database of Systematic Reviews. An additional search was

undertaken in Google Scholar. Papers published in English were sought, with no publication date limits being set. An example search can be found in Appendix 3.

The titles and abstracts of papers identified were screened for relevance by two reviewers using predetermined inclusion/exclusion criteria. In instances where it was not clear if a paper should be included, a full-text copy of the paper was screened. Data were extracted from the included papers using a review-specific data extraction tool. The methodological quality of the studies and information on the measurement properties of the instruments (i.e. reliability and validity) were assessed using the COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) (Terwee et al., 2007; 2012). One reviewer undertook data extraction and quality appraisal with oversight by a second reviewer. Based on the quality appraisal, the reliability and validity of the instruments and the reviewers' views on feasibility and acceptability, instruments were taken forward to the next phase of the study in which parents' opinions were sought.

Phase 3 – seeking parents' views on the acceptability of the instruments

The third and final phase of the study was undertaken to address Objective d) (see p11). Parents with children under the age of 12 months, who had experience of the neonatal care environment, were asked in individual face-to-face discussions, to share their views on the instruments identified in Phase 2. The parents were recruited through BLISS Scotland, a voluntary organisation which supports families with sick or premature babies. Two parents assisted with this phase of the study.

Guided by the literature on assessing the acceptability of instruments (Fitzpatrick et al., 1998; Tourangeau & Yan, 2007; Galesic & Bosnjak, 2009), the parents were asked to comment on the following: the length of the instruments; how easy it was to read and understand the content, including the completion instructions; and, the potential sensitivity of the questions asked. On completion of this initial task, the parents were asked to state which instruments they felt would be most appropriate to take forward to a future research trial to assess the effectiveness of the *mylittleone* technology.

Written notes were taken during the discussions with the parents, including their ranking of the instruments. These notes were then transcribed, summarised and synthesised.

Research Governance

Contact with the East of Scotland Ethics Committee (Ref: CYA/AG/13/GA/127) confirmed that the study was considered to be a service evaluation and did not require NHS ethics approval. Ethics approval was therefore sought and granted from the School of Health & Life Sciences Ethics Committee at Glasgow Caledonian University. In Phases 1 and 3, potential participants were provided with a study Information Sheet and those who wished to participate signed a Consent Form prior to the interviews/discussions being conducted.

The sections that follow will outline the findings from the three phases of the study. Findings from Phase 1 are presented in Section 5, with findings Phases 2 and 3 being presented in Section 6.

5 The views and experiences of the parents and professionals – what did we find?

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The findings presented in this section of the report are derived from the thematic analysis of the interviews with the parents and professionals in Phase 1 of the evaluation (i.e. the qualitative element of the evaluation). A total of 33 parents (25 mothers and 8 fathers) and 21 professionals shared their views and experience of the mylittleone technology. Information on the families who participated can be found in Table 1. As noted, 14 of the babies were born before 35 weeks gestation. Those who were born at 35+ weeks were most commonly admitted to the neonatal unit because they were jaundiced, they had an infection, breathing difficulties, their blood sugar was low and/or because they were of low birth weight. The professionals who participated were neonatal nurses, midwives, nursery nurses, doctors and staff working in the IT department who had responsibility for the deployment of mylittleone. Further information on the professionals can be found in Table 2.

Table 1: Parent participants and their babies

Mother's age / RANGE: 18–44 YEARS	Frequency
19 years and younger	1
20–29 years	13
30–39 years	10
40 years and older	1
Father's age / RANGE: 19–39 YEARS	
19 years and younger	1
20–29 years	5
30–39 years	2
Marital Status	
Married/living with partner	22
Single	3
Baby's gestation at birth in completed weeks / RANGE: 26 WEEKS–41 WEEKS	
Less than 30 weeks	3
30–34 weeks	11
35–39 weeks	3
40+ weeks	8
Baby's sex	
Female	16
Male (includes 1 set of twins)	10
Other children	
Yes	14
No	11
Scottish Index of Multiple Deprivation (SIMD)*	
1–2	10
3	9
4–5	6

* Scottish Government (2012) Participants' postcodes were used to calculate scores. Areas scoring 1 are the most deprived; areas scoring 5 are the least deprived.

Table 2: Professionals who participated

Place of work	Frequency
Neonatal Unit	10
Postnatal Ward	8
IT	3
Professional Background	
Neonatal Nursing	8
Midwifery	3
Nursery Nursing	5
Medical	2
IT/e-health	3
Gender	
Female	19
Male	2

Following a description of the context in which the *mylittleone* technology had been used, the findings are presented as follows: the benefits of *mylittleone*; the potential downsides of *mylittleone*; prioritising care; using *mylittleone* at home; and, implementation issues.

The interviews in context

Many of the mothers who were interviewed reported that they had experienced health problems in their pregnancy and some described a stressful birth experience. A small number of mothers were aware before the birth of their child that s/he may be admitted to the neonatal care unit; however, for most their baby's admission to the neonatal unit was an unexpected scenario. For some mothers, particularly those who had given birth to a baby who was extremely premature, there was concern about the health of the child and their subsequent development. Several parents had previous experience of a child/children being admitted to a neonatal care unit, most commonly because they had been born prematurely. This contextual information is important as it is likely to have impacted the parents' views and experiences. Also, there is strong evidence of an association between 'parenting' in the neonatal environment and increased levels of stress, anxiety and depression (e.g. Obeidat et al., 2009).

When considering the findings from the interviews with the professionals, *mylittleone* had been in use for more than four months when they shared their views and experiences of the technology. Eight *mylittleone* camera/tablets were available and could be used at one time. Some of the professionals had had experience of using BabySam, a precursor to *mylittleone*, which had been 'tested' in the neonatal unit for a number of months before the deployment of *mylittleone*. Levels of care provided in the neonatal unit include intensive, high dependency and special care (BAPM, 2010). In 2015, on average, 36 babies were admitted to the neonatal unit every month (Ainsworth, 2016a). The time that babies spent in the neonatal care unit varied from one day to 116 days (Ainsworth, 2016b). Most mothers are cared for in the post-natal care environment; a minority may require intensive or high dependency care. The length of time that mothers spend in hospital is generally associated with the method of delivery and any associated complications/ health problems. On average, mothers with babies admitted to neonatal care spend 4-5 days in

hospital prior to their discharge home; they can request to stay longer but pressure on bed-space means that they are unlikely to be able to stay much longer (Ainsworth, 2016b).

The benefits of *mylittleone*

The majority of the participants believed the development and deployment of *mylittleone* was an important advancement in the provision of neonatal care. The manner in which the technology had enhanced the parents' experience was a central theme in the accounts of both the parents and professionals, with their narratives focusing on: closeness and responsiveness; emotional well-being; physical recovery; and, family and friends. Each of these themes is discussed in the text that follows.

Closeness and responsiveness – helping mums to be mums

Mothers in the post-natal care environment most commonly have their babies with them immediately following the birth and throughout their hospital stay. However, when a baby is admitted to a neonatal care unit, periods of separation result and, depending on the mother's physical health, these periods can be lengthy. The impact of mother-and-child separation was discussed at length in the interviews and, as exemplified in the following quotes, *mylittleone* was reported as helping mothers to feel 'closer' to their babies:

> **[Mother 1; baby 6 weeks premature]** Oh, it was brilliant, absolutely brilliant … I was so tired, that I couldn't sit for longer than half an hour [in neonatal care] … I didn't feel well, I was sick and I was dizzy, so when I got up the stairs [to post-natal ward], I put [*mylittleone*] right next to the bed, and even though I fell asleep pretty quick, it was like … it was like she was near me, because I could see her. Instead of being completely cut off from her, she was still there.
>
> **[Mother 16; baby 5 weeks premature]** It was really good to see when she was awake and alert … and then watching her sleep it was, like, kind of, we weren't apart.

In addition to the increased feeling of proximity, there was a belief that *mylittleone* helped the mothers to be more responsive to their baby's needs and this included responding physically through the production of breast milk. As indicated below, parents who had had previous experience of the neonatal environment were able to make useful comparisons.

> **[Mother 2; baby 8+ weeks premature]** It's so different this time. With my little boy [who was also admitted to a neonatal unit] I couldn't see him straightaway … whereas this time having the *mylittleone* camera … I can see her constantly, she's right beside my bed, really. [Also], I've found with things like expressing milk, I've found that a lot easier.
>
> **[Mother 10; baby 9 weeks premature]** I was using [*mylittleone*] all the time because … I was trying to establish a milk supply and I found it quite useful to watch her when I was trying to express to, sort of, get the hormones [going].
>
> **[Professional 5, post-natal ward]** I think it's excellent … it's like [the mothers] are really close to their babies … A lot of the mums…when the baby's upset will go down the nursery. You know, they'll say, the baby's really upset I'm away down to see if it's needing fed or what's wrong with it. So, they'll toddle away down and see.

The feelings of 'closeness' and 'responsiveness' that *mylittleone* engendered appeared to be important in helping to facilitate the early bonding process between the mothers and their babies.

Emotional well-being – keeping mums [and dads] on an even keel

For many mothers, a key benefit of *mylittleone* was the reassurance connected with being able to see their baby was 'okay', that is, there had been no worsening of their condition. The comfort associated with seeing their baby was palpable in the mothers' descriptions, even when their child had not been particularly unwell.

> **[Mother 25; baby 8+ weeks premature]** You just sort of turned your head, and you knew that she was there. And it's quite comforting to see that, erm, you know she's okay, kind of thing.
>
> **[Mother 1; baby 6 weeks premature]** I'm not just saying this, but if I didn't have the camera … I think I would have cracked up, because it's been…I've been waking up during the night and kind of looking and being able to see that she was there and that she was sleeping, and I would be able to fall back asleep again.
>
> **[Mother 13; baby full-term]** We were lucky, [baby's name] … was just having antibiotics for a wee infection …. For us [*mylittleone*] was just a little bonus … there were a few nights it put my mind at rest just seeing her sleeping so you could go to bed knowing that she's okay and she's happy and everything.

Many of the mothers recounted their emotions when using *mylittleone*, initially, and also how the technology had enabled them to keep more stable emotionally during their stay in hospital:

> **[Mother 2; baby 8+ weeks premature]** I was amazed, I couldn't stop crying. As soon as the doctor [gave me the tablet] … I couldn't speak, I just kept crying [I was so happy] … it was amazing just to see this tiny little baby that you knew was yours, but there she was.
>
> **[Mother 21; baby full-term]** [*mylittleone*] helped me emotionally to keep that bit calmer and that wee bit stronger for her.

Discussions of emotions extended to the low emotional state, commonly referred to as the 'baby blues', that mothers may experience a few days after the birth of their baby.

> **[Mother 16, baby 5 weeks premature, also low birth weight]** Everyone was kind of saying I would have a 'baby blue day' and I think I didn't get that because I knew she was okay and I was able to see her. So that didn't hit me at all. So I was waiting on that and I think that having that and watching her probably helped quite a bit, I didn't ever have down days.

When summing up, this mother said: *I don't quite know what I would've done without it [mylittleone].*

Also, for some mothers, seeing their baby on the tablet device allowed them to prepare themselves emotionally for visiting the neonatal unit for the first time.

> **[Mother 23; baby 10+ weeks premature]** He was born at 11 minutes past four and my boy-friend went to see him about five and then brought [*mylittleone*] straight down, and I got to come up at about 11 to see him, so it was really good because I got to prepare myself by looking on the screen of what I was coming up to see, like the tubes and stuff, so it was quite nice.

The continuous ability to monitor their baby's progress was reported by some as giving them 'hope' in terms of the immediate and longer-term health and development of their child. The baby referred to in the illustrative quote below had had a serious respiratory problem at birth which had required intensive and prolonged medical interventions.

> **[Father 21; baby full-term]** Just little things isn't it [to mother]?
>
> **[Mother 21]** Yes.
>
> **[Father 21]** Because where we are it's little steps, really little steps at a time, just like her hand moving and she's trying to grab things and you can see.
>
> **[Mother 21]** Or she's trying to touch her face or things like that … It's just these things that's giving us that wee bit of hope.

Finally, staff in the neonatal care unit stressed the almost 'gift like' quality of *mylittleone*, something which again appeared to enhance the emotional well-being of the parents.

> **[Professional 8; neonatal unit]** You get such a great reaction the minute the baby's stable, and… Most of the time it's the dad you give the [tablet] to … and you would give him the [tablet] and say, you can take that round [to your partner], but anytime it's not been dad and I've had to take the [tablet] round, the mum's just so happy – you know, she knows she wasn't going to see her baby for [maybe] another 12 hours and you have appeared and said, here she is here and you can watch her.

From what was described, the positive impact on the parents' emotional well-being appeared to be an important outcome associated with their use of *mylittleone*.

Physical recovery – helping mums to take care of themselves

Another benefit related to the scope *mylittleone* provided in assisting the physical recovery of the mothers following the birth of their baby. The main issues discussed were sleep, rest, nourishment and the reduction of pain/discomfort. Addressing their own needs was something that allowed the mothers to better care for their babies.

> **[Mother 25; baby 8+ weeks premature]** But of course, after having a C-section, and being on a lot of medication, that…I was in a wheelchair, and I had my lovely catheter bag, and everything … I managed to sit with her for five minutes, but it's more comfortable sitting in your own room … You're very sore, and things. So it's nicer to see her, where you can be comfortable as well, and not just having to sit [in the neonatal unit] with other parents, and sort of, in your wheelchair, looking glorious!

Mothers who had had a baby in neonatal care previously were able to compare their experiences.

> **[Mother 4; baby 5+ weeks premature]** With my son, I was very stressed. I didn't eat much. I'm just comparing this time to the last time. … I wasn't eating, I wasn't drinking, but this time round because I can see her and I know how she's getting on… I'm doing better. I'm feeling a lot better. … Not feeling as apprehensive this time round.
>
> **[Mother 24; baby 13+ weeks premature]** This time [with *mylittleone*] it felt much better, like going back up to the ward, you know like you weren't so…I wasn't so reluctant to leave her … So, if you had to go for painkillers or…lunch or food or anything like that it was easier to do that than you would have found it previously.

The professionals also emphasised the importance of *mylittleone* in assisting the mothers' recovery, and similar to the mothers above, commenting on the situation prior to the technology being available.

> **[Professional 5, post-natal ward]** Before [*mylittleone*], they would go down to the unit and they would sit there for hours and hours and they would have to really pull themselves away to come back, but now they're coming back and having a rest in the afternoon or coming back for lunch. Before, we used to have to really chase ladies to say, you need to come back for your lunch, you know? But now, because they've got the [tablet], they're quite happy to come back because their baby is almost in the room with them, really. And they'll lie down and close their eyes for a bit, rather than thinking, I wonder what's happening? … They can see on the monitor that their baby's settled, it's sleeping so they tend to have a bit of rest which is really beneficial for them as well. So, that's helping.

Use of *mylittleone*, therefore, appeared to have played an important role in allowing mothers to concentrate on their own physical health following the birth of their baby. In some instances mothers were recovering from major surgery, as they had had a caesarean section.

Family and friends – sharing 'real-time' pics. of the baby

In addition to what has been discussed above, which has largely focused on the benefits to the mothers, the parents also raised the issue of partners, siblings and grandparents being able to see the baby using the *mylittleone* technology when visiting the mother. Restrictions on visiting meant that young children, members of the extended family, such as grandparents, and/or friends of the family, were not permitted entry to the neonatal care unit to see the baby.

> **[Mother 4; baby 5+ weeks premature]** [My partner] loves [*mylittleone*] … just being able to see her all the time … and my mum and dad, they were up visiting yesterday and they thought it was a fantastic idea as well … because she's in neonatal and they can't [go in] and they can't touch her or anything like that but it meant they didn't have to wait to see her sort of thing.
>
> **[Mother 5; baby full-term]** It was quite handy when the kids came to visit … they were able to see her on [the tablet].

The use of the *mylittleone* technology was, therefore, of benefit in allowing members of the wider family and friends to 'see' the new baby as soon as possible following their birth.

In sum, parents and professionals talked about *mylittleone* as a very positive development in the neonatal care environment. The issues discussed related to the early bonding experience, physical and emotional well-being and 'inclusion' of the wider family and friends in the days following the birth of the baby.

The potential downsides of *mylittleone*

Importantly, while most parents believed that *mylittleone* was a positive development, for a minority, its use had not enhanced their experience of parenting in a neonatal care environment. While they could see some benefits in its use, a few parents had decided not to use it for the duration of their hospital stay and/or would not use it again if they found themselves in a similar circumstance. A central theme was that the ability to see the baby whenever they wanted appeared to increase rather than decrease levels of stress and anxiety in some parents, with the narratives focusing on: dealing with dilemmas; wondering what is happening; anxious mums; and, switching the camera off and on.

Dealing with dilemmas

The following account demonstrates some of the tensions associated with seeking to be responsive to a baby's needs, particularly when these needs were highlighted by use of the *mylittleone* technology and might otherwise have gone unnoticed.

> **[Mother 17; baby born at full-term]** I remember at one point that I got quite upset and the reason was it was night time and I'd just been down to breastfeed him, and ....and by the time I got back up the stairs he was crying, I could see that he was crying on the screen and it really upset me … and … the staff member that was on that night, she … sort of kept putting his dummy back in and, you know, and sort of trying to shoogle the cot as it were, but you … could tell he wasn't settling. … And it just, yeah, it really upset me because I was kind of in two minds whereas it was like can I go back down again, can I not, you know, even though they've said that I can come and go whenever I please because I'm in the hospital, then, you know, would it be a case that, you know, would she not think, "Oh you've just been here why are you here again?", you know, so you were in that awkward sort of stage of will I or won't I type of thing … what I had to do was literally just put the tablet down so that I couldn't see it and go to sleep.
>
> **[Interviewer]** And did you feel you could have turned the tablet off?
>
> **[Mother 17]** Yeah but again it was almost like the sort of curiosity killed the cat, so it was like I don't want to turn it off but I just don't want to see it just now … And … you would almost feel like you were … like sort of not being a mother if you turned it off. You know it was almost like you don't care enough … would be the sort of psychological thing of, you know, if I turn this off then that means that I'm, you know, giving up on, not giving up on him but, you know.

The issue of not feeling it was 'appropriate' to turn off the tablet device was discussed by a small number of the mothers.

Wondering what is happening

Other concerns raised by participants, both professionals and parents, linked to the parents' ability to interpret what they we seeing on the tablet device.

> **[Father 9; baby 6 weeks premature]** It's a double edged sword [using *mylittleone*], I would say.
>
> **[Mother 9]** Yeah.
>
> **[Father 9]** You can see what's happening but you don't know what's happening. ... So every time they're doing something [to the baby], it might be routine, it either gets switched off or you see a pair of hands coming in [to the incubator/cot] with the gloves and then it gets switched off and you think, is it just something routine, is it not? And then you'd wait for maybe ten, fifteen minutes and it would come back on ... and then you might see five minutes later something else happening again. As I say, you're never quite sure...
>
> **[Mother 9]** Mm, because you were never updated as to what was happening; like nobody sort of then updated you saying, you would have seen us going in, this is what we were doing ... So eventually we did give it back [after 24 hours] and say, we don't want it anymore.
>
> **[Father 9]** It wasn't for us, no; it wasn't for us.

In addition to the above, one mother reported that technical issues with the picture she was viewing had caused her some concern.

> **[Mother 6, baby 7 weeks premature]** I woke up one morning and the picture was kind of freezing ... so my wee girl it was like she was taking a seizure. That's what it looked like. The nurse came in and she said we'll phone down and see if everything's okay. Everything was fine ... [but] I found it scary seeing that and I've never really watched it since.

The uncertainty described in the examples above had clearly raised anxiety levels.

Making anxious mums more anxious

The following quotes from professionals confirm the view that *mylittleone* did not meet the needs of every mother.

> **[Professional 4; neonatal unit]** [I remember one] mum who didn't want it switched on, because it freaked her out basically that she could see her baby all the time.
>
> **[Professional 2; Neonatal Unit; Participant A]**: I find that sometimes mums focus on it too much, so for instance, I had one baby that's...mum would [come down to the neonatal unit] like every 15 minutes because the baby had startled or...whatever reason because she was anxious, and she said that she couldn't switch it; she was watching it all the time, so it heightened her anxiety.
>
> **Participant B**: I think there is a general sort of...not all mums, some...obviously some mums are a wee bit more kind of laidback and they don't feel the need to have it, and they have said that they like having it there, that it's a good thing for them, but I think for the anxious mums it just makes them even more anxious.
>
> **Participant A**: I think a lot of the interpretation of [what they see on the tablet] and certainly where mum's anxiety comes from, comes from mum's experience, whether she's a first time mum or not, whether she's had a complicated pregnancy or not, whether there's been pre or post anxiety or complications and things. I think that alters their interpretation of [what she sees on the tablet].

Again, what was discussed demonstrates that for some, albeit a small number of parents, use of the technology had the potential to make them more anxious.

Switching the camera on and off

The switching on and off of the *mylittleone* camera by staff was the focus of much discussion and some debate among the parents and professionals. As noted above, when staff were undertaking a medical/nursing procedure, the policy was that the camera should be switched off. When the camera was switched off a notice appeared on the tablet device letting the parents know a procedure was underway. However, the notice was a standardised message that did not indicate what the procedure was or why it was being undertaken and there was no indication of how long the procedure would last. Procedures vary from the changing of a nappy to resuscitation of the baby.

It was not uncommon for parents to report delays in the camera being switched back on after a procedure. For some this raised concern as they began to wonder if there was 'something wrong' with their baby.

> **[Mother 11; baby 10 weeks premature]** There was only one thing I didn't like, because they turn the camera off when they're dealing with the babies and they used to forget to turn it on. I know I had to phone down to the Neonatal Unit quite a lot, well, the doctors did, to ask them to turn it back on.
>
> **[Mother 14; baby full-term]** You become dependent on [*mylittleone*] I think as time goes on so if it isn't working … they switch it off when they're doing something with [baby's name] and occasionally they'd forget to switch it back on again and you'd be waiting quite a while and then eventually you'd maybe go down [to the neonatal unit] and just say … but sometimes you felt that you were bothering them. It was like another thing that they had to do. You felt they had so much to do as it was, for them to be like checking on the computer, because of the logging in and things like that.

Another concern was that staff, very occasionally, forgot to switch the camera off when undertaking a procedure. This meant that a small number of parents had seen procedures that had the potential to cause stress and anxiety.

> **[Professional 7; post-natal ward]** I happened to have been going through someone's notes this morning to do a discharge and there was two instances where the mum got upset because someone had taken bloods and forgotten to turn the camera off.
>
> [Mother 9; baby 6 weeks early] At one point they forgot to switch [the camera] off and … what I saw I didn't need to see.

There was discussion in all of the interviews with staff about what would happen in relation to the switching off of mylittleone in an emergency situation, where a baby required immediate attention. Staff agreed that, when emergencies happen, the focus is always on taking swift and appropriate action to deal with the baby. This given, the scenario of an emergency clearly caused staff concern thinking about the possibility and (perceived/assumed negative) consequences of forgetting to turn off mylittleone as they sought to ensure the safety and well-being of the baby in their care.

In sum, while parents framed the 'downsides' of using mylittleone in different ways, there was a commonality in relation to the events that appeared to cause distress. Most often the downsides related to witnessing something on screen which they otherwise would not have seen, for example, the taking of bloods, a worsening of their baby's condition, a change in care, or their baby crying.

Staff agreed that while for most parents, use of mylittleone reduced their anxiety levels, for a small number it had the opposite effect. Some had observed that it was often late at night

that they would receive calls from parents about what they had seen on mylittleone. Similarly, they often received calls immediately the camera was switched off to undertake a procedure. The professionals felt the hyper-vigilance that could be associated with the constant ability to monitor the baby had the potential to impact negatively on the mental health and well-being of a small number of the mothers. The staff were aware that they needed to be able to identify these mothers and take appropriate action.

Prioritising Care

While mylittleone was viewed by the professionals as a positive development in neonatal and post-natal care, there was some discussion of how the technology had impacted workloads and priorities within the neonatal unit. The issue of taking and dealing with phone calls relating to mylittleone from mothers and also staff in the post-natal environment was raised. Staff reported that they occasionally felt under pressure to respond to requests from mothers who had noticed on the tablet device that their baby was unsettled at times when it was necessary for them to prioritise the immediate needs of other babies within their care. This tension is illustrated in the following extracts:

> **[Professional 2; neonatal unit; Participant A]** [The mothers] phone down, they have a tendency to phone down, my baby's doing this or they've just been sick or ... because they can only see the baby and at these particular moments when the baby's maybe had a posset or maybe been sick, well, where's the nurse, you should have seen that, forgetting that there might be three other babies in that room that you're also looking after and it's not a case of that we're not tending to that baby, but we've got other things to do, we won't see it at the exact time [it happens], and also because there's a [slight] time delay in the camera, they might have posseted and then, you know.
>
> **[Participant B]** We've cleaned it [already].
>
> **[Participant A]** [To the parents] it'll seems like it's five minutes later that we've gone over, but actually because of the time delay in the camera, we've seen the sick [and cleaned it up].
>
> **[Professional 4; neonatal unit]** You could have your hands in the incubator with your other... if you've got two babies, and you're attending to one and the other one starts crying. You can't stop attending to the one you're with. If the monitors are fine and the baby is just crying, you think, well we will get there as soon as [we can], which we do, or we'll shout on somebody else to attend to it.
>
> **[Professional 3; neonatal unit]** I suppose if you're quiet and you've not got a heavy workload and the unit isn't busy and somebody phones in and says, oh, that's been off, and somebody has forgotten to turn it back on, that's all right. But, if you've got five things to do and that's the last thing [you might be able] to do, then that's when it [becomes] a stressful thing.

While parents' telephoning the neonatal unit was a notable concern for staff who worked there, it was a negligible concern for post-natal staff, as mothers most commonly used their mobile telephones to contact the neonatal unit and so did not ask them to phone on their behalf.

Using *mylittleone* at home

At the time the interviews were conducted the *mylittleone* technology could only be used in the hospital setting. However, as it was anticipated that, in the future, video footage of the baby could be transmitted to family homes when, for example, the mother had been discharged and her baby

remained in hospital; parents and professionals were asked to share their views on this potential development.

The majority of parents felt that being able to use *mylittleone* at home would be beneficial.

> **[Parent 19; baby full-term]** I [am] starting to get really anxious about going home without her and thinking when I've been here I've had this camera that I've been able to just use all the time. Whereas at home I'm going to have absolutely nothing and I can't imagine having like a night's sleep. I [will] be having to phone the unit, like two or three times a night just to check on her.

Although parents were mostly positive about such a development, the possibility of not being able to respond to their baby's needs from the distance of home was raised as an issue.

Interestingly, some of the parents had used FaceTime® while in hospital as a way of involving the baby's father in interactions with their baby in the neonatal unit.

> **[Mother 16; baby 5 weeks premature + low birth weight]** [When I was in hospital] I would FaceTime® [my husband when he was at home] so he could watch her as well. So we could watch it at the same time. … Yeah, it would basically be, like, look what she's doing now or did you see that or, you know, look she's waking up or just even about her looks or she looks like me or anything like that. And she made good improvements all the time, you know, we'd see a difference in her and she would have a bit of equipment removed and things like that and we'd just talk about her, what will happen next and how soon until she gets out and things like that.
>
> **[Interviewer]** So it was like a wee, sort of, bonding session between the three of you?
>
> **[Mother 16]** Yeah, I've got pictures of us, kind of, three way conversation, except you couldn't talk [of course].

Hence mothers, to an extent, had already extended the use of the *mylittleone* technology to enable their partners to 'view' the baby from home.

Staff in the post-natal ward were well-positioned to comment on the potential for *mylittleone* to be used at home as they frequently witnessed mothers being discharged before their baby.

> **[Professional 5; post-natal ward]** I think they understand that, at the moment, there aren't the facilities to take [*mylittleone*] home and they seem to be happy enough to hand it back, but, ideally, they would like to know that they could take it home and then see their baby from home. Because, none of them want to go home [leaving] their baby in the hospital.

Similar to what was discussed in the previous section, staff in the neonatal unit raised concerns about the possibility of parents 'phoning in' regularly from home. While they understood why parents would do this, the implications for their workload and other care demands were highlighted.

> **[Professional 8, neonatal care]** I think a lot of the staff's reservations about if they can watch [their baby] from home is that it's a bit like Big Brother's watching you all the time really, and parents might be continually phoning to say, I can't see my baby, or my baby's been sick or my baby's crying, which does put a lot of pressure on the staff I suppose. But I guess that's something we would just have to deal with if it happened. I think the benefits would outweigh the [downsides].

Finally, insight into issues relating to internet security and the practicalities of transmitting video images to family homes was provided by the IT/e-health professionals.

> **[Professional 6; IT/e-health; Participant A]** We need to take that next step … rather than it being a separate [system] … it should feed into the neonatal system … so you could go into the app. and view it. So it's secure whether it is a live feed or whether it's even a recording or video.
>
> **[Participant B]** The Scottish Government would need to be involved because of the aspect of security … if you linked it to the [BadgerNet] platform, which is a national maternity system and neonatal system, rather than a separate system, you would have [better security] … I think Clevermed [medical software company that developed the BadgerNet platform] and IC24 have already had conversations. They would need to develop a partnership.

In sum, the potential to use *mylittleone* at home was viewed positively by parents and professionals, with some caveats, as discussed.

Implementation issues – making sure *mylittleone* was fit for purpose

The findings in the preceding sections have focused, to the large extent, on the views and experiences of the parents and professionals, who were, essentially, the 'end users' of the *mylittleone* product. In what follows, findings are presented from a small group interview with IT/e-health professionals who were members of the local implementation team. These professionals shared their views and experiences of the development and deployment of the *mylittleone* technology. The themes that emerged from the analysis were: collaborative working; making *mylittleone* user friendly; and, suggestions for future revisions.

Collaborative working

It was very clear from what was discussed, that Integrative Care 24 (IC24) was perceived as having worked in very close collaboration with the local IT/e-health professionals and staff in the neonatal care unit when developing and deploying *mylittleone*.

> **[Professional 6; IT/e-health; Participant A]** IC24 were very driven, they were very focused … I knew they were going to deliver … They were very efficient in their project management. It was great. We had regular calls, regular meetings. Their correspondence and everything, you know, they were very much … everybody was involved. Everybody knew what was happening.
>
> **[Participant B]** They were willing to listen to what we wanted. And they came up [to Scotland to the neonatal unit] three to four days before we went live. And again, that's …. that was above and beyond.
>
> **[Participant C]** Yeah, it was like, the full team [came up].
>
> **[Participant A]** I'd say IC24 are one of the best suppliers we've, I've certainly worked with.

The support provided following the 'launch' of the technology was also viewed positively.

> **[Professional 6; IT/e-health; Participant C]** We've had, like a couple of issues with some cameras, but that's hardware issues … they were losing their settings.
>
> **[Participant B]** They've lost their IP address settings, so that meant there were no pictures being sent to the [tablet] or to the console system … I contacted them and pretty much straight away they came back to me to say package up these cameras, send them down to us and we will send replacements. We plugged them in and they were fine … So their support's been really good.
>
> **[Participant C]** It is good that you can deal directly with the people who are actually providing the solution … the person you email is the person that is implementing the solution and so they are familiar with [the technology] and they understand … they know it inside out.

The local IT/e-health professionals reported that they had maintained communication with the staff using the technology on a day to day basis to ensure any problems were identified in a timely manner.

> **[Professional 6; IT/e-health; Participant B]** I've been trying to keep in touch with the main nurses up in the unit to make sure everything's working and running as it should be and they know to contact me if they've got any issues … so I just drop them a message to let them know that we're still looking out for them.

From what was discussed, the collaboration among, IC24, the local IT/e-health professionals and the staff using the technology appeared to have resulted in its successful deployment.

Making *mylittleone* user friendly

Linked to the above, the IT/e-health professionals discussed efforts that had been made to ensure the technology was as user friendly as possible.

> **[Professional 6; IT/e-health; Participant A]** I mean from an e-health perspective, we had to make sure it was secure ... but we also had to make sure it was user-friendly. Because what we didn't want was the nursing staff having to phone these guys up [IT Support] and say "I've got a baby being born. How can I attach the camera to that [tablet]?" It was very much, you know, we wanted to put the solution in and be able to walk away and only be called in when the server had problems or if the network had problems.
>
> **[Participant C]** Yeah, something that would pretty much manage itself ... once it was in it was in.
>
> **[Participant A]** Babies are born at any time and we don't work 24/7, so ... that was the key thing, if a baby was born at two o'clock in the morning, the mum shouldn't have to wait until nine, half nine before one of us can get up there to configure that camera and [tablet].

Comments were also made about the quality of the cameras and the tablet devices that were the main components of the *mylittleone* technology. The importance of this was emphasised as the professionals believed it enhanced the parents' experience when 'viewing' their baby remotely.

> **[Professional 6; IT/e-health; Participant C]** With the cameras, its, I don't know how many frames per second exactly, but it looks natural. If you look at the feeds, you can see the heart beating, like, through the skin, 'cause their skin's so thin. But that's what you want to see. You wouldn't want to see a pixilated, laggy image ... so it's a high end solution, you know, it looks really good ... IC24 are not vendor specific ... they can look at [different technological solutions] and pull them together ... the screens on the [tablets] are amazing, retina displays [high resolution]
>
> **[Participant B]** We had another system before but when you turned the lights down in the room you couldn't see the baby. We fed that in to IC24, we were like it has to work at night. And their camera quality at night is great.

The interviews with the parents and professionals confirmed the above views.

Suggestions for future revisions

While the IT/e-health professionals were generally very positive about *mylittleone*, they did make two suggestions that they believed would enhance the product. The first related to knowing whether the camera was switched on or off.

> **[Professional 6; IT/e-health; Participant C]** Staff have said that there is an issue with the switch attached to the camera, where they aren't sure if they are turning it on or off ... we had spoken about the switches when we were installing the solution, like maybe it should have a light on it to indicate if it is on or off ... sometimes in an emergency where they need to turn a camera off they aren't sure if it was on or off ... and that might mean the mother is viewing the baby.

The second related to knowing exactly what the mother was seeing.

> **[Professional 6; IT/e-health; Participant B]** The nurses want to see what the mums can see. Before [when using the BabySam technology] we had a small device that sat at the baby's cot. That would be something that we would want to provide [in future developments].
>
> **[Participant C]** At the moment the feed is a composite feed. The issue with that is it can only be viewed by one user at a time [and at the nurses' station].
>
> **[Participant A]** Or we should be able to provide a PC that constantly runs the eight views from the cameras. So someone glancing at it can see if the cameras are on or off very easily … at the moment the nurses have to log in to see [what is on the camera].

Finally, the IT/e-health professionals reported that they were very pleased to have played an important role in the development and deployment of a technology they firmly believed had made a difference to patient care.

Summary

The findings from the qualitative evaluation highlighted that, broadly speaking, parents spoke about *mylittleone* in one of two ways. The majority of parents talked about it in positive terms, with some including caveats in their accounts, which they marked out as small and downplayed. The benefits were in four key areas: closeness and responsiveness to the baby's needs; emotional well-being; physical recovery; and, the ability of family and friends to 'see' the baby. The caveats discussed by the parents, who were predominantly positive, included staff forgetting to switch the camera back on after they had undertaken a nursing/medical procedure. In contrast, for a minority of parents, while they could see some benefits in using the *mylittleone* technology, they felt it had increased, rather than decreased, their levels of anxiety and so their preference was not to use it.

The professionals were also generally very positive in their views, highlighting a number of important benefits associated with use of the technology. The benefits discussed by the professionals were very similar to those discussed by the parents. The professionals were aware that a minority of parents did not feel they had benefitted from use of *mylittleone*. Staff working in the neonatal unit raised the issue of the occasional impact of the *mylittleone* technology on issues relating to workload and prioritisation of care.

Finally, the IT/e-health professionals shared their views on the development and deployment of *mylittleone*. The issues discussed included the very positive experience of collaborating with the company who developed the technology (Integrated Care 24) from an early stage.

6 Identifying instruments for a future trial – what did we find?

Susan Kerr, Caroline King, Rhona Hogg, Kerri McPherson, Janet Hanley, Maggie Brierton and Sean Ainsworth

The Results presented in this section of the report are derived from a systematic review of the literature (Phase 2) and a consultative exercise with a small number of parents (Phase 3). Each is discussed below.

Phase 2

As noted in Section 4 (p13), the systematic review of the literature was undertaken to: a) identify instruments used to assess maternal bonding and a range of psychological indicators of post-natal adjustment (identified in Phase 1 as key outcomes to be measured in a future trial); b) evaluate the reliability and validity of the instruments identified; and c) assess the feasibility and acceptability of the instruments for use in a future trial of the effectiveness of the *mylittleone* technology.

Selection of studies

The literature search yielded 656 papers (see Figure 1). Removal of duplicates led to the exclusion of 166 papers, leaving 490. After reviewing the titles and abstracts (and full text copies of papers, when required), a further 456 papers were excluded; therefore, 34 papers met the inclusion selection criteria for the review. The main reasons for exclusion were as follows: the paper did not report on a 'validation' study; the paper reported on a validation of a non-English language version of an instrument; and/or, the paper focused on validation of an instrument with a specific population e.g. mothers with substance misuse problems.

Figure 1 – Search and selection of papers
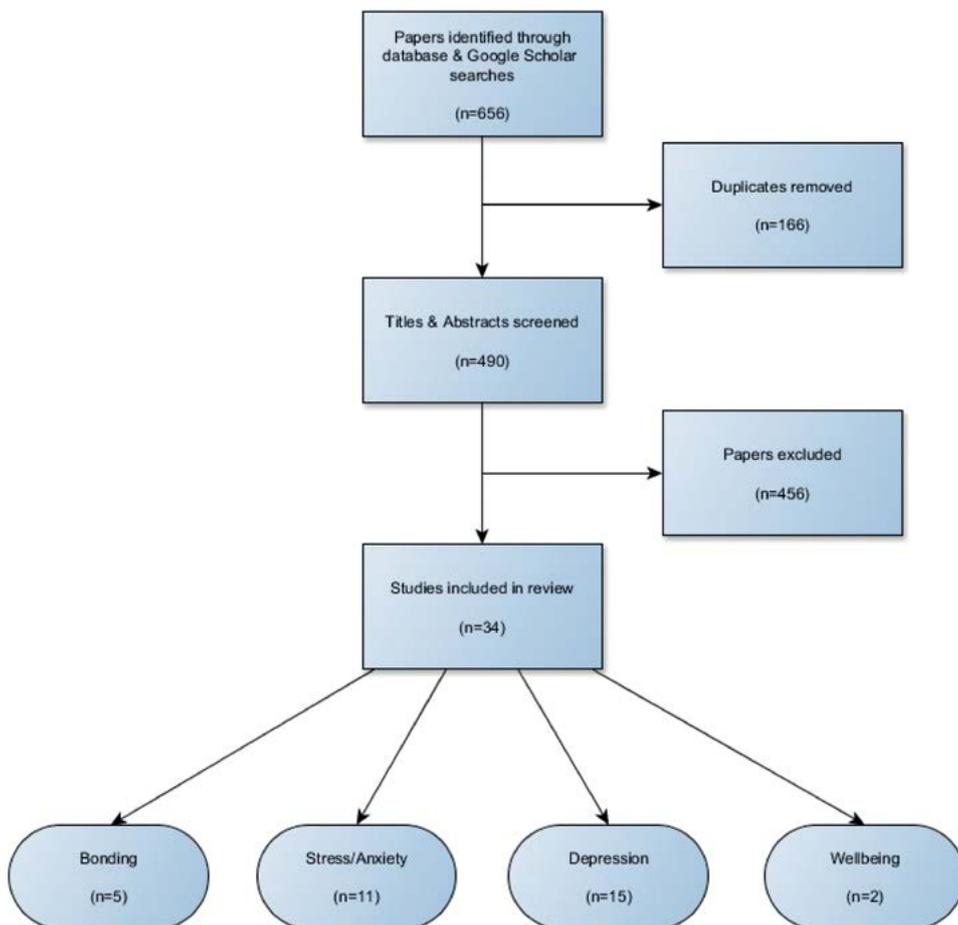
Instruments

Bonding

Four instruments were identified in 5 papers. Four of the studies were undertaken in the UK or included UK-based samples (i.e. Bifulco et al., 2004; Brockington et al., 2006; Taylor et al., 2005; Wittowski et al.,2007) and one study was undertaken in Australia (i.e. Condon & Corkindale, 1998). The instruments identified were as follows:

• Postpartum Bonding Questionnaire (Brockington et al., 2006; Wittowski et al., 2007)
• Mother-to-Infant Bonding Scale (Taylor et al., 2005; Wittowski et al., 2007)
• Attachment Style Interview (Bifulco et al., 2004)
• Parent-to-Infant Attachment Assessment (Condon & Corkindale, 1998)

The COSMIN ratings for methodological quality and the properties of the 'bonding' instruments (i.e. reliability and validity) are summarised and synthesised in Appendix 4. As indicated, the methodological quality of the papers was assessed on a 4-point rating scale (i.e. Excellent, Good, Fair, Poor), with the properties of the instruments being rated as 'positive', 'intermediate' or 'poor' (Terwee et al., 2007; Terwee et al., 2012).

It was more common for the papers to have assessed the reliability of the instruments than to have assessed their validity (Appendix 4). While the methodological quality of the papers varied, most were judged as 'good'. The properties of the instruments were generally 'positive'; however, the methodological quality of the paper/s should be borne in mind when this is considered.

Stress/anxiety

Nine instruments were identified in 11 papers. Seven of the studies were undertaken in North America (Berry & Jones, 1995; Haskett et al., 2006; Thomas et al., 2004; Karam et al., 2012; McDonald et al., 2012; O'Hara et al., 2012; Moran et al., 2014;), three in Australia (Matthey, 2008; Swalm et al., 2010; Somerville et al., 2014) and one in the Netherlands (Brouwers et al., 2001). The instruments identified were as follows:

Stress

• Parental Stress Scale (Berry & Jones, 1995)
• Parenting Stress Index (Thomas et al., 2004)
• Parenting Stress Index (Short Form) (Haskett et al., 2006)
• Perceived Stress Scale (Karam et al., 2012)

Anxiety

• Edinburgh Postnatal Depression Scale (anxiety sub-scale) (Brouwers et al., 2001; Matthey, 2008; Swalm et al., 2010)
• Psycho-social Screening Tool (postpartum anxiety) (McDonald et al., 2012)
• Postpartum Worry Scale (revised) (Moran et al., 2014)
• Postpartum Anxiety – Brief Scales (O'Hara et al, 2012)
• Perinatal Anxiety Screening Scale (Somerville et al., 2014)

The COSMIN ratings for methodological quality and the properties of the instruments used to assess stress and anxiety are summarised and synthesised in Appendix 5. Again it was more common for reliability to be assessed than validity. The quality of the studies was variable. The majority of the measurement properties were 'positive'.

Depression

Eight instruments were assessed in 15 papers. Thirteen of the studies were undertaken in North America (Beck & Gable, 2000, 2001; Mitchell et al., 2006; Hanusa et al., 2008; Gjerdingen et al., 2009; Ji et al., 2011; Barrick et al., 2012; Beck et al., 2012; Chae et al., 2012; McCabe et al., 2012; Davis et al., 2013; Manion et al., 2013; Blucker et al., 2014) and two were undertaken in the UK (Cox et al., 1987; Murray & Carothers, 1990). The instruments identified were as follows:

- Postpartum Depression Screening Scale (Beck & Gable, 2000, 2001; Mitchell et al., 2006; Hanusa et al., 2008; Beck et al., 2012; McCabe et al., 2012; Blucker et al., 2014)
- Edinburgh Postnatal Depression Scale (Cox et al., 1987; Murray & Carothers, 1990; Hanusa et al., 2008; Ji et al., 2011)
- Patient Health Questionnaire – 9 (Hanusa et al., 2008; Gjerdingen et al., 2009; Beck et al., 2012; Davis et al., 2013)
- Patient Health Questionnaire – 2 (Gjerdingen et al., 2009; Chae et al., 2012)
- Beck Depression Inventory II (Manian et al., 2013)
- Pregnancy Risk Assessment Questionnaire (Davis et al., 2013)
- Hamilton Rating Scale for Depression (Ji et al., 2011)
- Correa-Barrick Postpartum Depression Scale (Barrick et al., 2012)

The COSMIN ratings for methodological quality and the properties of the instruments used to assess depression are summarised and synthesised in Appendix 6. The methodological quality of the papers was variable. The most commonly assessed instruments were the Postpartum Depression Screening Scale, the Edinburgh Postnatal Depression Scale and the Patient Health Questionnaire. Measurement properties were generally 'positive', with criterion validity being the most commonly assessed property (i.e. the degree to which the scores of an instrument reflect the 'gold standard').

Well-being

Two instruments were assessed in 2 papers. The studies were undertaken in South East Asia (an English language version was tested) (Sell, 1994) and the UK (Tennant et al., 2007). The instruments identified were as follows:

- Subjective Well-being Inventory (Sell, 1994)
- Warwick-Edinburgh Mental Well-being Scale (Tennant et al., 2007)

The COSMIN ratings for methodological quality and the properties of the instruments used to assess well-being are summarised and synthesised in Appendix 7. The methodological quality of the study undertaken by Tennant et al (2007) was good/excellent, with the instrument shown to be both valid and reliable. The study undertaken by Sell (1994) was of 'fair' methodological quality and no tests of reliability had been undertaken.

Instruments selected

Based on the quality ratings and measurement properties, and following discussions among members of the evaluation team that focused on the feasibility and acceptability of the instruments, a decision was made to take eight instruments through to Phase 3 of the evaluation. When considering the feasibility and acceptability of the instruments, factors considered were, ease of administration and completion, and the likelihood that three or four would be used, together, in a future trial. Respondent 'burden' is known to impact completion rates and so our aim was to keep this to a minimum (Rolstad et al., 2011).

The eight instruments were as follows:

Bonding

- Mother-to-Infant Bonding Scale (8 items)
- Postpartum Bonding Questionnaire (25 items)

Stress/anxiety

- Parental Stress Scale (18 items)
- Perceived Stress Scale (4 items)
- Edinburgh Postnatal Depression Scale (anxiety sub-scale contains 3 items)
- Perinatal Anxiety Screening Scale (31 items)

Depression

- Edinburgh Postnatal Depression Scale (7 of 10 items measure depression)
- Patient Health Questionnaire (9 items)

Well-being

- Warwick-Edinburgh Mental Well-being Scale (14 items)
- Copies of the instruments are included in Appendices 8-15.

In sum, following an assessment of the quality of the papers, the measurement properties of the instruments and issues relating to feasibility and acceptability, eight instruments were selected as appropriate to take forward to Phase 3.

Phase 3 – consulting with parents on the acceptability of the instruments

Two mothers commented on the acceptability of the eight instruments identified in Phase 2, participating in separate face-to-face discussions with two member of the research team. Both were mothers of babies who had been born prematurely and who had spent a number of weeks in a neonatal unit. According to the Scottish Index of Multiple Deprivation (Scottish Government, 2012), both were living in areas of low socio-economic deprivation.

The mothers' views

The mothers' views on each of the instruments are summarised and synthesised in Table 3. Their opinions were informed by how the found the instruments themselves and how they believed other mothers would find them (based on their knowledge of issues linked to literacy and learning difficulties, such as dyslexia). As indicated, the instruments were generally considered to be easy to read, understand and complete. The balance of positive and negative statements in the majority of the instruments was considered to be important. While statements in some of the instruments were highlighted as 'sensitive', given the outcomes of interest (e.g. anxiety, depression), the mothers stated that they understood why these questions would be asked. Two instruments were considered to be lengthy (i.e. Postpartum Bonding Questionnaire; Perinatal Anxiety Screening Scale), but the individual item statements that make up each of the instruments were noted as 'short'.

In addition to the above, the mothers commented that if completing more than one instrument, differences in the types of scales and/or in the period respondents were being asked to reflect on (e.g. 7 days, 1 month) had the potential to be confusing.

Table 3: Mothers' views on the acceptability of the instruments

Instrument	Comments
Mother-to-Infant Bonding Scale (8 items)	**Instructions**: respondents may not understand the word 'adjectives' but when they look at the words they will know what is meant **Statements**: words may be open to slightly different interpretations; balance of negative and positive statements **Completion**: easy to complete **Sensitive questions**: Q3 'Felt nothing for baby' **Length**: short
Postpartum Bonding Questionnaire (25 items)	**Instructions**: easy to understand **Statements**: easy to read and understand; balance of negative and positive statements **Completio**n: easy to complete **Sensitive questions**: Q6 'The baby does not seem to be mine', Q17 'I wish my baby would somehow go away', Q24 'I feel like hurting my baby.' **Length**: looks daunting at first, but the statements are quite short
Parental Stress Scale (18 items)	**Instructions**: the instructions are lengthy and the wording quite complex **Statements**: the language is complex in places e.g. Q7 'My child is an important source of affection for me' **Completion**: use of numbers and words may be difficult for some mothers **Sensitive questions**: nothing noted **Length**: satisfactory
Perceived Stress Scale (4 items)	**Instructions**: fairly clear **Statements**: easy to read and understand **Completion**: asked to 'circle' the correct response but should be asked to 'tick' or 'cross' a box (based on the layout). **Sensitive question**s: nothing noted **Length**: short
Edinburgh Postnatal Depression Scale (3 of 10 items measure anxiety)	**Instructions**: clear **Statements**: easy to read and understand **Completion**: response options change slightly, so need to pay attention **Sensitive questions**: nothing noted **Length**: short
Perinatal Anxiety Screening Scale (31 items)	**Instructions**: clear **Statements**: respondents may struggle what is being asked in places e.g. Q7 'Really strong feelings about things e.g. blood, pain, needles'; Q16 'Concerns about repeated thoughts'. **Completion**: easy to complete **Sensitive questions**: nothing noted **Length**: lengthy, but the statements are quite short
Edinburgh Postnatal Depression Scale (7 of 10 items measure depression)	**Instructions**: clear **Statements**: easy to read and understand **Completion**: response options change slightly, so need to pay attention **Sensitive questions**: Q10 'The thought of harming myself has occurred to me' **Length**: short
Patient Health Questionnaire (9 items)	**Instructions**: respondents may find the instructions difficult to follow **Statements**: statements all negative, one is lengthy and focuses on two issues **Completion**: one mother felt some mothers may struggle **Sensitive questions**: nothing noted, other than, all were negatively focused **Length**: short
Warwick-Edinburgh Mental Well-being Scale (14 items)	**Instructions**: clear **Statements**: easy to read and understand **Completion**: easy to complete **Sensitive questions**: nothing noted **Length**: satisfactory

Instruments selected

Following discussion of the individual instruments, the mothers were asked if they had a preference in terms of what they considered to be the most acceptable instruments, bearing in mind that three-four may be used in tandem and that only one was required to measure each outcome (e.g. stress). Based on the discussion with the mothers, the following instruments are proposed for use in a future trial:

• Mother-to-Infant Bonding Scale
• Perceived Stress Scale
• Edinburgh Postnatal Depression Scale (measures anxiety and depression)
• Warwick-Edinburgh Mental Well-being Scale

Summary

A systematic review of the literature (Phase 2) resulted in the identification of eight outcome measures/instruments judged by the research team as being valid, reliable, feasible and acceptable. In Phase 3, the acceptability of the instruments was discussed with mothers of children who had been cared for in a neonatal unit. Following this process, four instruments were considered appropriate to be taken forward to a future trial to assess the clinical effectiveness of *mylittleone*.

7 Discussion

As noted in Section 3, the aim of the study was to explore the use of the mylittleone technology and make recommendations for its future development and deployment. In addition, information was gathered to inform the design of a future trial to assess the clinical effectiveness of the technology. The findings presented in Sections 5 and 6 are now summarised and discussed in light of extant literature.

a) Parents' and professionals' views and experiences of the *mylittleone* technology

The majority of the parents and professionals spoke very positively about *mylittleone*. The availability and subsequent use of the technology was perceived as having enhanced the parents' hospital experience.

The impact of mother-infant separation was discussed at length in the interviews. From what was described, *mylittleone* appeared to help mothers feel 'closer' to their babies, despite periods of separation while their baby was cared for in the neonatal unit. In addition there was a belief that the technology helped mothers to be more responsive to their baby's needs and this included physically through encouraging the production of breast milk. Importantly, the emotions and sentiments described appeared to relate to the early 'bonding' process i.e. the emotional attachment of the mother to her newborn baby. It is widely acknowledged that the mother-infant bond can be compromised when a child is admitted to a neonatal unit and this can impact the development of the subsequent attachment relationship (Aagaard & Hall, 2008; Cleveland, 2008). As maternal bonding and attachment have been shown to influence an infant's emotional and physical development, it is important that efforts are made to encourage the process (Bowlby, 1980; Bienfait et al., 2011). As discussed in Section 2, a range of interventions designed to promote physical closeness (and thus bonding), have been developed and tested in neonatal units (Feldman et al., 2002; Ferber et al., 2005). To date, however, little has been available to help parents 'keep in touch' with their baby when they are physically separated from them. The findings from this qualitative evaluation suggest *mylittleone* may have an important contribution to make in facilitating the early bonding process when periods of separation are imposed.

Other issues discussed related to feelings of stress and anxiety. The distress experienced by many parents when their child is admitted to a neonatal unit is well-established (e.g. Holditch-Davis & Miles, 2000; Aagard & Hall, 2008). Parents of children who are very sick or premature often struggle with the uncertainty associated with their child's short and longer term prognosis and the highly technical and somewhat 'alien' environment in the neonatal unit (Cleveland, 2008). From what was described, the ability to see their baby was 'stable' when they were not with them provided the majority of parents with an important level of reassurance that, in turn, impacted positively on their emotional well-being. Use of the technology also allowed mothers to prepare themselves for seeing the baby for the first time in the neonatal unit, and this was reported as helping to diminish the stress which has been shown to be associated with this event (Aagaard & Hall, 2008).

The above said, for a minority of parents (n=5), the almost constant ability to see the baby, issues associated with the switching on and off of the camera and the fact that they could 'see but did not know what was happening' appeared to increase rather than decrease feelings of stress and anxiety.

Other benefits discussed by the majority of parents and professionals related to the scope *mylittleone* provided in assisting the mother's recovery, following the birth process. As noted, mothers were reported as better able to sleep, rest, eat and drink, knowing that they could 'keep in touch' with their baby. The increased ability to rest was also reported as helping to reduce pain

and discomfort associated with the birth. The opportunity to rest and recuperate in the early post-natal period has been associated with both the emotional well-being of the mothers and the production of breast-milk (Brown & Lumley, 2000; Grassley et al., 2015).

In addition, parents appreciated being able to introduce the baby (via *mylittleone*] to the wider family, including siblings and friends, who were not allowed access to the neonatal unit. This appeared to be important in normalising the situation when they came to the hospital to visit the mother, as family and friends expect to 'see' the new baby. From what was discussed, the ability to see the baby may also have encouraged the number of visitors and visits. Access to existing support networks has been highlighted as important for maternal well-being in previous research and may help protect mothers who are confined to hospital from feelings of isolation (Aagaard & Hall, 2008). In the current study, the shared experience of viewing and discussing the 'real time' video footage of the baby appeared to be important in this regard.

Finally, as noted in Section 5, mothers are frequently discharged from hospital in advance of their baby, who remains in the neonatal unit (Ainsworth, 2016b). When asked to share their views on the potential use of *mylittleone* at home the majority of parents believed this extension to its current use would be a welcome development. The parents understood the importance of continuing to visit the neonatal unit to maintain physical contact with their baby, but being able to see him/her when they wanted, including first thing in the morning and last thing at night, was considered to be important in relationship building. On the other hand, some mothers were concerned about their inability to respond to their baby's needs when viewed from the distance of home. Staff highlighted the same issue, raising concerns that mothers may experience anxiety from seeing from a distance that their baby was unsettled.

b) Factors that appeared to have influenced the views and experiences of the parents and professionals

The collaborative nature of the development and deployment of the technology appeared to have been central to the generally positive view of *mylittleone*. Driven by Integrated Care 24, working in partnership with the IT/e-health professionals in NHS Fife, staff in the neonatal unit, and a small number of parents, the end result was considered to be a user friendly 'solution' that was generally fit for purpose in addressing an identified need.

When considering factors that resulted in more negative views, it is important to bear in mind that parenting in the neonatal care environment is stressful for the majority of parents (Holditch-Davis & Miles, 2000). Accounts from the professionals suggested that the ability to see their baby 24/7 had the potential to make parents who were possibly less resilience more anxious. Also, in situations where there was considerable uncertainty about the condition of and prognosis for the baby, for some, use of *mylittleone* had the potential to exacerbate feelings of concern.

Importantly, the professionals appeared to be aware that for a minority of parents use of *mylittleone* was not helpful. From what was discussed it seemed to have been made very clear to parents that the decision to use the technology (or not) was very much within their control. Another strategy suggested by the findings is that it may be useful to encourage mothers to switch off the device at times, if this helps them to rest, and to reassure them that this will not lead to them being judged as being uninterested in their baby's welfare. The identification and meeting of individual needs and preferences by professionals is in line with expectations associated with the delivery of person-centred care (e.g. Scottish Government, 2008).

Another factor that appeared to be influential was that babies who are full- or near to full-term are generally more able to express their needs than babies who are very premature (O'Donnell et

al., 2010). This means that they are more likely to cry and to do so more loudly. A small number of mothers reported that their inability to respond immediately to their baby's perceived needs when they were in the postnatal ward was distressing. Had these mothers not had access to the *mylittleone* technology they would have been unaware their baby was crying. This highlights a tension between 'access' (seeing the baby) and 'responsiveness.'

Discussions with staff and other mothers highlighted that the 'stuttering' of the video feed that had concerned one mother so much that she had stopped using *mylittleone* had happened on a small number of occasions. From what was reported other mothers were reassured and continued to use the technology, believing this was a minor issue. While a technical response was sought[1], staff highlighted to parents that an occasional freezing or jumping of the picture on the tablet device may occur.

Finally, while *mylittleone* was undoubtedly viewed as a positive development by staff working in the neonatal unit, staff expressed a tension between the need to prioritise their work in relation to the care needs of all of the babies in the unit whilst responding to requests from mothers who had contacted the unit to highlight their baby was unsettled (having noticed this on the tablet device). Professionals working in the postnatal care environment did not experience this tension.

c) Identification of appropriate outcome measures/ instruments to evaluate the effectiveness of *mylittleone* in a future research trial

While the qualitative approach taken in Phase 1 of the current study is appropriate when exploring the views and experiences of parents and professionals, when seeking to determine the effectiveness of *mylittleone* in promoting outcomes such as bonding and well-being and reducing levels of stress, anxiety and depression in mothers, a controlled trial is required (Bruce et al., 2008). In Phase 2, systematic review methods were used to identify outcome measures/instruments to be used in a future trial. The COSMIN checklist was used to assess the methodological quality of the papers and to assess the measurement properties of the instruments, that is, reliability, validity and responsiveness (Terwee et al., 2007; 2012). In addition, the feasibility and acceptability of the instruments were considered (Fitzpatrick et al., 1998).

The process involved in identifying appropriate instruments was discussed in Section 6, with the results of the assessment of the methodological quality of the papers and the measurement properties of the instruments presented in Appendices 4-7. The eight instruments identified as being the most appropriate to take forward to the next phase of the study (where mothers would share their views on their acceptability) were as follows : the Mother-to-Infant Bonding Scale; the Postpartum Bonding Questionnaire; the Parental Stress Scale; the Perceived Stress Scale; the Perinatal Anxiety Screening Scale; the Edinburgh Postnatal Depression Scale; the Patient Health Questionnaire; and, the Warwick-Edinburgh Mental Well-being Scale.

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1   NB The 'stuttering' of the video feed, which appeared to be due to a loss of wireless connectivity, was reported to Integrated 24, who were asked to undertake a technical review to determine if this issue could be resolved.

d) Parents' views on the acceptability of the outcome measures/instruments identified in Phase 2

As discussed in Section 4, 'good practice' in the identification of patient-reported outcome measures suggests that people similar to those who might be asked to complete instruments in a future research trial, are asked to comment on their acceptability during the final selection process (Fitzpatrick et al., 1998). Recommendations are that conversations focus on: the length of the instruments; how easy they are to read, understand and complete; and, whether any questions/statements are particularly sensitive (Fitzpatrick et al., 1998; Tourangeau & Yan, 2007; Galesic & Bosnack, 2009).

In Stage 3 of the current study, two mothers assisted with this process. Based on the discussion with the mothers and bearing in mind that three-four instruments will likely be used together in a future trial, the following instruments were selected: the Mother-to-Infant Bonding Scale; the Perceived Stress Scale; the Edinburgh Postnatal Depression Scale; and, the Warwick-Edinburgh Mental Well-being Scale.

Conclusion

The majority view of parents and professionals was that *mylittleone* is a very welcome addition to the neonatal/postnatal care environment. Benefits discussed were linked to the early bonding process, emotional well-being, physical recovery, and the 'inclusion' of family and friends. A small number of parents believed that use of *mylittleone* had increased rather than decreased their levels of anxiety and further work is required to determine if specific maternal and infant attributes are associated with this negative outcome. Staff working in the neonatal unit raised the issue of the occasional impact of the technology on workload and prioritisation of care. Extension of its current use to the family home was generally viewed as a positive development, given that mothers may be discharged weeks or even months in advance of their baby.

Finally, systematic review and consensus methods were used to identify outcome measures/instruments to be used in a future trial to assess the clinical effectiveness of *mylittleone*.

8. Recommendations and learning points

Practice

The main issue for practice relates to the switching 'on' and 'off' of the cameras. The anxiety caused by failure to switch cameras back on after medical or nursing procedures has been highlighted in Section 5. Also, on occasion, failure to switch off the camera resulted in a parent seeing a medical procedure that they would 'rather not have seen'. Given the nature of the neonatal care environment, we suggest the best solution is to make revisions to the technology. The suggested revisions are discussed below (Development of *mylittleone*).

Policy

Our opinion is that the views expressed by the parents and professionals in the current study provide sufficient support for consideration of a 'roll-out' of *mylittleone* to other neonatal units in Scotland (where the appropriate infrastructure is in place or can be put in place). Extension of its use to the home environment should also be considered. Assistance/backing from the Scottish Government will be required to facilitate these developments.

Research

While views of *mylittleone* in the current study were generally very positive, its effectiveness in promoting bonding and well-being and reducing levels of stress, anxiety and depression should now be assessed in a clinical trial. The setting up of a robust trial will require deployment in a number of neonatal units in Scotland, with others used as 'controls'.

Development of *mylittleone*

Two suggestions are made to enhance the current product. First, it is suggested that a light be added to the camera to ensure that it is very clear, at source, whether the camera is switched 'on' or 'off'. Second, staff should be able to see, with minimal effort, what the parents are seeing on the tablet device i.e. without having to log in to a computer at the nurses' station.

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10 Appendices

Appendix 1 – Interview Guide (parents)

1	**First of all, could you tell me a bit about your pregnancy? How did you keep?**
2	**Can you tell me about the situation which brought you to the neonatal unit (refer to as 'unit' after first reference to neonatal unit)?** Probes: Was the delivery arranged (elective section); was the baby born and something unanticipated led to the need for neonatal care?
3	**Did you know before you gave birth that your baby would need to spend time in the unit?**
4	**Can you describe in your own words your experience of your baby being cared for in the unit?**
5	**How has your own (the mother's) health been since your baby was born? How has the condition of your own health impacted on your experience of caring for your baby within the unit?** Probes: Explore both physical and mental health.
6	**How have your family circumstances impacted on your experience of caring for your baby in the unit?** Probes: caring for baby on own or with partner/ husband/ baby's father; geographic distance of home from the unit; other children at home; other caring commitments; extent of support from family members; availability of transport; financial costs.
7	**Can you describe to me what happened when you were asked whether you would like to use *mylittleone*?** Probes: when were you offered *mylittleone*; who offered it to you; how was *mylittleone* described; what made you decide to take up the offer?
8	**Had you seen/held your baby previous to seeing him/her using *mylittleone*?**
9	**Can you tell me about the first time you used *mylittleone*?** Probes: what did it feel like; what do you recall noticing first about your baby
10	**Can you tell me about your experience of *mylittleone* since then?** Probes: where do you usually place it; when do you look at it; how often do you look at it; what feelings do you experience when you do look at it; how does it compare with spending time in the unit with your baby?
11	**If a family chose not to use *mylittleone* or didn't have access to it, do you think their experience of caring for their baby might be different to yours?**
12	**How have other family members experienced/ what have they said about *mylittleone* e.g. children, grandparents?** Probes: what have they done with it; what have they said about it?
13	**Are there any particular aspects of caring for your baby which have been made easier by *mylittleone*?** Probes (ask about each in turn if they have not already been discussed): breastfeeding/feeding; physical closeness/contact; coming to/spending time in the unit; developing your relationship with your baby; getting to know your baby's mannerisms; becoming familiar with knowing when your baby is showing signs of a change in his/her condition; building confidence in caring for your baby; building confidence around monitoring/technical equipment; managing infection concerns; building relationships with nursing staff; the passage of time; your own emotional and physical health.

14	**Are there any particular aspects of caring for your baby which have been made more difficult by mylittleone?**
	Probes (ask about each in turn if they have not already been discussed): breastfeeding/feeding; physical closeness/contact; coming to/spending time in the unit; developing your relationship with your baby; getting to know your baby's mannerisms; becoming familiar with knowing when your baby is showing signs of a change in his/her condition; building confidence in caring for your baby; building confidence around monitoring/technical equipment; managing infection concerns; building relationships with nursing staff; the passage of time; your own emotional and physical health.
15	**Have you any suggestions about how the mylittleone might be developed to make it more useful for parents in the future?**
	Probes: any design issues; extending *mylittleone* so it can be used at home; sound; changes to the criteria for switching-off *mylittleone* for medical/nursing procedures.
16	**Have you any other points you would like to raise before we finish?**

Appendix 2 – Interview Guide (professionals)

1	**What do you think about/what are your experiences of *mylittleone*?**
2	**When you heard that *mylittleone* was being introduced within the Unit, what did you expect?**
3	**How have these expectations compared with your actual experience of using *mylittleone*?**
4	**Can you describe to me the first time you used *mylittleone* with a parent/parents/baby/babies? And, subsequently?**
5	**How have you, as a neonatal nurse/midwife/nursery nurse/doctor, experienced *mylittleone*?** Prompts: extra/less work; more/less contact with parents; more/less holistic care
6	**What have you observed about parents' experiences of *mylittleone*?** Prompts: Frequency of visiting the baby, way of interacting with baby/babies; ways of interacting with staff; tiredness/how rested parents are; emotional state e.g. anxiety, calmness; mental health; physical health; relationship with their baby; ability to care for and respond to their babies cues.
7	**What have parents told you about their experiences of *mylittleone*?**
8	**When introducing *mylittleone* to parents for the first time, what have been their responses?** Prompts: what are the important aspects to convey to parents; timing?
9	**Are there any difficulties which you have experienced when using *mylittleone*?** Prompts: with the equipment; relating to parents/babies use of it; relating to specific scenarios e.g. turning off when medical/nursing procedures.
10	**Have you observed any benefits have been gained for parents using *mylittleone*?** Prompts: Also for other family members; for babies.
11	**Have you observed any disadvantages for parents from using *mylittleone*?** Prompts: Also for other family members; for babies.
12	**Are there any babies and/or families you think particularly benefit from using *mylittleone*?**
13	Are there any babies and/or families for whom you think *mylittleone* is not appropriate?
14	**Are there any ways that *mylittleone* might be developed in the future to make it more useful for parents?** Prompts: Design; sound; criteria for switching on/off for nursing/medical procedures; to be able to use *mylittleone* at home.
15	**Are there any ways that *mylittleone* might be developed to make it more user-friendly for staff?**
16	**Have you any other points you would like to raise before we finish?**

Appendix 3 – Search terms (PsycINFO)

Bonding and attachment	MH Attachment behaviour MH Attachment disorders MH Parent child relations MH Psychological distance
Psychometric properties	MH Psychometrics MH Rating scales MH Test reliability MH Test validity MH Factor structure or factor analysis
Post-natal	KW post#natal KW post#partum

Depression	MH Postpartum depression
Psychometric properties	MH Psychometrics MH Rating scales MH Test reliability MH Test validity MH Factor structure or factor analysis

Anxiety/stress	MH Anxiety MH Anxiety disorders MH Separation anxiety MH Stress
Psychometric properties	MH Psychometrics MH Rating scales MH Test reliability MH Test validity MH Factor structure or factor analysis
Post-natal	KW post#natal KW post#partum

Emotional adjustment	MH Adjustment MH Emotional adjustment
Psychometric properties	MH Psychometrics MH Rating scales MH Test reliability MH Test validity MH Factor structure or factor analysis
Post-natal	KW post#natal KW post#partum

wellbeing	MH Well being
Psychometric properties	MH Psychometrics MH Rating scales MH Test reliability MH Test validity MH Factor structure or factor analysis
Post-natal	KW post#natal KW post#partum

Limiters (all searches)	Peer Reviewed English Language Adult

Appendix 4 – Bonding (COSMIN ratings)

Methodological Quality of Papers (n=5)

Bonding		Reliability			Validity				
Authors	**Instrument/s**	**IC**	**R**	**ME**	**CV**	**SV**	**HT**	**CrV**	**Res**
Bifulco et al (2004)	Attachment Style Interview		P						
Brockington et al (2006)	Postpartum Bonding Questionnaire		G					G	
Condon & Corkindale (1998)	Parent-to-Infant Attachment Assessment	G	G			G			
Taylor et al (2005)	Mother-to-Infant Bonding Scale	G							
Wittowski et al (2007)	Mother-to-Infant Bonding Scale Postpartum Bonding Questionnaire	F				P			

Internal Consistency (IC); Reliability (R); Measurement Error (ME); Content validity (CV); Structural Validity (SV); Hypothesis testing (HT); Criterion validity (CrV); Responsiveness (Res)

Ratings: Excellent (E); Good (G); Fair (F); Poor (P)

Measurement Properties

	Reliability			Validity				
Instrument (n=4)	**IC**	**R**	**ME**	**CV**	**SV**	**HT**	**CrV**	**Res**
Attachment Style Interview (1 study)		+						
Postpartum Bonding Questionnaire (2 studies)	+	+			+		+	
Parent-to-Infant Attachment Assessment (1 study)	+	+			0			
Mother-to-Infant Bonding Scale (2 studies)	0+				+			

Ratings: + = positive; 0 = intermediate; - = poor

Appendix 5 – Stress/anxiety (COSMIN ratings)

Methodological Quality of Papers (n=11)

Stress		Reliability				Validity			
Authors	**Instrument/s**	**IC**	**R**	**ME**	**CV**	**SV**	**HT**	**CrV**	**Res**
Berry & Jones (1995)	Parental Stress Scale	P	F			P	P		
Haskett et al (2006)	Parenting Stress Index (SF)	G	F			G	F		
Karam et al (2012)	Perceived Stress Scale (4 & 10 item)	P	F			G			
Thomas et al (2004)	Parenting Stress Index	P		P					
Anxiety									
Brouwers et al (2001)	Edinburgh Postnatal Depression Scale	E				P	F		
Matthey (2008)	Edinburgh Postnatal Depression Scale	P				P	P		
McDonald et al (2012)	Psychosocial Screening Tool						G		
Moran et al (2014)	Postpartum Worry Scale (revised)	G				G	G		
O'Hara et al (2012)	Postpartum Anxiety – Brief Scales						F		
Somerville et al (2014)	Perinatal Anxiety Screening Scale	E	P		E	F	F		
Swalm et al (2010)	Edinburgh Postnatal Depression Scale	G				F	P		

Internal Consistency (IC); Reliability (R); Measurement Error (ME); Content validity (CV); Structural Validity (SV); Hypothesis testing (HT); Criterion validity (CrV); Responsiveness (Res)

Ratings: Excellent (E); Good (G); Fair (F); Poor (P)

Measurement Properties

Instruments (n=9)	Reliability				Validity			
Stress	**IC**	**R**	**ME**	**CV**	**SV**	**HT**	**CrV**	**Res**
Parental Stress Scale (1 paper)	+	+			+			
Parenting Stress Index (SF) (1 paper)	+	+			-			
Parenting Stress Index (1 paper)	0		-					
Perceived Stress Scale (1 paper)	+	+						
Anxiety								
Edinburgh Postnatal Depression Scale (3 papers)	+++				+++			
Psychosocial Screening Tool (1 paper)						0		
Postpartum Worry Scale (revised) (1 paper)	0				+			
Postpartum Anxiety – Brief Scales (1 paper)						-		
Perinatal Anxiety Screening Scale (1 paper)	+	+			+			

Ratings: + = positive; 0 = intermediate; - = poor

Appendix 6 – Depression (COSMIN ratings)

Methodological Quality of Papers (n=15)

| Authors | Instrument/s | Bonding | | | | Reliability | | Validity | | |
		IC	R	ME	CV	SV	HT	CrV	Res
Barrick et al (2012)	Correa-Barrick Postpartum Depression Scale	P			F				
Beck & Gable (2000)	Postpartum Depression Screening Scale	F			E	F			
Beck & Gable (2001)	Postpartum Depression Screening Scale		F			P			
Beck et al (2012)	Postpartum Depression Screening Scale/Patient Health Questionnaire - 9	F							
Blucker et al (2014)	Postpartum Depression Screening Scale	F				F			
Chae et al (2012)	Patient Health Questionnaire - 2							F	
Cox et al (1987)	Edinburgh Postnatal Depression Scale	G			G			F	F
Davis et al (2013)	Pregnancy Risk Assessment Questionnaire/Patient Health Questionnaire - 9							F	
Gjerdingen et al (2009)	Patient Health Questionnaire – 9 Patient Health Questionnaire -2							F	
Hanusa et al (2008)	Edinburgh Postnatal Depression Scale Patient Health Questionnaire – 9 Postpartum Depression Screening Scale							F	
Ji et al (2011)	Edinburgh Postnatal Depression Scale Beck Depression Inventory Hamilton Rating Scale for Depression							F	
Manian et al (2013)	Beck Depression Inventory					E			
McCabe et al (2012)	Postpartum Depression Screening Scale	P				P			
Mitchell et al (2006)	Postpartum Depression Screening Scale	F							
Murray & Carothers (1990)	Edinburgh Postnatal Depression Scale							F	

Internal Consistency (IC); Reliability (R); Measurement Error (ME); Content validity (CV); Structural Validity (SV); Hypothesis testing (HT); Criterion validity (CrV); Responsiveness (Res)

Ratings: Excellent (E); Good (G); Fair (F); Poor (P)

Measurement Properties

Instruments (n=8)	Reliability				Validity			
	IC	R	ME	CV	SV	HT	CrV	Res
Postpartum Depression Screening Scale (7 papers)	+++++	+		+	+++-		0	
Edinburgh Postnatal Depression Scale (4 papers)	+			+			++++	+
Patient Health Questionnaire – 9 items (4 papers)	+						+++	
Patient Health Questionnaire – 2 items (2 papers)							++	
Hamilton Rating Scale for Depression (1 paper)							+	
Beck Depression Inventory (1 paper)					0		+	
Pregnancy Risk Assessment Questionnaire (1 paper)							+	
Correa-Barrick Postpartum Depression Scale (1 paper)	+			0				

Ratings: + = positive; 0 = intermediate; - = poor

Appendix 7 – Well-being (COSMIN ratings)

Methodological Quality of Papers (n=2)

Authors	Instrument/s	IC	R	ME	CV	SV	HT	CrV	Res
		Bonding			**Reliability**		**Validity**		
Sell (1994)	Subjective Well-being Inventory				F	F			
Tennant et al (2007	Warwick-Edinburgh Mental Well-being Scale	G	G		E	G	G	G	

Internal Consistency (IC); Reliability (R); Measurement Error (ME); Content validity (CV); Structural Validity (SV); Hypothesis testing (HT); Criterion validity (CV); Responsiveness (Res)

Ratings: Excellent (E); Good (G); Fair (F); Poor (P)

Measurement Properties

Instruments (n=8)	IC	R	ME	CV	SV	HT	CrV	Res
	Reliability				**Validity**			
Postpartum Depression Screening Scale (7 papers)				0	+			
Edinburgh Postnatal Depression Scale (4 papers)	+	+			+		+	

Ratings: + = positive; 0 = intermediate; - = poor

Appendix 8 - Mother-to-Infant Bonding Scale[1]

Name: Hospital number:

These questions are about your feelings for your child in the first few weeks. Some adjectives are listed below which describe some of the feelings mothers have towards their baby in the FIRST WEEKS after they were born. Please make a tick against each word in the box which best describes how you felt in the FIRST FEW WEEKS.

		Very much	A lot	A little	Not at all
1	Loving				
2	Resentful				
3	Neutral or felt nothing				
4	Joyful				
5	Dislike				
6	Protective				
7	Disappointed				
8	Aggressive				

Date of birth of baby: Date form filled in:

1 Source: Taylor A, Atkins R, Kumar R, Adams D, Glover V (2005) *A new Mother-to-Infant Bonding Scale: links with early maternal mood*. Archives of Women's Mental Health, 8: 45-51.

Appendix 9 - Postpartum Bonding Questionnaire[1]

		Always	Very often	Sometimes	Rarely	Never
1	I feel close to my baby					
2	I wish the old days when I had no baby would come back					
3	I feel distant from my baby					
4	I love to cuddle my baby					
5	I regret having this baby					
6	The baby does not seem to be mine					
7	My baby winds me up					
8	I love my baby to bits					
9	I feel happy when my baby smiles or laughs					
10	My baby irritates me					
11	I enjoy playing with my baby					
12	My baby cries too much					
13	I feel trapped as a mother					
14	I feel angry with my baby					
15	I resent my baby					
16	My baby is the most beautiful baby in the word					
17	I wish my baby would somehow go away					
18	I have done harmful things to my baby					
19	My baby makes me feel anxious					
20	I am afraid of my baby					
21	My baby annoys me					
22	I feel confident when caring for my baby					
23	I feel the only solution is for someone else to look after my baby					
24	I feel like hurting my baby					
25	My baby is easily comforted					

1   Source: Brockington LF, Fraser C, Wilson D (2006) *The Postpartum Bonding Questionnaire: a validation. Archives of Women's Mental Health*, 9: 233-242

Appendix 10 - Parental Stress Scale[1]

The following statements describe feelings and perceptions about the experience of being a parent. Think of each of the items in terms of how your relationship with your child or children typically is. Please indicate the degree to which you agree or disagree with the following items by placing the appropriate number in the space provided.

1 = Strongly disagree 2 = Disagree 3 = Undecided 4 = Agree 5 = Strongly agree

#	Statement	
1	I am happy in my role as a parent	
2	There is little or nothing I wouldn't do for my child(ren) if it was necessary.	
3	Caring for my child(ren) sometimes takes more time and energy than I have to give.	
4	I sometimes worry whether I am doing enough for my child(ren).	
5	I feel close to my child(ren).	
6	I enjoy spending time with my child(ren).	
7	My child(ren) is an important source of affection for me.	
8	Having child(ren) gives me a more certain and optimistic view for the future.	
9	The major source of stress in my life is my child(ren).	
10	Having child(ren) leaves little time and flexibility in my life.	
11	Having child(ren) has been a financial burden.	
12	It is difficult to balance different responsibilities because of my child(ren).	
13	The behaviour of my child(ren) is often embarrassing or stressful to me.	
14	If I had it to do over again, I might decide not to have child(ren).	
15	I feel overwhelmed by the responsibility of being a parent.	
16	Having child(ren) has meant having too few choices and too little control over my life.	
17	I am satisfied as a parent	
18	I find my child(ren) enjoyable	

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1 Source: Berry JD & Jones, WH (1995) *The Parental Stress Scale : initial psychometric evidence.Journal of Social and Personal Relationships*, 12: 463 – 472.

Appendix 11 - Perceived Stress Scale[1]

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling how often you felt or thought a certain way.

Name _____   Date _____

0=Never   1=Almost   Never   2=Sometimes   3=Fairly   Often   4=Very   Often

		0	1	2	3	4
1	In the last month, how often have you felt that you were unable to control the important things in your life?					
2	In the past month, how often have you felt confident about your ability to handle your personal problems?					
3	In the past month, how often have you felt that things were going your way?					
4	In the past month, how often have you felt difficulties were piling up so high that you could not overcome them?					

Appendix 12 - Edinburgh Postnatal Depression Scale1[1]

As you are pregnant or have recently had a baby, we would like to know how you are feeling. Please check the answer that comes closest to how you have felt IN THE PAST 7 DAYS, not just how you feel today.

Here is an example, already completed.

I have felt happy:
- ☐ Yes, all the time
- ☒ Yes, most of the time
- ☐ No, not very much
- ☐ No, not at all

This would mean: "I have felt happy most of the time" during the past week.

Please complete the other questions in the same way.

In the past 7 days:

1 I have been able to laugh and see the funny side of things
- ☐ As much as I always could
- ☐ Not quite as much now
- ☐ Definitely not so much now
- ☐ Not at all

6 Things have been getting on top of me
- ☐ Yes, most of the time I haven't been able to cope at all
- ☐ Yes, sometimes I haven't been coping as well as us
- ☐ No, most of the time I have coped quite well
- ☐ No, I have been coping as well as ever

2 I have looked forward with enjoyment to things
- ☐ As much as ever I did
- ☐ Definitely less than I used to
- ☐ Hardly at all
- ☐ Rather less than I used to

7 I have been so unhappy that I have had difficulty sleeping
- ☐ Yes, most of the time
- ☐ Yes, sometimes
- ☐ Not very often
- ☐ No, not at all

3 I have blamed myself unnecessarily when things went wrong
- ☐ Yes, most of the time
- ☐ Yes, some of the time
- ☐ Not very often
- ☐ No, never

8 I have felt sad or miserable
- ☐ Yes, most of the time
- ☐ Yes, quite often
- ☐ Not very often
- ☐ No, not at all

4 I have been anxious or worried for no good reason
- ☐ No, not at all
- ☐ Hardly ever
- ☐ Yes, sometimes
- ☐ Yes, very often

9 I have been so unhappy that I have been crying
- ☐ Yes, most of the time
- ☐ Yes, quite often
- ☐ Only occasionally
- ☐ No, never

5 I have felt scared or panicky for no good reason
- ☐ Yes, quite a lot
- ☐ Yes, sometimes
- ☐ No, not much
- ☐ No, not at all

10 The thought of harming myself has occurred to me
- ☐ Yes, quite often
- ☐ Sometimes
- ☐ Hardly ever
- ☐ Never

1   Source: Cox JL, Holden JM, Sagovsky R (1987) *Detection of postnatal depression: development of the 10-item Edinburgh Postnatal depression scale.* British Journal of Psychiatry, 150:782-786.

Appendix 13 - The Perinatal Anxiety Screening Scale[1]

Over the past month, how often have you experienced the following?
Please tick the response that most closely describes your experience for every question.

		Not at all	Sometimes	Often	Almost Always
1	Worry about the baby				
2	Fear that harm will come to the baby				
3	Sense of dread – something bad is going to happen				
4	Worry about many things				
5	Worry about the future				
6	Feeling overwhelmed				
7	Really strong feelings about things e.g. blood, pain, needles				
8	Sudden rushes of extreme fear/discomfort				
9	Repetitive thoughts difficult to control				
10	Difficulty sleeping even when there is the chance to sleep				
11	Having to do things in a certain way or order				
12	Wanting things to be perfect				
13	Needing to be in control of things				
14	Difficulty stopping checking or doing things over and over				
15	Feeling jumpy or easily startled				
16	Concerns about repeated thoughts				
17	Being 'on guard' or needing to watch out for things				
18	Upset about repeated memories, dreams or nightmares				
19	Worry that I'll embarrass myself in front of others				
20	Fear that others will judge me negatively				
21	Feeling uneasy in crowds				
22	Avoiding social activities because I might be nervous				
23	Avoiding things which concern me				
24	Feeling detached like watching yourself in a movie				

25	Losing track of time and can't remember what happened				
26	Difficulty adjusting to recent changes				
27	Anxiety getting in the way of being able to do things				
28	Racing thoughts making it hard to concentrate				
29	Fear of losing control				
30	Feeling panicky				
31	Feeling agitated				

1 Source: Somerville S, Dedman K, Hagan R, Oxnam E, Wettinger M, Byrne S, Coo S, Doherty D, Page AC (2014) *The Perinatal Anxiety Screening Scale: development and preliminary validation.* Archives of Women's Mental Health, 17:443-454.

Appendix 14 - Patient Health Questionnaire – 9[1]

Over the last 2 weeks, how often have you been bothered by any of the following problems? (Use ✔ to indicate your answer)	Not at all	Several days	More than half the days	Nearly every day
1 Little interest or pleasure in doing things	0	1	2	3
2 Feeling down, depressed, or hopeless	0	1	2	3
3 Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4 Feeling tired or having little energy	0	1	2	3
5 Poor appetite or overeating	0	1	2	3
6 Feeling bad about yourself – or that you are a failure or have let yourself or your family down	0	1	2	3
7 Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8 Moving or speaking so slowly that other people could have noticed? Or the opposite – being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9 Thoughts that you would be better off dead or hurting yourself in some way.	0	1	2	3

If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	Somewhat difficult	Very difficult	Extremely difficult
☐	☐	☐	☐

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1   Source: Kroenke K, Spitzer RL, Williams JB. (2001) *The PHQ-9: validity of a brief depression severity measure.* Journal of General Internal Medicine, 16(9):606-613.

Appendix 15 - Warwick-Edinburgh Mental Well-being Scale[1]

		None of the time	Rarely	Some of the time	Often	All of the time
1	I've been feeling optimistic about the future					
2	I've been feeling useful					
3	I've been feeling relaxed					
4	I've been feeling interested in other people					
5	I've had energy to spare					
6	I've been dealing with problems well					
7	I've been thinking clearly					
8	I've been feeling good about myself					
9	I've been feeling close to other people					
10	I've been feeling confident					
11	I've been able to make up my own mind about things					
12	I've been feeling loved					
13	I've been interested in new things					
14	I've been feeling cheerful					

1   Warwick-Edinburgh Mental Well-Being Scale (WEMWBS)

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