The Role and Impact of User Representation and Involvement in Neonatal Network Boards

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Exploring the Role and Impact of User Representation and Involvement in Neonatal Network Boards

Introduction: involving parents in the work of neonatal networks

Having a baby is a time for great celebration. All new parents go through a complex set of emotions and experiences. This is particularly the case for parents of babies that are born earlier than expected or who are born sick. The birth of their baby is also a time to celebrate. Parents play a unique position in relation to neonatal services. They have a dual role in representing both their baby's needs and their own needs, as indirect users of neonatal services who play a central role in their babies' care. As such they have a valuable insight into the operation of neonatal services. The findings presented in this report suggest that parental involvement can, if it well planned and supported, make a valuable contribution to the development of neonatal services.

The project team was based at the Institute of Health, in the School of Health and Social Studies at the University of Warwick and the team are available for further discussion, dissemination or knowledge translation of the findings and recommendations.

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Executive Summary

This research project aimed to explore the development of parental involvement and roles within neonatal networks at a local and national level and to identify strategies for recruiting, supporting and training parents to be effective participants.

Methodology

The study consisted of a national repeated survey of all neonatal networks in England and four network case studies. Data for the case studies included

- Informal interviews with involved professionals
- Observation of meetings and review of minutes
- Informal interviews with involved service users

Findings

The surveys revealed wide variation nationally in the level and type of parental involvement in neonatal networks, ranging from no representation to relatively well-developed mechanisms for involvement. However, the evidence also suggests that there is a lack of diversity among parental board members, i.e. under representation of fathers, ethnic minorities and people from lower socio-economic groups. Relatively few boards pay parents for attendance at meetings.

Many board members are very supportive of parental involvement. However, some board members feel that parents attending board meetings may not be the best way to involve parents or may be 'tokenistic'. These concerns are also frequently shared by parents. A common concern among professional members of network boards is that parents may become involved because they have a particular *"axe to grind".* There are also concerns that that some parents will represent their own interests rather than the broader view of parents. In some cases, where such concerns have been expressed, a cautious approach to parental involvement has been adopted. Involvement may begin on a limited basis, but then develop as both professionals and parents gain confidence. A crucial issue regarding the success of parental involvement within a particular network appears to be the presence of someone who is prepared to act as a facilitator and supporter of the involvement process. In many cases this role falls to the network manager.

Despite the concerns described above, the evidence collected for this report suggests that parents have been involved in developing a wide range of initiatives which have enhanced the work of neonatal networks (examples on page 31).

Models of parental Involvement

Parents play different roles on network boards, depending on how differing networks conceive of and organise parental involvement. Broadly speaking, these roles fall into three main types. These are parents as:

- Sources of information
- Consultants
- Representatives of other parents

These modes of parental involvement are not mutually exclusive. Networks may make use of more than one approach, although particular networks appear to be characterised by one or other of these approaches.

Parents as sources of information

When parents are sources of information, they are treated as providing raw data. This data can be collected in a number of ways, e.g. via a survey or via the use of focus groups. The information thus obtained can then be analysed and the results fed into a network's decision-making processes. This approach has the advantage that information from a relatively large number of people can be obtained. However, the type of information produced is determined by the agenda of the board, rather than the parents. It also precludes parents from any involvement in the decision-making process.

Parents as advisors

The approach of framing parents as advisors recognises that parents not only possess important information, but that their specific experiences as users of the service mean that they can make a significant contribution to the decision-making process of the network. This approach has the advantage that it allows some parents to contribute to the decision-making process. However, the number involved is relatively small and the agenda is still largely determined by the board itself.

Parents as representatives

The approach of parents as representatives involves framing the role of parents on network boards as being to represent the views of other parents who have used neonatal services. This potentially increases the numbers of parents, who can contribute to the decision-making processes of a network board, either directly or indirectly. It also has the potential to provide a greater opportunity for parents to place on the board agenda issues of importance to them, as they emerge through discussion. However, the difficulty here is that this requires a relatively large commitment in terms of time and effort from both staff and parents. This may be difficult to sustain, given that the parents involved are also likely to have significant caring commitments.

Conclusions

The research has uncovered wide variation nationally in the level and type of parental involvement in neonatal networks. Concerns have been expressed by both parents and professionals that involving parents in strategic decision making may be 'tokenistic' and ineffective. However, the research has also found evidence that where parental involvement is well planned and supported, parents can make a valuable contribution to the development of neonatal services.

Recommendations

The following recommendations are designed to strengthen parental involvement, with the aim of contributing to the development and improvement of neonatal services. They are that:

- Networks should develop a clear idea about what they want to achieve through involving parents in their work. This in turn will determine the type and level of involvement and the nature of the support and training that staff and parents may require. Accessing parents as sources of information, as consultants or as representatives of other parents, place very different requirements both on network staff and on parents.

- Each network should nominate one person to act as the network's parental involvement coordinator. This person would be responsible for developing the networks approach to parental involvement in partnership with the network board and parents. In most cases this person will be the network manager.

- BLISS will need to develop training packages which reflect the diversity of approaches to parental involvement within neonatal networks. This may involve working with networks beforehand to design an appropriate training package. Ideally, training should be run jointly for both parents and network managers.

- There is a tendency for parental involvement to exclude already marginalised groups. If this tendency is not checked there is a danger that the process of parental involvement will entrench, rather than reduce, health inequalities. It is, therefore, important that networks develop models of participation that are as representative as possible of the population they serve.

- All networks who involve parents in their work should make arrangements to recompense parents for any expenses incurred as a result of the involvement process (e.g. travel, parking, child care) and make payments which recompense parents for the time, effort and inconvenience that involvement requires. This is particularly important if people from lower socio-economic groups are not to be disadvantaged by the involvement process.

- Networks should collaborate locally and nationally on the further development of parental involvement. Such collaboration should focus on the development of best practice, the sharing of experiences, training and support. This could be facilitated through regional events and/or an annual conference. The University of Warwick is currently working with the London Perinatal Network to organise such an event on November 14th 2008.

- Network managers should have training on user involvement as an integral and important part of their role and requires listing within their job description

Exploring the Role and Impact of User Representation and Involvement in Neonatal Network Boards

Background to the report

On 10 April 2003 the Department of Health (DoH) published an expert working group report on Neonatal Intensive Care Services (DoH, 2003). The report proposed the reorganisation of neonatal care into managed clinical networks. Within each network there would be at least one specialist hospital providing the most advanced level of intensive care (level three) with other hospitals within the network providing high dependency and special care (levels two and one respectively). Each network would be managed by a network board consisting of clinicians and NHS managers. These managed clinical networks would be responsible for the organisation and development of neonatal services in a geographic area. The Department of Health also recommended that there should be at least two user representatives on each Neonatal Network Board. User representatives have been defined as a carer or parent of a baby who is receiving or who has received neonatal care. In addition, section 11 of the Health and Social Care Act 2001, the earliest legislation for involvement, places a duty on NHS organisations to involve and consult with patients and the public on how services are planned and developed.

The development of neonatal networks and the requirement that these new structures engage with parents, presented an opportunity to carry out research which explores how parental involvement is being developed within neonatal networks. The charity BLISS has been informing parents nationally about the networks and has also been supporting network boards in developing user involvement through providing support for recruitment and training of representatives and it was thought by BLISS and NHS commissioners that an evaluation of user involvement in neonatal networks could inform the development of best national practice in this area.

Aims of the study

- Evaluate the development of user representation and roles within neonatal network boards locally and nationally
- Identify differing approaches to recruiting, supporting and training parents to be effective representatives
- Support the development of recruitment and training by BLISS for user involvement in neonatal network boards.

Structure of the report

The report is divided into two parts. Part A of the report consists of a preliminary literature review carried out at the beginning of this project. Part B reports on the findings from the research conducted for this report.

Part A: Preliminary Literature Review

Social policy background

The 1990s were marked by increasing interest in patient and public involvement (PPI) within the Department of Health and the NHS (Barnes 1997). It can be argued that these developments have their origins within the Conservative governments attempt to re-model the relationship between the NHS and service users along consumerist lines. Documents such as *Working for Patients* (DoH,1989) the *Patients Charter* (DoH, 1991) placed emphasis on individual 'rights' and 'choices'. Since 1997 and the election of Labour, Patient and Public Involvement (PPI) has became a central plank of both healthcare policy rhetoric and structures (Milewa et al., 2002). Subsequently this agenda has now developed to include greater involvement of both patients and the public in corporate decision making (Sitzia et al 2006). Legislation has now been passed which requires NHS organisations to engage with service users in the planning and delivery of local services (Health and Social Care Act, 2001; National Health Service Reform and Health Care Professions Act 2002 and the Local Government and Public Involvement Health Act 2007). However, despite the growing emphasis on PPI in the Health Service, there is relatively little literature which explores the nature and outcomes of long-term patient involvement initiatives, particularly at the level of corporate decision making.

Parental involvement in neonatal services

In line with the developments noted above, increasing emphasis has been placed on the consumer rights of parents within neonatal services. For example informed choice for mothers about the care and facilities offered to them during childbirth has been promoted. [1]

However, despite the fact that parental participation appears to be commonly accepted (Newton 2000), there is a lack of clarity about the concept itself (Prasopkittikun 2003). Coyne's (1996) review of the British research literature on parental participation indicates that it is a complex and multi-dimensional concept, with changing terminology frequently being employed.

Newton (2000) also points out that, despite the apparently wide support for parental participation within neonatal services, its implementation still presents a number of challenges including difficulties associated with role stress, negotiation failure and power struggles. There is also evidence that support for parental involvement may be regarded by some clinical

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[1] From a legal perspective parental involvement in neonatal services within the UK is also supported by the fact that parents have in general been acknowledged as the appropriate advocate for young children. However this general acceptance does not mean that on occasion doctors will not attempt to overrule parents if they think that parental decisions may jeopardise the welfare of the child.

professionals as only appropriate within clearly defined limits (Daneman et al 2003).

Individual parental participation

Perhaps reflecting the emphasis on individual 'rights' and 'choices' dominant in the 1980s and 1990s, much of the research in this area focuses on parents' involvement in decisions about the care of their own children. Research in this area frequently makes a case for increased parental involvement on the grounds that it will improve clinical outcomes (Merenstein, 2005).

However, Neill (1996) conducted qualitative research to examine parents' views and experiences of parent participation. This research found that parents wished to be involved in decision making about the care of their children, but at a level of their own choosing. In particular, the evidence presented suggested that parents wanted professionals to be in charge of their child's clinical care, while they continued to be in charge of their child's 'normal' day to day care. Problems centred on communication and the continuing paternalistic nature of the relationships between doctor and parents.

International comparisons

Tyler (2001) compares the level of parental involvement in neonatal services across three European countries: Germany, the Netherlands and England. This study utilised data on visiting policies, presence during medical examinations, and involvement in decision making (including characteristics of communication such as how information is delivered, e.g. is information delivered to the main care giver or to both parents, is it given via appointment only or is it available on an on-call basis). Interestingly, her research indicates that the UK has the most open approach to parental involvement in neonatal services of these countries. Tyler suggests four interrelated contextual factors that might account for the differences between the countries. In particular, she emphasises the role played by the organisation and delivery of health care; the specific historical traditions of maternity care; the scale of emergence of consumer movements in health care; and lastly the degree of development of women's activism.

Ethnicity and parental participation

Another important but relatively unexplored area is the impact of ethnicity on parental participation. Xu, Borders and Arif (2004) in a study conducted in the USA, compared ethnic differences in parent's perceptions of their children's physicians' participatory decision-making styles. They found that Hispanics gave a significantly lower rating, as compared to white non-Hispanics, of their children's physician's participatory decision-making style. However the research did not establish what perceptions the physicians had of these encounters or whether these differences in decision-making styles were associated with any particular characteristics of the physicians.

The purpose of parental participation in managed clinical networks

Despite the wealth of literature on parental involvement at the individual level, there is relatively little research literature which explores the experience of parental involvement in corporate decision making in neonatal services. However, it is clear that user involvement in NHS services does not have to be limited in this way. Crawford et al (2003) identify three purposes of user involvement in the NHS:

1. To increase accountability
2. To promote the interests of service users
3. To improve the effectiveness of services and improve the health of the public

It could be argued that all these three purposes are in operation in relation to parental involvement in Managed Clinical Networks (MCN). However, although these purposes overlap it should be remembered that they are not the same and place different demands on involved service users.

Managed clinical networks

There is some evidence that informal clinical networks have always played an important part in the way that NHS services are managed. Cropper et al (2002) point out that the management of resources can be carried out formally via contracts, service agreements and protocols, or informally via personal acquaintances, trust, cooperation and verbal agreement. Ferlie and Pettigrew (1996) found that informally-governed networks were commonplace, if difficult to map, in paediatrics. Part of the idea behind Managed Clinical Networks (MCN) is to formalise and build on these 'natural' alliances for the benefit of service users (Holmes and Langmaack, 2002), while at the same time increasing accountability and transparency.

Baker and Lorimer (2000) define a MCN as,

"A linked group of health professionals and organisations from primary secondary and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care…The emphasis…shifts from buildings and organisations towards services and patients".

Cropper et al (2002) emphasise the opportunities created by MCNs to utilise the skills of a wide range of differing professionals, including a wide range of people with various non-clinical competencies.

The core principles of MCNs as laid out by the (Scottish Office Department of Health 1988) include:

- The appointment of one person with overall responsibility for the operation of the network, be it a clinician, manager or other professional

- A clearly mapped-out structure, which sets out the points at which the service is to be delivered and the connections between the points
- A statement of expected service improvements and the preparation of an annual report. The potential to generate better 'value for money' must have been explored
- Adherence to evidence-based treatment guidelines and formal agreement of the entire network to participate in the network and to participate in accordance with the evidence base.
- Quality assurance procedures, including audit
- Patients involved in its management arrangements

It is this last point that we are primarily concerned with here. Tritter et al. (2004) in their work on user involvement in cancer networks (where the use of MCNs is perhaps most developed within the NHS) make use of a 'cycle of involvement' to help ensure that all stages of the process are systematically thought through and linked to service improvements which are evaluated by service users.

Sitzia et al (2006) in their research on the impact of patient participation on professionals and patients in cancer services found five types of outcomes of service user participation. These were:

1. 'Just being there'. Taking pride in being involved in NHS decisions and being taken seriously
2. Patients beginning to provide an important reference group for consultation on various projects
3. Patient representatives acting as a 'nucleus' for further patient involvement and networking
4. Development of patient communication projects e.g. developing 'Breaking Bad News Standards' or improving communication skills of staff.
5. Proactive involvement to change service policy and delivery

Service users generally felt positive about their involvement and emphasised the important enabling role played by some professionals. In particular they stressed the importance of the interpersonal skills necessary to help service users to participate in meetings. Service users also generally felt that the clinical knowledge and personal commitment of professionals was a key issue in ensuring that improvements to services were achieved.

Contradictions and tensions

Sitzia et al's (2006) research also suggests that a number of tensions can develop between professional and patient representatives. They found that service users are more likely to express their commitment to participation in personal terms, reflecting the fact that the knowledge that they bring to corporate decision making is based on their own direct experience of services. Professionals were far more likely to express their interest in terms of it being 'part of the job', and, in some cases, only a small part of a very complex job. This tension was sometimes expressed in disagreements about the times and dates of meetings, with professional staff preferring meetings

within 'office hours', while service users tended to find it easier to attend at weekends or in the evenings.

A further area of tension was the tendency of some service users to discuss personal issues in meeting. Professionals, both clinical and non-clinical, were often uneasy about this since it breaks a number of professional codes e.g., discussing the particulars of an individual case in a public forum. Furthermore, if these views were expressed too strongly there was a possibility that they could be interpreted as a statement of personal grievance. Professionals often saw this as unhelpful and inappropriate in a management meeting.

A third area of tension was emotional commitment. Service users tended to feel that their participation entailed a degree of emotional commitment, since it had grown out of personal experiences, whereas professionals were more likely to express little or no emotional commitment to patient involvement.

Concerns about the representativeness of the service user representatives were also expressed, although significantly never about the professionals present.

However not all the difficulties were related to tensions between professionals and service users. The evidence presented also indicated that both clinical staff and service users tended to believe that senior NHS managers were only paying 'lip service' to patient participation.

Concluding comments

This brief look at the literature on patient participation raises a number of issues:

- It suggests that despite the wide spread acceptance of the notion of parent participation, significant barriers to its effective implementation remain. In particular the attitude of professionals can vary considerably and this will in turn have a significant impact on whether parent participation becomes a reality or not. The presence of a core of professional who are committed to partnership working may therefore be crucial.

- Sitzia et al (2006) suggest that the development of a 'culture of partnership' may also be essential to this process. Such a culture in neonatal services might consist of a number of unwritten 'ground rules', e.g. an acceptance of equality between service users and professionals and recognition that both sides are 'specialists' with a specific interest in neonatal services; acknowledgment of a common purpose i.e. to improve neonatal services and the experience of service users; and recognition of the complexities involved in delivering improvements. The evidence suggests that it is when one of these 'rules' is broken that difficulties arise.

- Even where these elements are in place partnership working is unlikely to be effective unless it is felt that this is supported by a wider institutional

commitment. If this does not occur parents may feel that only 'lip service' is being paid to the concept of participation.

- The price to parents of participation is also an important factor. There are important financial, social, time and emotional cost implications for parents who choose to participate. As a result, parents are unlikely to participate on a sustained basis if they feel that their contribution is not valued by health care professionals. Developing and sustaining involvement parental involvement may therefore be difficult, particularly where, as in neonatal services, the service user population is inherently transient.

- The model of participation within MCNs also needs to be explored. Parents could be involved on an individual basis. However Sitzia et al's (2006) research on cancer services explores the use of 'partnership' committees, where a group of service users, rather than individuals, meet with health care professionals. This 'partnership' model may put parents on more of an equal footing with health care professionals.

- Mechanisms that might enhance the ability of parents on MCNs to adequately represent the views of a diverse group of service users also need to be explored.

- The experience of user involvement in different countries may have important lessons to teach us about how user involvement might be developed in the British context.

Although this is only a very preliminary look at the literature in this area it does illustrate some of the complexities involved. In particular, it emphasises the need to develop a long term strategy to develop and sustain parental participation in neonatal services. The danger is that if parents do not see their involvement resulting in tangible improvements in neonatal services their involvement will not be sustained.

Part B: Exploring Parental Involvement in Neonatal Networks

Introduction

This section of the report describes the methodology and findings from the research conducted for this report.

Methodology

The research was a national study with case studies conducted at a regional level. At a national level two surveys, using structured questionnaires, have been undertaken of all neonatal network boards in England to gather some basic information about the level and types of parental involvement and how these are being developed. The first was conducted in 2006 and the second in 2007.

Regional area case studies

Detailed area case studies have also been undertaken of four networks in different regions of England, to gain a more nuanced understanding of the process and mechanisms used for involving parents on neonatal network boards. The case studies made use of a variety of qualitative methods based on ethnographic fieldwork combined with formal interviews. These included:

- Interviews and discussions with the four network managers
- Non participant-observation of meetings and analysis of minutes of neonatal network boards
- Interviews and discussions with parents and other involved professionals
- Non participant -observation of other forums within which parent representatives play a role.
- Documentary analysis of policy and minutes of meetings of MCNs

The case studies were selected to reflect the diversity of the differing approaches being taken to the recruitment, training, support and involvement of parents within neonatal networks across England in 2006.

Advisory group

The research was overseen by an advisory group with representatives from the major stakeholders. These were: BLISS, West Midlands Specialised Commissioning Team, the Royal College of Nursing Research Institute, Graces Research Fund and one parent representatives. The advisory group met twice a year.

Ethical approval

The proposal received ethical approval from the University of Warwick's Humanities and Social Studies Research Ethics Committee.

Findings

Survey results

Introduction

Two surveys designed to ascertain basic information about the level and types of parental involvement in neonatal networks across England were carried out of all neonatal networks in England. The first was circulated in 2006 and the second at the end of 2007. Between these dates some re-organisation and amalgamation of the networks took place. This makes comparing the results of the surveys difficult, since in some areas one survey response has been received to cover the same area that had been previously provided two separate responses. Where this has occurred the response have been adjusted to take account of the fact that the response reflects the situation in what was previously more than one network or was managed separately.

In the first survey 23 questionnaires were sent out and 22 returned, giving a response rate of 96%. In the second survey 23 surveys were sent out and 20 responses were received, giving a response rate of 87%. Both surveys were sent to network managers and were in most cases completed by them.

Network board membership

Both surveys indicated that the average number of board members is between 20 and 29. Responses from the survey indicate that the representation at board meetings varies between networks and, in some cases, over time as arrangements are reviewed. Most boards are made up of a combination of clinical representatives, specialist commissioners and senior management representatives. How this representation is constituted may vary, i.e. it may consist of representatives from PCT commissioners, specialist commissioners, unit representatives, clinical leads and various Trust representatives.

Parental representation on network boards

The number of parent representatives on network boards varied from none to three in 2006 and from none to five in 2007. Eight networks in 2006 and nine in 2007, reported that they had no parental representatives on their boards. There were a number of explanations for this, including difficulties in recruiting and retaining parents. However, it is also clear that some networks had made a purposeful decision not to involve parents at this level, preferring to engage with parents in other ways.

"There is no appetite for having one parent representative on our Board, as the concern is that this will be a difficult environment for a parent to contribute. The preferred way forward is to hold a series of focus groups to obtain parent feedback and we would ask BLISS to assist in this. The proposals are currently going through our Board." (network manager).

The numbers of parents on boards in 2006 and 2007 are given below. Broadly speaking, the picture appears to have remained static. However, these figures do not reflect the development of parental involvement in forums other than the network board. This is discussed below.

Table 1 Number of Parents on Boards

Number of parents on the board	Number of boards in 2006	Number of boards in 2007
0	9	8
1	3	2
2	6	7
3	4	2
5	0	1
Total	22	20

Recruitment of parents

The majority of neonatal boards with parental involvement reported that they recruited parents either via staff recommendations or through an advertisement and interview procedure developed in conjunction with BLISS. In some cases a combination of these methods was used. However, networks also used a wide variety of other methods. These included recruiting via:

- Maternity Services Liaison Committees
- Neonatal unit parents' groups
- Advertising through the units across the network
- Community road shows
- Direct invitation
- Community nurses
- A letter to parents

Some networks have used a combination of approaches. The approach to recruitment does not appear to have changed significantly between the two surveys. However, the wide variety of approaches does indicate that neonatal networks have used different strategies to engage with parents. There is some evidence, as we shall see below, that this is indicative of more general differences in approach.

Parental representation at other levels within the networks

Representation on network boards is only one forum within the networks where parents may contribute. Both surveys therefore asked if parents were

involved in network sub-groups or had other mechanisms for involving parents.

Table 2[2] Mechanisms for Involving Parents

	2006	2007
Parents involved in sub-groups	7	11
Other mechanisms for involving parents	13	15

In the 2006 survey only seven networks reported that they regularly involved parents in sub-groups, with one additional network reporting that parents were involved as and when needed. In the 2007 survey eleven networks reported that they involved parents in the work of sub-groups. Examples of the types of these sub-groups were:

- Transport
- Nursing
- Clinical governance and audit
- Developmental care
- Bench marking

Although the number of parents who were members of network boards did not seem to have changed much between 2006 and 2007, these figures seem to indicate that there has been a significant increase in parental involvement in network activity outside of the board meetings.

The repeated survey also asked whether networks have other mechanisms for involving parents in their work. In the 2006 survey thirteen networks responded positively to this question. This rose to fifteen in the 2007 survey. Interestingly, the types of engagement reported under this heading also appear to have changed. In 2006 examples given in response to this question included:

- Engagement through Maternity Services Liaison Committee
- E-mail
- Post
- Website
- Overview and Scrutiny Committee

The networks that responded positively to this question in 2007 gave examples that appeared to reflect a shift toward more direct forms of engagement.

These included:

- Involving parents in the review of neonatal units
- Focus groups
- The development of unit parent groups
- Surveys
- Parents giving presentations at network events
- Regular contact with the parents via e-mail, telephone, or meetings etc

Reimbursement

In 2006, eleven networks reported that they paid travel expenses to parents, and nine reported that they paid for child care costs. In 2007 sixteen networks reported that they paid travel expenses and twelve reported that they paid child care costs. In 2006, three reported that they would consider paying parents for a specific contribution to a meeting e.g. giving a presentation, with one indicating that this happened routinely. In 2007, five networks reported that parents are paid for attending meetings, but two of these indicated that it was at the network managers' discretion.

Table 3[2] Payment to Parents

	2006	2007
Travel expenses	11	16
Child care	9	12
Attendance at meetings	1	3

It is essential to the development of parental involvement within neonatal networks that parents are offered adequate reimbursement for any costs they may incur and for the time and effort they put into this role. Parents who get involved in network activities should not be disadvantaged financially. Expecting a parent on income support to wait weeks to be reimbursed for a train or taxi fare is also unacceptable. An organisational policy on reimbursement for PPI helps to demonstrate that participants are valued for the time they give to involvement work (see *Reward and Recognition*, Department of Health, 2006).

Discussion

The two surveys provided us with an interesting overview of how parental involvement has developed within neonatal networks. Judged solely in terms of representation at Board level it would appear that little has changed. In particular the number of networks that do not have parental involvement at Board level has not changed significantly. This may be for a number of reasons, including difficulties associated with recruiting, sustaining and retaining parental involvement. However, it is also clear that for at least some

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[2] NB the figures in this table do not necessarily add up to the number of networks surveyed because in some cases a particular network reimbursed parents for more than one activity.

network boards this is the result of a positive decision not to involve parents in board meetings.

In some networks, where board representation does exist, it is relatively undeveloped, perhaps consisting of one or two representatives attending a board meeting every few months, depending on the specific network's meeting cycle. However, in other cases, parental involvement has developed further, through the involvement of parents in specific pieces of work, perhaps within a network sub-group. There were also instances where dedicated parent user groups have been developed, which attempt to give a voice to parents from across the units in a specific network. Interestingly, the survey results indicate that during this period there has been a significant growth of this type of involvement. This is perhaps also reflected in the growth of the number of networks paying expenses to parents, although this is still low, as Table 3 shows.

Given the wide variety of approaches to parental involvement described in the two surveys, it may be useful to think of parental involvement as existing across a continuum in neonatal networks; from no representation at one end, to fairly well-developed mechanisms designed to involve parents at a local and regional level at the other. The four case studies undertaken for this research illustrate this diversity.

Case studies

The case studies have highlighted a number of factors which impact on the development of parental involvement in neonatal networks. These are:

- Recruitment
- Organisation and culture of meetings
- Role of intermediaries
- Barriers and facilitators to involvement
- Models of involvement
- Training and support for parental involvement
- Evidence of parent-led change

Recruitment

The survey results showed that neonatal networks have taken very different approaches to involving parents in their work. However, the survey results and the information gained from the case studies suggest that the type of parents who become involved as parents are relatively homogeneous. They are female (only two networks reported involving fathers), predominately white and tend to be from professional backgrounds. The epidemiological evidence suggests that families with a lower socio-economic status and families from certain ethnic minority groups are more likely to experience a premature birth or the difficulties associated with giving birth to a sick baby (Gardosi and Francis, 2005). However, at present the parents involved within neonatal networks do not generally reflect this picture. It therefore appears that there is

a danger that the current methods used for involving parents are inadvertently excluding certain groups and are not representative of parents of all neonates. There may be a number of reasons for this.

The majority of boards reported that they recruited parents either via staff recommendation or through an advertisement and interview procedure developed in conjunction with BLISS. It is easy to see how recruitment via staff recommendation might unintentionally result in a biased selection process.

A more formal application and interview procedure might therefore help safeguard against this danger. The potential danger here is that an over formal procedure might put off some parents from participating, particularly if they do not have previous experience of involvement in committees or management.

The evidence from the case studies also indicates that for some people involved in the recruitment of parents, the interviewing process represents an opportunity to check that potential recruits *"do not have an axe to grind".* As one board member put it, *"I think it is essential that parents subscribe to the current ethos in neonatal services, instead of wanting a level 3 neonatal unit on their door step".* (clinician)

While it is understandable that boards may wish to ensure that parental involvement is constructive, care needs to be taken to ensure that this does not result in the exclusion of potentially valid, if differing, perspectives, either during the recruitment process or within meetings to which parents have been invited in order to contribute their views.

Selection by interview and selection by staff recommendation both represent approaches in which the Board selects which parents are to participate in the work of the network. However, this is not the only approach. One of the network case studies facilitated the setting up of parents' groups in each of its neonatal units. These user groups were invited to send a representative to a network wide parents' group, which in turn chose two of its members to participate in network board meetings. In this approach it is the parents who choose their representatives as opposed to the board. This approach by itself does not automatically improve the representation from marginalised social groups. However, it does provide a mechanism whereby parents at Board level may be in a position to express the views of the parents participating in unit groups, where it may be easier to engage so-called 'hard to reach' groups. One network manager who has adopted a similar approach describes some of the issues

"We have a very large ethnic population in X and we don't have that representation…. The Asian families tend to come to the user group meetings but I don't think that anybody has ever come to a Board Meeting. We do tend to get the sort of educated middle class sort of women coming to the board meeting." (network manager)

Structure and culture of board meetings

The timing of Board meetings can exclude some parents as most are scheduled during office hours. This may not be the best time for some parents, given their likely caring commitments and possible employment commitments. Developing mechanisms which allow parents to have an input who cannot attend meetings may therefore be essential. For example one Board has set up a "partnership group" which meets on a Saturday. This meeting then feeds the views of parents into the Network Board meetings.

The structure of Network Board meetings is also likely to impact on whether parents feel that they are able to meaningfully contribute. As indicated by the survey results the average Network Board has a membership of 20+, made up of a combination of clinical and managerial staff as described previously with, on average, two parent representatives involved.

Board meetings themselves are often tightly chaired. Frequently a report is received in writing with an oral introduction from someone involved in its production. Reports are often accepted or accepted with minor amendments. This makes it very difficult for parents to intervene if they do not have previous knowledge of the issues. Parents may potentially experience these meetings as intimidating and difficult to contribute to, particularly when they first attend.

"I have to admit that I was terrified walking in that room today. I don't know why, it wasn't as if they were all going to quiz me or anything" (parent on her first Board meeting)

As a result parents whose sole mode of involvement is attendance at Board meetings frequently find themselves in the position of passively observing what happens at these meetings rather than actively contributing. When this occurs, both parents and professionals are likely to feel that parental participation in board meetings is "tokenistic". In some cases this type of experience has led boards to conclude that parents do not have anything to contribute to this type of meeting.

"Having one person on a board is tokenistic and unrepresentative" (network manager).

It is important to point out that parents themselves share these concerns. Parents participating in training organised by BLISS identified the following as the main perceived threats to the success of their involvement:

- Concerns that parent representative involvement is only tokenistic, or that parents' views are not high priority
- Limits of time and energy
- Unsupportive boards

Some of the difficulties outlined above may be overcome by the role played by other board members in facilitating parental participation.

The role of intermediaries

Within the board meeting itself the Chair can play an important role in ensuring that parents are welcomed to meetings, that jargon is explained and that they get an opportunity to contribute.

"We've got a large clinical representation on the board, so if you get sort of lost in the clinical discussion, then you almost need a translator at the end of it for the users. So our Chair is very good at either directing me or the clinical lead to translate for the User reps and ask for their feedback on it, and not just them. You've also got commissioners and other people who aren't necessarily au fait with all the clinical jargon that spills out of consultants' mouths quite easily, even if they try not to" (network manager).

However, this sort of intervention, although important, does not address the concerns of both professionals and parents regarding "tokenism". The evidence gathered from the case studies suggests that the role played by professional board members who are prepared to facilitate the development of parental involvement is central. It appears that often this role, if it is taken up at all, is taken up by network managers.

This does not necessarily happen in a pre-conceived manner. One network manager recounted that she set out with two basic ideas, that parents should have a voice at board meetings and that their involvement should not be tokenistic.

From these premises, parental involvement developed organically via a process of consultation with parents. At the beginning of the study, this network had recruited four parents, two of whom attended board meetings. One of these had also been a member of a reviewing team which visited the units in the network. This network now has six parents involved in its work, two of which attend board meetings. However, parents are also involved in five board sub-groups and have been involved in assessing the neonatal units in the network. This has resulted in the parents producing action plans for the board designed to address the issues that they have identified.

Another network participating in the study began from a similar starting point, but developed an alternative approach. In this case the network manager felt that parents' views would carry more weight if they were "translated" into the format that other professionals use. This was done through the setting up of a Parent Task Group. The Group was set up to pursue parental recommendations derived from visits to the units in the network. The Task Group is composed of two parents and "parent champions" from each unit in the network. The Task Group's role is to ensure that the parents' recommendations are acted on. This approach is intended to create a more structured and transparent approach to parental involvement. The lead nurse in the network feels that,

 "*this approach is much less tokenistic than it could have been.*" (lead nurse)

The above discussion highlights the complex nature of facilitating parental involvement. Network managers who take on this work often perform a number of roles including:

- mediator
- advocate
- translator
- interpreter
- broker

Despite the complex nature of this work there are relatively few resources or training that network managers can draw upon for support or guidance.

The approaches to parental involvement described above are not without their problems. However, they do represent an important development beyond simple parental presence at board meetings. The growth of parents involved in various activities outside of Board meetings, noted in the survey, suggests that this type of development is not unique, but reflects a broader trend, at least in those networks that have begun extending the participation of parents.

Barriers and facilitators to parental involvement

The issues affecting the success or otherwise of parental involvement are not limited to the Board meetings. This section of the report will consider the broader factors that appear to have an impact on parental involvement.

Sustaining involvement

Many network managers report that sustaining parental involvement in neonatal networks is difficult. There are a number of reasons why parents may drop out from this kind of activity. By definition they are people who are likely to have substantial caring commitments. Work pressures, the arrival of a new baby and a wish to move on from the issues surrounding having a premature baby may also impact on parents' abilities or wish to participate. Crucially, parents are unlikely to stay involved if they think their participation is a mere formality.

A high turnover of parents can create several problems. Recruiting new people to become involved may be time consuming. Some network mangers also report that it can be difficult to maintain continuity when working on a project, if the parents involved keep changing. Networks whose involvement strategy is dependent on one or two parents are particularly vulnerable to this type of problem. Some networks recruit parents continuously in order to build up a strong base for future activity. This ensures that should one parent be unable to attend board meetings, either occasionally or on a permanent basis, there are potential substitutes available to step in.

Some network managers also feel that it is important that the parents working with the network, and particularly those on the network board, are periodically rotated. This is done to ensure that the parents do not become

professionalised; a process that is felt would potentially erode the distinctive perspectives that parents bring to meetings.

Structural constraints

Neonatal networks consist of units based in different provider Trusts. Each may have its own policies which have an impact on parents and their babies. This can make it difficult to ensure that relatively simple suggestions are taken up systematically in all the units in a network. Furthermore, many neonatal networks are struggling to provide the best level of care for neonates within limited budgets (BLISS, 2005). In these circumstances, parental involvement can be seen by some professionals as peripheral to the main business of saving babies' lives.

For example, in one network parents wanted to introduce a document describing parents' experiences of a neonatal unit. The aim was for this to be used with staff in order to help them gain some insight into what parents are going through when they come to a neonatal unit. However, this was objected to on the grounds that the document could potentially antagonise staff, who it was pointed out, already feel under pressure from high work loads and stress levels. As one professional put it:

"We are meant to be nurturing the family, but in the real world...?" (neonatal nurse)

These issues can also effect participation at board level. As one parent explained after a board meeting discussion about maintaining staffing levels,

"I feel that the meeting has been depressing. I think the people present are doing the best they can in difficult circumstances and therefore it's not easy to criticise them." (parent representative)

The two parents present at this meeting had wanted to raise the issue of how professionals communicate/interact with parents. However they felt that they had been unable to do this because the people present seemed to be struggling to cope with basic problems such as inadequate funding and insufficient staffing. Compared to this, developing staff communication skills seemed a low priority.

Funding of parental involvement

Several network mangers pointed out that, unlike cancer networks, there is no specific funding and staff time allocated to developing parental involvement. This means that parental involvement is only likely to develop where specific individuals are committed to ensuring that parental involvement is implemented in a way that moves beyond parental attendance at board meetings.

Professional attitudes

Although Patient and Public Involvement is now a cornerstone of every aspect of the NHS, it cannot be assumed that this is accepted by all. Some professionals remain sceptical of the ability of parents to contribute to strategic decision making in the NHS. One clinician remarked:

"*Involving parents in high level decision making can be quite destructive because they don't have a handle on all the different angles.*" (clinician)

Even where board members have a positive attitude to parental involvement this may not be shared by staff in neonatal units. If parental input is confined to the Board meetings it is unlikely to become embedded in other aspects of the networks' work.

However, the data from the case studies suggests that that there are also subtler shades of opinion at work within neonatal networks. These are concerned with assumptions about the specific role that parents are expected to play in the work of neonatal networks. These are rarely explicitly articulated. However they appear to shape the approach taken to parental involvement.

Models of parental involvement

As has been noted above, there is a wide range of approaches to parental involvement in neonatal networks. The data collected so far suggests that parents play different roles on network boards, depending on how differing networks conceive of and organise parental involvement. Broadly speaking, these roles fall into three main types. These are parents as:

- sources of information
- consultants
- representatives of other parents

These modes of parental involvement are not mutually exclusive. Networks may make use of more than one approach, although particular networks appear to be characterised by certain approaches.

Parents as sources of information

Parents when used as sources of information are providing raw data that This can be collected in a number of ways, e.g. via a survey or via the use of focus groups. The information thus obtained can then be analysed and the results fed into the networks decision-making processes. For example one network manager described the approach that had been taken by her Board to the unit designation process. This consisted of an initial "*complete option appraisal process*" which involved assessing what the network currently provides, current workloads and finances. This information would then be used to generate various options. The Board then chooses one of them. Once

implemented it would be regularly reviewed, with parents being consulted via parent questionnaires.

This approach is frequently adopted by networks which are sceptical about the value of parental membership at board level. It has the advantage that information from a relatively large number of people can be obtained. However, the type of information produced is determined by the agenda of the board, rather than the parents using the service. It also precludes parents from any involvement in the decision-making process. As one clinician of a board, which adopted a similar approach, put it

"We do need reps or consultants, otherwise how do we know what we don't know?" (clinician)

Parents as consultants

This approach recognises that parents not only possess important information, but that their specific experiences as users of the service mean that they have the potential to make a significant contribution to the decision-making processes of the network. For example in one network the nursing sub-group was working on developing service benchmarks. A mother was involved to give a parental perspective on service quality.

The parent involved reported that she found it much easier to make an active contribution at this level compared to board meetings. This was because the meeting focused much more on issues of direct care, which she felt she could comment on, as someone who has used the service and thought a lot about the needs of babies and their families. This contrasts with discussions at board meetings which may concern budgets or the designation process. These types of meetings are also generally smaller than Board meetings. This may be another factor which makes it easier for parents to make their contribution.

However, parents can and do act as consultants at Board level. One parent described her role as that of making the documents and the information the networks produce parent-friendly. In this particular network, draft documents produced by the sub-groups are circulated to the parents and other board members via e-mail. They can then comment on them. Final documents are then produced and come to the Board. This particular parent said that she did not feel able to comment on the technical or medical aspects of documents, but she would make suggested alterations to documents which would be read by parents and seemed to her too cold or clinical.

The difficulty with the 'parents as consultants' approach is that it frequently relies on a relatively small number of parents. Besides the difficulties that arise when a parent is unable to continue participating, it leaves the parents open to the accusation that their views are not representative of the wider parent population that neonatal networks serve. This kind of criticism is likely to come to the fore where parents find their views in conflict with those of

professional board members. It offers a rationale for members of a board to reject parental suggestions.

Thus in the example referred to above where parents had produced a short document describing parental experiences of a neonatal unit, one professional criticised the document on the grounds that it was 'unrepresentative' of parents' experiences.

Furthermore, in some instances this form of involvement can be used to justify a lack of wider consultation. For example, one network manager felt that the outcome of a public consultation, involving her network's designation process, was likely to be a foregone conclusion. However, she pointed out that parents had been present at Board meetings where the designation process had been discussed, so there had already been some public/user consultation.

Parents as representatives

Although parents who participate in Boards are frequently referred to as parent representatives, in most cases they do not represent the views of other parents. In the approach described in this section of the report the role of parents on network boards is to represent the views of other parents who have used neonatal services. This is something that most network boards see as desirable, but relatively few have developed mechanisms which would allow it to develop. The term representative is used here to specifically refer to a form of parental involvement where mechanisms have been developed which link parents on network boards to a wider group of parents who use neonatal services.

This approach has a number of advantages. It potentially increases the numbers and diversity of parents who can contribute to the decision-making processes either directly or indirectly. It also has the potential to provide a greater opportunity for parents to place on the board agenda issues of importance to them, as they emerge through their own discussions. Although this approach is relatively rare it has been adopted in a number of networks in various forms.

One network case study adopted this approach. It consisted of parents' groups based in neonatal units sending representatives to a regional parents' group which in turn sent two representatives to the network board. The regional parents' group, as well as linking local units to the network at a regional level, allows the parents to exchange experiences and advice and provide peer support to one another.

The network adopted this approach after it held five community road shows throughout its region, designed to give the network the opportunity to meet and talk to parents about their experiences. These consisted of presentations, conversation cafés (a form of structured focus group) and drum workshops. Parents were asked about their experiences of the service and whether and how they wanted to be involved in the network. The findings from these road

shows were then used to design the network structure for parental involvement.

The major difficulty here is that this approach requires a relatively large commitment in terms of time and effort from the parents involved.

"Between this (running a local parents' group) and the network it is taking up a lot of time and effort. It is hard fitting it round home life, and I don't want to spread myself too thinly. I think I need to stay focused and maybe dedicate a day every fortnight to doing BLISS/network stuff then I can keep on top of it – this is becoming like a full-time job!" (parent representative)

In particular it requires the successful setting up and running of local parents' groups to provide the basis for this approach. The experience of the networks that have implemented this model suggests that this is not a straight forward process, particularly where large geographical distances are involved.

There are two major potential difficulties. One is that the running of the local groups requires specific skills. This is because the groups perform two separate but related functions:

1. to act as a support group for local parents
2. to act as a parent forum where issues that relate to the provision of neonatal services can be discussed and fed back locally or to the Network Board, as is appropriate.

Managing these two functions is a difficult task and one that parents may require support to carry out successfully. The following is a description of how one such group operates.

Parent's Meeting

The meeting was held in the offices of the local Sure Start. It was informal and lasted for approximately one hour. Tea, coffee and biscuits were available and there were toys for the children. There were three mothers present and four young children. The parents used the group as an opportunity to socialise and to discuss their experiences, both positive and negative, of neonatal services. Where significant issues were raised e.g. a series of complaints regarding one doctor's attitude to parents and breast feeding, or problems regarding transfers and the distances being travelled by parents, the parent representative made notes and said that she would raise them at the regional parents' group.

(Field notes, 28 February 2007)

The evidence suggests that it is important that local staff understand the role played by these types of group in promoting parental involvement. If local staff are not aware of why these groups are being set up, or why existing groups

are being approached to participate in this process, they may respond with indifference or even hostility.

Despite these potential difficulties this approach gives parent representatives at Board level a clear role. It also creates an important link between the network board and what is happening in local units.

Discussion

The term parent representative is often used quite loosely. It can be used to denote a variety of different roles that parents may be expected to play within neonatal networks. This lack of clarity sometimes results in parents being asked to participate in network boards without it being clear what is expected of them. It may also be the case that network boards seek parental involvement before clarifying what they want to achieve beyond the notion that they should have some form of involvement as a matter of good practice.

However, the analysis conducted here suggests that networks tend to develop different models of parental involvement which fall broadly into one of the three categories described above. These categories should not be thought of as mutually exclusive. Some networks may display elements of more than one approach. Nevertheless, categorising these different approaches in this way helps clarify the assumptions underlying the different approaches. The fact that networks tend to develop a particular mode of parental involvement, whether explicitly or implicitly, also has important implications for the type of support and training that the parents and neonatal staff involved will require.

Training and support for parental involvement

The type of role that parents are expected to play in neonatal networks has important implications for the training and support that may be required both for parents and for those board members who may be responsible for facilitating involvement. The skills, knowledge and the information needs of both staff and parents required to support participation effectively in a board meeting or sub-group are different to those that are required to run an effective parents' support group/forum. It is therefore important that networks attempt to clarify at as early a stage as possible what role they want parents to play at what level in the network. Once this is has been clarified it will be possible to put into place the appropriate supporting structures and develop appropriate training either within the network or with an outside partner such as BLISS. Training therefore needs to be designed which is flexible and adaptable to local needs and targeted at those parents who will be taking on specific roles.

It is also important that the provision of support and training is seen as an ongoing process. There are several reasons for this. In the first place it is likely that as networks develop the roles that they expect parents to perform will change. Initial training carried out by BLISS in the West Midlands region in 2006 tended to focus on the skills and knowledge required to participate

effectively in Board meetings. In a similar training day carried out in 2008 a major concern of parents was accessing the time and support required to build local parent groups. This seems to reflect a wish to develop parental involvement beyond simple attendance at Board meetings.

Parents who have attended training days have also found the opportunity to share their experiences with other parents very valuable. This is particularly important where the structures do not exist within networks to allow this to happen. Although contact by e-mail and other methods are important, the opportunity to directly learn from the experiences of other parents is valuable.

Given the complex nature of the role carried out by those professionals who facilitate parental involvement in neonatal networks it is also desirable that they participate in training with parents and that time is given to examining the complex nature of their role.

Evidence of parent-led change

Despite the scepticism expressed by some NHS professionals about the efficacy of parental involvement at network board level; this research has identified a number of examples of parent-led change within neonatal networks. The following list gives some examples of how parents have stimulated service development:

- The tightening of confidentiality and consent procedures in relation to the reporting of critical incidents. This was prompted by the comments of a parent representative at a Board meeting.

- Contribution to Board meeting discussions e.g. highlighting the positive impact of the Working Time Directive on patient care during a discussion of the human resource implications of this legislation.

- The production of information leaflets for parents explaining the issues involved in transferring a neonate from one unit to another. This information was written jointly with parents.

- Amendment of network services specifications referring to facilities and support for parents on neonatal units.

- The adoption of standardised identification badges for staff across the network to reduce the confusion and stress caused to parents when babies are transferred between units.

- The adoption of a unit exit questionnaire to monitor the quality of neonatal services against a network average.

- Recognition of the inequity in therapies and psychological services available for families across a particular network and the problems associated with accessibility and availability of services for families following discharge from hospital. This was based on feedback from

parents and highlighted the need for an audit of services across the network.

- The development of a network funded film in DVD format charting the experience of parents on a neonatal unit for use with both parents and clinicians.

Conclusions

The development of parental involvement in neonatal networks is at different stages across England. In some networks the involvement of parents in Network Boards has not happened at all. In others this has occurred but in a relatively undeveloped form. At the same time there are networks who have invested considerable time and effort in establishing systems for supporting parental involvement. One of the reasons for this unevenness appears to be that in some networks the potential benefits of parental involvement are not recognised.

The research has also uncovered concerns from both parents and professionals that involving parents in strategic decision making may be 'tokenistic' and ineffective. This is reinforced where there is little practical support for parental involvement. Since lack of support reduces the scope for meaningful involvement which in turn reinforces low expectations, this state of affairs may result in a self-fulfilling prophecy.

Where parental involvement has developed a range of models are in use. It may be helpful to think of these approaches as existing along a continuum, with survey-based approaches at one end and more developed representative models at the other, with a mixture of consultative type models in the mid-range. Each approach has its uses within specific contexts. However, the evidence suggests that where parental involvement is well planned and supported, parents can make a valuable contribution to the development of neonatal networks and future neonatal services

Recommendations

Based on the work carried out for this report, the research team would make the following recommendations:

- Networks need to develop a clear idea about what they want to achieve through involving parents in their work. This may require facilitated discussion. This, in turn, will determine the type and level of involvement and the nature of the support and training that staff and parents may require. Accessing parents as sources of information, as consultants or as representatives of other parents place very different requirements both on network staff and on parents

- Each network should nominate one person to act as the network's parental involvement coordinator. This person would be responsible for developing the network's approach to parental involvement in

partnership with the network board and parents. In most cases this person will be the network manager

- BLISS will need to develop training packages which reflect the diversity of approaches to parental involvement within neonatal networks. This may involve working with networks beforehand to design an appropriate training package. Ideally training could be run jointly for both parents and network managers

- There is a tendency for parental involvement to exclude already marginalised groups. If this tendency is not checked there is a danger that the process of parental involvement will entrench rather than reduce health inequalities. It is therefore important that networks develop models of participation that are as representative as possible of the population they serve

- All networks who involve parents in their work should make arrangements to recompense parents for any expenses incurred as a result of the involvement process (e.g. travel, parking, child care) and make payments which recompense parents for the time, effort and inconvenience that involvement requires. This is particularly important if people from lower socio-economic groups are not to be disadvantaged by the involvement process

- Networks could collaborate locally and nationally on the further development of parental involvement. Such collaboration should focus on the development of best practice, the sharing of experiences, training and support. This could be facilitated through regional events and/or an annual conference. The University of Warwick is currently working with the London Perinatal Network to organize such an event on November 14th 2008

- Network managers could have training on user involvement as an integral and important part of their role and requires listing within their job description

Dissemination and knowledge translation 2007-8

There have been many presentations during 2007-8 with more planned for the autumn of 2008. In addition to presentations to professional groups and Network Boards, there have been academic presentations and there will be peer reviewed and professional publications.

Professional Audiences
Meeting of Trent Neonatal Network Nursing Group – 7/07
Staffordshire, Shropshire and Black Country Network AGM – 9/07
Influencing Change in the NHS – Neonatal Care – national meeting – 9/07
Partners in Paediatrics Steering Group meeting -1/08
Care and innovations in practice: sharing ideas - practice across four networks 1/08
Central Newborn Network board meeting - March 2008
Staffordshire, Shropshire and Black Country board meeting – May 2008
Trent Neonatal Network Parents Advisory Group- May 2008

Academic Presentations
British Sociological Association Medical Sociology 39th Annual Conference - 9/07
Institute of Health seminar, University of Warwick - 9/07
Perinatal Medicine Conference, poster presentation - June 2008

Planned Dissemination for Autumn 2008
Conference
One day national meeting on user involvement in neonatal networks organized jointly with Jacquie Kemp, London Network Manager – 14th of November 2008

Web based dissemination
The findings will be published on the Institute of Health website, the BLISS website and the Grace's Fund website.

For Parents:
A summary of findings briefing for parents and practitioners will be produced.

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