

SUPPLEMENTARY MATERIAL 2

QUALITATIVE STUDY

1 MATERIALS

This supplementary information contains materials used in the qualitative study including: advert used to recruit parents into study (1.1), the informative sheet (1.2) and the consent used for parental involvement (1.3).

In our study we interviewed ten parents in order to understand the preferences in terms of neonatal care and to collect useful information to develop a further DCE. Each interview followed a topic guide 2.

Policy interviews were also used to collection information on the factors thought important by decision makers which followed the topic guide reported in 3

A framework was developed in order to define the topics and the determinants of the interviews for the qualitative study 4.

1.1 Advertising

Are you a parent who has used a neonatal service and been discharged from the service within the last 6 months to 5 years? Are you keen to influence the future planning of neonatal services in England?

If so, we are looking to invite parents to take part in an interview to share their experiences of neonatal services.

Why are we looking for parent input?

We are hoping to interview a selection of parents about their experiences of neonatal services, so that they can have a say about the services. We will pay travel expenses, child care costs and a small 'thank you' in recognition of your time and effort.

What is the aim of the project?

The project is part of a larger study which aims to have the right cot, in the right place, at the right time to maximise the quality of neonatal services. We have built a computer model of neonatal services to look at the impact that changes in services will have on the

care of infants. This includes the impacts on the travel time to neonatal units and overnight stays in hospital. The objective of this part of the study is to find out how important some of these changes might be to families and if there are any other aspects of the service that we need to consider.

Would you like to be involved?

If so, please register your interest with Sue Prosser by 15th March 2017.

Susan.prosser@nhs.net or 01392 XXXXXX

1.2 Info sheet

EXPLORING THE FACTORS IMPORTANT TO CONSIDER IN ORGANISING NEONATAL SERVICES

INFORMATION SHEET FOR PARTICIPANTS FOR QUALITATIVE INTERVIEW

VERSION NUMBER 2: DATE 08/03/2017

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

What is the aim of the project?

The project is part of a larger study which aims to have the right cot, in the right place, at the right time to maximise the quality of neonatal services. We have built a computer model of neonatal services to look at the impact that changes in services will have on the care of infants. This includes the impacts on the travel time to neonatal units and overnight stays in hospital. The objective of this part of the study is to find out how important some of these changes might be to families and if there are any other aspects of the service that we need to consider.

Description of participants required

We are keen to speak to a range of parents who have had experience of neonatal services and have been discharged from the service within the last 6 months to 5 years to share their experience of neonatal care and what they consider to be important to them as users of the service.

What will participants be asked to do?

You will be asked to participate in a face-to-face interview with a researcher. The project involves an open-questioning technique where the precise nature of the questions asked

has not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the Research Ethics Committee is aware of the general areas to be explored in the interview, the Committee has not been able to review the precise questions to be used.

You will be asked if you are happy for the interview to be recorded and to provide some basic information about yourself, your experiences of neonatal care and what aspects of the service were important to you. At the end of the interview, you will have the chance to make any additional comments about your experience.

Time commitment and location of interviews

The interview will take 40-60 minutes at St Luke's Campus at the University of Exeter. If travelling to the university is not convenient for you, the researcher, Katie Kelsey, can come and interview you in your home or a place of your choosing.

Can I change my mind and withdraw from the Project?

If at any stage you feel uncomfortable or hesitant during the interview you can decline to answer. You can also choose to withdraw at any stage without any disadvantage to yourself.

What data or information will be collected and what use will be made of it?

The views you express in the interview will be used solely to investigate people's views and experiences about Neonatal services. Only our Project Team will have access to your interview responses: Dr Jo Day (qualitative researcher employed by the University of Exeter Medical School), Dr Anne Spencer (Associate Professor of Health Economics, University of Exeter Medical School), Dr Paolo Landa (a Research Fellow at the University of Exeter) and Katie Kelsey (a qualitative researcher employed by the University of Exeter). An anonymised transcription of the interview will be securely stored in such a way that only those mentioned above will be able to gain access to it.

Results of this project may be published but there will be no reference to any individual involved. Participants in this project will be provided with a copy of the final report.

If you consent for the interview to be shared with other researchers we will store an anonymised transcription of the interview in safe storage at the University of Exeter data storage.

Why me?

You have responded to an advertisement asking for people to participate in this research. Because you have shown an interest in this research, we would like to invite you to take part.

Payments to interviewees

You will be paid travel expenses, child care costs and a £15 gift token as a small 'thank you' in recognition of your time and effort. The gift token can be used in many retail outlets (see one4allgiftcard <https://www.one4allgiftcard.co.uk/gift-cards-online>) from Amazon. All travel expenses will be reimbursed in line with standard University rates. Please bring your bank details to the interview so we can arrange payment.

What if participants have any questions?

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Mrs Katie Kelsey	or	Dr Anne Spencer
Health Economics Group		Health Economics Group
University of Exeter Medical School		University of Exeter Medical School
South Cloisters		South Cloisters
St Luke's Campus		St Luke's Campus
Exeter		Exeter
EX1 2LU		EX1 2LU
07XXXXXXXXXX		01392 XXXXX

Complaints

If you have any complaints about the way in which this study has been carried out please contact the Co-Chairs of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD.

Chairs, UEMS Research Ethics Committee

E-mail: R.Garside@exeter.ac.uk

**This project has been reviewed and approved by the University of Exeter Medical School
Research Ethics Committee**

UEMS REC REFERENCE NUMBER: Dec16/B/096Δ2

1.3 Consent

EXPLORING THE FACTORS IMPORTANT TO CONSIDER IN ORGANISING NEONATAL SERVICES

CONSENT FORM FOR PARTICIPANTS FOR QUALITATIVE INTERVIEW

VERSION NUMBER 2: DATE 08/03/2017

I have read the Information Sheet Version Number 2 Dated 08/03/2017 concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1. my participation in the project is entirely voluntary; Yes /No
2. I am free to withdraw from the project at any time without any disadvantage;
Yes /No
3. this project involves an open-questioning technique, and I can decline to answer any particular question(s) without any disadvantage; Yes/No
4. the interviewer will ask for my experience of neonatal care and what factors were important to me; Yes/No
5. the interview will take between 40-60 minutes to complete; Yes/No
6. my travelling expenses will be reimbursed in line with standard University rates;
Yes/No
7. the results of the project may be published but my anonymity will be preserved.
Yes/No
8. if information given during the interview gives cause for concern for the safety of myself or my family, appropriate others may need to be informed and this will be discussed with me. Yes/N
9. I agree that my anonymised data will be retained in secure storage and shared with other researchers (I can still take part if I do not agree). Yes/No

10. I agree to the recording and transcription of my interview. Yes/No

I agree to take part in this project.

.....

(Printed name of participant) (Signature of participant) (Date)

.....

(Printed name of researcher) (Signature of researcher) (Date)

2 FLEXIBLE TOPIC GUIDE FOR INDIVIDUAL INTERVIEWS

Start

- Refreshments.
- Information sheet talk through the main points it covers and check clear about what to expect and how the interview will work.
- Remind that if at any time want to stop, prefer not to answer a question or take a break that is absolutely fine.
- Any further questions or queries.
- Provide the consent form and explain purpose of this and check happy for the interview to be recorded.
- If not happy to proceed then thank them for taking the time to consider and confirm that all personal information they have provided will be deleted.
- If happy to proceed then confirm that will start recording and the interview.

Interview Topics

General introduction:

As the introduction leaflet explains we are seeking a range of families' views on neonatal services and will start with just a few background questions.

1. Opening question

Can you tell me about yourself? Your experience of the neonatal services...

(We will now move to consider specific aspects of your experience)

2. What were your experiences of the hospital environment?

Probe: Were you satisfied with the care received in the neonatal unit?

3. How did you travel to the neonatal unit?

Probes: What type of transport did you use?

How long did it take?

Did you travel alone?

Did you have to stay overnight?

How did this travel affect the family? (Strain?)

4. What impact did the neonatal care have upon the rest of the family?

Probes:

What were the main challenges faced by the family?

Did you have to take time off from work?

Did you have to pay for childcare?

How did this affect the family? (Strain?)

I'd like to talk about the information you were given at the time:

5. What do you remember about the information you were given to do with the risks involved, for babies coming to a neonatal unit?

- ***Prompt...Were you informed about the risks of long term health problems for your baby, (name?)?, such as problems with eye sight and hearing.***

6. Did you use any neonatal support groups?

Probes:

Locally there is an organisational called SNUG to help women through neonatal care.

Nationally there is an organisation called BLISS. Did you use these or any other support groups?

If usedhow did these support groups affect the family?

If did not use the reason for this?

7. Relating to your specific circumstances (using the specific information from the first questions)

a. What factors are/were important to you when considering the care you received for your child?

Probes: Could you say which factors were/are more important to you? How do you feel about it now?

b. What factors do you think might be important for other families?

Probes: If you think of other families you met, what factors of neonatal might be important to them?

Explore issues raised in the public and patient involvement if not already covered e.g.

- Concerns over risks of infant death
- Uncertainties over childhood illness
- Travel time.
- Access to support networks
- Psychological strain
- Impact on rest of family

(If not addressed above)

C. Close of interview.

Is there anything else that you would like add that not already covered?

D. End recording and then complete the demographic in the form of a tick box questionnaire.

Explain that would like you to answer some questions about yourself and family

. All of the answers you provide will be confidential – they will only be seen by members of the project team

3 TOPIC GUIDE FOR NEONATAL NETWORK MANAGER – DECISION MAKER

Warm up

- 1) What is your role in the _____ neonatal network?
- 2) What constraints might we aim to build into the modelling work?
- 3) How feasible is it for a unit to transform from a lower level unit, like a special care unit, to high dependency or a NICU?
- 4) Is the aim to have one NICU in every local neonatal network?

Centralisation

- 1) How would you suggest the units offset the negative consequences to families of centralisation? (Wi-Fi, parking, accommodation)
- 2) How would you prioritise these facilities?
- 3) Most families where it is their first child prefer to stay close to the infant. To what extent/proportion (cover X%?) should the accommodation of families be provided for these families (either by charity or by NHS)?
- 4) When do you provide overnight stays to families?
- 5) Currently units are charged an overhead for the proportion of floor area devoted to neonatal care – some of this floor space is used for clinical care some for family spaces. Do you have an example of best practice for space provided to families in a neonatal unit?

Cost algorithm

Table 1: What are the critical levels where we should think of using different cost models?

	Percentage of cost	Impacts due to centralisation/assumptions
Costs affected by economies of scale		
Overheads	5%	<ul style="list-style-type: none"> Percentage of space for clinical Percentage of space for families
Wi-Fi public	variable	<ul style="list-style-type: none"> Family use
Auxiliary	15%	<ul style="list-style-type: none"> Do not change OR Sicker infants kept alive so increased costs (but no evidence).
Consultants	20%	<ul style="list-style-type: none"> Granularity issue for smaller units
Nurses (60% cost)	60%	<ul style="list-style-type: none"> Model will estimate impacts based on percent of nursing achieving BAPM
Allied professionals (dieticians, physiotherapist) and non-clinical		<ul style="list-style-type: none"> Granularity issues for smaller units
Costs NOT affected by economies scale		
Flats	Variable-Some sites 30-60 time taken to travel, others 60-120 minutes.	<ul style="list-style-type: none"> Hospital in larger cities assign flats if more than 1 hour travel Hospitals in smaller cities assign flats if more than 2 hours travel Accommodation provided to all families where infant is first child and income less than XX.
Free car park		<ul style="list-style-type: none"> All infants
Food and drinks family		<ul style="list-style-type: none"> All families
Family support services – available network level	Online support	<ul style="list-style-type: none"> Not affected by changes

Review the factors suggested to be included to assess impact of centralisation

Previous interviews with families suggest the following factors are included in the study (draft attributes given for illustration only here).

Table 2: Factors to include in study

Option A
maternal mental health
risk of infant mortality
risk of childhood long term health problems
Travel time to neonatal services

Table 3: What are the feasible levels that these different attributes take?

Factor	New service
Maternal mental health	Reduce anxiety and depression
Risk of infant mortality	Reduce from 5 in 100 to 2 in 100
Risk of childhood long term health problems	Reduce from 2-6 in 100 to 1-3 in 100
Access of neonatal services	Increase time of travel for all families from 60 minutes to 120 minutes



Figure 1 : Pyramid of priority for parents and themes adopted to analyse neonatal care

What configurations should we model?

Are there any policy documents around configurations that service might take?

Plan of work so far

Current units:

Current NICUs, LNUs and SCUs with patients going to the closest unit

Reducing numbers of NICU:

- 100 % of VLBW attend units with more than 100 VLBW / year. (Such configuration has 48 NICUs, so it would mean upgrading some units to NICUs and downgrading some NICUs to other).
- Optimal configuration of LNUs
- The remaining units are SCUs.

Greater centralisation:

- 30 NICUs which maximise proportion in 30 minutes with all having >100 VLW per year
- 30 LNUs that leads to greatest proportion of infants requiring HDU care being within 30 minutes of home
- 30 SCUs that leads to greatest proportion of infants requiring SCU care being within 30 minutes of home

Dissemination Strategy

Is there are meeting where all network managers attend?

4 CODING FRAMEWORK

This coding framework was developed for analysing the transcripts of the qualitative interviews. It was devised with the following objective in mind and developed during the coding process as themes began to emerge:

The objective of this part of the study is to find out how important some of these changes might be to families and if there are any other aspects of the service that we need to consider;

- identify outcomes important to parents of children with neonatal care;
- refine the language used to describe the outcomes;
- explore the extent to which these outcomes are perceived to vary by parents

Table 4 : Coding framework for qualitative interviews

Short Code	Long Code In addition to the overall heading	Topic Guide	Notes, examples definitions
1. Background/story	1.1 Gestation 1.2 Length of stay 1.3 Family size	1	Circumstances leading to the admission to Neonatal ward
2. Hospital Environment	2.1 Confidence with nursing staff 2.2 "ownership of infant"	2	Busy, Calm, helpful. Parents felt involved and part of the care of their baby.
3. Travel Time		3	Time and distance from the hospital. Means of transport
4. Family disruption	4.1 Emotional 4.11 Couple 4.2 Financial	4	Includes emotional and financial costs
5. Understanding of Risks	5.1 Infant Death	5	

	5.2 Long term disability/illnesses		"...thought she might not make it..."
6. Mitigating aspects	6.1 Family Support 6.2 SNUG and BLISS 6.3 Hospital Staff	6, 2	E.g. Support Groups, facilities
7. Language	7.1 Medical Language 7.2 Outcome language (parents) 7.3 Information	7	How the parents explain the events, services, treatments, How well they understood what was happening. How well was it explained?
8. Health of Mother	8.1 Pre-natal 8.2 Post-natal 8.3 Post hospital	8	Eg, High blood pressure, Preeclampsia C section Emotional state
9. Condition of baby	9.1 in hospital 9.2 post discharge 9.3 preparing for discharge	1, 4, 6	
10. Post discharge		1, 4, 6	Follow up, support (or lack of), confidence of parents with caring responsibilities
11. Emotional responses			'Scary', 'Angry', 'terrified',
12. Other	12.1 trial 12.2 no baby 12.3 suggestions		Sensitive to the feelings of other families "...because you don't know how poorly that other person is..."
13. Most important thing		7	When asked what was important to them.