Weak and Strong Publics: Drawing on Nancy Fraser to Explore Parental Participation in Neonatal Networks

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Abstract

Public involvement has now become a cornerstone of the NHS. Recently this has moved beyond the individual level to include greater involvement of both patients and the public in governance. However, there is relatively little literature which explores the nature and outcomes of long-term patient involvement initiatives, or has attempted to theorise, particularly at the level of corporate decision making, the process of patient and public involvement. We draw on the work of Nancy Fraser, and in particular her concepts of weak and strong publics, in order to explore the processes at work in the case of managed neonatal network boards.

A survey of all neonatal network managers in England was carried out. This was designed to elicit information about the current status of parent representation on neonatal network boards. Four networks were also selected for more in-depth study. This involved interviews with ‘key’ members of each network board, interviews with parent representatives, observation of meetings and access to board minutes.

The data collected shows that a wide range of approaches to involving parents has been adopted. These range from decisions not to involve parents at this level, to relatively well developed systems designed to link parent representatives on network boards to parents in neonatal units. The different approaches taken result in different degrees of weak to strong publics. However, despite these variations, we suggest that parental participation within neonatal services remains an example of a weak public.
Introduction
Over the past decade, there has been a renewed emphasis on the involvement of citizens in decisions about health policy, planning and service provision (WHO European Region 1994; Council of Europe, 2000). Institutional changes to strengthen patient and public involvement (PPI) have been introduced in several countries, including the UK, Canada, Holland and Australia (Lister 2001).

Within the UK context the 1990s were marked by increasing interest in patient and public involvement (PPI) within the Department of Health and the NHS (Barnes 1997). These developments may be seen as a response to two major factors: public demands for a greater voice in decisions about their services, and demands from politicians for greater efficiency and effectiveness in the use of public funds and increased quality of services, reflecting the growing influence of the New Public Management approach to health services management (Rowe and Shephard, 2002). It can be argued that this latter development has its origins within the Conservative government’s attempts to re-model the relationship between the NHS and service users along consumerist lines. Documents such as Working for Patients (DoH, 1989) and the Patients Charter (DoH, 1991) placed emphasis on individual ‘rights’ and ‘choices’. Since the election of a Labour government in 1997, PPI has become a central plank of both healthcare policy rhetoric and structures (Milewa et al., 2002). Subsequently this agenda has 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 Act 2006 and the Local Government and Public Involvement Health Act 2007).

Despite the extensive interest in the development of PPI within the UK National Health Service, the research evidence base underpinning this, as Staniszewska et al (2008) point out, is partial and lacks coherence. There are a number of reasons for this. Some arise from the lack of clarity with regard to
conceptualisation which in turn makes evaluating the impact or outcome of involvement difficult. Furthermore, comparatively little of the literature has attempted to theorise PPI. Little attention in particular has been given to how areas of professional decision making are opened up to public involvement, the construction of boundaries around these areas and the degree to which these boundaries are open to negotiation.

**Theoretical background: drawing on Nancy Fraser**

Nancy Fraser has developed the concepts of weak and strong publics (1997). This provides a constructive theoretical framework for the analysis of the processes of PPI in this national case study of parental involvement in managed neonatal network boards.

Fraser argues that a public is formed where private individuals come together to discuss issues publicly. The public sphere is here distinguished from both the state and the economy and is seen as providing an important counterweight to both the power of the state and to the interests of capital. Nevertheless the boundaries of the public sphere are not fixed. Differing social groups may have an interest in keeping certain issues in or out of this public domain. For example, in the past, decisions about medical treatment were largely seen as being in the exclusive realm of doctors who have frequently sought to keep the issue of how they make decisions out of the public realm. Similarly, various disability and service user groups have successfully challenged the right of doctors to make decisions about the care they receive without involving them.

Part of the process of challenging these boundaries may involve creating what Fraser terms ‘subaltern counter publics’ (1997), where subordinate social groups can develop and circulate alternative understandings and descriptions of the social world. It is important to recognise the heterogeneous nature of counter publics. Anti-abortion campaigns, campaigns for the reintroduction of the death penalty or far right nationalist groups could all be seen as counter publics which seek to challenge the boundaries of public discourse.
Fraser goes on to make a distinction between strong and weak publics. She defines a strong public as one where not only discussion takes place, but also decisions are made. Weak publics are publics which discuss issues, but which have little chance of influencing decision making. The ability to access decision making processes may occur through having access to the state’s decision making bodies or being able to bring pressure to bear on them (Davies, 2007).

Fraser’s discussion of the politics of needs interpretation is also pertinent. She points out that at a general level it is relatively uncontroversial to argue that homeless people need shelter in order to survive; what Fraser, (1989) calls ‘thin needs’. As soon, however, as questions arise, such as precisely what form of shelter is to be provided or how is it to be supplied, disagreements emerge. She states,

“Precisely how such chains are unraveled depends on what the interlocutors share in the way of background assumptions. Does it go without saying that policy designed to deal with homelessness must not challenge the basic ownership and investment structure of urban real estate. Or is that the point at which people’s assumptions and commitments diverge?” (Fraser 1989, p. 163).

From this perspective, the development of user involvement might be seen as the identification of a specific need, but the legitimacy and scope of the need and how it might be met, e.g. in consumerist or democratic terms, along with the potential impact of these approaches on existing power relationships, might all be highly contested. The attempt to restrict the debate to the technicalities of implementation as evidenced in the production of a plethora of ‘how to’ manuals (Beresford 2002) might be seen as an attempt to depoliticize the process.

Related to the above concerns is Fraser’s concept of participatory parity. Here Fraser is critical of liberal attempts to bracket rather than eliminate the impact
of social inequality on public participation. Thus she argues that it is inadequate for liberals to suggest that participants should act 'as if' they were equal when participating in the public sphere. This is because inequality inevitably taints deliberations within publics. This occurs not simply because of inequalities in economic resources (the politics of redistribution), but also because of subtle processes of social and cultural distinction (the politics of recognition). Here Fraser references Bourdieu’s work on the role played by cultural capital in maintaining social distinctions (Bourdieu 1984). Thus for Fraser achieving participatory parity is only possible if underlying economic and status inequalities are first addressed. Much of Fraser’s work takes place at the level of the nation state or relations between nation states, however her analytical framework could be applied to initiatives designed to remedy the ‘democratic deficit’ in the NHS.

In the following section a review of the relevant literature will be presented. This will be followed by a description of the research methodology employed, presentation of the findings and finally some concluding comments will be made.

**Managed clinical networks and parental involvement in neonatal services**

In 2003 the Department of Health recommended that neonatal services across England should be organised into managed clinical networks. Managed clinical networks had been previously established in other areas of care e.g. cancer to encourage integration and interagency working.

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 or informally. 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”.

Some research has already been carried out which explores user involvement in managed clinical networks.

Tritter et al. (2004) in their work on user involvement in cancer networks, make use of a ‘cycle of involvement’ linked to service improvements that are evaluated by service users as a way to develop participation in service delivery. 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 being present, being consulted, representing the views of others, working in partnerships to improve care and proactive involvements to change service delivery.

Sitzia et al’s (2006) research also suggests that a number of tensions can develop between professional and patient representatives. They found that whilst service users are more likely to express their commitment to participation in personal terms, 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. 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. A third area of tension was emotional commitment. Service users tended to feel that their participation entailed a degree of emotional commitment, whereas
professionals were more likely to express little or no emotional commitment to patient involvement. 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.

**Parental involvement in neonatal services**

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. The Department of Health also recommended that there should be at least two user representatives on each Neonatal Network Board.

Despite the fact that parental participation appears to be accepted within neonatal services (Newton 2000), there appears to be 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 professionals as only appropriate within clearly defined limits (Daneman et al 2003).

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’s (1996) 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.

However, despite a relatively wide ranging 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.

**Methodology**

This national research study with four regional case studies was conducted in 2006-7. At a national level two surveys, using structured questionnaires, were sent to managers 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.

**The surveys**

Two surveys about the level and types of parental involvement in neonatal networks across England were carried out in 2006 and 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.

**Regional area case studies**

Detailed area case studies were undertaken of four networks in North and Central 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 with the four network managers
- Non participant-observation of meetings and analysis of minutes of neonatal network boards
- Observation and informal interviews with 14 parents across four networks while attending various network activities, for example parents groups, visiting neonatal units, training events and attendance at network meetings and conferences.
- Documentary analysis of policy and minutes of meetings

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, i.e. from approaches which saw parents primarily as a source of information to relatively well developed systems designed to link parent representatives on network boards to parents in neonatal units.

**Data analysis**

The team independently read and coded thematically a sample of the qualitative data in order to generate an agreed analytical framework for the data. The bulk of the data coding and analysis was then undertaken by AG with input from the other two authors. Ethics approval was given by the University of Warwick’s Humanities and Social Studies Research Ethics
Committee and an advisory group with representatives from the major stakeholders as well as parents met biannually.

Findings
The findings suggest parental involvement in neonatal network boards offers relatively limited opportunities to influence decision making processes or alter agendas. This was manifested in different activities that were shared by the network boards. However, within this general picture, some boards had mechanisms allowing for more parity than others. These issues will be discussed below.

Levels of parental involvement in neonatal networks 2006-7
The results of the two surveys give an overview of the state of parental involvement in neonatal services. These results indicated that the number of parent representatives per network board in England varied from none to three in 2006 and from none to five in 2007. Nine networks in 2006 and eight in 2007, i.e. 41% in 2006 and 40% in 2007 reported that they had no parental representatives on their boards.

Table 1 Parent representation on neonatal network boards 2006 - 7

There were a number of explanations for this, including difficulties in recruiting and retaining parents and wishing to delay parental involvement until difficult decisions regarding the organisation of the network had been made. In some cases it was also clear that 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).
Both the decision to delay involvement until after difficult decisions have been made or to restrict participation to the gathering of parental views via focus groups obviously represents an attempt to control the boundaries of public involvement and in particular to exclude parents from direct participation in important decision making processes. However, where boards have taken the decision to involve parents in their work the survey results indicate that they have taken very different approaches to doing this.

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 (BLISS is the leading national charity in the UK in neonatal care). In some cases a combination of these methods was used.

The survey and the information gained from the case studies suggest that the types of parents who become involved in neonatal networks 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. This has the effect of rendering invisible the views of parents from lower socio-economic groups and ethnic minorities. Of course engagement with a more demographically representative group of parents would not automatically lead to the creation of a stronger public. However, if involvement initiatives do not involve marginalised groups, particularly where these make up a substantial proportion of the people using the service concerned there is a danger that the process will help entrench rather than reduce health inequality. The reasons for this bias in the selection of parents will be explored in more detail below.
The evidence from the case studies 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”. In some cases this reflects a concern that parents should not use their position on network boards to pursue individual grievances against the service. In others it represented a concern not to involve people who might be actively involved in local public campaigns related to the provision of neonatal services. 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 speaking during a network board meeting).

The deliberate exclusion of people actively involved in campaigns related to the provision of neonatal services suggests that even where the need for participation has been accepted the scope and nature of that participation is closely managed. In particular there appear to be unwritten ground rules which govern who and what is open to discussion in relation to parental/public involvement in board meetings. These rules may vary between boards but they are clearly important in shaping the process of parental involvement within each.

Selection by interview and selection by staff recommendation both represent approaches in which the board effectively controls which parents are to participate in the work of the network and are therefore able, if they wish to, to exert strong control over the nature of this interaction. 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 representative nature of involvement or create a strong public in the terms that Fraser
means; however, it does give parents some control over who represents their views at board levels.

*Participation at board level*

Having once been selected for participation, there are still a number of hurdles for parents to overcome if they are to meaningfully participate. The first is the timing of board meetings. These are frequently 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 these meetings may therefore be essential but, unfortunately, examples are rare. In order to deal with this problem one board set up a “partnership group”. This 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. The survey results indicated that the average network board has a membership of twenty or more people, made up of a combination of clinical, managerial staff and commissioners. Where theses boards have involved parents they have, on average, recruited two parents, although it is not unusual for one or both not to be present. Both clinical and managerial members of these boards carry with them significant social status based on their respective domains of professional expertise. Although parents bring with them their own experimental knowledge based on their use of neonatal services, it is not always clear that this knowledge carries equal status within the arena of board meetings.

Furthermore, board meetings themselves are often tightly chaired. Frequently a report is received in writing with an oral introduction from the lead person 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. In these circumstances, participatory parity is difficult if not impossible to achieve.

“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)

Perhaps unsurprisingly, 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. All these issues are likely to be more acute for parents from lower socio-economic backgrounds. Crucially, parents are unlikely to stay involved if they think their participation is a mere formality.

The danger inherent in these types of involvement structures is that do precisely what Fraser warns against, i.e. they create nominal equality of participation, while creating structures which in reality make it very difficult for lay people to participate, thus making the achievement of participatory parity, to use Fraser’s terminology, difficult if not impossible to achieve. It is partly in response to these problems that various service user movements have developed what Fraser (1997) term counter publics outside of these types of structures.

Furthermore, as Fraser (1997) indicates, attempting to channel diverse social groups with differing cultural forms of expression through a single mechanism is likely to perpetuate inequality, since any single mechanism is liable to privilege the expressive norms of one cultural group over another, thereby making discursive assimilation a condition for participation. She concludes that in general the idea of engaging with diverse social groups on an egalitarian basis only makes sense if there is a plurality of public arenas in which groups with diverse values and discursive norms can participate.
Reimbursement for participation

The 2006 survey results indicate that eleven networks 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 2 Reimbursement for participation

It is unlikely that parents from lower socio-economic backgrounds will be able to participate within neonatal networks unless they are offered adequate reimbursement for the costs incurred by participation. This is also an issue of social recognition. Parents are the only members of network boards who are expected to work for free. Reimbursement carries with it both an economic and symbolic value. From a sociological perspective the lack of reimbursement represents a form of what Bourdieu (1999) terms ‘symbolic violence’ i.e. it represents a tacit form of discrimination.

Professional attitudes

Although PPI 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.”

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 one or two people attending board meetings it is unlikely to become embedded in other aspects of the networks’ work. It is therefore unlikely that a culture will develop which recognises that both service users and professionals are ‘experts’ with a specific interest in neonatal services. As we have seen not all professionals feel that participation is desirable. However, even within those professionals who do accept the need for participation there are different shades of opinion concerning the specific roles of parents in neonatal networks. These are rarely explicitly articulated but appear to shape the approach taken to parental involvement and lead to the construction of publics of differing strengths.

**Modes of parental involvement, participatory parity and the politics of recognition**

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 each with differing levels of participatory parity. These are:

1) sources of information  
2) consultants  
3) representatives of other parents

These modes of parental involvement are not mutually exclusive but the degree of participatory parity is the least strong when parents are solely used as sources of information and strongest when they represent other parents through links with parent groups external to the boards. Networks may make use of more than one approach, indeed this can result in some confusion and contradiction about the role or roles that parents are expected to play, although particular networks appear to favour one mode over another.

*Parents as sources of information*

Parents when used as sources of information are seen as a source of raw data that 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.

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 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 network structure. 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.
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 was likely to be a foregone conclusion. However, she pointed out that parents had been present at board meetings where the issues had been discussed, so there had already been some public/user consultation. In these circumstances participation can be used to legitimise existing decision making structures and processes.

*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. However, in this approach 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, allowed the parents to exchange experiences and advice and provide peer support to one another.

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 also major difficulties involved in the running of these groups. This is because the groups frequently 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 as parents and as users 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 between units 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)

Despite these potential difficulties this approach gives parent representatives at board level a clearer role and status. It also creates an important link between the network board and what is happening in local units. However, there is still the danger, as Wakefield and Poland (2005) point out, that this type of structure will only allow those particular individuals to directly participate who have become familiar and comfortable, perhaps through education, with the cultural modes of expression required by those organising the involvement process. These types of approaches to building public participation can, therefore, have the unintended consequence of concentrating the power of particular groups into the hands of a few spokespersons while at the same time introducing social distance between those speaking and those being spoken for (Bourdieu, 1984).
Concluding comments

Fraser’s ‘politics of recognition’ (1997) is predicated on there being some level of participatory parity. In the majority of neonatal networks, as they were organised in 2006-7, parent involvement was being constructed, we would argue, as a weak public, lacking in general participatory parity and therefore unable to challenge the boundaries and discourse of the boards.

Furthermore, the development of involvement in neonatal boards has been a predominately top down process. Parents have rarely been asked how, when or where they would like to be involved. Where structures designed to ensure accountability exist the line of accountability appears to be upward rather than downward towards those people using the services provided. It can be argued that the structures that have emerges from this process reflect the managerial needs of the networks rather than those of the people who use this service.

There is also a failure to adequately address the impact of social and economic inequality on participation. While it is obviously beyond the power of neonatal networks to remedy broader issues of inequality among its members, it is possible to deal with some aspects of this problem. One example of the failure to do this is the lack of opportunity for the paid participation of parents in the work of network boards. Parents are the only members of network boards who are expected to work for free (the politics of redistribution (Fraser, 1997)).

However, it is not only financial recognition that is at issue here. Both clinical and managerial members of these boards carry with them significant social status based on their respective domains of professional expertise. It is these professional members of a board and in particular the core management team that play a significant role in determine both the written and unwritten agenda of the board. Within this particular context the clinical members of a board also possess an important symbolic power related to their ability to save life, which may help to legitimise and perpetuate a set of paternalistic relationships. These factors make it difficult for parents to challenge this
agenda or professional judgements unless the issue involved directly relate to parental experience of neonatal services.

This apparent lack of status may be further aggravated by the fact that some 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. This lack of clarity may result in parents being asked to participate in network boards without it being clear what is expected of them and this lack of clarity extends to the way in which professionals view their roles.

It is only where parents are members of boards in a representative capacity that the issue of parental involvement is related to a need for wider parental participation. However, the institutional arrangements designed to ensure the accountability of representatives to their external publics (usually organised around a particular neonatal unit) are largely embryonic or non-existent. There is also evidence that action is taken to exclude parents who might be actively involved in local campaigns which relate to neonatal services.

Using Fraser’s framework makes it clear that remedying the problems inherent in the types of user involvement described above goes beyond the production of involvement ‘toolkits’ or ‘how to manuals’. Rather it suggests that underlying issues of economic and status inequalities continue to taint the interaction between lay and professional participants within this arena. Fraser’s analysis also alerts us to the fact that the boundaries of public debate and participation are dynamic and, in certain instances, highly contested. These boundaries do not merely consist of which issues are in or out of the public sphere, but also which solutions may be deemed acceptable or unacceptable resolutions to a particular problem. In the arena of public engagement that may result in debates about the legitimacy and scope of involvement along with a concern to limit the potential impact of any chosen approach on existing power relationships.
Importantly Fraser's framework also helps us to think about what an alternative model of involvement might look like. The analysis presented here suggests that professionals and lay people need to be able to participate from a position of equality, beginning with a recognition that far from representing a potential block to effective policy-making (Pickin et al 2002), the diversity and strength of lay expertise may contribute to the generation of forms of understanding which may compliment those possessed by clinical and managerial professionals (Popay and Williams, 1996). Each side needs to acknowledge that there are complex questions of evidence and value involved in healthcare policy decisions and that each has a legitimate role to play (Elliott and Williams, 2008). It also suggests that attempts at engagement may necessitate the development of initiatives which may require professionals to engage in deliberations with differing social groups outside their traditional professional terrains both intellectually and sometimes physically as the situation demands (Elliott and Williams, 2008). Such deliberations must be enabled to have real influence on decision making processes rather than creating forums for debate, which have been artificially denuded of any decision-making capability. Unless this happens the mechanism designed to engage with lay people by professional are in danger of becoming irrelevant to all but a small minority of people.

Acknowledgements
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Tables

Table 1 Parent representation on neonatal network boards 2006 - 7

<table>
<thead>
<tr>
<th>Number of parents on the board</th>
<th>Number of boards in 2006</th>
<th>Number of boards in 2007</th>
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Table 2 Reimbursement for participation

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<td>Child care</td>
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<td>Attendance at meetings</td>
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