

**Title Nursing and Public Participation in Health: An Ethnographic Study of  
a Patient Council.**

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## **Title Nursing and Public Participation in Health: An Ethnographic Study of a Patient Council.**

### **Abstract**

**Background:** Conceptualisations of the nurse patient relationship tend to view nursing as embodying an empowering approach to patients, one that places the service user perspective at the centre of decision-making. However the relationship of nursing to public participation in health service planning and development has been under examined.

**Aims:** The aim is to explore the relationship of the nursing profession to public participation as enacted through a UK based patient and public council, located in an acute hospital. The council was developed by nursing staff and aimed to achieve service user participation in strategic level health care decision-making. The views and experiences of participants and the applicability of the 'nurse-patient partnership' construct to public participation are considered.

**Methods:** The study employed integrative ethnography, involving multiple field methods: non-participant observation of council meetings i.e. 14 three hour meetings (n=42 hours); in-depth interviews with councillors in (n=17) and interviews with key hospital staff (n=18). A documentary review and mapping of the actions of the council was undertaken.

**Results:** A nurse-patient partnership was not initially intrinsic to the operation of the council or embedded in the perspectives of the nurse or patient participants. Professional vulnerability and the organisational context constrained the nursing response. Councillors and nursing staff moved to create a shared set of understandings in order to progress change in service organisation and delivery. Nurses' repositioning

vis-à-vis the credibility of user experiences and status was central to the effective progression of the council.

**Conclusions:** Partnership in public participation requires a shift by nurses' towards acceptance of members of the public functioning as informed, critical and powerful agents in health care decision-making. Equipping nurses with the skills to communicate with patient representatives in a position of interactional equality is likely to be a pre-requisite for successful engagement by nursing with public participation.

**Key words:** Public involvement, Public participation, Nurse-patient partnership, health care-decision making, ethnography.

## Summary

### What is already known about this topic

- Cultural and policy change have created an agenda for increased representational public participation in health care decision-making. However the relationship of nursing to public participation has remained relatively under examined.
- Conceptualisations of the nurse-patient relationship at the level of the consultation have tended to view the nursing profession as embodying an empowering approach to patients.

- However the marginalisation of nursing within the health care division of labour and organisational, managerial and policy may serve to constrain the development of a nurse-patient partnership.

### **What this paper adds**

- Instead of being intrinsically directed by concepts of partnership, organisational and managerial agendas and professional norms concerning patients created barriers to nurses' engagement with public participation.
- Nurses were found to be ill-equipped to engage with patients in the situation of increased interactional equality provided by a public participation initiative.
- The development of a partnership between nurses and patient representatives was possible to achieve in public participation, once attention was given to professional repositioning concerning the credibility of patient experiences and expertise.

# **Nursing and Public Participation in Health: An Ethnographic Study of a Patient Council.**

## **1. Introduction**

Public participation in health service decision-making has been represented as an essential ingredient of democratic and accountable health systems (WHO, 2003). Over the last two decades incorporating the patient perspective in service development and planning has become an iconic vehicle through which particularly North American and European policy makers have sought to create health services that are more effective, accountable and responsive to user definitions of need (Brooks, 2001, Crawford et al., 2005, Thurston et al., 2004). In part the growth of public participation strategies is based on a view that public involvement may offer the potential for improved service development, as service users are able to generate creative solutions to organisational and care problems that benefit the organisation as a whole (Wennberg 1984, Seymour 1997). At the strategic or policy level of health care decision-making insights gained from experience of receiving health care services has been seen as offering an additional valuable component, in so far as patients bring both experiences of their health encounters *and* knowledge of their local communities and the health issues facing them (DOH, 1999, DOH, 2000). Participation in public involvement initiatives may also be beneficial for participants through improving self-esteem and developing skills (Wallerstein, 1992).

User participation in health care decision-making encompasses a wide range of practices and user/provider relationships, the meanings and definitions of which are also contested and evolving (Herxheimer and Goodare, 1999, Warren, 1999).

Representational public participation may involve groups, communities or individuals

participating in strategic decision-making such as service commissioning, service evaluation and resource allocation. Representational public participation may also involve users in service delivery issues relating to monitoring and enhancement of quality issues such as clinical governance.

In the UK the nursing leadership has advocated the need for nursing to prioritise engagement with the process of public participation in health service decision-making (Mullally, 2001). However despite public policies that have enacted strategies for increased public participation in health care decision-making and an accompanying burgeoning international academic literature (Abelson et al., 2003, Cayton, 2004, DOH, 2004, DOH, 1999, Zakus and Hastings, 1998) the relationship of nursing to such programmes has remained relatively under examined, both conceptually and in practice (Poulton, 1999). Moreover accounts of nurse-initiated or nurse-facilitated public participation initiatives are notably scarce.

### *1.1. Nursing and public participation in health care decision-making*

The gaps in empirical and theoretical consideration of the relationship of nursing to representational public participation and the absence of nursing innovations in this field, are likely to be bound up with the position of nursing in western health care systems. Explanations may lie in the health care division of labour, the managerial and organisational structures of health care systems, as well as the character of the nurse-patient partnership.

Conceptualisations of the nurse-patient relationship at the level of the consultation have tended to view the nursing profession as embodying an empowering approach to patients, one that places the service user perspective at the centre of decision-making

(Brooks, 1998, Gallant et al., 2002, Jewell, 1994, Luker et al., 1998, Munro et al., 2000).

The patient-partnership concept could mean that nursing is ideally located to support and empower representatives from the public to effectively influence strategic and policy decision-making in the health sector. However, the extent that concepts of partnership routinely guide health professional practice including nursing practice, has been problematised (Rowe and Shepherd, 2002, Waterworth and Luker, 1990).

'Partnership working' has tended to be equated with increased alignment between patient and professional perspectives, however in reality it may intensify conflict (Anderson et al., 2006). Patients functioning as equal partners in decision-making (at the level of care delivery and at the strategic representational level) may be viewed ambivalently and defensively by welfare and health professionals who are unused to having to be accountable to service users (Barnes, 1999). Poulton (1999) found that while nurse coordinators were highly committed to participatory decision-making, resistance existed among members of the wider nursing team who failed to perceive positive strengths and were fearful of the impact of patient participation on resources. There is also some evidence to suggest that nurses may perceive patient participation as threatening to the professional status of nursing (Cahill, 1998, Tritter et al., 2003). If part of the defining character of nursing is a claim to constitute the patients champion, based on a special and unique access to the patient experience, then empowered patient representatives who actively voice a patient-led agenda could result in the nurse-as-advocate role becoming unnecessary (Wilson et al., 2006). Consequently, nurses and nursing could become further marginalised in the health care division of labour and in popular public perceptions. An explanation for the source of such a tension may be found in the location of nursing within the division of labour in health policy and planning.

In relation to health care policy and planning nursing internationally has often occupied a marginalised and culturally ambiguous position (Davies, 1995, Davies, 2004). Health policy and service planning has predominantly functioned in such a way as to systematically devalue and sideline the elements of health care delivery that are fundamental to nursing, notably caring and an holistic approach to patients that responds to vulnerability (Brown and Seddon, 1996). This process of marginalisation has resulted in nurses tending to remain disengaged from public policy making, both at the local and the national levels (West and Scott, 2000). At the local level for individual nurses the normative expectations of their organization and a focus on task driven, protocol-led decision-making may result in a restrictive role (Colyer, 2004, Cott, 2000, Manthey, 1992), that provides little opportunity to acquire the skills necessary to develop as effective agents in the policy making process (Brooks and Scott, 2005). The consequence of the exclusion of nursing from the policy making process is that the contribution of nurses are likely to remain invisible in any key shifts in policy direction, such as the emergence of public participation. Moreover at the local level nurses may be disinclined to engage with developments such as public participation feeling that such policy led initiatives have little to do with their fundamental day to day work of delivering care.

Managerial agendas can also serve to direct the enactment of public participation initiatives towards organisationally driven priorities and outcomes that have implications for the relationship of nursing to public and patient participation, as managers and policy makers tend to legitimise those user perspectives that fit with strategic and policy imperatives (Milewa et al., 1999). However when patient participation operates as a technology of legitimation (Harrison and Mort, 1998) this can lead to issues of

sustainability, as patient representatives become disillusioned with the process (Brooks, 2001, Brown, 1999).

The existing literature on representational public participation in health leaves a number of questions for nursing. In particular empirical studies are needed to examine the nursing perspective on public participation and also undertake observation of nurses' real world engagement with such initiatives (Cahill, 1998). This paper reports on a nurse-led public participation initiative, in which nursing staff undertook primary responsibility for the inception, implementation and progression.

## **2. The patient and public council**

The patient council was established by senior nursing staff as part of a locally initiated patient and public participation strategy, but was not part of a UK government initiative termed 'patient forums' (Department of Health, 2003). The council was located in a non-teaching, acute hospital trust in England, with a largely stable nursing workforce. Nursing staff initially promoted the concept of the council due to the emergence of public and patient involvement as an identified area for further development from within the nursing managerial and governance structures. Nursing management operated within a flattened, horizontal hierarchical structure, known as shared governance. Nurses within the hospital were therefore likely to have had some experience of critical discussion with peers and involvement in decision-making processes.

The advertised terms of reference of the council encompassed both the *promotion* of patient participation for individuals at the level of the consultation and the *active involvement* in policy and strategic decision-making about the character and quality of

services. The local patient and public participation strategy also outlined corporate level and staff responsibilities and commitments for the implementation of patient and public participation. The activity of the council was constructed partly from referred work, in the form of requests from hospital staff for the council to have an input on an issue, and partly by councillors raising items for the agenda.

The deputy director of nursing acted as chair of the council so that there would be an immediate and direct link to the hospital managerial and governance structures (such as the trust board). It was the stated intention of the nurse chair that as the council developed a patient councillor would ultimately chair the council. The council was also supported by a part-time administrator (4 hours per week) and a specialist nurse, whose responsibilities include nursing governance and public participation. All three staff members attended all meetings. The remaining 16 councillors were all members of the public.

Patient councillors were not paid for their time, but expenses were reimbursed. The patient and public councillors were recruited entirely via internal and external advertisements in the hospital and local press, membership was drawn entirely from the local community of the hospital, the only inclusion criterion was that applicants had to have been a patient at the hospital or were a carer for someone who was a patient. Recruitment was undertaken via a brief letter of application and prospective members were not interviewed, all 16 applications were accepted and appointed for 18 months. Training was provided for the councillors over a series of sessions encompassing health service policy and structures and team building; internal and external facilitators were employed to deliver the training. The final composition of the council reflected the tendency for such initiatives to be largely supported by older adults with few members of

minority communities (Brooks, 2001). Only four of the patient councillors were aged less than 65 years and all were white European (eight women and six men), although this is broadly representative of the demographic composition of the local population. However the composition of the council was not predominately middle class, with only two members of the council having retired from professional or managerial occupations. Nine members of the council had either a chronic or an acute health condition and five were full-time carers for relatives with serious long-term health problems.

### **3. Aims**

The primary focus of this paper is an exploration of the relationship between nursing and public participation as enacted through a nurse-initiated patient council, designed to achieve service user participation in strategic level health care decision-making and planning at the local level within one acute hospital. Specific attention is also given to the following objectives:

- To examine how nurses and patient representatives would engage with each other throughout the first term of office of the councillors, including consideration of agreement over prioritisation of issues and agenda setting for the work of the council.
- To consider the relevance of the concept of nurse-patient partnership to public participation.
- To explore how shared understanding and effective collaboration between patient representatives and nursing staff might be attained.

#### **4. Methodology**

The framework for the conduct of the research was that of integrative ethnography (Baszanger and Dodier, 1997) in which emphasis is placed on the importance of multiple field methods (observation, interview, documentary analysis) in order to explore aspects of culture in situ and enable the generation of a layered account about a phenomenon (Silverman, 1997). In other words, the field notes and in this case patients' and nurses' interview accounts of a particular phenomenon are not treated as competing with each other, the one verifying the other, but instead as revealing distinct and important aspect of the nursing/ patient interaction. Multiple qualitative data collection methods were employed to achieve 'across method' triangulation (Dootson 1995). To this end, data collection involved non-participant observation (video, audio recording and verbatim notes) of council meetings i.e. 14 three hour meetings (n=42 hours); in-depth interviews with council members in their own homes (n=17), a final focus group interview of remaining council members and interviews with staff within the hospital (n=18). In addition, semi-structured interviews were also undertaken with key external respondents with experience or expertise relating to public participation. These included members of relevant consumer organisations, policy makers, academics and spokespersons on consumer participation (n=5). Two academic researchers who were external to the hospital undertook all the fieldwork.

In order to evaluate staff views and experiences relating to the council the 18 staff interviews were conducted with staff (12) who had referred work to the council and with those who had not (6). This included nursing (16) and medical staff (2) from areas which had had both significant involvement with the council, in the form of patient surveys and visits, and those which had had less involvement as well as key managerial staff from

each of the directorates. Staff were approached to participate initially by a member of the external research team and then formally consented. No member of staff refused to participate.

Interviews with the patient councillors explored: motivation to participate, priorities, operation and success of the council, perceptions of patient participation and views on staff. Staff interviews covered their views and experiences of the council, attitudes toward public and patient participation and their definitions of council work priorities. Perceptions on specific incidents that occurred during meetings were also discussed with staff and patient councillors. In addition, a documentary review and mapping of the actions of the council was also undertaken.

#### *4.1 Data analysis*

All interview and observation data was recorded and transcribed verbatim. Qualitative data were analysed using a grounded theory approach (Glaser and Strauss, 1967). This process followed broadly the process of '*discovery, audit, comparison and falsification*' described in the methodological literature (Gubrium and Lincoln, 1985; Maykut and Morehouse, 1994; Silverman, 1998). The analysis was facilitated by the use of Atlas.ti software that enabled a systematic approach to coding and checking ideas. Each piece of data was examined for examples that were different, or 'discomforming' (Silverman, 1998). Four researchers, two sociologists and two nurses were employed to code the transcripts. This process of multiple coding enabled critical discussion of competing explanations and refinement of the coding frames.

#### *4.2 Ethical considerations*

All patient members of the council and staff involved were aware of the evaluation as part of the recruitment process to the council and consent was obtained from all participants. Individual consent was obtained from each councillor and member of staff for participation in the interviews and video recording of the council meetings. Local ethical committee approval was granted. The council had a patient councillor representative on the steering committee for the evaluation and all councillors were able to contact the researchers directly. All participants have been anonymised in this paper. Approval for the study was gained from the Local Research Ethics Committee.

### **5. Findings**

#### *5.1 The relationship of nursing to the council: Referral rates*

The council engaged in a wide range of activities, from commenting and advising on documents, establishing working parties on specific topics, to membership of hospital multi-disciplinary groups such as involving service audits or reviews of cancelled operations. During the two years of field work, the minutes of 15 meetings (included in the documentary review) recorded 55 separate work items (excluding those relating to the function and operation of the council), the majority (21 items) were generated by the councillors, 14 items were referred by nursing/midwifery staff and 18 by other non health professional staff only two items were referred by medical staff. Members of the nursing staff were also much more likely than other groups to undertake presentations to the council detailing service developments, although members of the senior management team and medical staff did all present to the council at least once. The referral pattern to the council did reveal a willingness among the nursing staff group to connect with public

participation processes.

The next sections seek to elaborate the character of the nursing relationship to the council.

### *5.2 The relationship of nursing to the council: Constructing and controlling the agenda*

A difference in priorities over the focus of the work of the council was a source of tension in the developmental stages of the council. Organisational pressures to demonstrate user input in the implementation of new government directives resulted in tensions between patient councillors and the nurse chair of the council over work priorities. The councillors all stated that, they joined the council with clear ideas about how services could be developed, based primarily from observations drawn from their own or their families experiences of receiving care.

*Q What sort of work do you want the council to do?*

*It was things like they tell you not to lift anything at all (after the operation) and then the chairs they have are so heavy you can't move them normally! Just things I experienced or observed and you think, well, they could change that! Simple! (PPC councillor. Interview data)*

In contrast, nursing management was facing demands from senior hospital management and central government to demonstrate consultation with service users in a range of policies, developments and organisational structures. Consequently, the external demands of macro policy had a very direct impact on the creation of tensions over agenda setting and the work priorities of the council.

*The patients' council wouldn't necessarily know what needs doing over the next 5, 10 years, but I do. I thought, I want them to do what I want them to*

*do, and I've got lots for them to do. When they started coming up with their own ideas I thought, 'there isn't time for all this; this is what I want them to do'. (Nurse chair of the council. Interview data)*

As noted earlier, underlying values about the purpose of public participation have been found to lead to problems of sustainability for initiatives as participants are likely to 'vote with their feet' and leave if they feel that their agendas are being subordinated to organisational or political agendas (Brown, 2003). As the following interaction in a council meeting illustrates, councillors were highly sensitised to any message that implied the council might simply have been initiated to satisfy a politics of presence:

**Observation example from meeting 2: discussion of terms of reference**

Councillor 1: Can we not use the word 'support'?

Nurse chair: Support? It means help me!

Councillor 2: It sounds as though we are. (*pause*) I just don't like it.

Nurse chair: You don't like it?

Multiple Voices: No!

Councillor 2: It sounds as though we are just here to say OK to the trust decisions (*the hospital*), agree with them.

Nurse Chair: What shall we say instead?

Councillor 1: Well you actually said the word I was thinking of 'to work with.'

Councillor 3: Yes that's it! 'To work with.'

Dominant professional and organisational work place norms influenced how nurses responded to patient councillors attempts to raise agendas. Negative reactions from nurses were most notable when the patient councillors attempted to raise their personal experiences of care as a means to suggest an issue for the agenda. Narratives or 'story telling' about experiences of care were felt by nursing staff on the committee to be unnecessary 'subjective interruptions' that hindered the smooth running of meetings.

*A lot of them come with their personal experiences: they cannot put them behind them and constantly interrupt... and yet in a professional*

*setting people have to put all their personal stuff behind them, don't they?* (Nurse specialist & council member. Interview data)

The experiential knowledge of the councillors was predominantly viewed by the nursing staff as private experiences that were irrelevant to discussions of service or practice development. This operation of a hierarchy of knowledge resulted in professional resistance to attempts from the councillors to articulate their experiences. During meetings nursing staff were observed to meet an experiential account from a councillor with either silence or verbal 'moving on' techniques, designed to refocus the discussion back to the professional priorities. In interview this marginalisation of experiential narratives caused the patient councillors to express frustration, because they felt they were voicing such accounts in order to generate action. Overall councillors felt left in something of a vacuum, feeling blocked from bringing what they felt was their unique perspective and specialist knowledge to the forum, but without possession of the form of knowledge valued by professionals.

*The only thing that we've got to bring to it (is) our own experiences. Other than that we don't have any clinical experience, so that is all that we can bring to it.* (PPC councillor. Interview data)

Consequently, in the initial months (1-8 months) of the council operation nurses and the patient councillors came to the process with different agendas and fundamentally different conceptions of appropriate forms of knowledge that could be used to set those agendas.

## *5.2 The relationship of nursing to the council: nurses vulnerability*

Nurses more than any other profession who worked with the council tended to express a sense of professional vulnerability and defensiveness relating to their interactions with

the council. This vulnerability manifested in a number of ways through both, direct interactions with councillors and through professional blocking of extensions to the influence and involvement of the councillors in the work of nurses. At various points during the first term of office of the council nurses were also overtly protectionist of professional control over decision-making processes and opposed having council members on working groups or as members of previously 'nurse only' committees.

*I am not sure nursing is ready for it yet, you know people outside the meetings have said things like 'but we wouldn't be able to discuss such and such and we wouldn't be able to discuss this, it would spoil the meeting. (Nurse chair of the council. Interview data)*

Significantly, it was only members of the nursing profession who expressed such tensions, other professionals and managers who encountered council representatives (on joint working groups and through presenting to the council during meetings) tended to view the contributions in a much more positive light, as the following comment from a manager within the organisation illustrates:

*All I can say is that the members of the council that we work with have a very supportive attitude to this trust and support the initiatives we've worked on jointly to improve the patient's lot. It's been very positive, very much so. (Non-professional manager – responsibility for information. Interview data)*

In the initial six-eight months of the councils' existence nursing staff almost exclusively held to a discourse that the council was composed of difficult '*tricky customers*' (nurse specialist). The councillors were repeatedly described by nursing staff with negative terms such as, '*intimidating*', '*ungrateful*', '*difficult*', '*challenging*' and even '*unprofessional*'. Nursing staff expressed particular vulnerability in relation to direct

interactions with councillors during council meetings, when questions from the councillors about their presentations were felt to be very challenging: The following comments are from nurses who presented accounts of 'innovations' or service developments to the council.

*I was actually quite shocked, one by the amount of work that I am getting from the council and two also the way that I've been shot down a couple of times. (Ward sister. Interview data)*

*I felt rattled really, them asking me how I analysed my data. (Clinical nurse specialist. Interview data)*

Frequently, nursing staff would express the view that presenting to the council was a challenging, daunting prospect, where they would be answering questions from a very hostile audience who would leave nurses '*rattled*' (staff nurse) or '*torn to shreds*' (nurse specialist). However analysis of interactions from the meetings suggested that nurses were certainly encountering a detailed and probing form of questioning style, but not an aggressive, combative mode. The following interaction in a council meeting illustrates a typical 'questioning' interaction between the councillors and nurses who were presenting to the council: The '*thanks*' and depreciative verbal style, for example, '*excuse me not knowing*' was highly typical of comments from the councillors:

**Observation example from meeting 7: discussion of findings from a patient survey. Two presenting staff a nurse and midwife.**

PPC1: Excuse me not knowing, but I wondered if there was any difference between the wards?

Nurse: No, No difference of any import.

PPC1: I just wondered if there was any difference at all?

Nurse: Well, ward A does have more high dependency women, who have had more difficult deliveries or their babies might be ill, but not exclusively.

PPC1: Thanks

PPC2: Some of the women did say that they thought that a consultant would have visited them before discharge?

Midwife: This is because they don't understand that we are skilled and allowed to discharge them.

PPC3: Yes, but aren't all those comments from women on the higher dependency ward? Could it be, if you have had an ill baby or you have been ill then you might be expecting to see a consultant?

Midwife: I suppose, they might be (*pause*), maybe we need to explain it and say they are OK now.

Councillors did express (during the interviews) an understanding that nursing staff had felt intimidated during their interactions with the council. Moreover, councillors also felt that nursing staff were ill-prepared for encountering a service user who overtly articulated a critical perspective on nursing practice.

*They are used to being challenged from other professionals and other people in the health service, but they are not used to it coming from people. People who are going to come back to them and say, 'yes but that doesn't work,' or 'we would prefer you to do something else' they're not used to that confrontation. (PPC councillor. Interview data)*

A senior member of nursing staff also acknowledged that nurses lacked experience with public participation in health care decision-making and that an empowered questioning group of patients was particularly challenging for nurses.

*My theory is that in the NHS they wanted to say, 'Oh we have got a patient council,' tick the box and you just have this toothless group that agrees with everything that you say and adores you because you're a nurse and we haven't got that at all. (Senior nurse manager. Interview data)*

Consequently, despite nurses demonstrating a willingness to engage with the structures of public participation (through for example the referral of work to the council), the public participation initiative provided a number of direct challenges to nurses' expectations of patient-nurse interaction.

The remainder of the paper focuses on how nursing staff moved from the somewhat polarised position documented so far in this paper, to a position of improved understanding of the perspectives and agendas of the patient councillors.

### *5.3 Shared Agendas*

This section explores how the councillors and nursing staff moved towards conflict resolution and the extent to which this move arose from a transformation in the professional discourses concerning the patient perspectives. In the case of the council this was largely and effectively achieved through holding (at the recommendation of the evaluation team) a meeting to give voice to the members experiences as patients and set an agenda for action. The meeting not only allowed members to voice their own situated and experientially based agendas, but also significantly impacted on the way nursing staff perceived the council

#### **Observation example from 'narrative session':**

Chair: How useful do you think this has been?

PP1: Jolly useful!

PP2: Yes I think it's useful because we've, I think we've all felt a little bit that we're not quite sure what information you were wanting in from us, because we were a bit restricted in a way as to what we were to talk about; you didn't want personal involvement, but that's all we can offer you really, is personal involvement and feedback from other patients. And I think what's come out here today has probably brought some things that, well you wouldn't have thought about.

Chair: No, no, that's true; yes I agree, I agree.

PP3: Do you feel it was good?

Chair: I think it was very useful and I have to say, you know, I've said all along with the patient council, it's our first attempt at trying to have proper public involvement in decisions at *this hospital (name deleted)* and I was concerned at the beginning that what I was going to end up with was 14 people, each with their own, individual complaint that they wanted me to deal with and I didn't think I - (a) I didn't think I'd be able to do that and also I didn't think that was going to be very productive if we were, you know, talking about people's personal complaints. But I do think that is what you do bring to the council, you bring your own personal experiences...

PP4: I think it's cleared the air though as regards my fetish as regards linen.  
*(laughter)*

The evaluation of the patient council highlights the significance attached both to professional repositioning concerning the credibility of user experiences and to the contribution of personal situated and embodied knowledge to improved health care delivery, particularly as a starting point for the creation of shared understandings. For some of the nursing staff engaging with these accounts had a revolutionary impact on their relationship to the public participation:

*I think we naively sort of missed a trick there because I, we, took it the wrong way, we said that some of our patients had an obsession about linen or something, and we didn't know why until we did the story telling. It isn't an obsession, it is a desire to put things right. Those stories had a real impact on me, I have been in nursing 17 yr. and never heard them before (Senior nurse manager. Interview data)*

As the council evolved, staff working with the council came to understand that effective user participation required the development among nurses of new ways of interacting and engaging with users.

*We don't want the council to lose its edge, it's teeth, But also I don't know how you'd do it, but trying to prepare people for that change is what is needed so that they almost embrace it rather than kick against it. (Senior nurse manager. Interview data)*

Moreover senior staff argued that the very way public and patient participation was defined and therefore understood by nurses and healthcare professionals needed to undergo a radical transformation.

*I think there is a fundamental misunderstanding about patient participation because we're just about to advertise our patient advocacy and liaison services facilitator and I've had numerous enquiries from people who believe that they have extensive experience in patient participation because they're a nurse or because they're a doctor, or because they are a therapist. (Senior nurse. Interview data)*

Significantly in the council members interviews, the need for a re-positioning of professional approaches and understandings concerning patient and public participation was also a consistent feature. Frequently, interview respondents argued that health care organisations needed to commit to providing the levels of staff support and training needed to effectively engage with patient and public participation.

*It's a culture shock for them. There has to be a written policy and somebody named on the policy as being overall in charge of doing a re-training job. It's going to be a big re-training job to get people from the old culture to the new. (Key respondent from health authority. Interview data)*

## **6. Discussion**

### *6.1 Nurse and patient councillor interaction*

The levels of nursing involvement in relation to implementing, maintaining and facilitating the council appeared to suggest that favourable conditions were in place for nursing to be able to establish a constructive relationship with the patient council. However

organisational pressures, nurses' vulnerability in the face of critical feedback from service users and professional expectations concerning how work priorities for the council should be constructed, all served to shape the relationship of the nurses' to public participation. In particular differences were found between patient councillors and nurses in terms what constituted appropriate forms of knowledge that could be used to set the work priorities of the council. Patients joined the council in order to recount their experiences of care in a forum that would allow them to be influential in shaping professional practice and service delivery. In contrast, nurses initially operated with a medicalised hierarchy of knowledge, with the consequence that they actively resisted the experiential knowledge of the councillors, as simply personal understandings that were of little relevance to shaping policy or practice.

It has been suggested that the context in which health care is delivered may generate barriers to attempts by both users and providers to shift the balance of decision-making toward the user voice (Stevenson and Parsloe 1999). In the case of the PP council '*service agency discourse*' (Beresford et al., 2000) concerned with the agendas set by central government and local organisational pressures did operate to place nurses in an oppositional relationship with the agendas promoted by the public patient representatives. However macro and even local micro policy were not the main factors that created tension between nurses and the patient representatives. The potential for user participation to create real change in the organisation and delivery of health care appears, from this study, to be predicated on a change in the expectations of professionals concerning their relationship with users of health care services.

## *6.2 The nurse-patient partnership and public participation*

The findings presented in this paper illustrated that the development of an equitable dialogue between service users and nurses represented a challenge for nursing staff. Instead of being intrinsically directed by concepts of partnership, the relationship of nurses to public participation initially appeared to mirror the professional defensiveness and protectionism found among other health and social care professionals (Barnes, 1999). Overall nurses seemed ill-equipped to engage with patients in the situation of increased interactional equality that the council provided. The councillors in this study did not present as passive, deferential patients within the health care division of labour, with the consequence that nurses' strategies for interaction with patients and their normative expectations of service users became dysfunctional and required re-formulation. In particular the nurses in this study had to accept that the patient councillors had decision-making competency, and that critical dialogue would be part of the nurse/patient relationship.

The findings from this study indicated that effective public and patient participation requires an additional letting go by the nursing profession of the 'collective illusion' of the exclusive character of their knowledge (Stacey 1992). In order to achieve user-centred care it has been argued that it is necessary to reconstruct the social rules governing the patient-provider interaction away from the expert vs. lay person distinction, by giving 'voice to the lifeworld' of the patient (Barry et al., 2001). At the representational level of participation a similar reconstruction of the normative expectations of user-provider interaction appears to be required in order to prevent the interaction between user and professional from becoming dysfunctional. A main criteria for the establishment of such a relationship appears to be predicated on an acknowledgement by professionals that situated and embodied knowledge held by patients constitutes a valid form of knowledge for shaping policy and practice (Barnes, 1999). Implementation of patient participation

schemes often place considerable emphasis on training for patient participants, however one largely unanticipated need emerging from the implementation of the patient council was for staff training, to enable nurses to understand patient knowledge and to work constructively with patient members of public participation initiatives.

### *6.3 Developing shared understandings*

The challenges provided for nurses in this study represented a starting point in the development of effective engagement with public participation by nursing. The expression of unheard or devalued accounts has been perceived as a mechanism by which stakeholders, such as professionals, can critically reflect on the partiality of their knowledge base and begin a process of dialogue with patient perspectives (Davies, 2000, Phillips, 1993, Young, 1990). Empowering nursing care giving relationships have been seen as dependent on supportive 'social conditions' that allow for the emergence of shared understandings, particularly in terms of language and concepts (Nolan et al., 2004). Similarly, in relation to public participation shared understandings began to be developed once conditions had been put in place for the open engagement with the patients concepts.

Through the process of listening to the councillor experiences of patienthood nurses were able to develop a new understanding of the value of service users experiential knowledge and perceive this knowledge as an expert resource from which to enhance service delivery. It has been suggested that the way forward for nursing is to move away from claiming advocacy for patients, and instead look to joint initiatives with patients as a way forward (Davies, 2004). The findings from this study suggest that in relation to

nurse-public participation such joint initiatives are likely to raise considerable, but not insurmountable, challenges for the nursing profession.

## **7. Conclusions: Implications for nursing**

Cultural change and policies within health systems seem poised to further advance the role of patient and public participation in health care decision-making. Nursing may currently stand in an ambiguous relationship to the patient participation in health decision-making, claiming to be in partnership with patients at the consultation or bedside, but disengaged from an increasingly significant and widespread aspect of patient empowerment. Involvement with patient and public participation is likely to be important for the future development of the profession as nursing risks becoming further marginalised, as service users become more central in the decision-making processes of health systems. Instead of claiming an intrinsic partnership with patients, effective engagement with public participation processes by nursing appears to necessitate nurses developing an understanding of the competing and conflicting nature of discourses, values, and assumptions between nurses and users.

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