Agenda No 3

AGENDA MANAGEMENT SHEET

Name of Committee	**Health Overview and Scrutiny Committee**
Date of Committee	**15th June, 2005**
Report Title	**Access to Maternity Services**
Summary	This report reviews the access to maternity services in Warwickshire.

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Would the recommended decision be contrary to the Budget and Policy Framework?	No.
Background papers	None

CONSULTATION ALREADY UNDERTAKEN:- Details to be specified

Other Committees	☐	.....
Local Member(s)	☐	
Other Elected Members	☐	
Cabinet Member	☐	.....
Chief Executive	☒	David Carter.....
Legal	☒	Jane Pollard.....
Finance	☐	.....
Other Chief Officers	☒	Marion Davis.....
District Councils	☐	.....
Health Authority	☐	.....

Police	☐	.....
Other Bodies/Individuals	☐	.....

FINAL DECISION NO

SUGGESTED NEXT STEPS: Details to be specified

Further consideration by this Committee	☒	.....
To Council	☐	.....
To Cabinet	☐	.....
To an O & S Committee	☐	.....
To an Area Committee	☐	.....
Further Consultation	☐	.....

Agenda No 3

Health Overview and Scrutiny Committee - 15th June, 2005.

Report of Access to Maternity Services Panel

Report of the County Solicitor and Assistant Chief Executive

Recommendation

1. That the committee considers the final report of the 'Access to Maternity Services Panel'

2. That the committee considers the recommendations as set out in section 9 of the report

1. Background

1.1 At it's meeting on the 23rd July, the Health Overview and Scrutiny Committee agreed its programme of work for 2003-2005. This followed extensive consultation with the statutory and voluntary sector to identify initial issues to be scrutinised. The programme included the scrutiny of 'Access to Maternity Services'. This review was chosen out of concerns raised by some women that maternity provision locally did not always give them the care they expected when having a baby. The Terms of Reference for the scrutiny exercise were agreed and are attached (appendix 1)

1.2 The Committee nominated the following County Council Members to the scrutiny exercise panel: Cllr Sarah Boad (Chair), Cllrs Marion Haywood, Helen McCarthy, Sidney Tooth and Dot Webster. Stratford District Council Member Cllr Jane Harrison. Officer support provided by: Alwin McGibbon (Health Scrutiny Officer) and Josephine Haworth (Committee Services).

1.3 The first panel meeting was held on 29th June 2004 and the majority of the scrutiny was carried out between July 2004 and March 2005.

2. Recommendations

2.1 The Committee is asked to consider the report and its recommendations.

DAVID CARTER
County Solicitor and Assistant
Chief Executive

Shire Hall
Warwick

April 2005

Health Overview and Scrutiny Committee

Report of the Access to Maternity Services Panel

Contents

Appendices

Glossary of Terms

CNN – Central Newborn Network
NCT – National Childbirth Trust
NSF – National Service Framework
MSLC - Maternity Services Liaison Committee
PCT – Primary Care Trust
PPFI – Patient & Public Involvement Forum
RCN – Royal College of Nursing
SCBU – Special Care Baby Unit
Ante natal – before birth
Post natal – after birth
Neo natal – new birth (relates to baby only)

Acknowledgements

The Health Overview and Scrutiny Committee would like to thank the following people and organisations for their help and support while conducting this review.

Helen Walton – Maternity Services Manager, Warwick Hospital

Richard de Boer – Consultant Paediatrician, George Eliot Hospital

Hilary Schmidt – Hansen & Catherine Williams - Warwick Maternity Services Liaison Committee

Nicola Jones – National Childbirth Trust

Dr Sophie Stanisweska – Senior Research Fellow, RCN Institute

Health Overview and Scrutiny Committee would also like to thank all those who helped distribute the Access to Maternity Services questionnaires - Warwick & George Eliot Hospitals; Maternity Services Liaison Committee; Parent Centres in Nuneaton & Bedworth, Warwick and Rugby; Leamington Sure Start; Health Visitors; Bath Place Community Venture and the local NCT.

1. Introduction

1.1 The Health and Social Care Act 2001 gave English Local Authorities with Social Services responsibilities a new power. From January 2003 Local Authority Overview and Scrutiny Committees have been required to review and scrutinise the operation of health services in their area and make reports and recommendations to NHS bodies relating to these investigations. This scrutiny does not only look at services provided by the NHS, but considers the services provided by Warwickshire County Council and the Borough and Districts, which could impact on the health of their citizens.

1.2 Warwickshire's Strategic Plan for 2002-2005 and the County Council's Best Value Performance Plan 2003-2004 both identify 'improving health and well being of Warwickshire citizens' as a key priority. This new responsibility reinforces existing plans, actions and targets set out in these documents.

1.3 At its meeting on 23rd July 2003, the Health Overview and Scrutiny Committee agreed its Health Scrutiny Programme of work for the period 2003-2005. This followed extensive consultation with the statutory and voluntary sector to identify initial issues to be scrutinised. The programme included the scrutiny of 'Access to Maternity Services'. The terms of Reference for the scrutiny exercise were agreed and are attached **(Appendix 1)**.

1.4 The Committee nominated the following County Council Members to the scrutiny exercise panel:
Cllr Sarah Boad (Chair)
Cllrs Marion Haywood, Sidney Tooth, Helen McCarthy and Dot Webster.
Cllr Jane Harrison (Stratford District)
Officer support provided by:
Alwin McGibbon (Health Scrutiny Officer)
Josephine Haworth (Committee Services)
Expert help and information was provided by:
Richard de Boer (Consultant Paediatrician, George Eliot Hospital)
Helen Walton (Maternity Services Manager, Warwick Hospital)

2. Aims and Objectives

2.1 The aim of this scrutiny exercise was to examine the access to maternity services throughout Warwickshire. It involved scrutinising all maternity services through pre-conception, early pregnancy, antenatal and postnatal care, the midwifery services and services provided by hospital maternity units. It also looked at neonatal provision in Warwickshire. It discussed maternity provision with members of the National Childbirth Trust, Central Newborn Network and the local Maternity Services Liaison Committees from George Eliot and Warwick Hospital.

2.2 A successful outcome from this review would be that Warwickshire Maternity Services provides a flexible, appropriate, clinically effective and accessible service in response to the needs of women and their families. It takes account of equity of access to service in line with the social inclusion agenda.

2.3 In response to the Health Select Committee's report on maternity services, the Health Minister, Stephen Ladyman said:

"We believe that improving maternity services around the country is essential to giving babies and mothers the best start in life.

"Our highest priority must be to tackle inequalities in access to services and health outcomes for women and their babies.

"A key theme of the Children's National Service Framework (NSF) is to reduce inequalities and improve access to care. The maternity module of the NSF will set national standards of care, covering antenatal, birth and postnatal services.

"We are committed to extending choice and support provided in maternity services for all women throughout their pregnancy."

3. Maternity Provision in Warwickshire

3.1 **Maternity Services Warwick Hospital**
The geographical area covered by Warwick Hospital, includes most of Stratford upon Avon District, as well as the major towns and rural areas of Warwick District.

3.1.1 In 2003 there were 2700 births, 2% of these were home births. Broken down further 62.4% were by normal delivery, 13.5% required instrumental assistance and 24.9% were delivered by caesarean section.

3.1.2 The antenatal care offered at Warwick Hospital includes GP surgery/home visiting, antenatal clinics, ultrasound scans, parentcraft classes, on-call system and home birth services.

3.1.3 Warwick Hospital has recently increased the number of beds from 20 back to 27 (the unit had 27 beds in 2003). They have 7 delivery rooms, birthing pool, 6 flexibeds, they have the capacity for 11 Special Care Baby Unit (SCBU) cots, but only have staff for 8. They provide breastfeeding support and are in the process of appointing joint Surestart breastfeeding advisors. Also they intend to apply for accreditation with UNICEF UK Baby Friendly Initiative

3.1.4 Mothers are given choice on the type of care, place of birth, monitoring, screening, pain relief and length of stay.

3.1.5 User involvement is via the Maternity Services Liaison Committee, Labour Ward Forum, Parentcraft Group and Guideline Group.

3.1.6 Warwick Hospital are planning to expand midwifery led care, increase home births, increase the normal birth rate (by reducing the number of caesareans), provide an alternative therapy service, have a day assessment unit and provide transitional care. In 2004 the home birth rates increased to 3% and they reduced the number of caesareans by 2%

3.2 Maternity Services George Eliot Hospital

3.2.1 The geographical area of George Eliot Hospital extends as far as the rural areas of North Warwickshire and includes the towns of Nuneaton and Bedworth.

3.2.2 In 2003 there were 2346 births at George Eliot Hospital, 0.9% of these were home births. Broken down further 69% were by normal delivery, 7.5% required instrumental assistance and 23.5% were delivered by caesarean section.

3.2.3 George Eliot has 32 beds, 9 delivery rooms, birthing pool and 12 SCBU cots. They provide breastfeeding support through a La Leche volunteer and a newly appointed parent educator (a non professional). George Eliot Maternity Unit is planning to apply for accreditation with UNICEF UK Baby Friendly Initiative.

3.2.4 There is a very useful website for mothers planning to have a baby at George Eliot Hospital with a welcome page, advice on what to expect, choice on whether to have a home or hospital birth, parent preparation sessions, neonatal care and health tips.

3.2.5 User involvement is also available via the Maternity Services Liaison Committee at George Eliot Hospital.

3.3 Maternity Services University Hospitals of Coventry and Warwickshire NHS Trust

3.3.1 In 2003 the Walsgrave Hospital Maternity Unit in Coventry had 3861 births. Broken down further 66.4% were by normal delivery, 7.4% required instrumental assistance, and 26.2% were delivered by caesarean section.

3.3.2 The University Hospitals Coventry and Warwickshire NHS Trust not only provides level three - intensive care for babies via the Central Newborn Network, but covers maternity provision specifically for the Rugby area. Mothers from Rugby are given a choice of attending either Warwick or Walsgrave Hospital.

3.3.3 The Walsgrave Hospital has a Certificate of Commitment to the UNICEF UK Baby Friendly Initiative.

3.3.4 The new Coventry and Warwickshire Hospital will be fully opened in 2006. This may impact on the number of mothers continuing to elect to go to either Warwick or George Eliot Hospital as they do at the moment.

3.4 Maternity Services Provision Elsewhere

3.4.1 Mothers living near the borders of Warwickshire do attend hospitals other than those already mentioned.

3.4.2 Mothers in the south of the county can attend Alexandra Hospital, Redditch. In 2003 they had 1825 births, 27.2% were delivered by caesarean section.

3.4.3 Mothers in north of the county can attend Birmingham Women's Hospital, which include Solihull and Heartlands Hospitals. In 2003 they had 6506 births, broken down further 70.7% were by normal delivery, 6.6% needed instrumental assistance and 22.7% were delivered by caesarean section.

4. Scope

4.1 In order to achieve the aims set out in **Section 2,** the scrutiny explored the following as set out in the terms of reference.

a) Provision of Neonatal Care in Warwickshire

b) Patient Choice – whether to have a baby at home or hospital, normal delivery or caesarean?

c) Is there equity of access such as the provision of antenatal classes

d) Is a 20 week scan really necessary? What do mothers think?

e) How many link workers are there in Warwickshire that can provide interpretation/translation services?

f) Whether the lack of 20 week scan at the Walsgrave Hospital, Coventry has an impacted on maternity provision in Warwickshire? (Both George Eliot and Warwick Maternity Units provide a 20 week scan)

g) Is a 20 week scan necessary? What do the Royal College of Obstetricians think?

h) Attitudes of health professionals?

i) Perception of certain hospitals is this justified?

j) What support mechanisms are there for mothers and their families?

k) What support mechanisms are there for mothers and fathers on first discharge?

l) What support is given to promote breastfeeding?

m) What provision is there for ethnic minority groups such as interpreters for mothers where English is not their first language?

4.2 To complete the scope an area still to be explored is whether Portuguese mothers' maternity needs are being met. There was a delay in appointing a community worker, which would have assisted with this part of the review. The panel have decided to conduct a smaller separate review on Portuguese women's maternity needs and report the findings at a later date.

4.3 To achieve the scope's objectives the panel have sought advice from Richard de Boer, Consultant Paediatrician, George Eliot Hospital and Helen Walton, Maternity Services Manager, Warwick Hospital.

4.4 Initial desktop research, talking with interested parties such as the National Childbirth Trust (NCT), Warwick Hospital Maternity Services Liaison Committee (MSLC) formed the basis of this review. The panel did try to meet with George Eliot MSLC, but unfortunately due to a change in the MSLC chair and time constraints this did not happen. The panel visited Parent Centres and Sure Starts in Nuneaton and Warwick.

4.5 The panel had some involvement with the Central Newborn Network (CNN) in assessing the level of care that Maternity Units could provide in the Coventry & Warwickshire area.

4.6 To gain a broader understanding of access to maternity service provision a questionnaire circulated throughout Warwickshire **(See Appendix 2)**. This also included a section on breastfeeding and the results from this are going towards the Joint Review with Coventry City Council on the initiation and duration of breastfeeding.

5. Provision of Neonatal Care in Warwickshire

5.1 Central Newborn Network

5.2 In September 2004 the Central Newborn Network (CNN) agreed criteria for the designation of neonatal units and the standards expected for each level of neonatal care[1]. There are three levels of care:

- level one, special care – continuing care for babies who need specialist support such as tube feeding or care in incubators
- level two, high dependency care – specialist care for babies requiring continuous support and observation for neonatal conditions
- and level three, intensive care – critically ill babies requiring continuous support for organ failure and continuous observation

5.3 These levels of care are in addition to the normal level of care provided to babies that are generally healthy and have gone to full term.

5.4 George Eliot and Warwick Hospitals are classed at level one. Babies requiring high dependency care or intensive care would in the first instance go to the University Hospitals Coventry and Warwickshire NHS Trust. This is the nearest Maternity Unit, which is classified at level three if there are no cots available at UHCW the next nearest alternative would be Leicester Hospital. The CNN boundary includes Leicestershire, Northamptonshire, Rutland, Coventry, Warwickshire and Burton and the aim is that all Warwickshire mothers will be covered within this network. However, at the moment approximately 40% of babies from Warwick go to the University Hospital Coventry and Warwickshire. The remaining 60% are transferred to hospitals elsewhere and can end up as far away as Liverpool or Leeds.

6. Patient Choice

6.1 The access to maternity services questionnaire (See appendix 2) explored the following:

a) Antenatal care – if women wanted to attend was it accessible?
b) Whether a 20 week scan was important to them
c) Whether women was given enough information to make the choice on whether to have a baby at home or in hospital
d) Whether women wanted a choice of hospital
e) Whether women had enough information to help them choose a hospital

[1] 'Standards for Hospitals providing Neonatal Care'. Version 1 agreed by CNN Network board 19.9.04. Based on the British Association of Perinatal Medicine and Department of Health Review Group recommendations.

'I initially didn't want to attend classes thinking they would have me sat on the floor doing breathing exercises! However, they were very useful and informative and I am glad I did go.'

6.2 Antenatal Care

6.2.1 Concerns were raised on whether antenatal classes were accessible to all women who wanted to attend. Just under half of the respondents (46%) were able to attend antenatal classes.

6.2.2 These respondents were then asked if they decided not to attend antenatal out of choice. This revealed that over three quarters of these had made the decision not to attend.

6.2.3 The remainder (just under 10% of all respondents) that wanted to attend antenatal classes, but could not, had several reasons for not attending.

6.2.4 One of the main problems was either insufficient information or no classes offered. There were also issues about the timing of the classes and not having access to childcare.

'The antenatal classes at George Eliot were fantastic. I went to the ones on yoga, aromatherapy and massage all of which were very useful. It was good to be offered alternative ways of dealing with the pain of childbirth.'

6.3 Twenty-Week Scan

6.3.1 It is commonly thought amongst members of the medical profession that a 20 week scan is not really necessary and that any problems in pregnancy would be picked up without the need for a scan. However, when women were asked if the 20 week scan was important to them 90% considered it was important. Twelve women even travelled to another hospital to obtain a scan, which was not available in their immediate locality. One mother paid to have her scan done privately.

6.3.2 Mothers were asked to give brief details on why it was important. Most women found the scan very reassuring and wanted to see if the baby was developing properly. Interestingly some mothers saw the scan as an opportunity to bond with the baby before it was born.

6.3.3 There is little evidence to indicate that mothers living in areas where the immediate hospital does not provide a 20 week scan, are substantially affecting maternity provision at other hospitals. Generally the hospital where mothers go to have the 20 week scan is where the baby is born.

'The scan provided me with peace of mind about the development of my baby. It helped me relax and enjoy being pregnant.'

6.4 Home or Hospital

6.4.1 Just under two thirds of respondents indicated that they had been given enough information to make a choice on whether to have the baby at home or hospital.

6.4.2 There is a move to encourage more births at home if there are not likely to be complications. To increase the number of home births it looks as though some improvement is required in the information provided.

6.4.3 Those mothers that decided to have a home birth found it a very positive experience.

'Home birth options were not really discussed at all'

6.5 Choice of Hospital

6.5.1 Just over two thirds (68%) of the respondents felt that they had not been given a choice of hospitals, however, when asked if they wanted to have a choice most of these women did not want one.

6.5.2 When broken down further the responses indicate choice is probably more about where the Maternity Unit is located, in relation to where the mother resides, rather than taking other considerations into account.

6.5.3 Only a third of women felt they were given enough information to be able to make a choice of hospital. Again there is an opportunity for hospitals to improve the information given to prospective mothers. George Eliot Maternity Services Website is an excellent resource and provides comprehensive information covering issues such as what to expect, introduction to the medical team, health in pregnancy, layout of the hospital and visiting times.

6.6 Attitude of Health Professionals

'The midwives gave excellent advice and help. They were friendly and helped me so much. I didn't have a clue on what I was doing.'

6.6.1 From the survey it is apparent that there are staff shortages at times and as a result some mothers found the standard of medical care and level of support did not meet their expectations. The main concern is that these staff shortages place additional pressure on health professionals and they may not be able to spend the time required with new mothers. Sometimes the abrupt response some mothers received from health professionals, to what may be seemingly trivial questions, made some mothers feel inadequate and quite stupid. This resulted in some mothers feeling that health professionals were not readily unapproachable and therefore their concerns about caring for a new baby were not resolved.

6.6.2 The survey also showed that there were problems about the continuity of care. Some mothers that required additional medication or treatment were left for very long periods on their own and felt they were being neglected. This was often due to a breakdown in communication between staff, especially when there was a change over of staff at a shift change.

> 'The actual standard of medical care was good when we actually saw the doctor, but the nurses were too busy to even check that everything was OK. I had no contact with nurses on the ward during my brief stay.'

6.6.3 Correct staffing numbers is particularly important for Warwick Hospital as it is already experiencing an increase in the numbers of births as is George Eliot Hospital and this is expected to continue. Warwick District [2] is projected to undergo the largest increase (40% by 2021) in the number of children aged 0 – 4. This increase may be in part due to number of new large housing developments in Warwick District. There is evidence to indicate that there may be already an increase in this age group, the number of childcare enquiries in the Warwick Gates and Warwick South ward area have been increasing year by year since 2002. There is an expectation that some mothers may go to the new maternity unit in Coventry, when it opens, but there are indications from the questionnaire that mothers tend to go to their nearest hospital. If this was the case it could cause an additional pressure on staff and resources at Warwick Hospital.

6.6.4 George Eliot Hospital is also experiencing increasing number of births again new housing developments in North Warwickshire and Nuneaton and Bedworth are thought to be the cause.

6.6.5 Also it expected that there may additional pressure on staff resources when the recommendations from the confidential enquiry into maternal deaths (2004)[3], have to be implemented.

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[2] Demographic & Social Briefing Note – 2005, Research Unit, Planning, Transport and Economic Strategy, Warwickshire County Council.

[3] Why Mothers Die 2000-2002 – Report on confidential enquiries into maternal deaths in the United Kingdom (2004)

'Increase the number of midwives so that they can spend more quality time with mothers.'

6.7 What support mechanisms are there for mothers and their families?

6.7.1 The survey identified that support was not always readily available for some mothers and as discussed in the previous paragraph support in the hospital was sometimes lacking, which may be in part due to staff shortages.

'I feel some information on actually coping with a baby when getting it home would be helpful – perhaps using the pre-natal classes.'

6.8 What support mechanisms are there for mothers and fathers on first discharge?

6.8.1 The majority of mothers (82%) found the support given at home very useful, although some mothers would have appreciated longer and more visits from their midwife. However, some mothers did find the advice given by different midwives contradictory, which left them feeling very confused. Usually only one midwife will visit a new mother when they first go home, but if this midwife is on leave, several midwives may be asked to cover this leave entitlement.

6.9 What support is given to promote breastfeeding?

6.9.1 Many mothers set out with the intention to breastfeed, however many drop out within the first few weeks for various reasons.

6.9.2 Some mothers wanted more support while in hospital and when they go home. The lack of success for some mothers has partly been attributed to being discharged from hospital without having breastfeeding fully established. Some mothers can be home within hours of delivery, with little or no real knowledge on how to breastfeed.

6.9.3 Also mothers wanted more information on how to continue breastfeeding, how to increase production, how to tell whether the baby is getting enough, what food to eat. The main reason and the first hurdle for stopping was that mothers thought that the baby was getting insufficient milk and was worried if they not gaining weight.

6.9.4 Some mothers found the experience much more time consuming and painful with one mother suggesting that the information given should be much more realistic. There is a notion that mothers will find it a wonderful experience, but initially, it is often not the case and it takes time and perseverance to continue.

6.9.5 There were medical reasons for not continuing to breastfeed, such as the baby not being able to suckle or being premature or the mother being ill. Despite this additional support for one mother did help her overcome these initial problems and she was able to breastfeed for six months.

6.9.6 The hospital environment was given as a reason for not finding breastfeeding a pleasant experience. A screened off area screened was found to be too hot and unpleasant and there were issues about privacy when a mother was readmitted to an ordinary ward.

There was a suggestion that there should be "breastfeeding advisors ……to encourage and reassure that thing are going OK"

6.9.7 George Eliot Hospital is providing breastfeeding support through a La Leche volunteer and a have newly appointed a parent educator (non professional) to help. Warwick hospital has registered their intention to join the UNICEF UK Baby Friendly Initiative and will be appointing breastfeeding advisors.

'Dedicated staff on shift to assist with breastfeeding would be great.'

6.10 What provision is there for ethnic minority groups such as interpreters for mothers where English is not their first language?

6.10.1 The survey showed that English was not the first language for 6% of respondents. Just under half of these would have liked an independent interpreter. Their preferred languages were Spanish, Gujerati, Thai and Zulu.

6.10.2 Sophie Staniszewska[4] identified through focus group work with women from ethnic minority groups 'that women's chief concerns during pregnancy, labour and delivery, and postnatally, were how much they understood about what was happening to them and their baby and the quality of their interactions with health care staff'. (See Appendix 3)

6.10.3 Also there was evidence to indicate that when a doctor or midwife is foreign there were difficulties in understanding them.

6.10.4 The panel noted that the diversity in the languages that would potentially need translation would require a significant number of interpreters. Also an interpreter would require a special level of trust in what is a very emotional and private experience. 'Language Line' was considered the most suitable approach and this is what is being used by hospitals already. Also 'Language Line' could help to overcome any private concerns of the parents, because interpretation services are via the telephone.

[4] The experiences of parents with pre-term babies: identifying effective interventions for communication, information and support.

6.10.5 There has been an influx of Portuguese in Warwick District and it was originally intended that the scope would look at maternity provision for Portuguese women. Unfortunately this could not be covered due to delays in being able to appoint a community worker. The panel intend to conduct a smaller, separate review to ensure that the scope looks at the specific needs of ethnic minority groups.

'In 1998 there was not the option for interpreters. I was left on my own with no explanation whatsoever. I did not have my husband with me, the lack of communication was a very traumatic experience for me.'

7. Babies Requiring Special Care

Support while in the Hospital

7.1 The maternity services' panel wanted to look at other specific areas where additional support may be required such as caring for a premature baby. This may incur travel costs especially if the baby has to go to a Special Care Baby Unit at another hospital.

7.2 Travelling for some respondents did cause problems especially when they did not have access to a car. Also the public transport links within the Central Newborn Network are not very accessible and it may be easier for some parents to attend other hospitals such as Birmingham. Some fathers found they did not have money for taxis and had to limit the times they visited. One respondent had to limit his visits to when another family member was travelling to the hospital. There was no support offered to these respondents to overcome their travel problems. People receiving income support can get help to visit in certain circumstances and accommodation costs may also be included. To find out if they qualify they would need to contact their local social security office or hospital social services department.

7.3 Having a small baby can be a very emotional time for both parents and their families. Although the standard of medical care and support in hospital was thought to be good or very good by most respondents they did have suggestions to where areas could be improved. They thought there should be more communication between paediatricians and midwives and wanted more information about their baby.

'My family had transport, but my husband didn't. This made it hard for us as he could only visit when a family member was coming over.'

Support at Home

> 'The level of care in SCBU was excellent. My main concerns are the lack of knowledge & understanding and access to advice and support in the community from the day you leave hospital with a very small fragile baby. Practically premature babies have very different needs and emotionally there is guilt, isolation, anxiety after a long time of highly skilled care.'

7.5 Mothers with premature babies had differing concerns when they first went home. After having all the support in hospital some mothers did not always confident on how to care for a very small baby and wanted advice. They did not have the same midwife support at home experienced by mothers with babies at full term and the health visitors that did visit could not always provide the necessary advice. Often it was because they did not have enough experience or knowledge on premature babies needs. A suggestion was made that being able to contact another family in a similar situation would be very useful.

> 'Although my baby was my second I did feel I would have benefited from more specific advice about feeding, sleeping & development of premature babies – even in leaflet form. I was able to phone SCBU, but felt I needed more specific advice after that time.'

8. Conclusions

8.1 The survey revealed a small number of women found it harder to access ante-natal classes either through lack of information, no classes being available, awkward locations or they were at times which caused problems. The panel recognises that ante-natal classes are important in promoting a healthy pregnancy through good diet, exercise as well as preparing for the delivery of the baby. It can also help encourage mothers that smoke to stop smoking. With this in mind the panel consider it is important that every mother who wants ante-natal provision should be able to access this service. **(See recommendations 9.1 and 9.2)**.

8.2 The survey revealed that most mothers found the 20 week scan very reassuring although the Screening Committee from the Department of Health considers that 20 week scans are not really necessary. The panel recognises that most mothers would want the 20 week scan to continue. (**See recommendation 9.3**).

8.3 The few respondents that had a home birth found it a very positive experience, but there is evidence to indicate that information on home births is not so readily available. The NHS Trusts are proposing to

encourage more home deliveries and this can only increase if more information is made available. (**See recommendation 9.4**).

8.4 Generally most prospective mothers chose the hospital nearest to where they reside. However, only a third of women felt they had been given enough information to make a choice of hospital. Whilst conducting this review George Eliot Hospital has been identified as a patient friendly site, which provided pertinent information, which help parents make an informed choice. **(See recommendation 9.5)**.

8.5 From the responses to the questionnaire staff shortages appear to be a major concern for respondents. These shortages appear to place staff under additional pressure which is probably a contributory factor to the sometimes abrupt and inappropriate response to a parent's request for information as well as mothers being left for long periods on their own. The review also identified that the additional pressures are partly due to the increasing number of babies being born. **(See recommendation 9.6).**

8.6 The review specifically looked at the support offered to encourage breastfeeding as part of the joint review with Coventry City Council on the implementation and duration of breastfeeding in Coventry and Warwickshire. The information from the survey highlighted the variations in the levels of support offered to mothers and the many reasons given for either not breastfeeding at all or giving up before the recommended 6 month period. **(See recommendation 9.7 and 9.8).**

8.7 Babies that had to go to a hospital elsewhere, to get specialist care, did cause travel problems for some parents, especially when they did not have access to a car. The survey identified that there appeared to be no information or support offered to help parents overcome their travel problems. These parents also wanted special care units to provide information pertinent to their babies needs which would help them understand what to expect. **(See recommendation 9.9 and 9.10).**

8.8 When mothers with premature babies went home they found they missed out on the midwife support given to mothers with full term babies. The health visitors did not always have sufficient knowledge to help with specific questions relating to the care of a premature baby. These mothers identified that specific advice and information in the first few days would enable them to confidently care for their baby. **(See recommendation 9.11).**

8.9 The Access to Maternity Services Questionnaire revealed that the issues around maternity provision were more extensive than at first anticipated. Originally this review was going to report to Health Overview and Scrutiny committee in March 2005 but a decision was made by the panel to give the review more time to explore some of the issues raised by the survey. Also due to unforeseen delays, the remaining area outlined in the scope, maternity provision for Portuguese women was not covered by this review.

Therefore it is recommended that this should be conducted as a smaller, separate review. **(See recommendation 9.12).**

9. Recommendations

9.1 **That the PCTs and NHS Trusts review how information about ante-natal classes is provided and look at alternatives, such as the Web, which may be more readily accessible for some women.**

9.2 **That the PCTs and NHS Trusts regularly review the location and timing of ante-natal classes to ensure they are accessible for women who work or those who have to arrange childcare.**

9.3 **That the 20 week scan should continue, because despite some health professionals considering it not really necessary, most mothers find the 20 week scan reassuring, which can only help their general health and well being.**

9.4 **More information should be readily available to encourage home births, if appropriate, to help mothers decide on whether to have a home birth or not.**

9.5 **George Eliot Hospital Maternity Services Website is an example of good practice and the recommendation is that other Maternity Units consider adopting similar approach in providing information to prospective mothers. Website Address: www.geh.nhs.uk/departments/maternity/index.htm**

9.6 **That the Primary Care Trusts look at how it commissions services from the NHS Trust and the NHS Trusts need to flag up when staff shortages and resources are causing concern. This should ensure that mothers have the level of care expected at such an important time. The PCTs and NHS Trusts need to be conscious of any large housing developments in their borough or district, especially if they are likely to encourage more families into the area. Also to take into account the projected increase in children aged 0-4 by 2021.**

9.7 **That the information gathered on attitudes to breastfeeding to be included in the joint review with Coventry City Council to help support the promotion of the initiation and duration of breastfeeding.**

9.8 **That the NHS Trusts continue to promote the initiation of breastfeeding through accreditation with UNICEF UK Baby Friendly Initiative.**

9.9 **Where babies have to go to another hospital due to being premature or illness, that NHS Trusts need to be more proactive in providing information at this time, such as advice for those on benefits in how to claim travel costs and more information about their baby. Suggest**

that a central information point, which parents could access to find out where a hospital is located and visiting times would be helpful.

9.10 There are concerns that only 40% of ill babies go to University Hospitals Coventry & Warwickshire and the remainder are coping with being transferred many 100's of miles away. It is hoped that this will be avoided when the Newborn Network is more established. Recommend that this to be reviewed in 12 months time.

9.11 That PCTs recognise that families with premature babies miss out on the support and advice of a midwife when they first go home and that this could be resolved by providing neonatal outreach workers or mothers to have at least one visit from a midwife.

9.12 That a separate, smaller review is conducted on the maternity provision for Portuguese women in Warwickshire, to help ensure that the needs of ethnic minority groups have been considered in this review process which could support existing research conducted by Sophie Staniszewska.

Appendix 1

Terms of Reference on Access to Maternity Services

1. Aims and Objectives

The aim of this scrutiny exercise is to examine the access to Maternity Services throughout Warwickshire. This will involve scrutinising all maternity services such as pre-conception, early pregnancy, antenatal and postnatal care, the midwifery services and services provided by hospital maternity units. It will also look at neonatal provision in Warwickshire. It may require involving other agencies such as the British Pregnancy Advisory Service or Pregnancy Counselling Service, Premature Baby Group & National Childbirth Trust. It will not consider health provision offered by Health Visitors.

A successful outcome from this review would be that the Warwickshire Maternity Services provides a flexible, appropriate, clinically effective and accessible service in response to the needs of women and their families. It takes into account equity of access to services in line with the social inclusion agenda. It will also help Members and officers have a better understanding of maternity services in Warwickshire

2. Background

2.1 National View

In response to the Health Select Committee's report on maternity services, Stephen Ladyman, said:

"We believe that improving maternity services around the country is essential to giving babies and mothers the best start in life. I welcome this opportunity to highlight the work we have done over the last couple of years to improve the quality of maternity services.

"Our highest priority must be to tackle inequalities in access to services and health outcomes for women and their babies. In 2001, we provided £100 million to improve over 200 maternity units around the country. This funding has been used to provide women with en suite bathrooms, single rooms for women in early labour, new home from home areas and new birthing pools. Also, a key theme of the Children's National Service Framework (NSF), due out later this year is to reduce inequalities and improve access to care. The maternity module of the NSF will set national standards of care, covering antenatal, birth and postnatal services.

"We are also committed to extending choice and support provided in maternity services for all women throughout their pregnancy. You're Pregnant launched last year by the Department, provides all mums-to-be with local information about maternity services in their area, so that they and their families can make real

informed choices about the NHS services they would like to use. It is also important to remember that some choices are not safe or appropriate for some women and their babies.

"However, we recognise that the rate of improvement and availability of choice may be governed by the recruitment of midwives and we are working hard to bring more into the service. Since 1997, there are 700 more midwives working in the NHS, an increase from 22,380 to 23,080. Also, the number of students entering midwifery has increased from 1,652 in 1996/97 to 2,122 in 2002/3.

"Despite the challenges we face to improve maternity services, we must remember that current services are of a high quality and childbirth is safer than ever before for both mothers and babies. Much of this is due to the hard work and commitment of dedicated NHS staff."

There is an External Working Group for Maternity nationally, which intends to address the inequality of access to services that face disadvantaged groups in society. Not only will it set national standards of care, but will look at how to make maternity services more flexible, accessible and appropriate. It will stress the importance of contact with health services early in and throughout pregnancy and ensure that there is a follow-up of those that fail to attend appointments and improvements in translation services.

2.2 Local View

George Eliot Hospital

- Low birth weight babies are dealt with at George Eliot Hospital – high dependency babies go to Walsgrave, Leicester or Birmingham, if they have space. This may result in the babies being taken as far as Wolverhampton or Liverpool.
- George Eliot Hospital has two high dependency units.

South Warwickshire General Hospital NHS Trusts

- South Warwickshire General Hospitals NHS Trust incorporates Warwick and Stratford-upon-Avon Hospitals. Again high dependency babies go to Walsgrave, Leicester or Birmingham, if there is the space.
- It provides maternity services for South Warwickshire and the surrounding areas. The largest population centres are the towns of Kenilworth, Royal Leamington Spa, Southam, Stratford-upon-Avon and Warwick.
- Through patient choice it appears that some expectant mothers are electing to come to Warwick Hospital rather than the Walsgrave, it is recognised that mothers that are more articulate may be more successful in choosing another hospital. Patient choice in according to the NHS guidelines seems to refer to reducing waiting time for elective surgery rather than choosing a particular maternity hospital. However, there are concerns that patient choice may be creating additional pressure on maternity services in Warwick, which has resulted in women in labour in

Warwick District being referred to hospitals outside the area when there are no spaces available at Warwick.

Walsgrave Hospital Coventry

- ❖ Walsgrave Hospital provides maternity services for women living in Rugby as well as providing specialist care for high dependency babies.
- ❖ The new Coventry and Warwickshire Hospital will be opening in 2006 – this may have an impact on the number of mothers electing to come to Warwick Hospital.

3. Scope

In order to achieve the aim set out in paragraph 1 this scrutiny will explore the following:

- Whether there is enough provision of antenatal or neonatal care in Warwickshire.
- Patient choice – What information is available to help prospective mothers make an informed choice on whether to have a baby at home or hospital or natural delivery or caesarean?
- Whether home delivery and/or natural delivery is encouraged.
- The attitude of maternity or neonatal staff to prospective mothers and fathers. Is there an inconsistency in the treatment of mothers depending on the hospital?
- Perception of certain hospitals – is this justified?
- What support mechanisms is there for mothers and their families travelling outside their normal catchment area due to health need?
- What support is given to promote breastfeeding?
- Is there equity of access in Warwickshire? For example what antenatal class provision is there for prospective mothers? This will look at costs of alternatives, geographical location and also whether antenatal classes are necessary.
- What service provision is there for those from ethnic minority groups – such as interpreters for mothers where English is not their first language? This will also look at the recent influx of Portuguese mothers in Warwick District.
- How many link workers are there in Warwickshire that can provide interpretation/translation services?
- Does the lack of 20 week scans in Coventry impact on maternity provision in Warwickshire?
- Is a 20 week scan really necessary? Will look at what information is available from the Royal College of Obstetricians.
- Finally what support mechanisms are available for mothers and fathers on first discharge?

What is not included in the scope is:

- The services provided by Health Visitors
- Smoking during pregnancy – this was comprehensively covered by Tobacco Control and Smoking Cessation Review earlier in 2004

4. Panel

Cllr Sarah Boad – Chair, Cllr Helen McCarthy, Cllr Marion Haywood, Cllr Dot Webster, Cllr Jane Harrison and Cllr Sid Tooth.

6. Methodology

- Desktop Research – to include information on caesarean and perinatal rates, patient choice, home births, hospitals, type of birth etc.
- To compare similar hospitals such as Manchester with Coventry or George Eliot with Warwick.
- A series of meetings – to include NHS Services, PPIF and user groups
- To partner Coventry City Council on the implementation and promotion of Breastfeeding. The members of panel will be able to attend an event at Coventry City Council in October.
- A video of either George Eliot Hospital, Warwick Hospital or Walsgrave maternity services. A decision was taken not to visit these hospitals, because of the risks of infection and the security of young babies.
- A questionnaire on maternity provision and support. This will include questions for fathers

7. Resources

Alwin McGibbon - Health Scrutiny Officer
Josephine Howarth – Political Assistant
Expert advice - Helen Walton (Manager Maternity Services Warwick) and Dr Richard De Boer (Consultant Paediatrician on Neonatal Care)
Morag Stern – Director of Public Health (North Warwickshire PCT)

8. Timetable

Activity	Timescale
Terms of Reference presented to Health and Scrutiny Committee	12th May 2004
Finalise Terms of Reference presented to Health Overview and Scrutiny Committee and agree Panel membership	27th July 2004
First Meeting of Panel	29th June 2004
Carry out scrutiny	June 2004 – February 2005
Report to full committee	2nd March 2005

Summary of Results from the Access to Maternity Services Questionnaire

November – December 2004

Over 2000 questionnaires were circulated throughout Warwickshire during November and December 2004. The questionnaires were left in various locations for mothers such as:

- The Maternity Units at George Eliot Hospital and Warwick Hospital
- Sure Start in Nuneaton, Leamington Spa, Atherstone
- Mother and Toddler Groups in Nuneaton and Leamington Spa
- Baby clinics in Studley
- A rural GP surgery in Stratford District

Also various groups and organisations helped to distribute questionnaires directly to mothers such as:

- Premature Baby Group
- National Childbirth Trust
- Health Visitors in North Warwickshire and Rugby

To date there have been 205 responses to this questionnaire and this report is a summary of the responses. Three of these arrived after the deadline and have not been included in the responses below
A further more detailed report will be available later in February 2005, which will include all the responses to the questionnaire. Recommendations from this overall survey will go to Warwickshire County Council, Health Overview and Scrutiny Committee on 2nd March 2005.

NB. Please note that the percentages do not always add up to 100%

General Information

1. What year was your youngest child born?

- 123 (61%) in 2004
- 43 (21%) in 2003
- 20 (10%) in 2002
- 6 (3%) in 2001
- 9 (4.5) 1997 – 2000
- 1 respondent did not include year

2. In which Borough and District do you normally reside?

- 25 (13%) North Warwickshire
- 37 (18%) Nuneaton and Bedworth
- 11 (5%) Rugby
- 40 (20%) Stratford
- 75 (37%) Warwick
- 14 (7%) Other

Section A – Antenatal Care

3. Were there antenatal classes (classes to help prepare for the birth) available in your area?

- 167 (83%) yes
- 32 (16%) no
- 3 respondents did not complete this question

4. If no, would you have liked to have classes in your area?

- 19 respondents would have liked to have classes in their area

5. Did you attend these antenatal classes?

- 93 (46%) did attend these classes
- 84 (42%) did not

6. If no, was this out of choice?

Of those that responded with no

- 62 (76%) said this was out of choice
- 20 (24%) indicated it was not out of choice

7. If no, please give details on what stopped you being able to attend?

- 8 had insufficient information or were not offered classes
- 3 found the classes were full
- 3 found the timing of classes did not help, 1 respondent was too tired for evening classes after work, 1 found night classes too difficult to attend, however 1 respondent would have preferred classes at night
- 2 did not have access to childcare
- 2 stated that only first time parents were invited
- 1 wanted her partner to attend was not prepared to go alone
- 1 did not like approach and did not attend another session

8. Did you have a routine scan at approximately 20 weeks?

- 197 (98%) yes
- 4 (2%) no
- 1 respondent did not complete this question

9. Did you go to a different hospital, to the one you would have attended, so that you could have a 20 week scan?

- 12 respondents did go to a different hospital to have a 20 week scan

10. In which hospital did you have the 20 week scan?

- 71 (35%) George Eliot
- 87 (43%) Warwick
- 12 (6%) Alexandra
- 17 (8%) Stratford
- 2 (1%) Rugby St Cross
- 5 (2.5%) other

11. Was a 20 week scan important to you?

- 181 (90%) Yes
- 16 (8%) To some extent
- 1 (0.5%) No

12. If yes, please give brief details on why you considered it important?

- 128 found it gave them reassurance
- 64 wanted to see if the baby was developing properly
- 30 had a scan for medical reasons
- 15 wanted to know the sex of the baby
- 5 saw it an opportunity to bond with the baby
- 1 respondent used it as an opportunity to ask questions
- 1 respondent wished she could have had one and considered that all hospitals should offer the facility

NB. The comments add up to more than the number of respondents, because there was an opportunity for a respondent to give more than one comment.

13. Were you given enough information to help you make the choice on whether to have the baby at home or at hospital?

- 126 (62%) respondents indicated they were given enough information to make the choice on whether to have the baby at home

A higher percentage of mothers attending George Eliot Hospital felt they had been given enough information to make the choice than mothers attending Warwick Hospital. Their responses were 73% and 60% respectively.

NB The other hospitals had a very small number of responses and have not been included.

- 70 (35%) thought they had not been given enough information
- 6 mothers did not respond to this question

Section B – Care at delivery time

14. Did you have your baby at home?

- 4 mothers had their baby at home

15. How would you rate the standard of care of having a baby at home?

Mothers were given five options from very poor to very good.

- All 4 mothers thought the standard of care was very good

16. If you had your baby at home were you given the support you needed?

- All 4 mothers indicated that they had the support they needed

17. If no, what support would you like to have?

All the mothers considered they had the support they needed however, these mothers wanted to back the former question with additional information.

They found the midwife very caring, they felt they had the freedom to do as they choose and there was the continuity of care. One mother thought that more midwives should give mothers birthing options.

19(a) If you had your baby at hospital were you given a choice of hospitals?

- 57 (28%) indicated that they had been given a choice of hospitals
- 138 (68%) had not been given a choice

Broken down by borough/district:

- More mothers North Warwickshire Borough and Stratford District were given a choice of hospital with 48% and 50% respectively
- 32% in Nuneaton and Bedworth were given a choice
- Mothers in Warwick District gave the lowest level of choice with just under 8%

NB Rugby Borough has not been included because of low numbers.

19(b) Did you want a choice of hospital?

- 60 (30%) wanted a choice of hospital
- 134 (66%) did not
- Warwick District had the highest proportion of mothers (90%), which did not want a choice of hospital. This was 78% in Nuneaton and Bedworth Borough, 61% in North Warwickshire Borough and 58% in Stratford District.
- However, all the mothers in Rugby Borough wanted to be given a choice.

The responses above seem to reflect on whether or not there is a Maternity Unit in the immediate vicinity of where the mother resides. Choice may not a major concern when it is more convenient to go to the nearest hospital.

19(c) Were you given enough information to help you choose a hospital?

- 61 (30%) indicated that they were given enough information
- 97 (48%) felt that they did not have sufficient information

Broken down by borough/district:

- 74% of mothers in Warwick District felt they were not given enough information, closely followed by 73% of mothers in Stratford District
- Fewer mothers in Nuneaton and Bedworth and North Warwickshire Boroughs felt they had been given insufficient information. However, both were still over half of all mothers with 57% and 55% respectively

20. Which hospital did you choose?

- 71 (35%) George Eliot
- 105 (52%) Warwick
- 7 (4%) Walsgrave
- 10 (5%) Alexandra
- 2 (1%) Others

Broken down by borough/district

- 95% of mothers living in Nuneaton and Bedworth and North Warwickshire chose to have their baby at George Eliot Hospital
- 90% of mothers living in Warwick and Stratford Districts had their baby at Warwick Hospital.
- Over half of mothers form Rugby Borough chose to have their baby at the Walsgrave Hospital in Coventry. NB Please note that this result is still significant even though the number of responses from Rugby Borough were quite small.

Again the responses indicate choice is probably more about where the Maternity Unit is located, in relation to where the mother resides, rather than taking other considerations into account.

21. Did you end up having your baby at this hospital?

- 187 (93%) yes
- 6 (3%) no

22. If no, please briefly explain why you had your baby elsewhere?

- The main reason given was the baby arriving early

23. Which hospital did you attend?

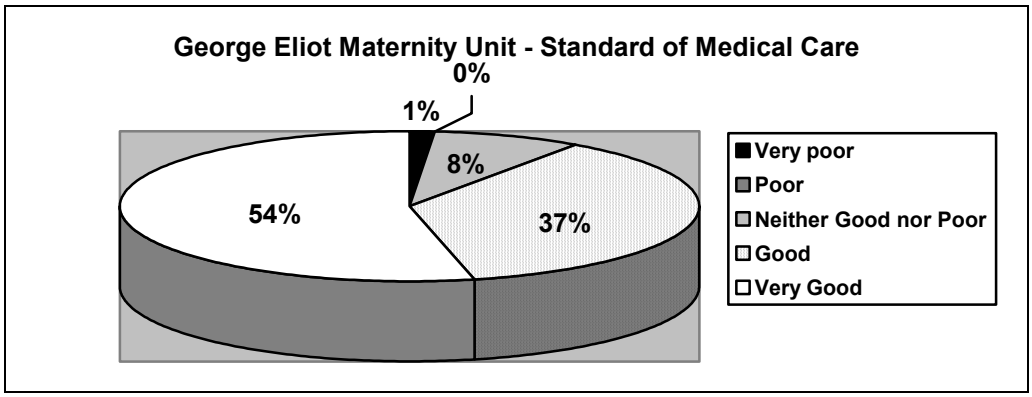
- 2 went to Birmingham
- 1 attended Boston Pilgrim, Lincolnshire
- 1 Walsgrave
- 1 George Eliot

24. How would you rate the standard of medical care while you were in hospital?

- 13 found the standard of care very poor or poor
- 21 thought it was neither poor nor good
- 165 thought the standard of care good or very good

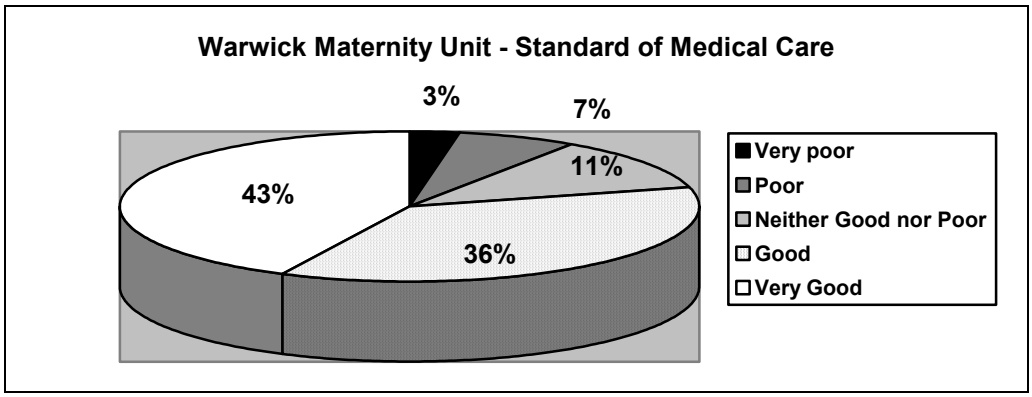
Standard of Care by Hospital

George Eliot



- 91% of mothers thought the standard of medical care was good or very good
- 8% thought it was neither good nor poor
- 1% thought it was very poor

Warwick hospital



- 79% of mothers thought the standard of care was good or very good
- 11% thought it was neither good not poor
- 10% thought the standard of care was poor or very poor

There was a higher satisfaction with the level of medical care at George Eliot Maternity Unit than with Warwick Maternity Unit.

The main concerns raised by mothers at Warwick Hospital appear to be mainly caused by inadequate staffing numbers and overcrowded wards. This resulted in mothers, feeling isolated and finding the midwives/doctors unsupportive. The

medical care tended to be poor because of the lack of continuity of care. Pain relief was not always given when requested and mothers were left for long periods before further treatment was completed.

25. If the standard of care was poor or very poor could you tell us why you considered it poor?

The main reason given by 10 mothers was the lack of staff. Other reasons included the ward being overcrowded, midwife unsupportive, forced to breastfeed, there was no privacy, being neglected and differing levels of care from different midwives. One mother was concerned, because the form she was given indicated that they had been shown how to perform the basic level of care to be able to look after their baby, which they had not.

26. What suggestions would you make to improve the standard of medical care?

- 15 mothers suggested more staff
- 12 mothers suggested improved customer care with two wanting doctors and midwives who listened
- 8 suggested more support with one specifying they would like more help with breastfeeding and another indicating that they need the same levels of support regardless of whether it is the 2nd 3rd or 4th child.
- 8 suggested more communication with two specifying that there should be an assigned midwife on change of shift and that they should introduce themselves
- 5 mothers wanted to have pain relief when requested. They found that the midwife had forgotten their request and it was sometimes hours later before they received the medication.
- 5 mothers suggested smaller wards, more privacy and time to bond with the baby especially after a caesarean
- 3 mothers had issues about hygiene and cleanliness of wards
- 2 mothers wanted not to be forgotten when receiving treatment. They were left for some time before treatment completed
- 2 mothers wanted to be able to stay longer especially after a caesarean
- 2 mothers suggested more information, which should include hospital routine such as time of breakfasts and where to go
- 3 mothers had issues about the medical care. One mother felt she was wrongly advised to have a caesarean, another that prostin gel should have been used not pessaries and another mother suggested that the babies health should be checked more thoroughly.
- 1 mother suggested that there should be better facilities for mothers and fathers and another suggested that the food should be improved.
- 1 mother had concerns about security
- 1 mother suggested a night nursery
- 1 mother suggested that they need to buy more equipment and maintain it properly
- Although the question asked for suggestions 3 mothers felt the standard of care was excellent.

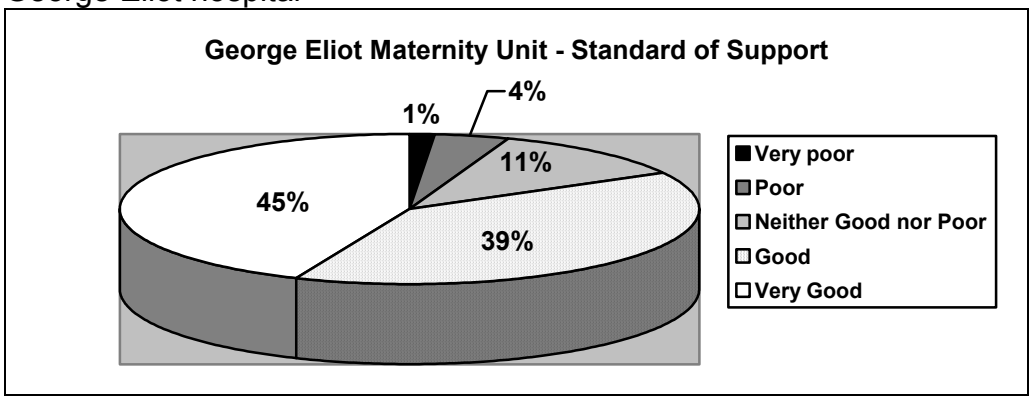
NB. Although suggestions were expected from mothers who thought the standard of care was poor or very poor, suggestions were received from mothers who considered the care was good or very good. This is a pattern of response that has been repeated throughout the questionnaire. This indicates that although a mother may have found the overall level of care quite good there are areas that could be improved.

27. How would you rate the level of support while you were in hospital?

- 150 (74%) considered the support as good or very good
- 29 (14%) considered it as neither good nor poor
- 20 (10%) thought the support as poor or very poor

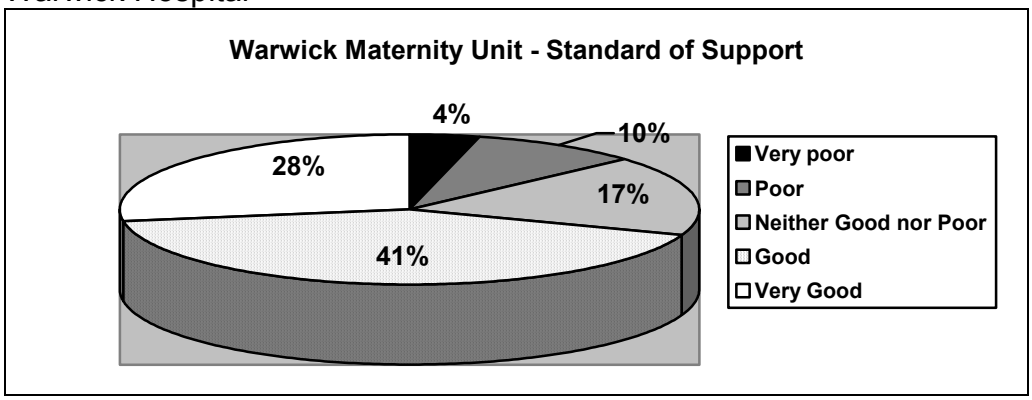
Standard of Support by Hospital

George Eliot hospital



- 84% of mothers thought the standard of support was good or very good
- 11% thought it was neither good nor poor
- 5% thought it was poor or very poor

Warwick Hospital



- 69% of mothers thought the standard of support was good or very good
- 17% thought it was neither good nor poor
- 14% thought it was poor or very poor

Again there was a higher satisfaction with the level of support at George Eliot Maternity Unit than with Warwick Maternity Unit. The issues with Warwick

Hospital again appear to be mainly around staffing levels, which has caused the support given on the wards to be, at times, poor.

28. If the level of support was poor or very poor could you tell us why you considered it poor?

- 19 mothers said there was a lack of support on wards. 5 mothers went onto explain that they were left to their own devices but they wanted help and reassurance; 3 mothers wanted help to breastfeed; 1 mother was depressed and wanted support and 1 mother had a baby in special care but did not feel informed
- 7 mothers considered it poor because of the lack of staff
- 6 mothers thought the staff were rude and unhelpful
- 2 mothers thought the food was awful

Other responses included length of recovery in hospital too short; poor cleanliness, pressure to breastfeed too great; baby was given the bottle when a mother wanted to establish breastfeeding, communication between departments poor

29. What suggestions would you make to improve the level of support?

- 21 mothers wanted more help with the basics, 9 specified they wanted guidance with breastfeeding
- 14 mothers wanted more staff
- 11 mothers suggested that they should improve customer care
- 6 mothers felt they should not be left alone for long periods
- 5 mothers wanted reassurance
- 4 wanted consistency of care
- 3 wanted more privacy and 1 mother specified there should be a separate labour ward
- 2 mothers wanted the option to stay longer, 1 mother specified this was especially important after a caesarean
- 2 mothers wanted more advice on premature births

Other suggestions included decent food; think of the needs of the baby over the mother; to be shown hospital facilities on arrival; explain the available pain relief; pain relief to be provided when requested; not to bottlefeed when asked not to; support for partners and the doctors to be more aware of the emotional needs of a mother especially when a baby is in SCBU

30. If you had a baby at another hospital was it further away from your home than you originally expected?

Nine mothers had a baby at a hospital further away from their home than originally expected. However, some of these mothers did choose this hospital rather than going to a hospital nearer their home.

31. If yes please give the hospital name and town where you had your baby?

The hospitals were located as far away as Boston in Lincolnshire, Leicester, Birmingham and Coventry. One respondent chose George Eliot in Nuneaton instead of Walsgrave, which would have been nearer.

32. Did your partner and family have transport to get to this hospital?

- 7 respondents did not have transport to get to these hospitals

33. If no, what travel arrangements were your partner and family able to make?

- 3 respondents used a taxi
- 2 travelled by bus, 1 mother made a 90 minute bus journey to get to antenatal classes
- 1 used a member of their family's car

34. Did this cause any significant problems?

- 6 respondents said yes that it did cause significant problems

35. What problems did this create?

Two respondents found it expensive and there was not always the money for taxis.
Other responses included difficulties in travelling and having to find childcare; being too far away from support network. One mother was concerned that she was going to have the baby on route. Finally one husband found he could only visit when a family member was visiting

36. Was there support to help overcome these problems?

- 6 respondents had no support to overcome travel problems

37. How would you rate the standard of care at this hospital?

- 5 rated the standard of care as good or very good
- 1 as neither good nor poor
- 1 thought the standard of care was very poor

38. Did you have a caesarean?

- 56 (28%) had a caesarean
- 141 (69% did not have a caesarean
- 5 (2.5%) did not respond to this question

39. Was the caesarean out of choice or for medical reasons?

- 7 (13%) had the caesarean out of choice
- 47 (87%) had the caesarean for medical reasons

- 2 did not respond to this question

40. If out of choice, did the midwife/doctor help you come to a decision on what was best for you?

There were 17 responses to this question even though only 7 mothers indicated that they had a caesarean out of choice. This is partly due to the midwife/doctor having to advise a mother even when the choice was due to medical concerns and is shown in the comments in the following question.

- 12 were given information to make a decision
- 5 were not given any information

41. How did the midwife/doctor provide this information?

- 6 mothers had an informal chat and discussion and leaflets
- 4 mothers had already had a c-section with their first child
- 2 mothers had no alternative but to have a c-section
- 1 mother was told through a series of consultations

There was conflicting advice given, one midwife said it would be OK to have a natural birth, but the doctor disagreed, a South African doctor said a c-section was the safest option, but the UK doctors disagreed.

One mother did want more information she had concerns for herself and her baby.

42. How would you rate this information?

- 12 thought the information was good or very good
- 1 thought the information was neither poor or good
- 4 thought the information was poor or very poor

43. Was your baby premature?

- 21 mothers had their baby before 37 weeks

Section C - Neonatal Care

44. If yes did he/she have to go to a special care baby unit?

- 18 babies went to a special care baby unit
- 9 babies did not require special care

The differences in the number of responses is partly due to some babies requiring special care, but were not in fact premature.

45. Was this at the same hospital or elsewhere?

- 13 babies stayed in the same hospital
- 5 babies had to go elsewhere

46. If elsewhere, please give the name and town of this special care baby unit?

The hospitals attended were the Walsgrave, Wolverhampton – New Cross, Birmingham City Neonatal Unit, Heartlands and Leicester

47. How would you rate the standard of medical care for your baby at the special care baby unit?

- 17 rated the standard of medical care as good or very good

48. If the level of care was poor of very poor could you tell us why you considered it poor?

One mother thought that the test results took too long. This revealed that an infection was acquired in Swan Ward.

49. What suggestions would you make to improve the standard of care?

There were several suggestions made even though the majority of mothers thought that the standard of medical care was good or very good.

- More communication between paediatricians and midwives
- Would have liked to be present when the doctors do their ward rounds, doctors to indicate when they are going to visit
- Although very good felt in the way sometimes
- After leaving hospital they wanted more community support
- Continuity of care between staff and patients
- A leaflet on group B strep infection would have been reassuring

50. Did this special care baby unit offer you/your partner support?

- 17 responded yes
- 1 responded no

51. How would you rate the level of support for you and your partner at the special care baby unit?

- 16 thought the level of support as good or very good
- 2 thought it was neither good nor poor

52. If poor or very poor please tell us what type of support you would liked to have?

One mother would have liked contact with another family in a similar situation they thought this would be useful.

One mother wanted more comfortable chairs in the day room they found it difficult to breastfeed with the chairs provided.

Section D - Feeding

53. Did your baby breastfeed?

- 142 (71%) responded their baby had breastfed
- 58 (29%) mothers decided not to breastfeed their baby

NB There was some confusion for some mothers on whether they had breastfed their baby or not. Some mothers felt because they had only breastfed for a few days that they had not really breastfed at all. Also mother's whose baby/babies were premature and could not suckle tended to give a period of time for expressing milk, but did not always consider this as breastfeeding.

54. If no what factors influenced your decision not to breastfeed?

There were several reasons given for making this decision and the main ones are:

- Not having the practical help (17)
- Personal Choice (16)
- Not having support (13)
- Family commitments – generally the demands of having older children (11)
- Partner (7)
- Not having information (4)
- Lack of amenities (3)
- One mother did not feel comfortable

Twelve mothers gave medical reasons given for not being able to breastfeed such as having a premature baby, being very ill after the birth or having to take medication for an existing condition.

All but one mother with a premature baby found they could not make the transition to breastfeeding their baby (being able to suckle). The main reason given was the impact of being separated when the baby was in SCBU, which made it too difficult to establish breastfeeding at a later date.

Sometimes the baby was given as the reason for not breastfeeding either they would not latch on or refused to take the breast.

55. Were you given advice on breastfeeding?

- 83% (168) mothers were given advice on breastfeeding
- 65% (109) found the information given helpful in making a decision on whether to breastfeed or not. 36 mothers responded that they had already decided on whether to breastfeed or not and the information had not changed their minds. For some mothers it was their second or third child and they had breastfed before.
- 16% (33) said that they had not received any information

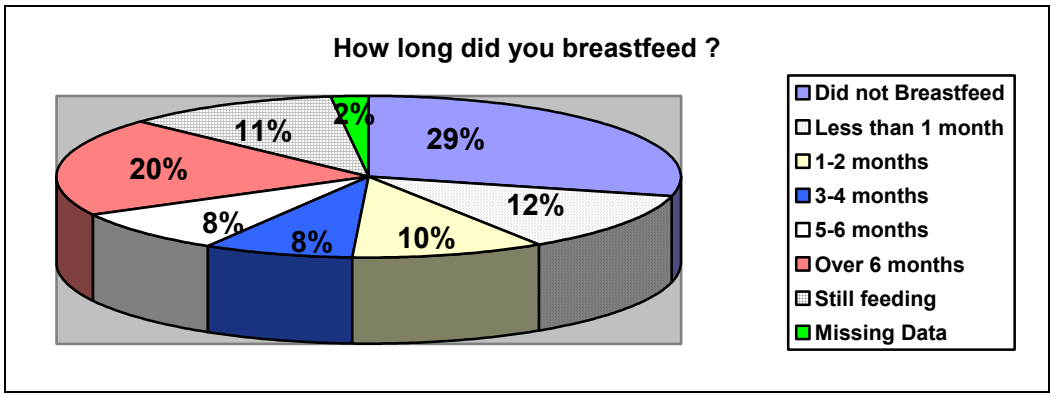
56 Did you find this information helpful?

- 32% (64) considered the information given or having no information was not helpful

57. If the advice did not help, what information would you have liked to have?

- 7 mothers wanted more realistic information such as breastfeeding may be uncomfortable and hurt, it can be very demanding on time and is sometimes difficult to fit in with family needs.
- 8 mothers wanted more support once the baby was born with advice given while in hospital and at home. One respondent wanted the advice given to be consistent
- 4 mothers wanted information on how often a baby needs feeding, they found it difficult to know if the baby was getting enough breast milk. One respondent had to go to their mother in the end for additional help.
- 3 mothers wanted not to feel guilty and have the choice on whether they should breast or bottle feed.
- 3 mothers wanted support in choosing to bottle feed
- Other responses included breastfeeding information needed earlier, more information on pumps, the foods to eat and storage. They also wanted to know how to increase production.

58. How long did your baby breastfeed?



- 29% (58) did not breastfeed at all
- 12% (24) breastfed for less than a month
- 10% (20) breastfed for 1-2 months
- 8% (16) breastfed for 3-4 months
- 8% (17) breastfed for 5-6 months
- 20% (40) had breastfed their baby for over 6 months. One mother was still breastfeeding their 18 month old child.

NB 11% (23) are still feeding their babies. All of these babies are less than 6 months old.

59. If your baby stopped breastfeeding before they were six months old please could you give the reasons why?

- 26 mothers gave insufficient milk as the reason for stopping. Six mothers went onto explain that they were concerned that the baby was not gaining weight and in some cases the midwife and GP also supported their concern and recommended they should stop breastfeeding.
- 22 mothers gave medical reasons for not continuing breastfeeding such as the baby not gaining weight, not being able to suckle properly or being premature. Also the mother's health also affected being able to breastfeed from being seriously ill after pregnancy or requiring medication for epilepsy. Most of the mothers with premature babies did provide expressed milk, but were not able to get the baby to suckle at a later date.
- 10 mothers did not enjoy the experience of breastfeeding found it difficult, felt trapped and were uncomfortable feeding in front of others.
- 9 mothers found the lack of routine, demands on time, the tiredness and babies wanting to continually feed too exhausting. 2 mothers found that changing to bottle feeding gave an opportunity for their partners to help.
- 10 babies did not readily breastfeed and mothers had to revert to using the bottle. 2 mothers managed to continue by combining both breast and bottle.
- For 8 mothers the return to work prevented them from breastfeeding for the suggested period of six months.
- 5 mothers found breastfeeding a too painful experience due to stomach cramps or sore nipples, which sometimes led to an infection of the breast.

- And finally one mother felt there were not enough facilities available for breastfeeding. She did not specify whether this was in public places or at work.

69. Any further comments not covered by questionnaire? (Breastfeeding)

"I feel that the SCBU at Warwick Hospital would benefit from a homely, nice breastfeeding area rather than a screened off area in the incubator room which can be stiflingly hot."

"Have breastfeeding councillors like the labour suite midwife and the community midwife that visited me at home on hand to encourage, reassure that things were going OK."

"Put breastfeeding mums together after delivery for mutual support"

"Ensure that nursery nurses are confident in supporting those with feeding difficulties."

"Checks that babies are feeding regularly"

"When staff eventually are aware that a baby can't breastfeed due to medical problems a mother needs emotional support to move to formula. The pressure to breastfeed is overwhelming and parents need to be reassured about moving to the bottle."

"Accessible out of hours breastfeeding advice required. NCT do have a helpline, but they put you on hold, which is no help."

"Although the overall care in hospital was very good I did notice that other mothers that were breastfeeding needed a lot of support from midwives as they were struggling. I don't think that they received that."

"Had to be readmitted into hospital, but was not allowed on a maternity ward, which made it difficult to breastfeed."

Further Analysis by District

District normally reside	Did Breastfeed		Did Not Breastfeed	
	Actual No	%	Actual No	%
North Warwickshire	19	**76.0**	6	**24.0**
Nuneaton/Bedworth	25	**67.6**	12	**32.4**
Rugby	4	**36.0**	7	**70.0**
Stratford	33	**82.5**	7	**17.5**
Warwick	56	**74.7**	19	**25.3**
Other	7	**50.0**	7	**50.0**

Generally between two thirds and three quarters of all mothers from all but of the districts and boroughs chose to breastfeed. The exception to this was Rugby where it was only 30%. However, there were very few responses from Rugby to be able to state conclusively that this is a matter for concern, further research is required.

The other responses to where the mother normally reside included Coventry, Hinckley, Worcestershire, Leicestershire, Milton Keynes and Watford. There were insufficient numbers to conclude whether there was a pattern to the number that chose to breastfeed.

Further Analysis by Hospital

Hospital	Did Breastfeed		Did Not Breastfeed	
	Actual No	%	Actual No	%
George Eliot	47	**66.2**	24	**33.8**
Warwick	77	**73.3**	28	**26.7**
Walsgrave	3	**43.0**	4	**57.0**
Redditch	8	**80.0**	2	**20.0**
Milton Keynes	1	**-**	0	**-**
Leicester	1	**-**	0	**-**

- Alexandra Hospital, Redditch had the highest percentage (80%) that breastfed. However, the overall numbers of responses for this hospital are quite small.

- Warwick hospital had the next highest percentage with 73% followed by George Eliot with 66%.

Conclusion – Breastfeeding

It is reassuring to see that many mothers set out with the intention to breastfeed, however many drop out within the first few weeks for various reasons. This lack of success may be partly due to being discharged from hospital without having breastfeeding fully established and not having enough information on how to continue.

The main reason and the first hurdle for stopping was that the baby was getting insufficient milk and not gaining weight. However, with the right support this could be resolved in many cases.

There were medical reasons for not continuing to breastfeed, such as the baby not being able to suckle or being premature or the mother being ill. Additional support for one mother helped her overcome these initial problems with her being able to breastfeed for six months.

Return to work was given as a reason for not being able to continue. There were no reasons given for why the mother had to stop. More research is needed to establish what would help the mother to continue.

Some mothers found the experience much more time consuming and painful with one mother suggesting that the information given should be much more realistic. There is a notion that mothers will find it a wonderful experience, but initially, it is often not the case and it takes time and perseverance to continue.

From this survey the reasons given for mothers deciding not to breastfeed at all are many and varied and it will take a concerted effort by midwives and health visitors to overcome these barriers. However, it is still important that mothers still are able to chose whether to breastfeed or not without feeling guilty. Also it is important that mothers who cannot breastfeed, are made to feel that bottle feeding is a valid alternative and that they are not made to feel any less a mother.

Section E - Postnatal

60. When you were first discharged from hospital did you have any support at home?

- 173 (86%) said yes that they had support at home
- 15 (7%) did not have support
- 14 (7%) did not respond to this question (these mothers were still in hospital and could not comment about support at home at this stage)

61. Did you find this support useful?

- 166 (82%) found the support useful
- 7 (3.5%) did not
- 29 (14%) did not respond to this question. This is partly due to some mothers being still in hospital and not able to answer this question.

62. If no what type of support would you have found useful?

Twelve mothers responded to this question although only seven in question 61 did not find this support useful.

- 2 mothers wanted advice and emotional support in the transition between hospital and home
- 2 mothers found different midwives gave contradictory advice which resulted in inconstancy of care
- 2 mothers found the gaps between visits to the home too long
- Other responses included wanting more medical help; help from La Leche (breastfeeding support group); help with domestic duties; a longer stay in hospital because partner was not supportive and finally one mother thought that more support from the midwife would be good and wondered why some of them are in the profession

63. If no to question 60 did you want some support at home?

- 10 mothers wanted some support at home
- 5 mothers did not want any support

64. If yes what type of support would you have liked to have?

- 4 mothers wanted support for parents of premature babies
- 1 mother wanted support for 1st time mums
- 2 mothers wanted longer and more visits from their midwife
- 2 mothers wanted reassurance
- 1 mother wanted bonding time with new baby
- 1 mother wanted information that wasn't later contradicted
- 2 mothers wanted anything but 1 mother was too emotional to know what she wanted
- 1 mother wanted help with domestic duties

Section F – Other Services or care that may be required

65. Is English your first language?

- 190 (94%) responded yes that English is their first language
- 11 (6%) responded no

66. Did you experience any difficulties in understanding the midwife/doctor or them understanding you or your partner?

- 13 did experience some difficulties

67. Would you liked to have an independent interpreter there who could have spoken for you?

- 6 would have liked to have an independent interpreter

68. If yes what is you preferred language?

The languages wanted were Spanish, Gujerati, Thai and Zulu. One mother wanted help in understanding the foreign doctor.

69. Any further comments that you/your partner may wish to make that have not been covered by this questionnaire?

- 29 mothers thought the hospital and all other services they had received were excellent.

Positive comments were made about the care in hospitals such as when their baby was ill the staff were very supportive even though they were under pressure; the care after the emergency caesarean was fantastic; they would go back to Walsgrave they were excellent.

Positive comments were received about the care at home; community midwives were excellent, home midwife was brilliant helped the baby to breastfeed. Three mothers wanted us to pass on their thanks to the staff at the hospital and at home.

- 5 mothers had issues about antenatal classes – information was inadequate; being contacted to attend after a miscarriage; having to pay.
- 2 mothers thought that their antenatal care was poor
- 3 mothers were concerned about the reliance on scans one mother had 7 which caused her to worry, another thought the reliance on scan date caused her to have a c-section
- 6 mothers were left for long periods waiting for treatment, which they found distressing.
- 7 mothers had issues about the management of the hospital – cleanliness, consistency on visitor numbers, using mobiles on wards, security needing to improve
- 3 mothers had problems with understanding the doctors either because the doctor was foreign or they were.
- 13 mothers wanted more support comments given were coping with depression needed more understanding and help; advice and support at home for mothers with premature babies; second mums still need support especially if there has been a long gap between children; midwives to spend more time talking, listening to the fears and joys of mothers
- 4 mothers wanted more choice on birthing methods and where they have their baby. One mother was told by her midwife that if she had her baby at home, the GP would deregister her.
- 9 mothers had issues about the continuity of care - conflicting advice given by midwives and doctors the mothers were not sure what they should be doing about caring for their baby
- 3 mothers having had issues about having a caesarean felt their choice was taken away. Conflicting advice given by midwives and doctors where they disagreed whether they the mother should have a caesarean or not

Appendix 3

The experiences of parents with pre-term babies: Identifying effective interventions for communication, information and support

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A project developed and led by a collaboration of the National Childbirth Trust (NCT), Warwickshire National Childbirth Trust Pre-Term Support Group (WPSG), Bliss and the Royal College of Nursing (RCN) Institute.

1.0 Summary

The need for this project was identified by the Warwickshire NCT Pre-Term Support Group (WPSG), a group affiliated to the National Childbirth Trust (NCT). Their experiences have highlighted the need to develop a better understanding of what interventions, or forms of help, are useful for parents of pre-term babies, particularly in relation to three key areas, communication, information and support. We plan to undertake a four-stage project in direct response to this identified need.

Stage 1

In the first stage a systematic review of the literature will be undertaken, in order to identify the most effective interventions that help to support, inform and communicate with a range of different parents.

Stage 2

In the second stage we will survey all neonatal units in order to identify which forms of support, information and communication are provided, as a baseline measure of current provision, and to help plan our dissemination strategy.

Stage 3

In the third stage, we plan to talk to a diverse range of parents about their needs and what they found effective or ineffective when using services. This is a key part of any attempt to identify effective, appropriate and acceptable interventions for parents.

Stage 4

The final stage of the study will ensure that the results of the study will be disseminated to all key stakeholders, including parents and prospective parents. The collaborative approach adopted in the development of this bid over the last fourteen months, has ensured that parents, researchers, clinical specialists and voluntary organisations have carefully considered the study aims, methods, ways of working and the strategy for dissemination. As a result of this extensive process we feel that the study addresses a real need and will provide a unique and important contribution to helping improve the experiences of parents and their babies at this vulnerable and difficult time in their lives. As such it will provide an important contribution to improving the quality of life of the wider community.

1.1 Ways of working

A collaborative bid

We are submitting this research study as a collaboration of organisations who have all contributed to the development of the study and will each lead on specific parts of the project. As we have already worked together on the development of this bid for the past fourteen months, we feel this has established an important groundwork for future successful working. This section describes how each organisation in the collaboration will contribute to the study.

National Childbirth Trust

NCT are the lead organisation for the bid as they are the national charity to which the Warwickshire NCT Support Group, the originators of the study, are affiliated. The National Childbirth Trust offers support in pregnancy, childbirth and early parenthood and aims to make sure that all services, activities and membership are fully accessible to everyone. The NCT will act as the main contact point for the Community Fund, and as the primary recipient of the research monies. Contract would be established between NCT and the RCN Institute and between the NCT and Bliss to ensure appropriate transfer of funds at the required points in the project. In addition, NCT will lead on specific parts of the dissemination strategy.

Warwickshire NCT Pre-Term Support group

As the affiliated group the Warwickshire NCT Pre-Term Support Group will have close input throughout the study and will be formally represented on the advisory group. Members of the group will be able to develop their research skills and run some of the focus groups or interviews planned in stage three of the study.

Bliss

Bliss is a key charity working in the field of prematurity and has extensive expertise in parental support and information, producing a range of leaflets and information sources. As such, Bliss is a key member of this collaboration. In addition, Bliss will lead on specific parts of the dissemination strategy.

Royal College of Nursing (RCN) Institute

The RCN Institute has significant expertise in undertaking systematic reviews and in using interview and focus group techniques. The RCNI is the research collaborator within the consortium and will lead on the research stages 1-3 with input and support from NCT and Bliss. The lead investigator, Dr Sophie Staniszewska is a Senior Research Fellow who leads a programme of work examining patients' evaluations, experiences and involvement within health care, and is well placed to undertake this work. Professor Kate Seers, Head of Research at the RCN Institute has specific expertise in systematic reviews and will act as specialist advisor for stage 1.

Advisory group

The advisory group for the study has been established (appendix 2) and has met to discuss the bid. The group includes some of the country's leading researchers, clinicians and academics in this area. Individuals from the advisory group have had significant input into the development of the aims, objectives and methods of the study. We are also establishing a broader advisory group (appendix 3) to ensure all the relevant organisations, such as the Neonatal Nurses Association and the British Association of Perinatal Medicine, have an appropriate input into the study.

A collaborative approach to research
The development of this bid has utilised a collaborative model of research that ensures the users perspective forms the central focus of the bid. This approach is encouraged by many policy initiatives as a way of making research more relevant to people's lives (Involve 2003).

We have achieved this by regularly discussing the aims, focus and methods with the Warwickshire NCT Pre-Term Support Group, NCT, Bliss and the RCN Institute, with key input from our advisory group. Dr Sophie Staniszewska is an advisory member of Involve, (http://www.invo.org.uk) the organisation that advises health researchers on how to involve individuals as collaborators in research, to ensure the relevance of research to the lives of real people.

As the collaborative approach to developing research studies is relatively innovative, we wished to disseminate our ideas about collaborative working, and so have presented a brief paper to the Involve away day in 2004, detailing this process. The paper was received very well and supported by those present, including users, as an example of good practice. On the basis of this, we are submitting an academic paper (written by the lead researcher and by the Warwickshire NCT Support Group) to a peer-reviewed journal, detailing the collaborative approach to research project development (Staniszewska S, Jones N, (2004). *Consumer involvement in the development of a research bid: Challenges and opportunities.* For submission to the international peer-reviewed journal Health Expectations in February 2004).

2.0 Background to the study
In summary, the overall aim of this study is to develop our understanding of the perceived effectiveness of the different interventions that can be used to help parents of pre-term babies, in relation to information, communication and support, three areas of central importance to parents. The next section briefly reviews relevant studies in order to provide a context for the study aims.

2.1 Prevalence of pre-term births
Of approximately 700,000 babies born each year, around 1 in10 will need some sort of special care at birth and around 1 in 50 will need the highest level of neonatal intensive care (Bliss 2002). Prematurity is thought to be associated with a range of factors, including maternal age (eg. teenage pregnancy), poor nutrition, smoking, poor maternal health (eg. anaemia and hypertension), maternal low socio-economic status (D'Alton and Grant 1990) and the increased number of multiple pregnancies due to invitro fertilisation, and increasing drug misuse (Northern and Yorkshire Public Health Observatory 2002).

The survival rate of premature babies has increased over the last few years and has been attributed to the use of antenatal steroidal therapy to decrease the incidence of respiratory distress syndrome by accelerating maturation of the lungs (Yu 1984, Liggins and Howie 1972). Other advances such as the use of surfactants, the introduction of high frequency oscillatory ventilation, which prevents chronic lung disease have also contributed to improved survival rates (Bancalari and Goldbery 1987, Yu 1984). Since the 1960's, the survival rate of very low birth weight infants has almost doubled from 50% to 90% (Yu 1984) and the survival rate for extremely low birthweight infants has also improved

significantly (Lau and Morse 1998). Thus, as the number of NICU admissions have increased as premature infants have a better chance of survival, so do the numbers of parents exposed to prolonged hospitalisation associated with a NICU (neonatal intensive care unit) or SCBU (special care baby unit) experience (Lau and Morse 1998). The 8th Confidential Enquiry into Stillbirths and Deaths in infancy (CESDI, 2003) has also found that premature baby survival rates in the UK could be substantially improved (Project 27/28). This suggests that the possibility of a baby and its parents spending a significant period of time hospitalised had increased over the last few decades. Studies also show a consistent relationship between social disadvantage and low birthweight (Collins et al 2003, Hodnett et al 2003), thus affecting vulnerably groups disproportionately.

2.2 The experiences of parents

While medical advances mean that very young babies have a good chance of surviving when they are born, the enormous impact of this experience on the baby and the parents cannot be underestimated. The birth of a pre-term baby can be an intensely stressful, confusing and difficult time for parents and families. Overall, studies indicate that the delivery of a premature infant and admission to NICU (neonatal intensive care unit) represents a crisis situation for the parents. In addition, parents of minimally ill premature infants have also been found to experience a range of emotions and reactions similar to parents of critically ill children (Lau and Morse 1998).

Through discussion with the Warwickshire NCT Pre-term Support Group, who are made up of parents who have had pre-term babies (appendix 1) and with our advisory group (appendix 2), who include leading academics and clinicians in this field, we have identified three key areas of parent experience, that will form the focus of the study. These areas include information, communication and support. Although each of these areas are described separately for the purposes of the bid, they are inter-connected and do overlap in some studies. Together they form a central part of many parents' experiences of having a pre-term baby. Each of these will be briefly reviewed in the following sections.

2.3 Information

One of the most important areas for parents having a baby is information. Research on women's views of maternity care has given an indication of the importance of good communication between mothers and health care professionals. The Audit Commission's national surveys of mother's views of maternity and the NCT's Choices and Access Projects have suggested that readily available and clear information is central to women's and men's needs (Garcia et al 1998, Gready et al 1995, Singh and Newburn (ed) 2000, Singh and Newburn 2000).

Access Project have suggested that readily available and clear information is central to women's needs (Garcia et al 1998, National Childbirth Trust 2001). A number of studies have examined different aspects of information provision, revealing the important role that information has for the parents of pre-term babies. Brazy et al (2001) found that parents of premature infants make a transition from being passive recipients of information to actively seeking it. In their study parents spent 10-20 hours a week gathering information during the

first month of their baby's hospitalisation. The authors identified an unmet need for information around infant health, infant care and coping. Veddovi et al (2001) highlighted the importance of information by finding that maternal knowledge of infant development may be protective against the development of depressive symptoms in the postpartum period. These results are reinforced by the results of a previous study which found that mothers who needed more information and did not receive it were more anxious and less confident in caring for their infant (McKim 1993), thus reinforcing the important role information can play in the parent's experience.

2.4 Communication

The way information is communicated can have an enormous impact on an individual's experience. The importance of effective communication is widely acknowledged by many studies (Rowe et al 2001). Changing Childbirth (1993) highlighted the importance of good communication in woman-centred care, as did the CESDI 8th Annual Report (2003), which pointed to the importance of good clear communication between health care professionals and women using the service. Studies have identified a range of concerns, which parents have reported in relation to communication. Difficulties in communicating with staff have been identified as one of the main stressors in neonatal intensive care. For example, having difficulties in getting enough time, or the opportunity to discuss issues with doctors (O'Shea and Timms 2002). The importance of communication is further emphasised by studies that have found that good communication may bring benefits in terms of outcomes for patients (Stewart 1995, Ong 1995). Despite these potential benefits, a recent literature review supports the need for further research to explore parents' experiences and expectations of communication (O'Shea and Timmins 2002).

2.5 Support

It is recognised that social support is important in the psychological recovery of stressful traumatic events (Cohen and Syme 1985). One definition of social support is offered by Cronenwett (1985) who describes it as having four dimensions – emotional, material, informational and comparison support, or the sharing of similar ideas and feelings. A number of studies have identified the great need parents have for support. One study found that the birth of an extremely low weight baby infant caused crisis reactions in 85% of mothers and 65% of fathers (Stjernqvist 1993) Families of extremely low birthweight infants undergo a vulnerable period during which they may greatly benefit from psychological support (Nordstrom- Erlandsson 1996). Eriksson and Pehrsson (2002) also found that increased emotional support during crisis reactions is particularly desirable in order to process feelings raised by the trauma. The provision of social support can be particularly important as this time, and can lead to enhancement of parental coping abilities, increased self-esteem, reduced parental anxiety and increased feelings of control (McKim 1993). Thus, it can enhance the possibility of a positive outcome for a high-risk premature infant (Schraeder 1986).

The importance of understanding the perspectives of parents in relation to communication, information and support is particularly emphasised by studies which indicate that parents often have clear priorities and preferences for the care of their child, and that parents and health care professionals can have

different perceptions about the role they each should have and how best health care professionals can support parents (Bialoskurski et al 2002, Johnson 1988, Hughes et al 1994, Paredes and Frank 2000). However, no studies have attempted an overall synthesis to examine which forms of support are most effective or most appropriate or acceptable from the parents' perspective.

2.6 Interventions

Overall, the literature highlights the key role of information, communication and support in the parent's experience of health care when they have a pre-term baby.

During this time parents may experience a range of interventions, or forms of help, in relation to communication, information and support. Examples include provision of different forms of information, specific support programmes and particular communication training packages for health care professionals, to help parents. For example, Safran (2003) describes the innovative use of information technology in supporting communication with families, which aim to help parental decision-making. While a range of interventions or forms of help exist, and are provided by both health care professionals and by charities working in this area, it is not clear which ones are most effective as a systematic review has not been carried out of the qualitative and quantitative literature. Our study will attempt to identify which types of help, or interventions, exist and which ones are most effective, based on both the literature and on parent's perceptions and experiences. The results of the study would help the charities working in this area to develop the services and support they offer for parents and would therefore benefit all prospective parents, particularly in helping those from disadvantaged groups who are more likely to have a pre-term baby (D'Alton and Grant 1990).

This section has described some of the literature that underpins the aims of the study, which are described in the next section.

2.7 Aims and objectives

a. To develop a better understanding of the experiences of a range of parents with pre-term babies, particularly in relation to communication, information and support. There will be a particular emphasis on exploring the needs of parents from different ethnic and social class backgrounds

b. To use this evidence-base to inform voluntary organisations and charities, such as NCT and Bliss, so that they can develop services and support mechanisms to meet the specific, and varying, needs of parents with pre-term babies.

c. To disseminate the study findings to inform the development of services that are parent and baby-centred.

These objectives underpin the more specific study aims;

Study aims:

a. To identify effective interventions for communicating with, supporting and providing information for parents of pre-term babies.

b. To establish which interventions neonatal units currently provide for parents of pre-term babies, in relation to communication, information and support.

c. To identify which communication, support and information interventions are effective, appropriate and acceptable from the parent's perspective.

d. To disseminate practical recommendations and provide training, based on the study findings to parents, voluntary organisations, health care professionals and the NHS.